West Yorkshire Health and Care Partnership

NHS West Yorkshire Integrated Care Board

West Yorkshire Integrated Care Board

LeDeR

(Learning from Lives and Deaths of People with a learning disability and autistic people)

Annual Report

2023 – 2024

Senior Responsible Officer:	**Philipa Hubbard**
West Yorkshire LeDeR Local Area Contact (LAC)/Governance Lead:	**Lisa McCabe**
Date signed off by SQG:	**July 2024**
NHSE submission date:	**July 2024**

Contents

Acknowledgements

Thank you to Laura Elliott for providing interim Senior Responsible Officer (SRO) to LeDeR and supporting the Local Area Contact to embed LeDeR as a core function within West Yorkshire.

It is important to again acknowledge the members of the Bradford District and Craven Quality Team who provided interim management and leadership, they have ensured the continuation of the hosted LeDeR Programme whilst there were several vacancies within the teams.

Thank you to Iram Amin a member of the Bradford District and Craven Quality Team who has provided the LeDeR review data for this report and for each of our place LeDeR learning disability leads and wider system partners contributions of information for this report. The report includes some examples of place projects implemented throughout the last year to support people to live well and also addressing health inequalities for people living in our communities with a learning disability and or autism.

Introduction

The purpose of this annual report is to share the LeDeR programme's activity within West Yorkshire Integrated Care Board during the reporting period of 1st April 2023 to 31st March 2024 and highlight the emerging data.

When reading the findings of this report consideration should be given to the limitations of the LeDeR programme where the notification to LeDeR is not a statutory requirement. Therefore, this report does not have complete coverage of all deaths of people with learning disabilities and/or autism in West Yorkshire. Numbers in some sub-categories are small so must be interpreted with caution and used in conjunction with other data and measurements to inform and support prioritising local programmes of work to address health inequalities. Some place led initiatives will be shared within this report which may be relevant to meet the population needs within other places across West Yorkshire we would therefore ask for consideration of adopting these at place.

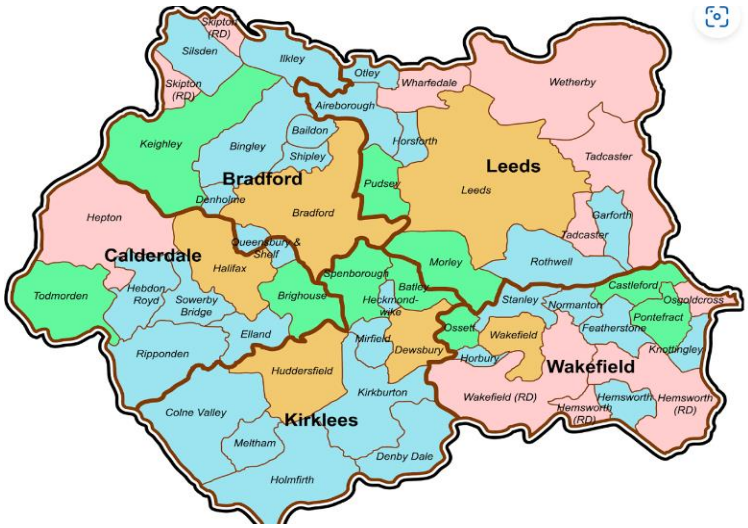
The LeDeR Team have completed a total of 150 Reviews during the reporting period which is a significant increase from last year's total of 81. This has been achieved with the additional support of bank Reviewers and outsourcing 53 reviews to agency. It is important to highlight that at the end of a reporting year there will always be a number of notifications that have not progressed to having a review completed. This may be due to other statutory processes, or when the notifications are received by the team for example within the last quarter of the reporting year. The data included in this report covers notifications received within the reporting period 1st April 2023 to 31st March 2024 period and also notifications received prior to 1st April 2023 which were unable to be completed at the time of last year's annual report.

Due to the significant backlog of notifications at the start of the reporting period which required some prioritising the team were only able to complete reviews for 54 of the 172 notifications they received in 2023/2024. In view of this the data has been separated to cover all 150 completed reviews within the infographics and within the report the data is broken down relating to the 96 completed reviews reported prior to 1st April 2023 and the 54 reported and completed within the reporting period as this should provide a clearer picture to the reader more in keeping with the current climate and working practices.

LeDeR

The Learning Disabilities Mortality Review (LeDeR) programme was established in 2016 because of one of the key recommendations from the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD, 2013). CIPOLD identified that many people with a learning disability were dying earlier than they should from preventable health conditions, and up to 30 years earlier than the remainder of the population. Known today as Learning from Lives and Deaths, People with a learning disability and autistic people (LeDeR) is a national NHS England (NHSE) service improvement programme for people with a diagnosis of a learning disability, autism, or both.

The West Yorkshire Integrated Care Board is made up of the five places shown on the map below and has a combined population of 2.4 million people (www.wypartnership.co.uk). The LeDeR Programme is hosted on behalf of West Yorkshire by Bradford District and Craven Health Care Partnership.



WY ICB includes the following Places.

Bradford District and Craven

Leeds

Wakefield

Kirklees

Calderdale

In March 2021, NHSE published their first LeDeR policy 'Learning from lives and deaths – People with a learning disability and autistic people'. The new policy places emphasis on the delivery of the actions from completed reviews and holding local systems to account for delivery, to ensure evidence of ongoing local service improvement. NHS England regional teams will hold Integrated Care Systems (ICS's) to account for the delivery of the actions identified.

In January 2022 the LeDeR Programme was updated to include people with a diagnosis of autism, with or without also having a diagnosis of a learning disability, to be included for a LeDeR review.

It is essential to clarify that a LeDeR review is not a full review of all health and social care records, but it aims to look at the key episodes of care the person received that may have affected their overall health outcomes. The review looks for areas that need improvement and areas of good practice. Through NHSE examples of good practice are shared across the country

with the aim to reduce inequalities in care for people with a learning disability and autistic people and reduces the number of people dying sooner than expected.

Families often know the most about the care the person who died received. In sharing their experience of services this will influence improvements to quality of care and other areas for improvement. This will also help learning and improve services for other people. Families will be informed when a review is undertaken and will be invited to contribute information about the person who died and provided with the option of receiving a redacted copy of the completed review.

The LeDeR programme also works alongside the many different review processes for people who die, for example:

- **Safeguarding adults' review (SARs)**
- **Review of deaths of people in hospitals, Serious Incidents, Structured Judgement Reviews, and internal mortality reviews.**
- **Coroners/inquest**
- **Police Investigations**
- **Death in Custody Reviews**

Initial and Focused LeDeR Reviews

Once the LeDeR Team receive a notification from NHSE National Database of someone's death, the review process begins and should be completed within six months which is the key performance indicator (KPI) set by NHSE. It may not always be possible to complete the review in 6 months because there might be other processes underway as mentioned on page 6. A LeDeR review needs to await all these other processes being completed before it can be fully completed as any identified learning through these processes will be fed into the leder review.

A Reviewer will undertake an initial review which includes:

- Speaking to the family member or someone close to the person who died. This allows the reviewer to build up a picture of their life and understand more about the person. The reviewer might also speak to someone they lived with or a carer who they were close to.
- A detailed conversation with the GP or a review of the person's GP records.
- A conversation with at least one other person involved in the care of the person who died.

A focused review will automatically be undertaken if:

- the reviewer finds areas of concern or things they think we can learn from.
- the person is from a Black, Asian or minority ethnic background.
- the person was autistic with no diagnosis of a learning disability.
- the person had been under mental health section or legally detained under the Mental Health Act or criminal justice restrictions at the time of death or 5 years previously.

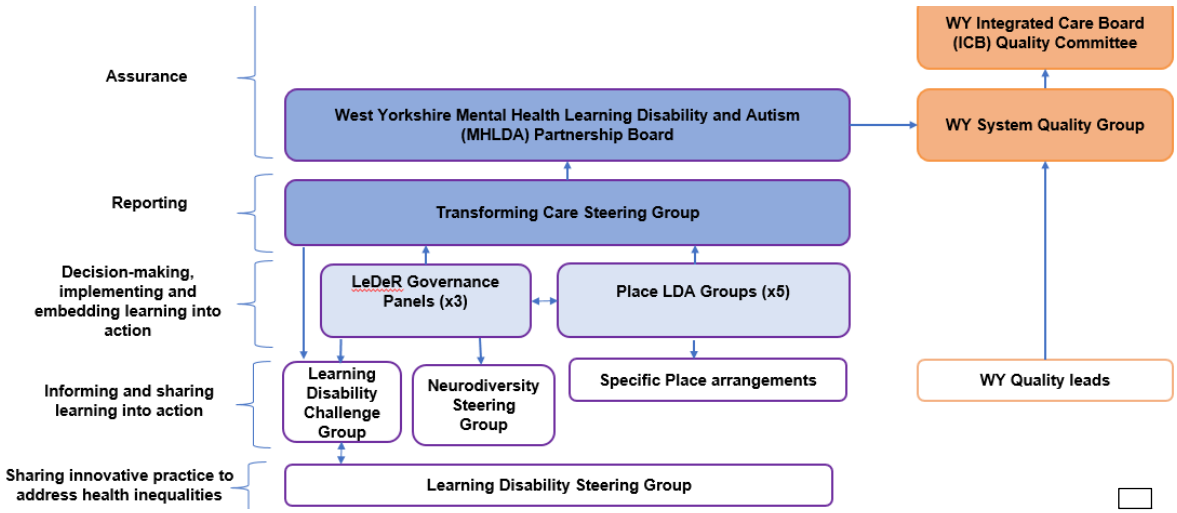
In addition to this guide there are also prompts available for the reviewer to consider if a focused review should be initiated. Following completion of an initial review, the Reviewer, and the Local Area Contact (LAC) decide if a focused review needs to happen. We have locally extended this focused review criteria to cover the transition period of 18 to 25 years based on feedback from our clinical colleagues to provide opportunity for learning and service improvement.

A family member can also request that a focused review is completed. A conversation will take place between the family and the Reviewer about the expected outcome of this focused LeDeR review.

LeDeR Governance Arrangements and Accountability

The Executive Lead for the West Yorkshire ICB LeDeR Programme is Philippa Hubbard, Executive Director of Nursing and Deputy Chief Executive of Bradford District Care Trust. Lisa McCabe is the WY ICB Local Area Contact (LAC)/Governance Lead and is the ICB's direct contact with NHSE for the LeDeR Programme. The LAC undertakes quality assurance processes and provides internal reporting, and the external Quarterly Quality Improvement returns to NHSE. These returns identify the learning and progress against actions from completed reviews alongside updates on other areas of work to address health inequalities for people with a learning disability and or autism. The West Yorkshire LeDeR Team is hosted by Bradford District and Craven Health and Care Partnership.

Due to the large geographical area of West Yorkshire and considering place feedback on local LeDeR cases three Governance Panels shown below are established. Completed Focused Reviews are presented for panel discussion, the agreeing actions where applicable and approval of all completed Focused Reviews. These Governance Panels have system wide membership from our partners alongside people with lived experience and the diagram below shows how this sit within our current Governance arrangements for LeDeR.



The West Yorkshire Hosted Service Operational Update

2023/2024 has continued to present challenges for the West Yorkshire LeDeR team with long term vacancies resulting in interim support. All roles within LeDeR are now substantive as part of the new operating model. The Band 7 Senior Reviewer who is now in post from 1st April 2024 and the Band 4 Administrator posts who has been in post from October 2023 on a part time basis. Workforce has impacted the team's ability to be 100% compliant with the NHSE nationally set 6-month KPI timeframe. As we continue to raise awareness of LeDeR across our system to ensure we receive notifications we are seeing consistency in the large numbers received which increases demand and impacts on the capacity of our workforce. The workforce model was reviewed for 2023/2024 to reflect the demand and the team from 1st April 2024 have an increase of Administrator, Reviewers and Senior Reviewer hours.

As shared in our previous annual report the contract with NECs (North of England Care System Support) has continued throughout the reporting period to support the ICB in addressing the backlog of reviews.

LeDeR activity for the reporting period 2023/2024

In the reporting period of 1st April 2023 to 31st March 2024, the LeDeR Team received 181 notifications of deaths. However, 9 of these notifications were deemed to be out of scope due to the person not having a formal diagnosis, a person living outside of the ICB's area. The breakdown of the remaining 172 notifications at place level can be seen below:

Table 1: LeDeR Notifications at Place Level

Place	Number of Notifications 2023/2024
Bradford District and Craven	44
Calderdale	12
Kirklees	29
Leeds	55
Wakefield	32
TOTAL	**172**

This is a small increase in notifications by 14 for this reporting period compared to West Yorkshire's 2022/2023 reporting period. Of the 172 notifications 54 of these have been completed within the 2023/23 reporting year. A further 96 additional reviews were also completed which cover the notification period prior to 1st April 2023. The remaining 116 notifications received in the 2023/2024 reporting period are still incomplete due to:

- Being on hold due to coroner's inquest, safeguarding investigation, police investigation.
- Awaiting completed structured judgement reviews or GP notes.
- At the request of the person's family for more time where they wish to be involved in contributing to the review.
- Capacity limitations of the reviewing team
- Notified to programme during quarter 4 of the reporting year.

Unfortunately, we have continued to see small number of notifications for autistic people, and we have small numbers of completed review where we have confirmation of a dual diagnosis of learning disability and autism. Therefore, we are not able to separate this data within this report. The 2022 LeDeR National Report found that only 36 reviews were completed for people with an autism diagnosis only. Increased reporting is needed both locally, regionally, and nationally to be able to better determine areas for improvement in the care of autistic adults without a learning disability.

Underlying cause of death for autistic adults without a learning disability reported in the 2022 National LeDeR Report were Suicide, misadventure (includes drug and alcohol related deaths that were not thought by the coroner to be intentional) or accidental death (includes falls) 11 Respiratory conditions 8 Cardiovascular and stroke related. Master LeDeR 2023 (2022 report) (kcl.ac.uk)

Below are West Yorkshire infographics for the total 150 reviews completed within the reporting year

LeDeR Reviews Annual Fact Sheet: West Yorkshire

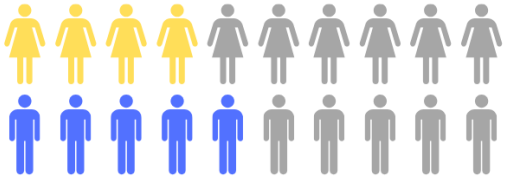
Reporting Period: 01/04/2023 - 31/03/2024

NHS West Yorkshire Integrated Care Board

Total Completed LeDeR Reviews: 150

Sex Demographics

45% of the population in the data were female while 55% were male.



Age of Death

57 Years

was the average age of death of people with a learning disability.

For females it was 59 years

For males it was 56 years

Place of Death

47%

47% of people died in hospital

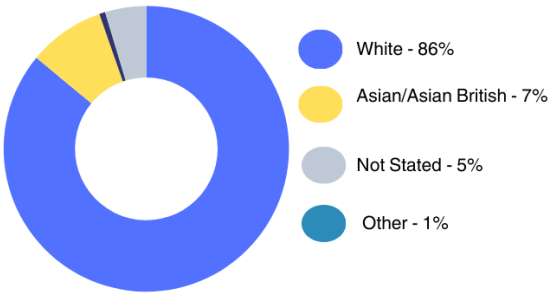
- 19% died where they usually live
- 24% died in a residential/ nursing home
- 5% died in a hospice

**some deaths occurred in community hospitals, family of a relative/ friend. A small minority of deaths recorded did not stated the place of death*

Early Death

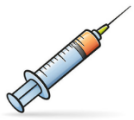
59% of people with a learning disability died before they were 65.

Ethnicity Demographics



Covid-19 Statistics

NHS West Yorkshire Integrated Care Board



70%

of people received a Covid-19 vaccination.

One person in our closed reviews died from Covid-19.

Number of Health Conditions

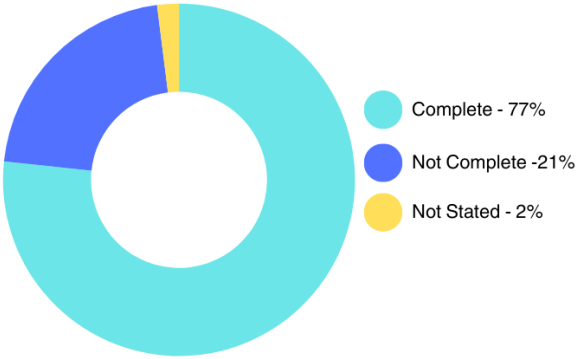
47% of people had 2 health conditions

33% of the people had 5 or more health conditions

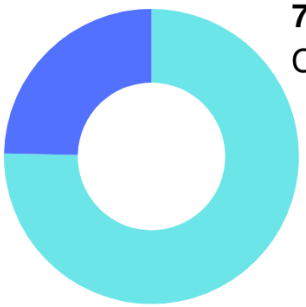
A minority of the population had less than 2 health conditions or no health conditions recorded

Annual Health Checks*

*Data accuracy may vary as it relies on the information provided to the reviewer



DNACPR



75% of deaths had a Do Not Attempt Cardiopulmonary Resuscitation decision in place.

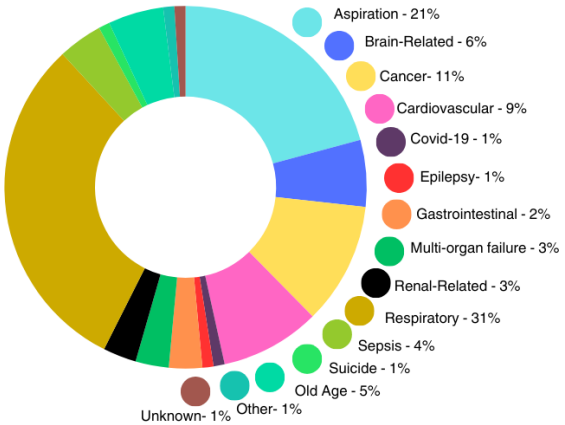
Causes of Death Demographics

31%

31% of people died from respiratory related causes.

The top five causes of death were:

- Respiratory
- Aspiration
- Cancer
- Cardiovascular
- Brain-Related



Gender

The gender of the cases notified to the LeDeR service are as follows:

Table 2: Gender of deaths of notifications received.

	Gender		
	Male	Female	Not Stated
Bradford District and Craven	39% (n=17)	59% (n=26)	<2% (n=1)
Calderdale	50% (n=6)	50% (n=6)	
Kirklees	34% (n=10)	66% (n=19)	
Leeds	49% (n=27)	51% (n=28)	
Wakefield	47% (n=15)	53% (n=17)	
TOTAL	**44% (n=75)**	**55% (n=96)**	**<1% (n=1)**

Age

All the average age of deaths relates to adults only, over the age of 18 years. From the notifications to LeDeR in the reporting period 2023/2024 this was for males averaging 56 years while females average 60 years. We have seen a slight decrease in comparison to 2022/2023 LeDeR. While this may be explained by external factors, it is important to note that not all deaths of people with learning disabilities are notified to the LeDeR programme, which means that smaller numbers can sometimes show large 'swings' from year to year.

The average age of death across West Yorkshire can be seen below:

Table 3: Average Age of Death for people notified to LeDeR Across West Yorkshire

	Gender	
	Male	Female
Bradford District & Craven	53 years	54 years
Calderdale	55 years	70 years
Kirklees	54 years	56 years
Leeds	61 years	64 years
Wakefield	52 years	60 years
TOTAL	**56 years**	**60 years**

In comparison to the general population and those with learning disabilities nationally: *Table 4: Average Age of Death Across West Yorkshire in Comparison to National Learning Disability and UK General Population Average Mortality Age*

	Gender	
	Male	Female
Notifications to LeDeR 2023-2024	**56 years**	**60 years**
Learning disabilities nationally*	63 years	63 years
UK general population*	83 years	86 years

**data taken from the LeDeR annual report 2023: Master LeDeR 2023 (2022 report) (kcl.ac.uk)*

Despite our average age of death falling significantly short of the national average we do also receive notifications for adults who have an age of 65 years or above at the time of their death which may indicate the right care, at the right time in the right place.

Table 5: The number of notifications received for people over the age of 65 years by place and West Yorkshire overall.

65 years and over					
Bradford	Calderdale	Kirklees	Leeds	Wakefield	West Yorkshire
10	9	10	18	7	**54**

Ethnicity

When reporting deaths to LeDeR, ethnicity is not always recorded for all people at the point of notification into the LeDeR National Programme therefor there is more reliance on GP records providing this data for all their patients. West Yorkshire has an ethnically diverse population with according to the latest census data has 373,000 people identifying as from an Asian, Asian British background. 72,000 identifying as from a black, black British, Caribbean, or African background and 65,000 identifying from a mixed or multiple ethnic groups. However as shown below in the breakdown of current notifications this diversity is not reflected.

Table 6: Ethnicity breakdown of LeDeR Notifications received in 2023/2024

Ethnicity	Number from LeDeR Notifications
Asian/Asian British	7% (n=12)
Black/Black British	<1% (n=1)
Mixed/Multiple Ethnic Groups	<0% (n=0)
White	86% (n=148)
Other	<1% (n=1)
Not Stated	6% (n=10)

Annual Health Checks

Table 7: Annual Health Checks from Closed Reviews

	Number from LeDeR Notifications
Annual Health Check Complete	83% (n=45)
Annual Health Check Not Complete	15% (n=8)
Not Stated	< 2% (n=2)

It appears that the number of people who have had an annual health check in the year prior to death has increased from our 2022/2023 data to 2023/2024 completed reviews data. The annual health check is a preventative measure, looking for potential causes of ill health and areas to intervene early, so an increase in numbers completed is to be applauded. Whilst we have seen the average age of death fall slightly in the 2023/2024 reviews, this may not

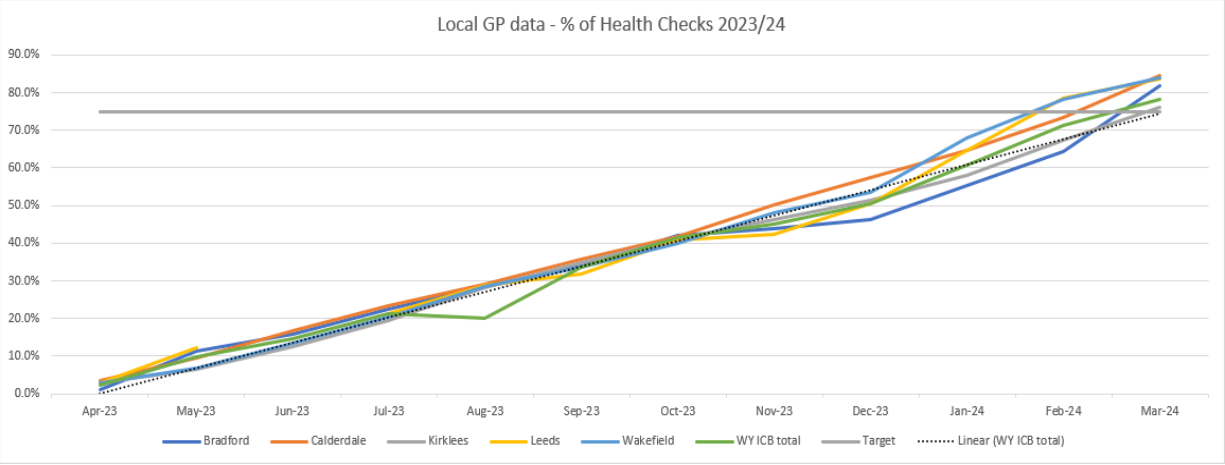
necessarily correlate with quality of annual health checks but potentially with causes of death that were not preventable, so these figures should be interpreted with caution.

The information sought to complete a LeDeR review is not the whole health record, and it is reliant on the level of details shared by record holders. Therefore, an annual health check (AHC) may have been completed by the GP surgery, but this information may not have been shared with the Reviewer. Table 7 shows the information available to the Reviewer and Table 8 shows the West Yorkshire ICB's published annual health check data for the reporting period. As you will see below 3 of our 5 places have exceeded the NHSE national target set of 75% giving a West Yorkshire total of 78.9%.

Table 8: Place and West Yorkshire overall published figures of completed Annual Health Check's (provided by Kirklees HCP BI)

NHS published figures March 2024			
HCP	**Completed Health Checks**	**Register**	**% Health Checks achieved**
Bradford District and Craven	3,813	4,733	80.6%
Calderdale	1,188	1,446	82.2%
Kirklees	2,475	3,386	73.1%
Leeds	3,609	4,334	83.3%
Wakefield	1,789	2,428	73.7%
WY ICB total	**12,874**	**16,327**	**78.9%**

Table 9: Progression of West Yorkshire's completed AHC across the reporting year.



The West Yorkshire Dashboard is now in place in respect of AHC which provides live data accessible by all five places enhancing monitoring, prioritisation, and progression in reaching consistent desired national and local targets. Work is continuing across West Yorkshire to improve the offer and uptake and the quality of the Annual Health Checks and ensuring patients are receiving a health action plan. Strategic Health Facilitators are key in this work providing guidance to practices raising awareness of reasonable adjustments and supporting implementation of these.

Causes of Death

The causes of death are officially concluded once the review has been completed and closed. When collating the information, the causes of death are put into a more generalised category as this allows the data to be more easily categorised into appropriate sections. The causes of death for the completed reviews are as follows:

Table 10: Causes of Death for 54 Completed Reviews from notifications received in the reporting period (Rounded Up or Down)

Cause of Death	Number of Causes of Death
Aspiration	22% (n=12)
Cardiovascular	7% (n=4)
Cancer	19% (n=10)
Gastrointestinal	<4% (n=2)
Brain Related Causes	5% (n=3)
Sepsis	<4% (n=2)
COVID 19	<2% (n=1)
Renal Related	<4% (n=2)
Respiratory	22% (n=12)
Multiple Organ Failure	<2% (n=1)
Old Age	9% (n=5)

Additionally, the causes of death for the additional 96 completed reviews from notifications received prior to the reporting period pre-1st April 2023 are as follows:

Table 11: Causes of Death for 96 Additional Completed Reviews notified Pre 2023/2024 (Rounded Up or Down)

Cause of Death	Number of Causes of Death
Aspiration	20% (n=19)
Brain Related Causes	6% (n=6)
Cancer	7% (n=7)
Cardiovascular	9% (n=9)
Epilepsy	<2% (n=2)
Gastrointestinal	<2% (n=2)
Multiple Organ Failure	<4% (n=4)
Renal Related	<2% (n=2)
Respiratory	38% (n=35)
Sepsis	<4% (n=4)
Old Age	<3% (n=3)
Other	<1% (n=1)
Suicide	<1% (n=1)
Unknown	<1% (n=1)

Our most common causes of death on both years are respiratory and aspiration, followed by cancers. Respiratory/aspiration has been replaced as the most common cause of death nationally in recent years but is still the most common in West Yorkshire – this was the driver for our West Yorkshire LeDeR learning event focused on respiratory health in December 2023. Cancer is becoming more prevalent in those with Learning Disabilities and/or Autism both locally and nationally – this may be reflective of difficulties in accessing routine screening and follow up care, but equally may be linked to increasing age of death and a move towards becoming more similar in death to the general population causes. This should be monitored as we move forwards and has prompted the theme of the second LeDeR learning event, taking place in July 2024.

Additional Health Conditions

When reviews are being completed, any additional health conditions are also noted. Additional health conditions are as follows:

Table 12: Other Health Conditions for 54 notified and completed within 2023/2024

	Number from LeDeR Notifications
1 Health Condition	17% (n=9)
2+ Health Conditions	48% (n=26)
5+ Health Conditions	35% (n=19)

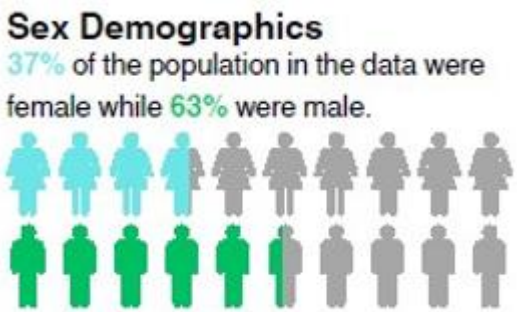
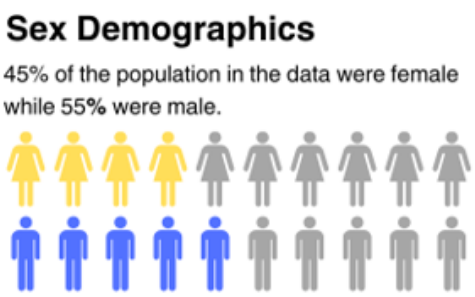
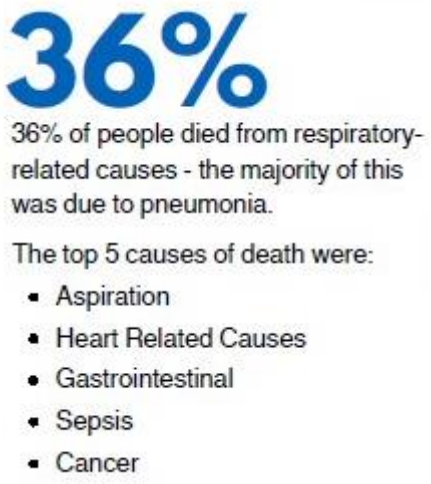
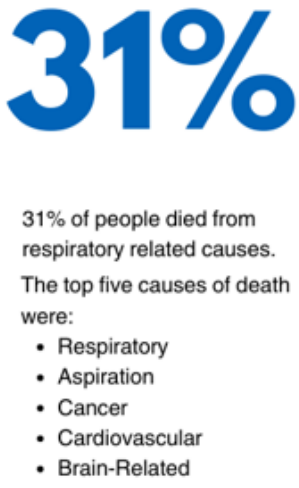
Furthermore, additional health conditions can be seen for the remaining 96 completed reviews:

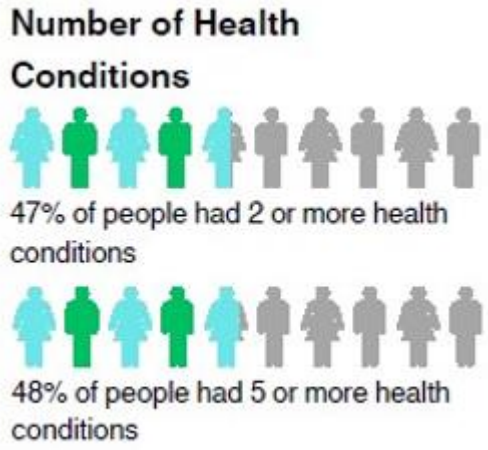
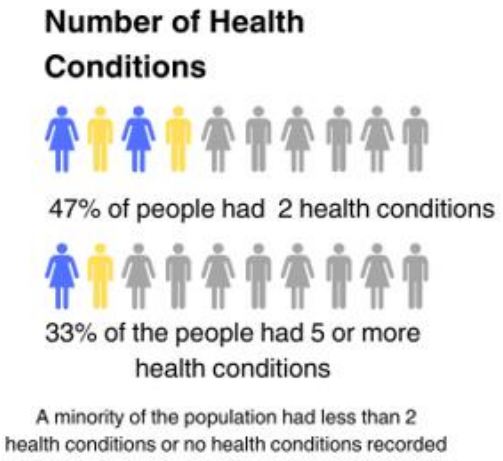
Table 13: Other Health Conditions for 96 completed reviews notified pre-1st April 2023

	Number from LeDeR Notifications
1 health Condition	16% (n=15)
2+ Health Conditions	46% (n=44)
5+ Health Conditions	32% (n=31)
Unknown	6% (n=6)

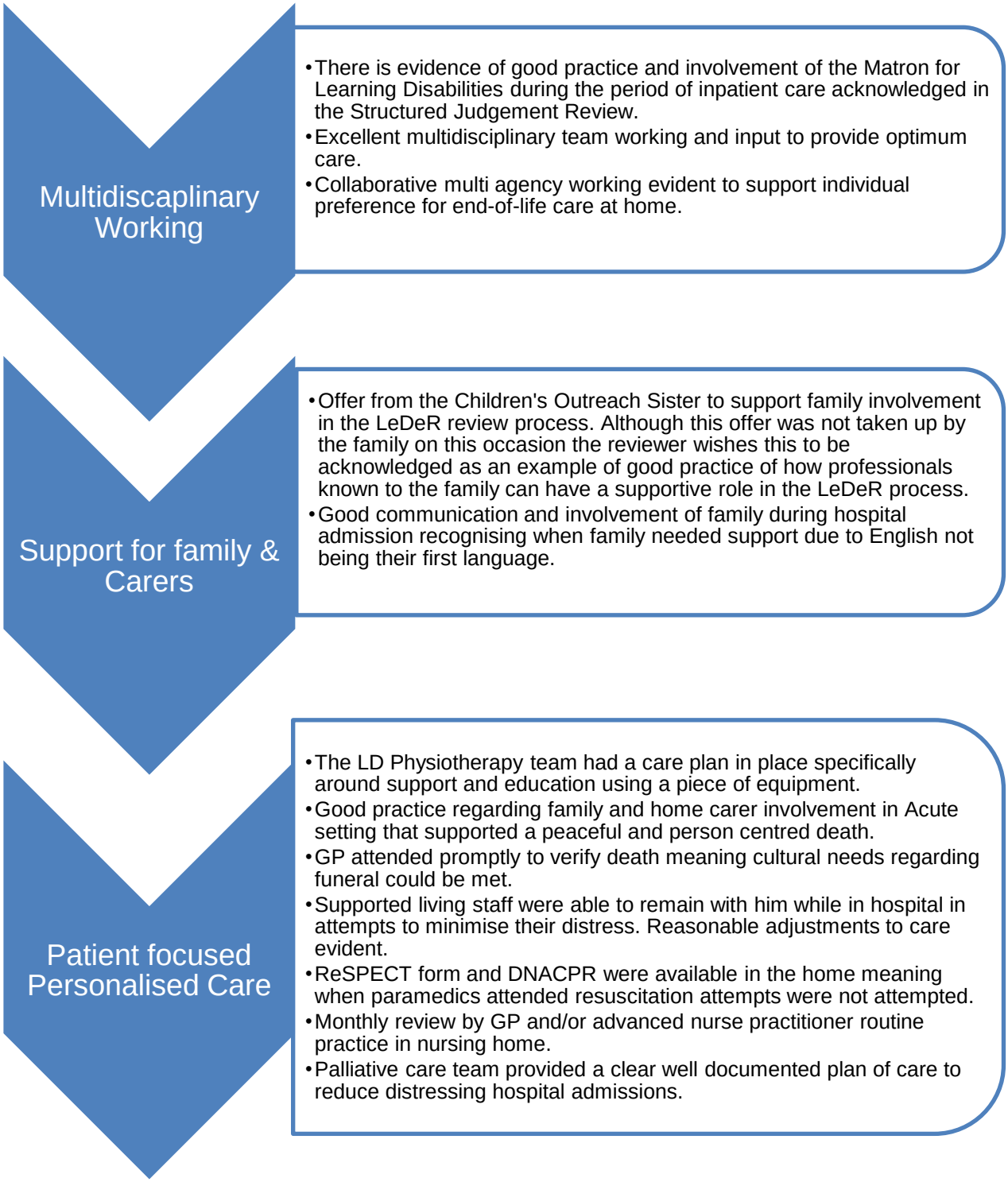
This data tells us several important things. Firstly, data quality is improving, and we are now able to say how many comorbidities are present for all those notified for a LeDeR review. Secondly, we can see that multiple comorbidities are extremely common in this population, a health state that we know can be associated with premature death and reinforces the need to support people to access annual health checks.

Below highlights some of the differences in the data from 2022/2023 LeDeR Annual Report data and 2023/2024 data.

2022/2023 data shows a significant difference between female and male population.	2023/2024 data shows a closer breakdown of female and male population. The latest national LeDeR data also showed 55% population of males [Master LeDeR 2023 (2022 report) (kcl.ac.uk)]().
	
2022/2023 data showed % of cancer related deaths within the main 5 common causes of death for the first time.	2023/2024 Shows that respiritory is still the most common cause of death but we can see the % of cancer is now within the highest 3 common causes of death. The latest national LeDeR data shows cancer as the 3rd common cause of death with respiritory the 4th [Master LeDeR 2023 (2022 report) (kcl.ac.uk)]().
	

2022/2023 data showed just under 50% of the population had either 2 or more health conditions or 5 or more health conditions.	2023/2024 data showed a significant decrease in the population that were known to have 5 or more health conditions.
	
2022/2023 showed 74% of the population received a COVID 19 vaccination and we had no recorded COVID 19 related deaths.	2023/2024 we saw a decrease of 4% in the population who received a COVID 19 vaccination, and we had 1 COVID 19 related death recorded. .
	

Good Practice examples highlighted by the Reviewers themed below.

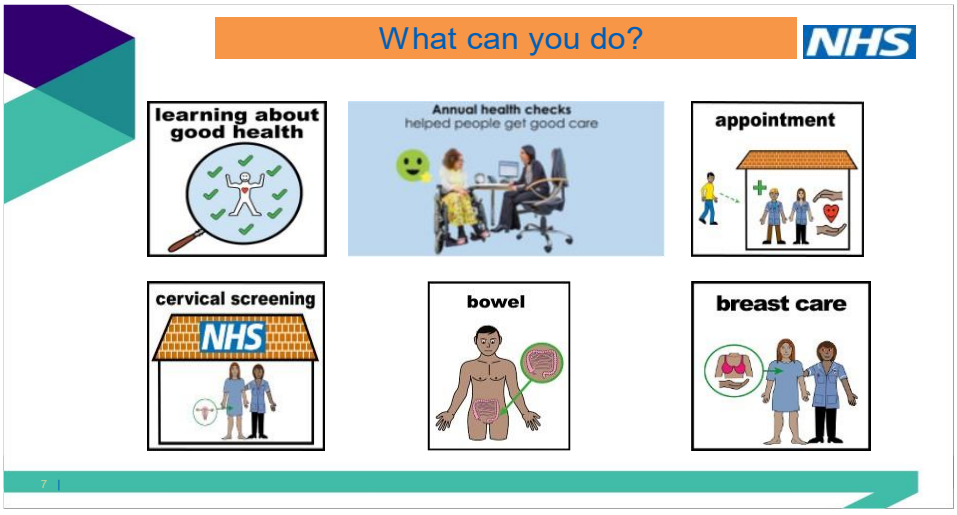


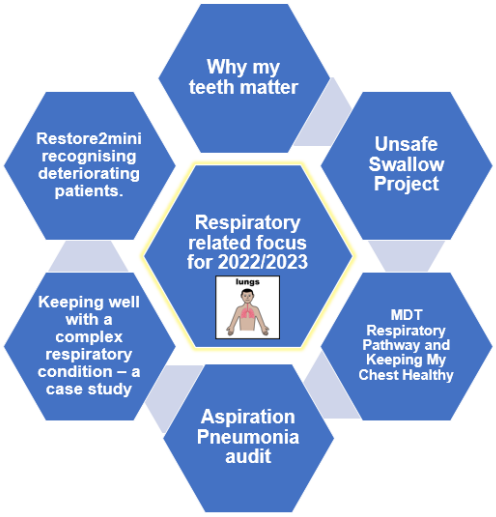
LeDeR Team Activities

The planned local introduction of the automatic inclusion for notifications falling within the transition period age 18-25 years to have a focused review completed is now in place. This will provide the opportunity for greater understanding and identification of requirements for service improvements were applicable.

In 2023 the team participated in events during Learning Disability Week which included our Reviewers been hosted by Airedale Hospital to raise awareness of the LeDeR programme as part of their local event. The LAC spent the day with colleagues from Leeds Health Care Partnership attending a Council Takeover where experts by experience showcased some fantastic co-production work. Then everyone participated in a pride march through the city centre onto a hosted event including VCSE, health and social care partners.

The LAC attended and presented at a Bradford Health Care partnership Cancer and wellbeing event attended by experts by experience, parents, carers, VCSE and health care professionals. This provided an opportunity to raise awareness of LeDeR, share the local LeDeR findings relating to cancer and the importance of attending annual health check health appointments and appointments offered for cancer screening.





In our 2022/2023 LeDeR annual report we found that we had a consistent picture across all five places within West Yorkshire in relation to respiratory related cause of death which attributed to 36% of the overall completed reviews with aspiration been recorded on the death certificate in a number of cases.

LeDeR hosted the first West Yorkshire LeDeR learning event focused on respiratory in December 2023. The diagram on the left shows the subjects covered in the presentations seen during the event. We had 50 attendees at the event including experts by experience who had been involved in co-production projects in Bradford and Leeds. The aim of the day was;

To bring people within our ICB, acute and community hospital trusts from all five places across WY together to facilitate networking. To share key findings from the 22/23 LeDeR annual report.
To focus on respiratory as our data from LeDeR reviews shows this is the largest cause of death across WY.
To learn what has been implemented at place-by-place representatives sharing their work to support people to live well.

It was a valuable day which enabled a system wide exploration of respiratory related illness and living well with respiratory illness to further inform our learning and reviewing interventions already put in place or in development some of which are highlighted within the place examples. Attendees were asked to participate in a place group discussion based on the presentation from the day to identify key things that they wanted to take back to place for further exploration and consideration. Below is the outcome of this group work.

Bradford & Craven

- Community development – think about preventative approaches – not unwell yet.
- Prescribing antibiotics (learning from SWYPFT case study)
- Explore data sharing across organisations at place

Kirklees

- Share ways of working and projects
- Use existing Easy Read information.
- Important questions in annual health check (AHC)
- Share videos on safe swallow

Wakefield

- Restore2mini –training to empower carers.
- Thinking about preventative approaches
- Share videos – use what's already been developed

Calderdale

- Restore2mini – cascade training for community health team
- Learning disability champions in primary care
- Importance of MDT approach
- Link with Active Calderdale around improving physical health.
- Additional questions in screening tools
- Align work with LD registers.

Leeds

- Share projects with LD Network
- Central repository for Easy Read information
- Include Restore2mini in annual health check template.
- Include LeDeR data and outcomes in local BI.
- CORE20PLUS5 – repository of information

LeDeR presentations including some in an accessible format have been delivered in several forums online and in person across West Yorkshire to raise the awareness of the programme and encourage notifications into the national NHSE LeDeR Programme. As well as ensuring it is known that LeDeR now includes adults with a diagnosis of autism without also having a diagnosis of a learning disability.

A LeDeR quarterly update is provided to our LeDeR place Leads for cascading at place. This is in addition to the operational position statement that continues to be shared monthly with LeDeR place Leads. Feedback from professionals and experts by experience have been shared with the LeDeR team and a number of improvements to the infographics have been made as a result such as the colour scales and shading of whole figures only.

Our 2022/2023 LeDeR Annual Report is now available in easy read and can be accessed via our updated LeDeR web page on the West Yorkshire Health Care Partnership website via this link; The Learning Disability Mortality Review (LeDeR) - Learning from Lives and Deaths :: West Yorkshire Health & Care Partnership (wypartnership.co.uk)

Oliver McGowan Training Update

Background

In November 2019, the government published *'Right to be heard'* which included a commitment to develop a standardised training package for learning disability & autism care, drawing on best practice, the expertise of people with a learning disability, autistic people, their family and carers and subject matter experts.

From 1 July 2022, a requirement was set out in the Health and Care Act 2022 for CQC registered service providers to ensure their employees receive learning disability and autism training appropriate to their role. This is to ensure the health and social care workforce have the right skills and knowledge to provide safe, compassionate, and informed care to autistic people and people with a learning disability.

The Oliver McGowan Mandatory Training on Learning Disability and Autism (OMG) is the standardised training that was developed for this purpose and is the government's preferred training for health and social care staff to undertake. It is named after Oliver McGowan, whose death shone a light on the need for health and social care staff to have better training. See links below for further information.

Paula McGowan: The Oliver McGowan Mandatory Training on Learning Disability and Autism - YouTube

The Oliver McGowan Mandatory Training on Learning Disability and Autism - YouTube

OMG was co-produced, trialled, independently evaluated and must be co-delivered by a trio, including a facilitating trainer, a trainer with a learning disability and an autistic trainer who are paid for their involvement.

Training Structure

The Oliver McGowan Mandatory Training comprises of all staff being asked to undertake a 90-minute e-learning that is found on ESR training systems. Then staff area asked to attend a Tier 1 – part two 60 minute live interactive webinar if they do not have contact with service users/patients. The 60 minute live interactive webinar is general awareness training for people who may have never had contact with an autistic person or a person with learning disabilities.

If staff have contact with service users/patient's, they are asked to also complete the 90-minute e-learning but are then taken forwards to complete a face-to-face full day classroom training called Tier 2.

NHS West Yorkshire ICB have been able to procure and contract with two advocacy groups to deliver the second part of the Tier 1- Oliver McGowan Mandatory Training. The second part of the Tier 1 comprises of a one hour long interactive webinar delivered by people with lived experience.

The two advocacy groups that are delivering this training now have 2 sets of trainers known as "Trio's so 4 Trios are established – two with Inclusion North and two with Cloverleaf and their names and details are published on the following website to confirm that they are approved trainers.

Leeds Teaching Hospital Foundation Trust also have an established Trio to deliver the Tier 1 – 60 Minute Webinar.

OFFICIAL - PERSONAL - Website upload - approved trainers_0.pdf (hee.nhs.uk)

Delivery of the Webinars

Since November 2023 to March 2024 Inclusion North have offered for a total of 525 places for staff across West Yorkshire to attend webinars. Each webinar can accept up to 30 staff joining the webinar session. Over that period of time 295 staff across West Yorkshire have attended the training. Their contract ends July 2024.

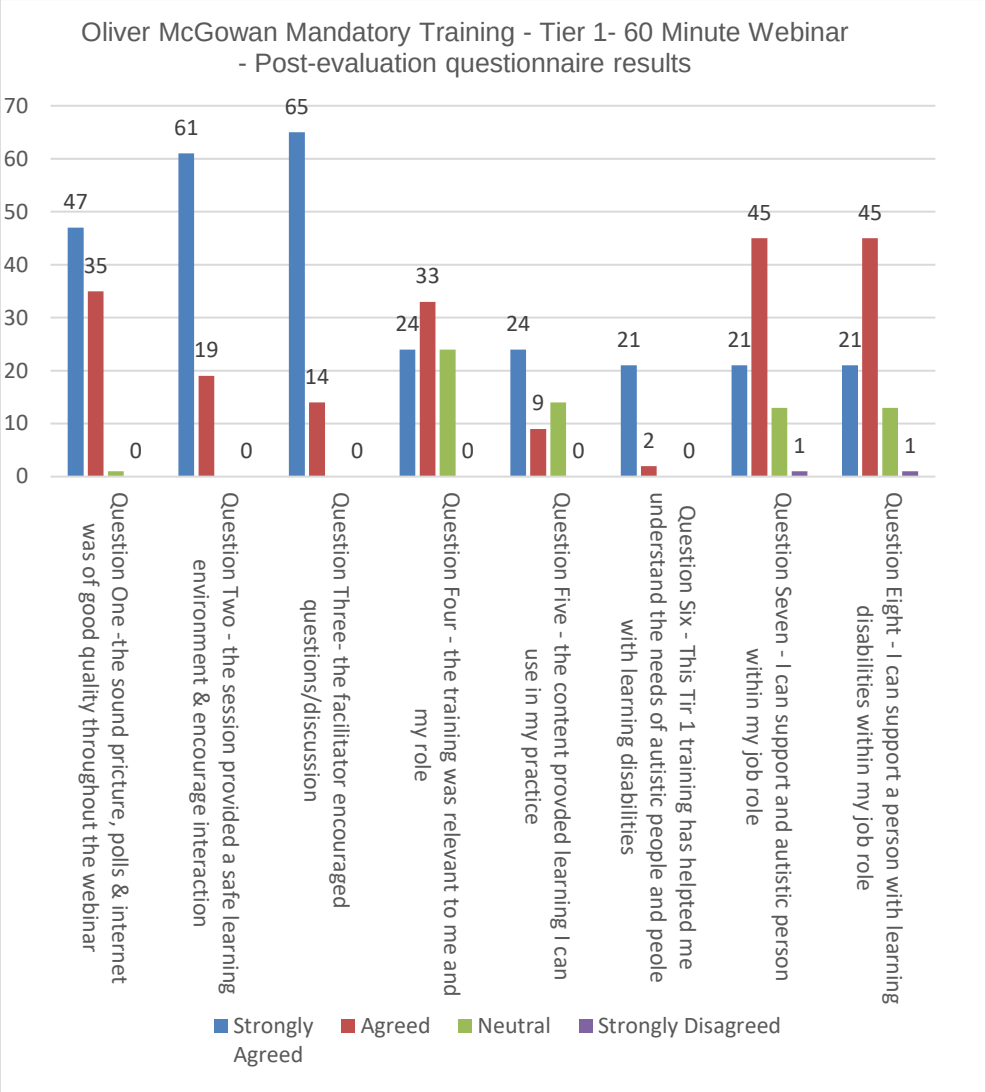
Cloverleaf the second advocacy group that have been contracted to deliver the webinar have commenced in March 2024. Cloverleaf are contracted to deliver 6 sessions a month until February 2025

Cloverleaf delivered 2 webinars in March 2024 and 2 webinars in April 2024 out of a total of 120 places 120 staff have attended.

Post-evaluation Questionnaire

Inclusion North have provided information back from the questionnaire filled out by 83 respondents over the November 2023 to March 2024 period.

The results are as follows:



Respondents were also able to leave comments on the questionnaire form. A snapshot of that feedback is below:

- Great presenters and really thought provoking.
- The joining instructions needed to be clearer – I registered and had confirmation that I had done so but still could not get on the call until I registered again. The Eventbrite automatic emails were unclear and need to be edited and tailored to include the MS Teams Link.
- I think the e-learning module would have been helpful to re-visit Oliver McGowan's case to link the opportunities for reasonable adjustments to his case/life and death to really bring the opportunities to save his life to the fore. I realise you may not be able to alter the content of this session.
- Diversity & Inclusion – Representation from minoritized communities as there is a diverse population across West Yorkshire.
- Both delivery and facilitation were perfect.
- I enjoyed the polls and would have liked to see some more.
- Great webinar, great presenters.

- I think the ask, listen, do was a major takeaway. So simple yet so powerful, which can be used in everyday life.

Tier 2 – Classroom Training

In terms of developing an infrastructure around the delivery of the face-to-face full day classroom training known as Tier 2. West Yorkshire now has 3 Lead Trainers – 2 in Bradford and 1 in Leeds. They have attended a 4-day training event and are now able to train the people with lived experience and a facilitator who can then deliver the classroom training.

At this point in time a classroom training offer is not in place. A decision has been made through the West Yorkshire Working group to adopt the "anchor" model. This is where each geographical place is awarded a percentage of funding pot to develop an offer across the health and social care partnerships in their geographical place. It is hoped over the next year that the classroom training offer will be made at place.

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The Mental Health, Learning Disabilities and Autism Programme

To support the learning through the LeDeR programme, we launched our Learning Disability Challenge in 2023, sharing our work in transforming care for people under the themes of Start Well, Live Well , Age Well and Working with People with Learning Disabilities.

This animation describes the work of the Challenge.

Across West Yorkshire we have a Mental Health, Learning Disabilities and Autism programme that supports our system's big ambition to reduce the gap in life expectancy between people with mental health conditions, learning disabilities and autism and other neurodiverse conditions, and the rest of the population. Our Learning Disabilities workstream has a number of objectives relating to the support for LeDeR. This includes delivering our Learning Disabilities and Autism Health Inequalities Challenge by developing a West Yorkshire dynamic communication hub with shared access to local resources, information and success stories, coordinating allocation of resources relating to roll-out of Oliver McGowan Training, supporting providers to expand how they identify people with Learning Disabilities and or Autism on elective waiting lists and identifying what can be 'done once' to ensure people with Learning Disabilities or Autism have equal access to better quality housing and employment.

Below are just some examples of actions to address Health Inequalities Across West Yorkshire

Calderdale

Calderdale continues to benefit the weekly **Learning Disabilities Action group** meetings. The partnership working has extended to a much wider group and multi agencies closely working to improve the acute and community learning disability services in Calderdale.

Calderdale has achieved above the expected 75% national target at 86% for **annual health checks**. Significant amount of work has been focused on awareness training to all GP practices by the strategic health facilitator and support from the advocacy network. There is also an increase in **learning disability champions in primary care** and they work closely with the strategic health facilitator.

This year we have done **Deep Dive** for LeDeR which was presented to Calderdale Care Partnership Quality Group. The Quality Committee was asked to note the content of the report from Calderdale place and the specific data and local work to improve quality, experience of care services and promote inequalities for people with learning disabilities and autistic people.

Calderdale has data sharing agreement with GP practices for the **alignment of register** which helps in data sharing for LeDeR reviewers. This is an ongoing alignment of learning disability register to ensure any changes are captured.

Calderdale took part in **WY Learning in Action Event** with focus on Respiratory as the top cause of death following LeDeR report. Calderdale presented a case study, talk about aspiration and swallowing risk, and provided various information/leaflets at the event in December 2023.

The roll out of **Restore 2** mini training to nursing, residential and supported living homes in Calderdale has supported the care for people at home to detect any difficulties early and to reduce admissions to hospital. This is recommended by LeDeR and through use of this tool, the Yorkshire and Humber Improvement Academy would be able to support and be a point of resource.

Calderdale has continued to support through the **Core 20+5** funding the Living well project commissioned to Lead the way who helps in supporting GP awareness training, wellbeing café and health projects where advocacy network closely supports individuals for awareness and encouragement.

For the last two years Calderdale have also funded the **Booking and Prioritisation project** by CHFT. They have developed KP+ such as Emergency care standard, outpatient DN's, cancer faster diagnosis standard, % of patients waiting less than 6 weeks for diagnostic test and patients waiting more than 40 weeks to start treatment. They have developed a business intelligence system, generate dashboards for analysing data through a health inequalities perspective. The focus has specifically centred on learning disabilities, IMD (index of multiple deprivation) 1+2, and ethnicity. Within KP+, it has implemented a robust flagging system for

learning disabilities, enabling to segregate and compare data against the general population and undertake deep dive audits and review disparity.

Earlier in 2023 an **Innovation funding** has given an opportunity for Calderdale Community Learning Disability Health Service led by the strategic health facilitator to create learning materials such as an easy read booklet, VIP wallet size cards and training materials. These were shared across the primary care services in Calderdale.

Active Calderdale partnership work with local authority to coordinate in improving access to physical activity. Two “Enabling People with Learning Disabilities to be active” workshops have already taken place in the last 12 months. The common purpose is to advocate people to keep moving and being active which for people with learning disability can help improve their physical health, mental health, social development, and individual development. This has linked well with the actions following the LeDeR focus reviews which highlighted cases for those who are morbidly obese as one cause of death.

Wakefield

Wakefield LD week Health events, The specialist LD team hosted two events. Supported by the full MDT and external stakeholders. Sharing information on Screening, hate crimes and sexual health, offering de-sensitising and de-medicalising access to secondary health services. They utilised a PROUD board to engage participants.

To increase the notifications of a death to LeDeR PCN’s run a monthly report of the deaths of patients over the age of 14, who are on the LD register and who have autism. Then check if a notification has been made, if one has not, they will notify the deaths to LeDeR for all people 18 years and over. This will give us accurate data across our district, to enable us to focus work streams accordingly.

Livewell Wakefield Core20PLUS5 Social Prescribing Project- Supporting patients to attend their appointments - Peer Support Volunteers will take a personalised approach, this may include, aiding understanding of public transport, overcoming literacy issues, or reducing anxieties to attend their appointment.

Vaccination Easy read guide to the pneumococcal vaccine - we requested help from the Strategy & Transformation Directorate at NHS England to produce an easy read guide, this has been shared widely across the district.

Learning disability Special interest group in primary care -Primary care staff who have a role or an interest in improving access and care for patients who have a learning disability, to come together bi-monthly to share best practice.

The ACE program Achieving Change through Engagement – Continues to facilitate webinar sessions, these have now also been included on the West Yorkshire training hub.

Yorkshire Ambulance service will be working with the Patient experience group PEG to share their Learning Disabilities & Autism Project, to support patients know “which service to call” 111 or 999.

Primary care health inequalities group Had a presentation on health inequalities in marginalised groups, who are themselves facing health inequalities, to broaden the discussions to meet these challenges.

Me and Menopause course Meno health and Coactive delivered sessions for women with learning disabilities.

Personalised care Members of “stronger together” who have a Learning Disability did a webinar on Reducing health inequalities for people with Learning Disabilities, show casing the **VIP Hospital passport** and **Red Bag scheme**. This is stored on Future learn.

Bowel Screening, We continue to work on the NHS Bowel Screening program. Sharing with Primary care and social care providers the new symptomatic faecal fit test, to enhance the offer.

Health champions in social care Learning Disability Nurses facilitated a session for social care providers, on the bowel screening. This has led to discussions around Health champions in social care settings, and more regular sessions being offered.

We deserve better: People from an Ethnic background with a learning disability and access to healthcare -We are starting to map out local groups, to connect with people from ethnic minority communities, to share information and build relationships.

LeDeR respiratory event 8th Dec We joined the West Yorkshire LeDeR Respiratory best practice event to showcase the working of our respiratory physiotherapy team and hear of the amazing work that is being undertaken across the wider district, to learn and implement new ways of working.

Learning taken from a focused review and shared by place in local professional forums-Issue: This person had a hospital passport however there is no evidence that this was kept up to date by those involved in her care and support.

An up-to-date hospital passport could have included information about Speech and Language Therapy recommendations and feeding preferences to make these available to hospital staff on admission.


NHS
The Mid Yorkshire Hospitals
NHS Trust

MY Hospital Passport

Please take your completed hospital passport when you go to hospital and share it with the hospital staff. Please ensure this passport is updated if your needs change.

This hospital passport will help you to communicate your needs and can be used by any patient with a complex need.

About me

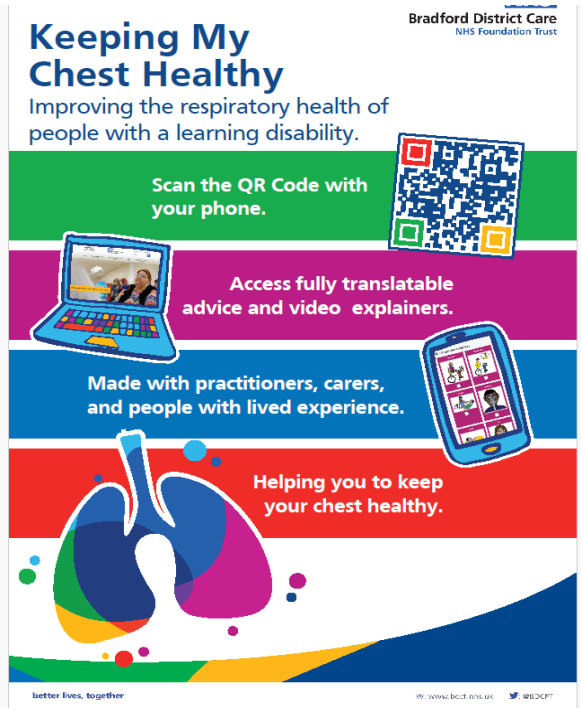
a hello my name is...	My name is: I like to be called:
	My address is: My telephone number is:
	My religion is: My ethnic background is:
	Things I like to do and talk about:

1

Learning: Responsibility for keeping hospital passports up to date should be identified as part of the individual’s care plan.

Bradford District and Craven

The Respiratory pathway for people with learning disabilities and the digital app Keeping My Chest Healthy are now live and have been shared locally and nationally. The digital app is a free app that can be downloaded from the QR code below and is accessible to people with learning disabilities and their support networks. It is available in different languages and shows people how to use equipment that they may have been provided with and tips for keeping healthy and well. People with learning disabilities who have difficulties with their respiratory health have been involved in the development of the resources and have been a key part of the production of the work.



Cancer screening related work The Bradford Learning Disabilities & Cancer group ran an event in October bringing together people with learning disabilities, carers and professionals involved in the cancer screening world to network and share information. The cancer screening uptake for those on the learning disabilities register has improved by a very small amount since last year and this may have helped with this.

Leeds

Strategic health facilitation team GP support has improved our figures of AHC uptake. As of April 2024, the data showed that our uptake of AHC stood at 85.4% uptake. The Health Facilitation Team have directed more of our support to practices who usually have lower uptake of AHC. This included a full and holistic review of the patients on the register, a review of the process of calling patients in, training practice staff, communicating with patients and the empowering a positive approach to meeting the Accessible Information Standard and The Equality Act, engaging patients before and after the AHC. Our Ten Steps to AHC success are

used as a framework to ensure that the needs of the service user are considered when the practice is building its operating procedures with regard to this offer.

Menopause booklet we are proud to say has been a collaboration with both professionals, families, and people with lived experience. The booklet aims to support people to document their experiences so that a positive clinical review can be made of the symptoms and the issues can then be addressed. Clinical review should ensure our client group are being supported appropriately to engage and communicate with

Restore we continue to offer training and equipment to monitor health and improve communication. We have now trained x number of staff, carers, and families to manage clinical readings and escalate concern.

Bowel screening pathway We started to offer a more patient centred approach to bowel screening. We are awaiting figures to highlight any improvement but have attached our highlight report slides to this email.

We have started a breast screening pack for GP practices to improve uptake for people with a Learning Disability. This includes s step by step guide of the pathway, suggested script for patients who have not attended for screening and accessible supporting documents such as easy read invitation and top tips. We are hoping to roll out this pack to GP practices within the next couple of months.

Physiotherapy We have recently updated our respiratory pathway as a result of last year's LeDeR report. As respiratory issues were the leading cause of death and avoidable deaths, we have updated our respiratory pathway to try and avoid hospital admissions, as we noted that most of the avoidable deaths occurred there. We have introduced a new assessment form, this is already helping identify if people need further investigations, for example we have had a service user who was being admitted to hospital with aspiration pneumonia, it turns out that this only happens after vomiting and is now undergoing further assessment to find the reason for vomiting. We have upskilled and can now offer suction training to carers who need this, as we had identified a gap in the Leeds area. We have put in place monitoring forms; this is allowing us to see if our treatments are of benefit and is also allowing us to gain peoples baseline. From the monitoring forms the information as allowed us to put together a one-page profile that can be sent into hospital along with the hospital passport. This give them information about what their baseline respiratory health is like and then a picture of how they present went becoming unwell.

Learning Disability Leeds Community Health We noticed that carers did not always know what red flags to look out for related to respiratory health, so we have put together an easy read red flags document and added the restore information on. we are also going to seek permission to share their detail so that training can be offered.

Development of the LD Hub internal intranet page for staff to access information and guidance relating to LD Presentation with video and awareness session produced for engagement team to ensure they understand the principles of ASK/Listen /Do who will now lead this initiative. Presentation produced and will be shared with all staff working in the engagement team to improve their skills and knowledge on the initiative of Ask / listen / DO. This is an

excellent way to ensure we meet the needs of people with a learning disability when contacting our organisation.

Development of the accessible complaints form & close working with the 'Ask Listen Do' champion to help make the complaints process more accessible and user friendly for people with Learning Disability Accessible complaints form and adapted process for complainants with LD recently been rolled out and is currently being trialled by the patient experience team. This is an excellent way to ensure that patients with LD and those who may have limited comprehension or difficulty understanding complex language, are able to engage with the complaints process and understand this and know what to expect. It also empowers the staff and patient experience officers who are managing the calls to better deal with people who may have limited understanding or communication.

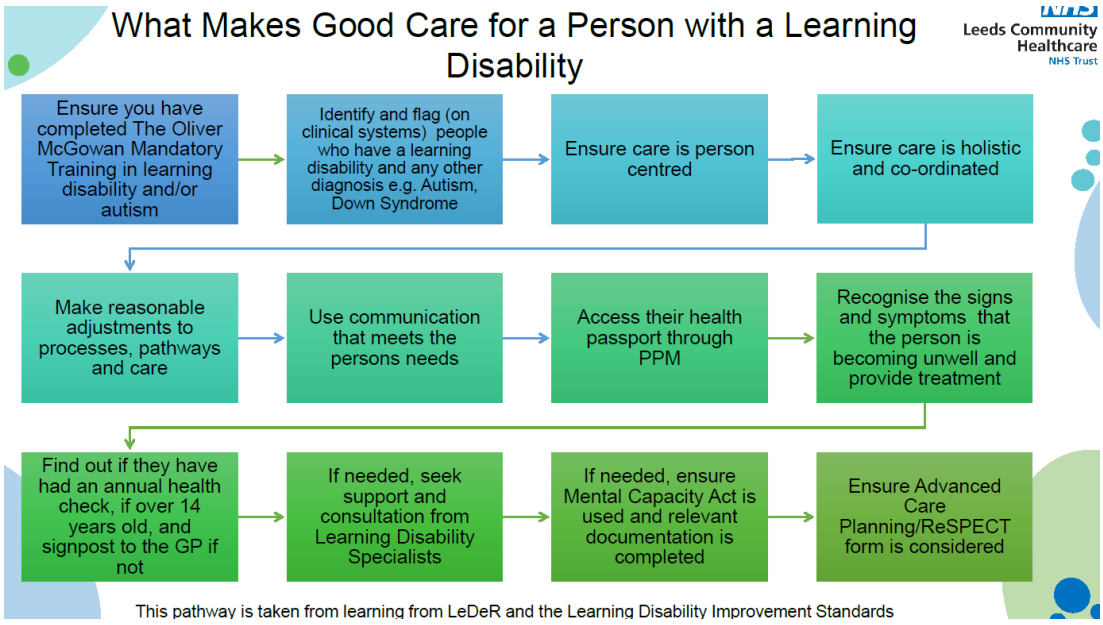
Increasing accessible information across the Trust Accessible information is increasing across the trust in both clinical information and information about services. We currently have 3 completed leaflets and 30 are in process. These are developed with clinical staff and people with a learning disability through an increased attendance and connection with groups held across the city. [progress towards LeDeR objectives of improving quality of care and reducing health inequalities]

Development & roll out of Easy Read COPD "keeping me well" booklet The COPD easy read document which has been rolled out for use within community respiratory and nursing services is a way of helping people with an LD or their carers to be more proactive in their care and helping them to better understand their early warning signs and know when to escalate/ seek further advice, care and treatment. This is a fantastic way of ensuring people with limited cognitive understanding are able equipped with information in an accessible format which is easy for them to understand and navigate their own care and seek early intervention when required.

Reasonable adjustments made to mortality process Following a review of the trusts mortality process it was noted that we do not review care if the person with a learning disability and or Autism has been admitted to hospital for 24 hours or more. For the next year following a person's death, the teams will review the care the person had. The Learning Disability Lead will then review for themes and consider any areas where improvements can be made.

Awareness raising Awareness of the LD Hub, the LD Lead who can offer consultation, accessible information, health passport and annual health checks are all raised through the launch of Learning Disability Champions, the quarterly newsletter, and a session at preceptorship events. These can be discussing peoples experience, culture, how care should be, access to care and sharing of improvements.

Development of the "what makes good care" flow chart below as a direct result of LeDeR outcomes and findings from the LD standards benchmarking. A flowchart to support staff when working with people with a learning disability available on the LD Hub and as a printable document for staff to keep available. The process can be followed when working in all services and also has headings that can be used when reviewing care under the mortality process.



Some of the key Achievements in 2023/24 from Leeds Teaching Hospital NHS Trust (LTHT) The work of the team continues to be recognised nationally, with multiple invitations to share best practice at conferences and most recently presenting at NHSE's HOPE (Patient Experience) network and also finalist for National Learning Disabilities Awards.

Desensitisation work has re-commenced as part of our post pandemic recovery strategy. With our clinicians working 1:1 with patients to enable them to access healthcare, often combining procedures.

Virtual Reality Headset We have successfully trialled and hired headsets to help with distraction and refocus for patients. This has enabled care without the need for sedation/ elective theatre bed. LTHT is the first Trust to achieve this for adults with Learning Disabilities and this success has been show cased nationally.

Emergency Department Care Bags the team has received additional funding for these, and the bags are currently being upscaled to all emergency admitting areas with 1000 care bags been given out. Fifteen other Trusts are now using care bags these have also been presented to regional and national education sessions as an example of good practice.

Accessible Leaflets/Letters this work continues to grow, with over 100 leaflets now live. The leaflets target key risk areas and LeDeR identified themes such as constipation and pneumonia also local incidents and national themes, for example pressure damage and respiratory care. The impact of the leaflets is also noted, for example with a reduction in falls following the introduction of an accessible falls leaflet. The leaflets continue to be coproduced and discussion is ongoing regarding future funding.

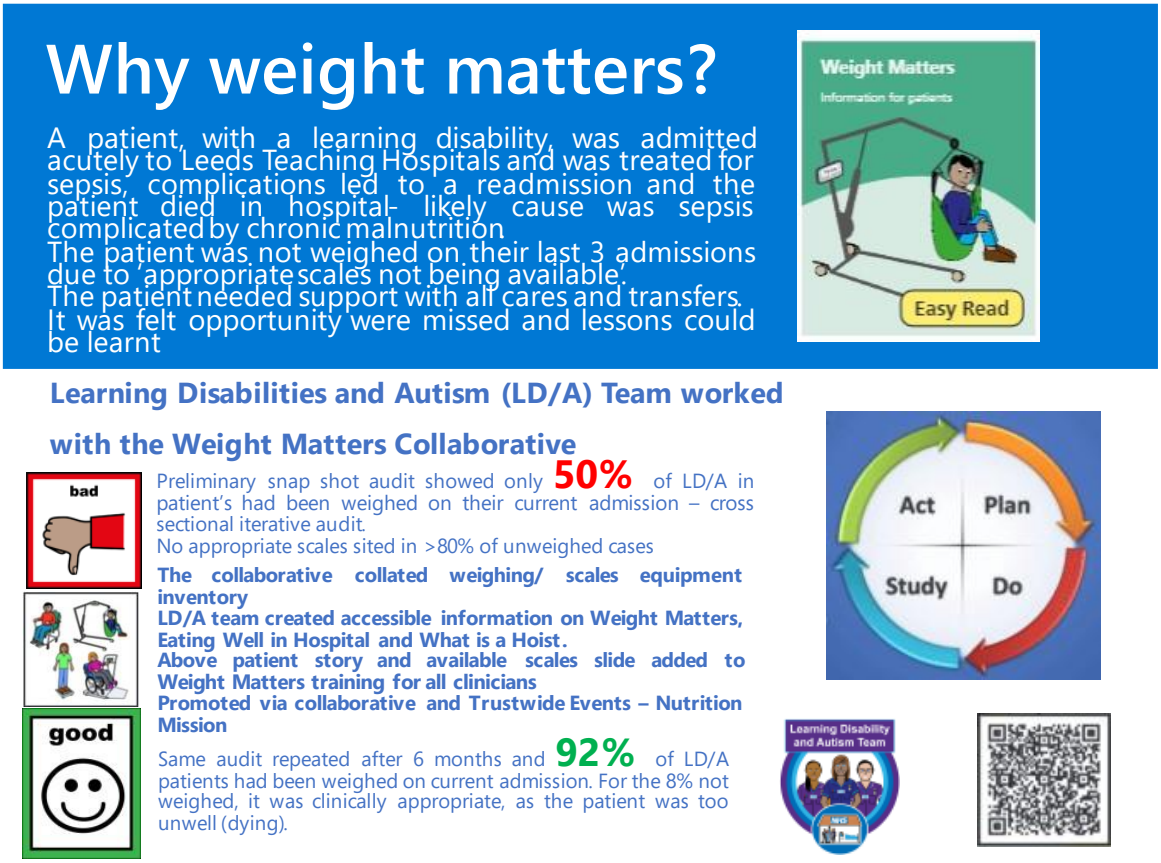
Elective recovery planning the PerCEPT (person centered planning tool) for patients is now ready to launch once the flags for Learning Disability and Autism have been shared. This will allow for improved planning so that hopefully our patients successfully access elective care, first time.

Audit/ Benchmarking The annual quarter 2 audit was completed and outputs from this will be presented to the quarter 4 Learning Disability and Autism Steering group. The benchmarking annually shows improvements to training figures, information sharing via health passports and a reduction in emergency department reattendance within 7 days.

Data Sharing there are now working agreements with partners completing Autism Diagnosis across the lifespan and this has contributed to the increase in flagged patients. Work is ongoing with the neurodevelopmental paediatricians to consider a similar arrangement for Learning Disability diagnoses. Data within the Trust is also improved following the reduction of a number of codes generated by having a single code for Learning Disability and a single code for Autism.

Health Passports Health passports are now live for Learning Disability and Autism; these were coproduced and have been noted to improve patient care. The next step for this project is for a version to be shared which can be completed online. The passports are shared proactively for people deemed likely to attend hospital, with a new agreement that people on the citywide Dynamic Support Register will be offered these.

Why weight matters? is an example of direct learning into action from a focused LeDeR review resulting in the development of this patient focused improvement work to ensure that patients are weighed on each admission to hospital.



Kirklees

Project 1: Introduction of social prescribing link workers (SPLW) – to all PCNs

Aim / objectives: Those included on the primary care LD Health register are supported to have a 'holistic *What Matters to Me* conversation' with the practices allocated social prescribing link workers. With the aim of promoting and or maintaining positive personal health & social interactions

Case study: 33-year-old male patient, lives alone, has a LD and history of drug misuse. Also identified with respiratory condition, possibly secondary to drug misuse.

Lung function test was identified as poor for an individual of this age as AHC.

Additionally, he found attending new places & meeting new people, independently challenging.

Expected Outcomes: Through the session with the SPLW individual set some goals to 1. increase their physical activity levels. They identified that they had previously done more exercise and enjoyed it, 2. hoped he could increase his social activities, with a different group of people – away from substances, 3. Improve his lung function reading.

Achieved Outcomes

1. he was supported with a referral to the KAL Fitness for Health Scheme & registered on the breathe easy scheme.
2. The SPLW attended the first 4 sessions with him to increase his confidence & he is now regularly attending the KAL sessions (with the help of text prompts/reminders) & meeting with his KAL coach at the centre & is enjoying them.
3. There was a recorded improvement on his last lung function test.
4. He has reduced his substance misuse activity.

Project 2: Supporting specialist care homes – Admission Avoidance – via specialist community Profound Multiple Learning Disability Nurse

Aim / objectives: to reduce hospital admissions in people who have a profound and multiple learning disability, living in nine Specialist LD care homes in Kirklees. The average age of the identified clients - 30years

Case study.

- The project included 9 care homes for people with a profound and multiple learning disability across Kirklees.
- The hospitals admissions wards, discharge teams, community teams, epilepsy teams, palliative care were included,
- Cases were identified where individuals had, had 4 or more admissions to hospital in the previous 12 months.
- The project was performed with a 360-degree review of all services, the care homes, including residents, family, nursing, and carers.

Expected Outcomes: To determine how avoidable hospital admissions could be reduced,

- Establishing baseline information on the use of services, hospital admissions, use of NHS 111, Urgent Community Response usage.
- Providing increased support to the care homes
- Developing models of anticipatory care,
- Developing models for timely supported discharge.
- Building awareness of the range of community services available,
- Supporting development of a network of care homes to enable shared learning.

Achieved Outcomes

- The specialist nurse was able to advise with common, recurring health issues & problems, and updating care plans; supporting the completion of mental capacity assessments and supporting home to identify and make reasonable adjustments.
- accessing specialist equipment, epilepsy alarms and invasive use of epilepsy monitoring.
- The specialist nurse will advise and support onward referrals to appropriate professional, regarding medication and management, follow up on certain health conditions and return to the GP to check on necessary follow ups.

Next steps

The project has been successful in identifying areas where additional training and guidance is required to make a further difference to support residents and potential further reductions in admissions.

Further action for Epilepsy care planning and management, and infection prevention and control with the potential use of / immediately available antibiotics for repeated infections could prevent admissions with short lengths of stay.

Some examples of issues/learning identified by Reviewers

In reviewing all of the identified learning from the 150 reviews completed which consisted of 115 initial and 35 focused reviews the following recurring themes were evident. Mental Capacity and End of Life are consistant themes from our last report with the additional these highlighted below. We would ask for consideration to these findings by all working within West Yorkshire with adults with learning disabilities and or autism in service improvement initiatives, resources and training packages;

Issues in obtaining blood samples	Engagement with screening	Weight management	Mental Capacity Act	End of Life (EoL)
We have noted within several completed reviews reference to people requiring blood tests and there been delays in this been achieved. This can be for a number of reasons, we have seen evidence of a lack of co-ordination or expectation of the family to make arrangments with their local hospitals and in some cases this is in relation to individuals complex needs.	Documentation referring to people not responding to invites and not attending for vacinations with no evidence of follow up or individuals not wishing to have relvant age related cancer screening. In some cases there is a lack of evidence of reasonable ajustments, or reference to capacity.	We have seen obesity recorded on death certificates as a casue of death. There is no evidence provided to demonstrate any form of weight management had been offered to support individuals. We have also seen within reviews low BMI and malnutricion recorded again with some cases having no evidence to support weight management.	We continue to see issues relating to lack of documentation of assessments taking place where there is documented evidence of need. Also a lack of documented best interest decision making processes taken place and who were involved in the process.	Some concerns regarding lack of referrals to EOL support in a timely manner. Families not feeling fully aware of what to expect when patients are discharged home. Concerns that care homes may not be equipped to meet the patient's palliative and EoL care needs. Many cases where there is no evidence of advanced care planning taken place.
Resource: Blood tests for people with learning disabilities: making reasonable adjustments - guidance - GOV.UK (www.gov.uk)	Resource: New guidance on improving access to NHS screening programmes for people with learning disabilities – PHE Screening (blog.gov.uk)	Resource: Obesity and weight management for people with learning disabilities: guidance - GOV.UK (www.gov.uk)	Resource: What is The Mental Capacity Act? | Mencap	Resource: Overview | Care of dying adults in the last days of life | Guidance | NICE

LeDeR key priorities for 2023/2024

- Continue to strengthen the Governance arrangements for LeDeR as the operational model work progresses to include implementation within the Mental Health Learning Disability and Autism provider collaborative.

- To continue to host West Yorkshire wide learning events, our next event is planned for 4th July 2024 and will be a cancer focus as we are seeing an increase in cancer related deaths from the LeDeR reviews. In our 2022/2023 LeDeR annual report we noted that cancer was within our five top causes of death which has not been seen previously. Cancer is also seen nationally as the second highest cause of death in LeDeR and is currently one of NHSE top three national priorities.

- For place and West Yorkshire wide feedback to be collated and shared on works undertaken or planned as a result of the December LeDeR Learning Event.

- To continue to embed findings from LeDeR within relevant programmes of work in order to support learning from deaths and service improvement priorities to support our communities. Ensuring ongoing monitoring and sharing of recurring themes and the causes of death and average age of death continue to be highlighted.

- Ongoing raising awareness of the LeDeR Programme and also the inclusion of autism, ensuring the reporting/notification process is understood to encourage uptake as at present there is no statutory requirement to report the death of people with a learning disability and or autism to the National NHSE LeDeR Programme.

- Ongoing quality improvement ensuring the reviews are able to provide a clear understanding of lived experience which will support the Governance Panels to produce SMART actions to improve quality of services and support addressing health inequalities.

- The West Yorkshire LeDeR Team to be fully operationally functioning in line with the LeDeR Policy, to be sharing completed redacted reviews with all relevant professionals, including good practice feedback and agreed action from Governance Panel meetings where the reviews are focused. Updates to also be shared with families or the person's next of kin where this has been their identified wish.

- To attend the planned regional information session with NHSE to gain feedback on the NHSE commissioned work to review ICB's 2022/2023 LeDeR annual report in order to implement the required changes in a timely manner to ensure the data is available to complete the 2024/2025 LeDeR annual report.

- For the reviewing team to prioritise focused reviews for notifications received for people with a diagnosis of autism and also a dual diagnosis of a learning disability and autism in order that relevant data can be captured and highlighted across the year and also to inform next years annual report.

- For the team to develop a distribution list of all relevant contacts across our ICS in order to support the sharing of information relating to LeDeR on a local, regional and national level directly to people providing care and support to people with a learning disability and autistic people across West Yorkshire.

- Implement planned improvement to the structure of Focused Governance Panels to support the team in meeting NHSE KPI targets for the completion of focused reviews and a WY action log to track locally identified actions from panel meetings.

Recommendations for WY ICB/ICS based on the LeDeR review findings

This report showcases some of the outstanding work undertaken within the last year to address health inequalities and improve access and service provision for people with a learning disability and or autism within West Yorkshire. Consideration should be given by all places to use what has already been implemented where there is a need within their place population. We have strong relationships system wide and the findings from LeDeR can support the facilitation of working collaboratively.

Place infographic fact sheets data from completed reviews.

LeDeR Reviews Annual Fact Sheet: Bradford

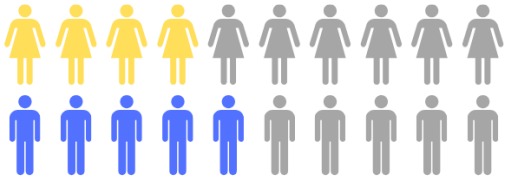
Reporting Period: 01/04/2023 - 31/03/2024

NHS West Yorkshire Integrated Care Board

Total Completed LeDeR Reviews: 34

Sex Demographics

47% of the population in the data were female while 53% were male.



Age of Death

52 Years

was the average age of death of people with a learning disability.

For females it was 59 years

For males it was 47 years

Place of Death

41%

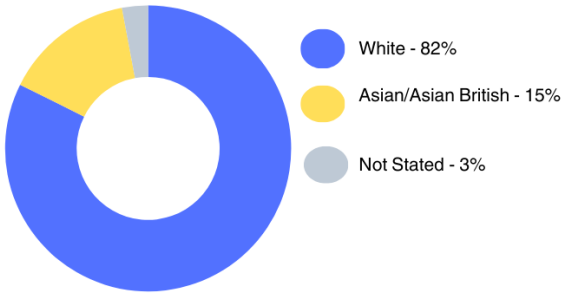
41% of people died in hospital

- 35% died where they usually live
- 21% died in a residential/ nursing home
- 3% died in a hospice

Early Death

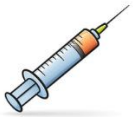
74% of people with a learning disability died before they were 65.

Ethnicity Demographics



Covid-19 Statistics

NHS West Yorkshire Integrated Care Board



71%

of people received a Covid-19 vaccination.

0 people in our closed reviews died from Covid-19.

Number of Health Conditions

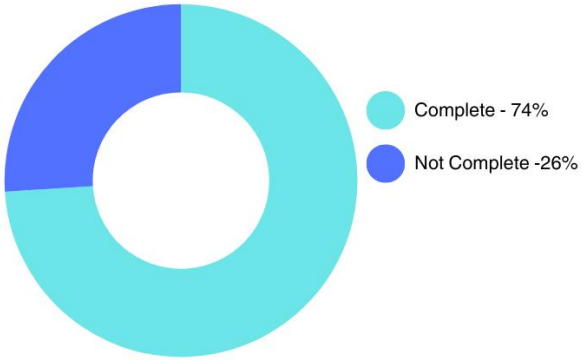
44% of people had 2 health conditions

38% of the people had 5 or more health conditions

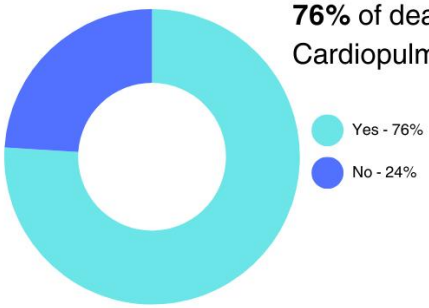
A minority of the population had less than 2 health conditions or no health conditions recorded

Annual Health Checks*

*Data accuracy may vary as it relies on the information provided to the reviewer



DNACPR



76% of deaths had a Do Not Attempt Cardiopulmonary Resuscitation decision in place.

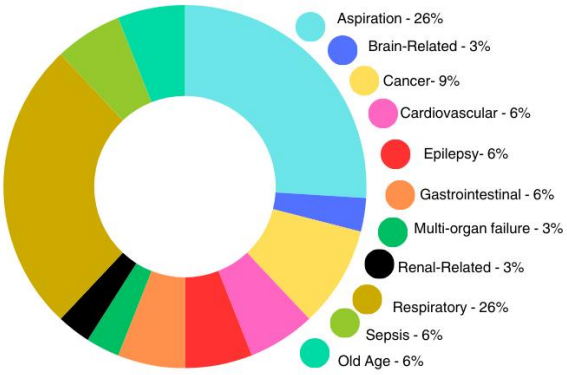
Causes of Death Demographics

26%

26% of people died from respiratory related causes.

The top three causes of death were:

- Respiratory
- Aspiration
- Cancer



LeDeR Reviews Annual Fact Sheet: Calderdale

Reporting Period: 01/04/2023 - 31/03/2024

NHS West Yorkshire Integrated Care Board

Total Completed LeDeR Reviews: 14

Sex Demographics

36% of the population in the data were female while 64% were male.

Age of Death

60 Years

was the average age of death of people with a learning disability.

For females it was 59 years

For males it was 61 years

Place of Death

43%

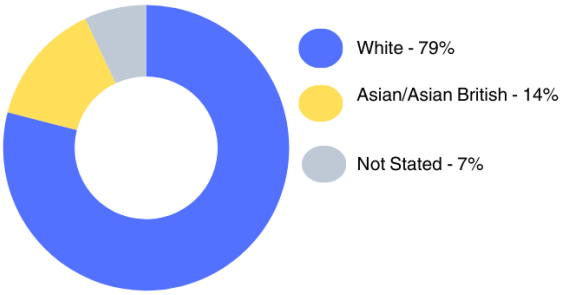
43% of people died in hospital

- 14% died where they usually live
- 43% died in a residential/ nursing home

Early Death

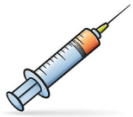
64% of people with a learning disability died before they were 65.

Ethnicity Demographics



Covid-19 Statistics

NHS West Yorkshire Integrated Care Board



64%

of people received a Covid-19 vaccination.

0 people in our closed reviews died from Covid-19.

Number of Health Conditions

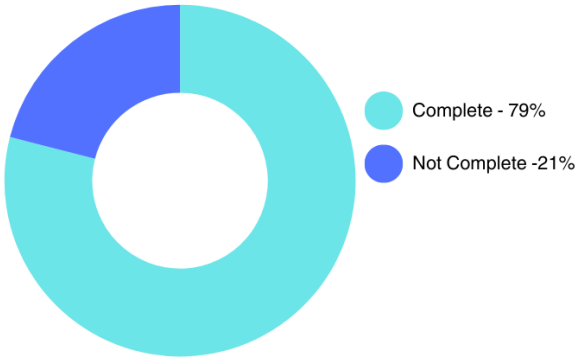
36% of people had 2 health conditions

36% of the people had 5 or more health conditions

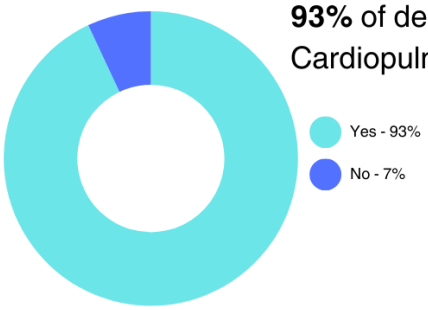
A minority of the population had less than 2 health conditions or no health conditions recorded

Annual Health Checks*

*Data accuracy may vary as it relies on the information provided to the reviewer



DNACPR



93% of deaths had a Do Not Attempt Cardiopulmonary Resuscitation decision in place.

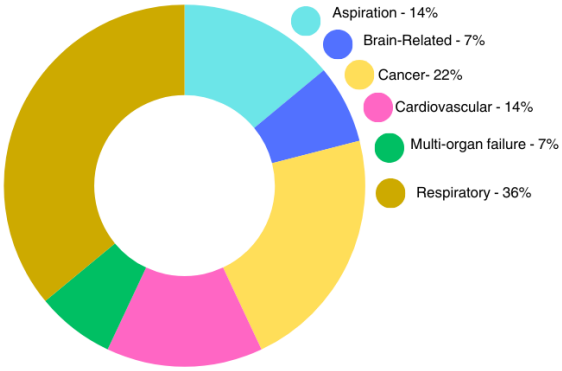
Causes of Death Demographics

36%

31% of people died from respiratory related causes.

The top three causes of death were:

- Respiratory
- Cancer
- Cardiovascular



LeDeR Reviews Annual Fact Sheet: Kirklees
Reporting Period: 01/04/2023 - 31/03/2024

NHS West Yorkshire Integrated Care Board

Total Completed LeDeR Reviews: 27

Sex Demographics

67% of the population in the data were female while 33% were male.

Age of Death

56 Years

was the average age of death of people with a learning disability.

For females it was 53 years

For males it was 61 years

Place of Death

37%

37% of people died in hospital

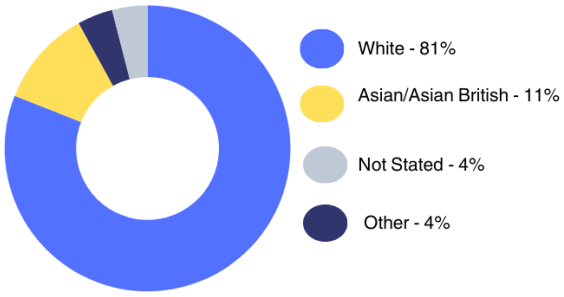
- 11% died where they usually live
- 41% died in a residential/ nursing home
- 4% died in a hospice

**some deaths occurred in community hospitals, family of a relative/ friend. A small minority of deaths recorded did not stated the place of death*

Early Death

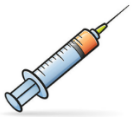
63% of people with a learning disability died before they were 65.

Ethnicity Demographics



Covid-19 Statistics

NHS West Yorkshire Integrated Care Board



74%

of people received a Covid-19 vaccination.

One person in our closed reviews died from Covid-19.

Number of Health Conditions

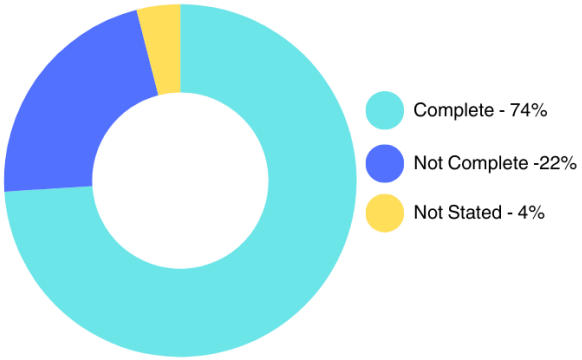
56% of people had 2 health conditions

33% of the people had 5 or more health conditions

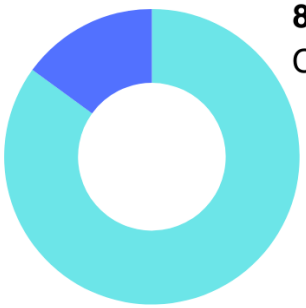
A minority of the population had less than 2 health conditions or no health conditions recorded

Annual Health Checks*

*Data accuracy may vary as it relies on the information provided to the reviewer



DNACPR



85% of deaths had a Do Not Attempt Cardiopulmonary Resuscitation decision in place.

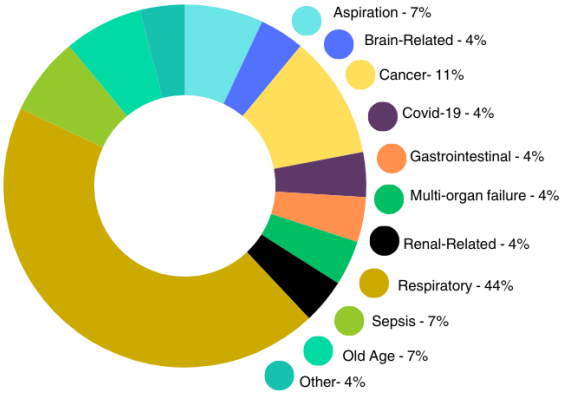
Causes of Death Demographics

44%

44% of people died from respiratory related causes.

The top three causes of death were:

- Respiratory
- Cancer
- Aspiration



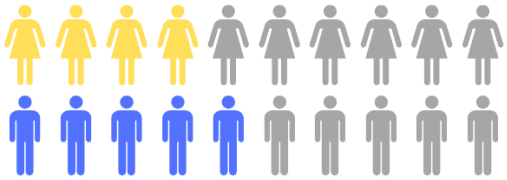
LeDeR Reviews Annual Fact Sheet: Leeds
Reporting Period: 01/04/2023 - 31/03/2024

NHS West Yorkshire Integrated Care Board

Total Completed LeDeR Reviews: 51

Sex Demographics

41% of the population in the data were female while 59% were male.



Age of Death

61 Years

was the average age of death of people with a learning disability.

For females it was 62 years

For males it was 60 years

Place of Death

63%

63% of people died in hospital

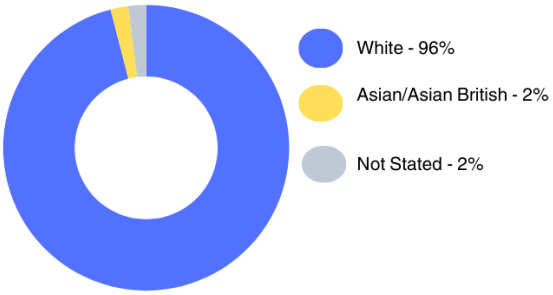
- 12% died where they usually live
- 12% died in a residential/ nursing home
- 10% died in a hospice

**some deaths occurred in community hospitals, family of a relative/ friend. A small minority of deaths recorded did not stated the place of death*

Early Death

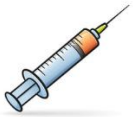
61% of people with a learning disability died before they were 65.

Ethnicity Demographics



Covid-19 Statistics

NHS West Yorkshire Integrated Care Board



73%

of people received a Covid-19 vaccination.

0 people in our closed reviews died from Covid-19.

Number of Health Conditions

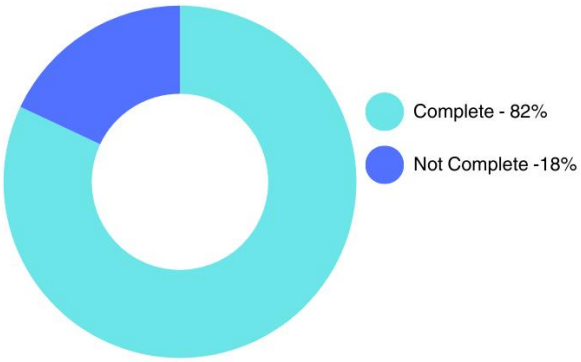
41% of people had 2 health conditions

35% of the people had 5 or more health conditions

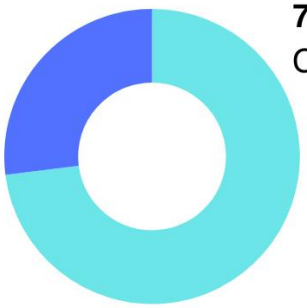
A minority of the population had less than 2 health conditions or no health conditions recorded

Annual Health Checks*

*Data accuracy may vary as it relies on the information provided to the reviewer



DNACPR



73% of deaths had a Do Not Attempt Cardiopulmonary Resuscitation decision in place.

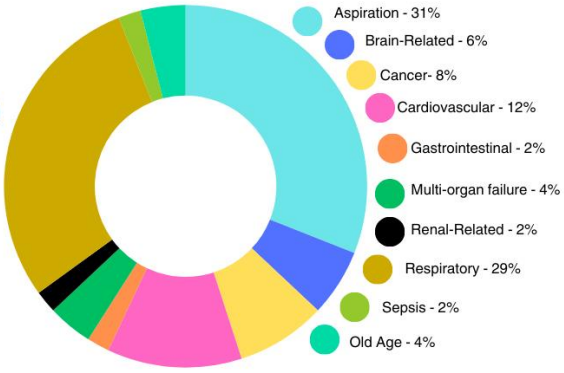
Causes of Death Demographics

29%

29% of people died from respiratory related causes.

The top three causes of death were:

- Respiratory
- Aspiration
- Cancer
- Cardiovascular



LeDeR Reviews Annual Fact Sheet: Wakefield

Reporting Period: 01/04/2023 - 31/03/2024

NHS West Yorkshire Integrated Care Board

Total Completed LeDeR Reviews: 24

Sex Demographics

33% of the population in the data were female while 67% were male.

Age of Death

56 Years

was the average age of death of people with a learning disability.

For females it was 65 years

For males it was 52 years

Place of Death

38%

38% of people died in hospital

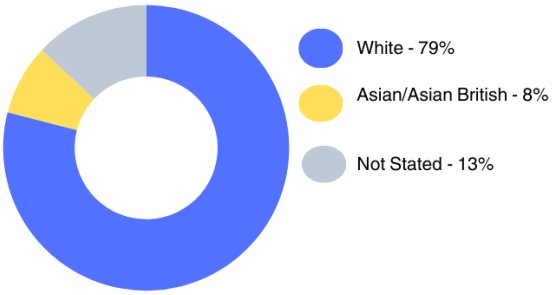
- 21% died where they usually live
- 29% died in a residential/ nursing home

**some deaths occurred in community hospitals, family of a relative/ friend. A small minority of deaths recorded did not stated the place of death*

Early Death

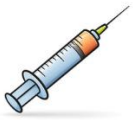
58% of people with a learning disability died before they were 65.

Ethnicity Demographics



Covid-19 Statistics

NHS West Yorkshire Integrated Care Board



63%

of people received a Covid-19 vaccination.

0 people in our closed reviews died from Covid-19.

Number of Health Conditions

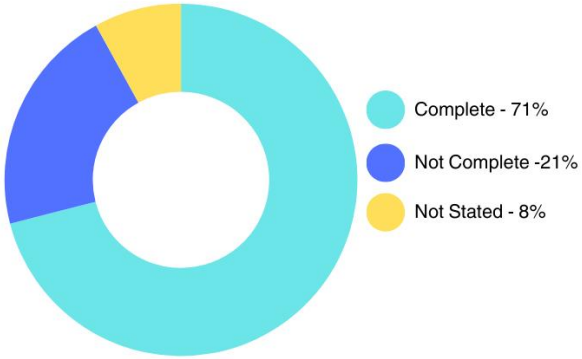
58% of people had 2 health conditions

21% of the people had 5 or more health conditions

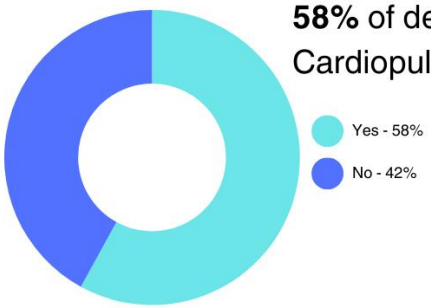
A minority of the population had less than 2 health conditions or no health conditions recorded

Annual Health Checks*

*Data accuracy may vary as it relies on the information provided to the reviewer



DNACPR



58% of deaths had a Do Not Attempt Cardiopulmonary Resuscitation decision in place.

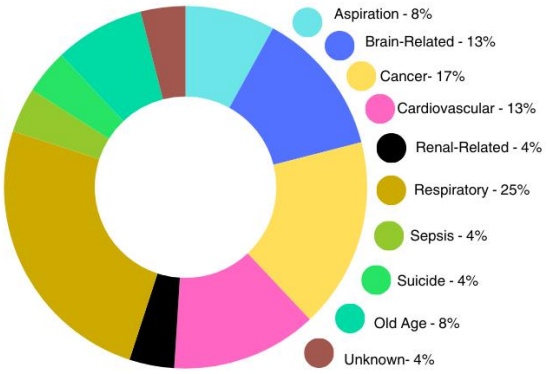
Causes of Death Demographics

25%

25% of people died from respiratory related causes.

The top three causes of death were:

- Respiratory
- Cancer
- Cardiovascular



Glossary

AHC	Annual Health Checks are available for people with a learning disability and aged 14 or over which is carried out by their doctor or nurse every year.
BCSH	Bowel Cancer Screening Hub is 1 of 5 Screening NHS Hubs part of the national population screening programmes available in England which aims to reduce the risk of dying from bowel cancer by at least 25%.
BMI	Body Mass Index.
CDOP	Child Death Overview Panel is a formal process of reviewing cases that happen after a child dies.
CIPOLD	Confidential inquiry into premature deaths of people with a learning disability was a Department of Health funded investigating looking at avoidable or premature deaths of people with learning disabilities through a series of retrospective reviews of deaths.
COVID-19	Coronavirus disease 2019 (COVID-19) is a contagious disease which effects the respiratory system.
DNACPR	Do not attempt cardio-pulmonary resuscitation (CPR) means that if a person has a cardiac arrest or dies suddenly, there will be guidance on what action should or shouldn't be taken by a healthcare professional.
GP	General Practitioner is a physician who treats various medical conditions and provides preventive care for patients of all ages.
HAP	Health Action Plan As part of the patient's annual health check, GP practices are required to produce a health action plan. A health action plan identifies the patient's health needs, what will happen about them (including what the patient needs to do), who will help and when this will be reviewed.
HCP	Health Care partnership.
ICB	Integrated Care Board is a statutory NHS organisation that plans and delivers health services in a geographical area.
ICS	Integrated Care Systems are partnerships of organisations that come together to plan and deliver joined up health and care services, and to improve the lives of people who live and work in their area.
KPI	Key Performance Indicators are a set of quantifiable measurements used to gauge a company's overall long-term performance**.** KPIs specifically help determine a company's strategic, financial, and operational achievements.
LA	Local Authority is an organisation that is responsible for all the public services and facilities in a particular area.
LAC	Local Area Contract acts as the ICB/ICS contact person for the NHSE regional Lead**,** works with the review team and promotes LeDeR at a local level across health and social care.
LD	Learning disability is a lifelong condition and cannot be cured and is different for everyone. The degree of disability can vary greatly, being classified as mild, moderate, severe, or profound.
LDA	Learning disability and or autism diagnosis.
LeDeR	Learning from the lives and death of people with a learning disability and or autism.

LTC	Long Term Condition are conditions for which there is currently no cure, and which are managed with drugs and other treatment.
LTHT	Leeds Teaching Hospital NHS Trust.
MCA	Mental Capacity Act 2005 is a law that sets out how you'll be supported to make decisions, or how decisions will be made for you.
MDT	Multidisciplinary Team are groups of professionals who deliver person-centred and coordinated care for people with complex needs.
NECS	North East Commissioning Support Unit.
NHSE	National Health Service England leads the National Health Service (NHS) in England.
PCN	Primary Care Network, are groups of GP Practices working closely together with health and social care providers locally.
PEG	Patient engagement group is made up of members patients and professionals.
SARs	Safeguarding Adults Reviews are a multi-agency review process that seeks to determine what relevant agencies and individuals involved could have done differently that could have prevented harm or a death from taking place.
TBC	To be confirmed as this information is not yet known.
VCSE	Voluntary, Community and Social Enterprise are partnerships between sector representatives including charities and the health and care system in England.
VIP	Vulnerable in patient is the VIP Red bag Scheme.
WY	West Yorkshire.
WTE	Whole Time Equivalent.