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

# 2022 – 2023

| | |
|---|---|
| **Executive Lead for LeDeR:** | **Philipa Hubbard** |
| **Interim Senior Responsible Officer:** | **Laura Elliott** |
| **West Yorkshire LeDeR Local Area Contact (LAC)/Governance Lead:** | **Lisa McCabe** |
| **Date signed off by SQG:** | **September 2023** |
| **Publication date:** | **September 2023** |

## Contents

## Acknowledgements

It is important to acknowledge the members of the Bradford District and Craven Quality Team who provided interim management and leadership, including the production of the 2021/22 first West Yorkshire ICB LeDeR Annual Report. They ensured the continuation of the hosted LeDeR Programme whilst there were several vacancies within the teams.

Thank you to members of the Bradford District and Craven Quality Team who have provided data for this report and also for our place LeDeR leads and wider system partners contributions of information for the report. The report includes some of the Place projects implemented over the last year to support 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 2022 to 31st March 2023 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 81 Reviews during the reporting period. It is important to highlight that at the end of a reporting year there will always be several 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 a significant time period therefore a breakdown of the total 81 completed reviews is shown below.

| | | |
|---|---|---|
| **Year of notification to LeDeR** | **2019-2020** | **1 completed review** |
| **Year of notification to LeDeR** | **2020-2021** | **4 completed reviews** |
| **Year of notification to LeDeR** | **2021-2022** | **43 completed reviews** |
| **Year of notification to LeDeR** | **2022-2023** | **33 completed reviews** |

Due to the backlog of 52 notifications at the start of the reporting period which required prioritising the team were only able to complete reviews for 33 of the 169 notifications they received in 2022/23. In view of this the data has been separated to cover both all 81 completed reviews and also relating to the 33 reported and completed within the reporting period as this provides 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 ICB 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 previously known as Bradford District and Craven Clinical Commissioning Group (CCG). LeDeR is funded via transformational funds.


**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 a diagnosis of autism, with no learning disability, as a qualifying condition for a LeDeR mortality review.

It is essential to clarify that a LeDeR review is not a full review of all health and social care records, but it looks 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:

- **Child death overview panel (CDOP)***
- **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**

**NHSE Policy change from 1st July 2023 children aged 4 years to 18 years will no longer be referred to the LeDeR National Programme and will continue to be reviewed under CDOP. Please see link for new policy details*
*https://www.wypartnership.co.uk/application/files/4016/8752/7454/20230601_CYP_LeDeR_policy_change_communication_002.pdf*

## 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.

## 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

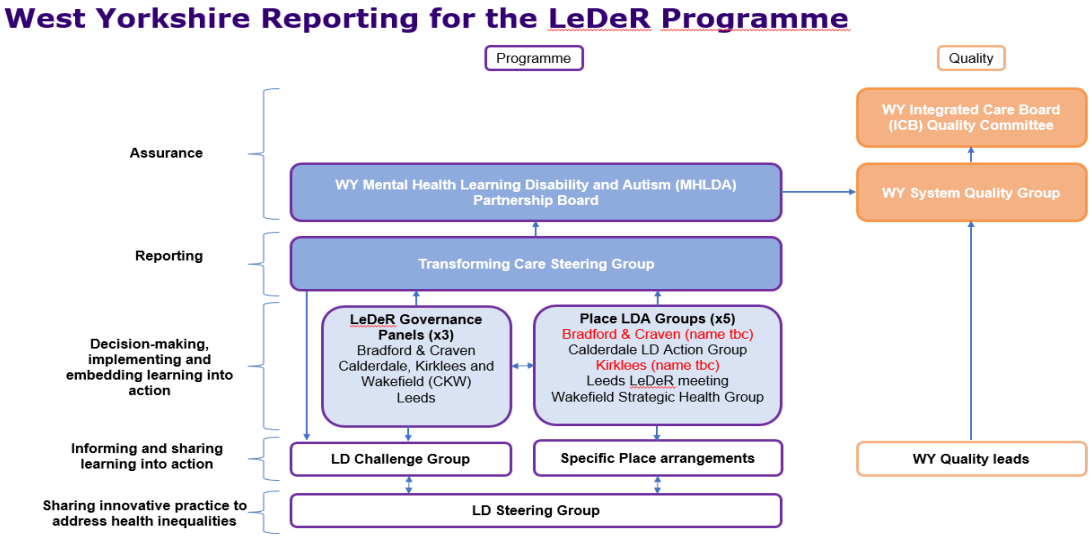
In addition to this guide there are also prompts available for the reviewer to consider if a focused review should be initiated. Following completion of an initial review, the Reviewer and the Local Area Contact (LAC) decide if a focused review needs to happen. We have extended these automatic criteria so from quarter 4 all referrals with both a diagnosis of a learning disability and autism will have a focused review completed. This will provide an opportunity for learning and understanding in relation to intersectionality.

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. The Interim Senior Responsible Officer is Laura Elliott, Head of Quality in Wakefield District Health and Care Partnership. 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 Operational Management Senior Lead is Jacqui McMahon, Senior Head of Patient Safety and Quality Improvement and Interim Operational Management is provided by Jackie Haw-Wells, Head of Patient Safety both at 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 have been set up during quarter 4 of the reporting period. All focused reviews are presented for panel discussion, 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 these are proposed to sit within our current Governance arrangements for LeDeR which are currently under review.

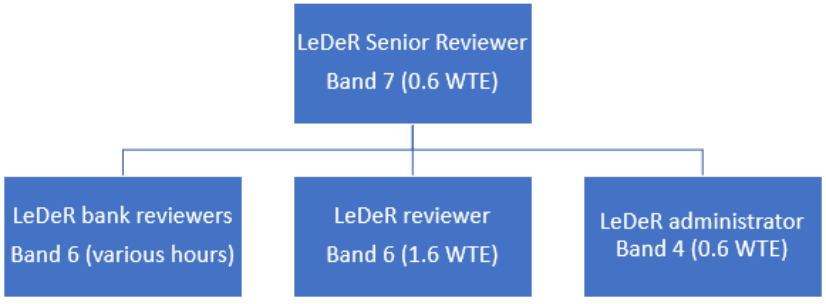


## The West Yorkshire Hosted Service Operational Update provided by the LeDeR Team

2022/23 has been a very challenging year for the LeDeR team with long term vacancies, in the band 7 senior reviewer and the band 4 administrator which has impacted the team's ability to be compliant with the 6 month KPI. An action from the 2021/22 annual report was to raise awareness of the reporting expectations for LeDeR with system partners, which has been successful however this has further impacted the team's ability to process the reviews within the timeframe set. The workforce model is being reviewed for 2023/24 to reflect these changes.

In order to sustain progression of reviews and to complete initial and focused reviews within the 6 month timeframe set by NHSE the team are in the process of reinstating the bank/agency pool of reviewers in house. Since ICB alignment in July 2022, and following new LeDeR policy the bank service ceased. This reduced reviewing capacity by affecting the amount of reviews that could be completed at any one time. As a result and following a sustainability plan with NHSE it was agreed this function could be reinstated and the operational team are in the process of re-recruiting and broadening their pool of bank reviewers. This will allow early allocation and progression of the reviews, ensuring learning is identifed and completed in a timely manner where exemptions do not apply.

As a further contigency plan NECs (North of England Care System Support) are continuing to undertake ad hoc reviews on a consultancy basis to meet KPI's. However as the bank service resumes and develops this will be withdrawn to provide a more long-term sustainable plan for the LeDeR programme in West Yorkshire. A full organogram of the LeDeR operational team is below. Please note that at the time of writing the LeDeR Administrator and Senior Reviewer post are currently vacant as well as some of the bank/agency reviewing posts, we currently have 2 bank Reviewers.



## LeDeR activity for the reporting period 2022/23

In the reporting period of 1st April 2022 to 31st March 2023, the LeDeR Team received 178 notifications of deaths. However, 6 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 and children under the age of 18 years therefore processed through CDOP. The breakdown of the remaining 158 notifications at place level can be seen below:

*Table 1: LeDeR Notifications at Place Level*

| Place | Number of Notifications 2022/23 |
|---|---|
| Bradford District and Craven | 48 |
| Calderdale | 16 |
| Kirklees | 24 |
| Leeds | 49 |
| Wakefield | 21 |
| **TOTAL** | **158** |

This is a significant increase in notifications by 42 for this reporting period compared to West Yorkshire's 2021/22 reporting period. Of the 158 notifications 33 of these have been closed within the 2022/23 reporting year. A further 48 additional reviews were also completed which cover the notification period of 2020 to 2022. The remaining 125 notifications received in the 2022/23 reporting period are still incomplete due to:

- Being on hold due to coroner's inquest, safeguarding investigation, police investigation, CDOP
- 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

Within the 158 adult notifications received within the reporting year 12 of these were for people with a diagnosis of both autism and a learning disability and 1 notification for a person with autism. This review has been completed and in line with the LeDeR Policy this person's death had a focused review completed and will be presented at the relevant place Governance Panel.

**Below are West Yorkshire infographics for the total 81 reviews completed within the reporting year**

## LeDeR Reviews Fact Sheet - West Yorkshire

NHS West Yorkshire Integrated Care Board

## 2022-23 - All Reviews

(Total Reviews: 158; Closed Reviews: 81)

### Sex Demographics

37% of the population in the data were female while 63% were male.

### Age of Death

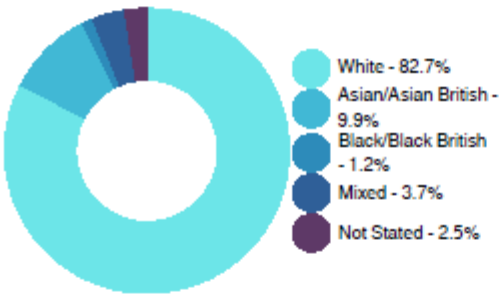
**58 Yrs**

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

**For females it was 61 years**

**For males it was 56 years**

### Ethnicity Demographics




### Early Death

56% of people with a learning disability died before they were 65.
Only 10% of the general population die before they are 65.

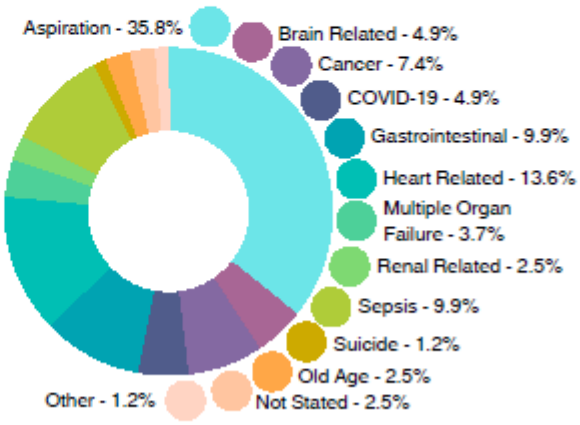
### Cause Demographics

**36%**

36% of people died from respiratory-related causes - the majority of this was due to pneumonia.

The top 5 causes of death were:

- Aspiration
- Heart Related Causes
- Gastrointestinal
- Sepsis
- Cancer



# LeDeR Reviews Fact Sheet - West Yorkshire

## 2022-23 - All Reviews

(Total Reviews: 158; Closed Reviews: 81)

NHS West Yorkshire Integrated Care Board

### COVID-19 Statistics

(4 cases of COVID-19)

**74%**

of people in our closed review population pool had at least 1 COVID-19 vaccination

0% of people who died of COVID-19 had a vaccination.

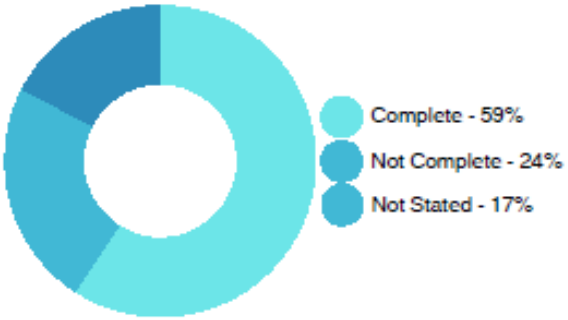
100% of people who died of COVID-19 did not have a vaccination.

### Number of Health Conditions

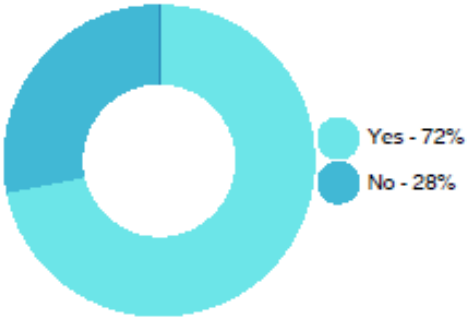
47% of people had 2 or more health conditions

48% of people had 5 or more health conditions

### Annual Health Checks




### DNACPR




72% of deaths had a Do Not Attempt CardioPulomary Resuscitation decision if a decision was made by or for the person.

### Place of Death

**56%**

**56% of people died in hospital**

(47% of the general population die in hospital)

- 25% died where they usually live
- 15% died in a residential/nursing home
- 6% died in a hospice

**Below are West Yorkshire infographics for the 33 reviews notified and completed within the reporting year**

# LeDeR Reviews Fact Sheet - West Yorkshire

NHS West Yorkshire Integrated Care Board

## 2022-23 - All Reviews

(Total Reviews: 158; Closed Reviews: 33)

### Sex Demographics

44% of the population in the data were female while 56% were male.

### Age of Death

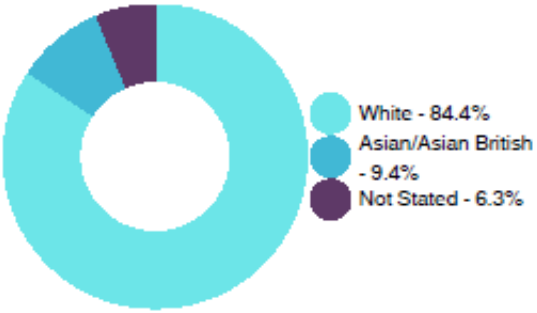
**52 Yrs**

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

**For females it was 52 years**

**For males it was 54 years**

### Ethnicity Demographics




### Early Death

32% of people with a learning disability died before they were 65.

Only 10% of the general population die before they are 65.

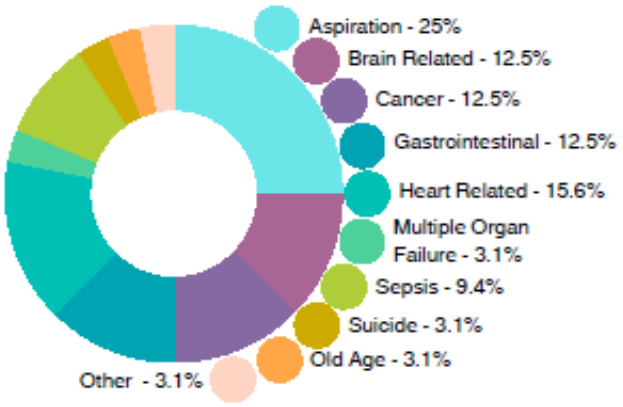
### Cause Demographics

**25%**

25% of people died from respiratory related causes - the majority of this was due to pneumonia.

The top 5 causes of death were:

- Aspiration
- Heart Related Causes
- Brain Related Causes
- Cancer
- Gastrointestinal



# LeDeR Reviews Fact Sheet - West Yorkshire

## 2022-23 - All Reviews

(Total Reviews: 158; Closed Reviews: 33)

NHS West Yorkshire Integrated Care Board

### COVID-19 Statistics

**73%**

of people in our closed review population pool had at least 1 COVID-19 vaccination

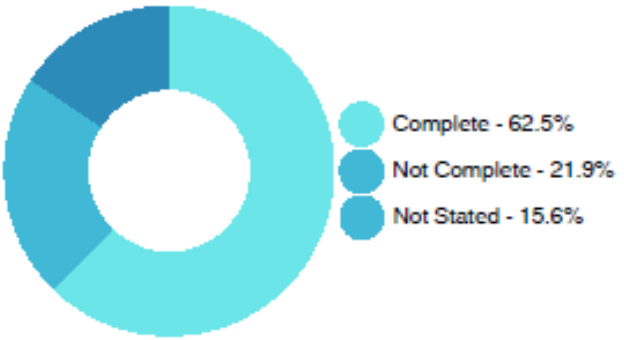
There were no people in our closed reviews who died from COVID-19.

### Number of Health Conditions

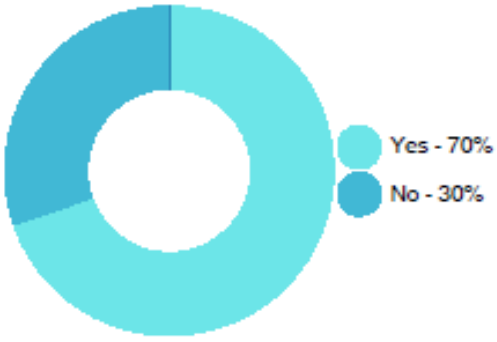
56% of people had 2 or more health conditions

41% of people had 5 or more health conditions

### Annual Health Checks




### DNACPR




70% of deaths had a Do Not Attempt CardioPulomary Resuscitation decision if a decision was made by or for the person.

### Place of Death

**42%**

**42% of people died in hospital**

(47% of the general population die in hospital)

- 18% died where they usually live
- 24% died in a residential/nursing home
- 9% died in a hospice

## 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 | 58% (n=29) | 40% (n=19) | 2% (n=<5) |
| Calderdale | 37% (n=6) | 61% (n=10) | |
| Kirklees | 50% (n=12) | 50% (n=12) | |
| Leeds | 65% (n=32) | 35% (n=17) | |
| Wakefield | 57% (n=12) | 43% (n=9) | |
| **TOTAL** | **57% (n=90)** | **42% (n=67)** | **>1% (n=<5)** |

The overall deaths reported for the West Yorkshire region are not representation of the general population which has a 49% male to 51% female split. The closest this can be seen is at place level in Kirklees. The biggest differentiations from the general population split can be seen in Leeds and Calderdale. In comparison to the 2021/22 LeDeR Annual Report, this year's data is closer to being more representative of the general population in terms of this.

## Age

All of the average age of deaths relates to adults only, over the age of 18 years and do not include children. From the notifications to LeDeR in the reporting period 2022/23 this was for males averaging 58 years while females average 56 years. As previously mentioned not all deaths of people with learning disabilities and or autism are notified to the LeDeR programme therefore this data is not wholly representative for West Yorkshire.

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

*Table 3: Average Age of Death Across West Yorkshire and at Place*

| | Gender | |
|---|---|---|
| | Male | Female |
| Bradford District and Craven | 48 years | 54 years |
| Calderdale | 66 years | 61 years |
| Kirklees | 63 years | 61 years |
| Leeds | 51 years | 55 years |
| Wakefield | 51 years | 60 years |
| **TOTAL** | **54 years** | **56 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 2022-23 | **58 years** | **56 years** |
| Learning disabilities nationally | 66 years | 67 years |
| UK general population | 82 years | 86 years |

National life tables – life expectancy in the UK - Office for National Statistics (ons.gov.uk)

The data suggests that:

Males over the age of 18 years with learning disabilities, autism or both living in West Yorkshire died 12 years sooner than the national learning disability average and 21 years sooner than the general population average age of death.

Females over the age of 18 years with learning disabilities, autism or both living in West Yorkshire died 11 years sooner than the national learning disability average and 27 years sooner than the general population average age of death.

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 indicates 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 combined total** |

## Ethnicity

When reporting deaths to LeDeR, ethnicity is not always recorded for all people at the point of notification into the LeDeR National Programme therefore there is more reliance on GP records providing this data for their patients. West Yorkshire is an ethnically diverse area, however as shown below current notifications do not reflect this. A breakdown from notifications received of ethnicity for West Yorkshire are:

*Table 6: Ethnicity of Notifications to LeDeR in 2022/23*

| Ethnicity | Number from LeDeR Notifications |
|---|---|
| Asian/Asian British | 8% (n=13) |
| Black/Black British | >1% (n=<5) |
| Mixed/Multiple Ethnic Groups | 0% (n=<5) |
| White | 86% (n=136) |
| Other | >1% (n=<5) |
| Not Stated | 4% (n=7) |

## Annual Health Checks

*Table 7: Annual Health Checks from 33 Closed Reviews*

| | Number from LeDeR Notifications |
|---|---|
| Annual Health Check Complete | 64% (n=21) |
| Annual Health Check Not Complete | 21% (n=7) |
| Not Stated | 15% (n=5) |

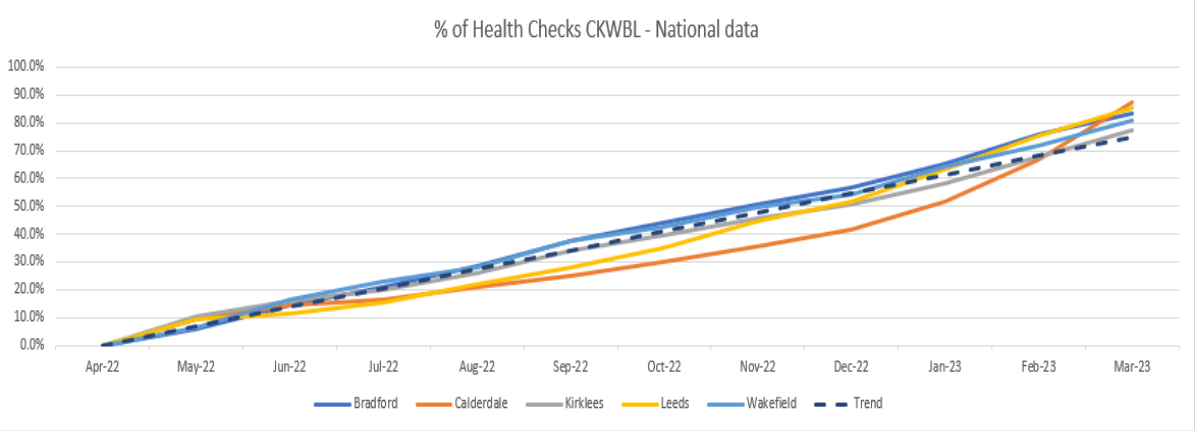
The NHS Long Term Plan aims to reduce health inequalities and offer people with learning disabilities an Annual Health Check with their GP if they are over the age of 14 and on their doctor's learning disabilities register. The Long Term Plan has set a target of 75% of eligible people having an Annual Health Check (source: Learning disabilities - Annual health checks - NHS).

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 all five places have exceeded the national target set of 75% giving a West Yorkshire total of 82.8%.

*Table 8: Place and West Yorkshire overall official figures of completed Annual Health Check's*

| NHS published figures March 2023 | | | |
|---|---|---|---|
| **Completed Health Checks** | **Register** | **% HC achieved** | **HCP** |
| 3,627 | 4,342 | 83.5% | **Bradford** |
| 1,118 | 1,278 | 87.5% | **Calderdale** |
| 2,225 | 2,871 | 77.5% | **Kirklees** |
| 3,386 | 3,964 | 85.4% | **Leeds** |
| 1,777 | 2,204 | 80.6% | **Wakefield** |
| **12,133** | **14,659** | **82.8%** | **WY ICB total** |

*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 will provide live data accessible by all five places and will enhance monitoring, prioritisation and progression in reaching desired targets. Work is continuing across West Yorkshire to improve the offer and uptake and also 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. West Yorkshire ICB now have a Strategic Health Facilitator in each place.

## 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 33 completed reviews are as follows:

*Table 10: Causes of Death for 33 Closed Reviews (Rounded Up or Down)*

| Cause of Death | Number of Causes of Death |
|---|---|
| Aspiration | 27% (n=9) |
| Heart Related Causes | 15% (n=5) |
| Cancer | 12% (n=<5) |
| Gastrointestinal | 12% (n=<5) |
| Brain Related Causes | 12% (n=<5) |
| Sepsis | 9% (n=<5) |
| Multiple Organ Failure | 3% (n=<5) |
| Suicide | 3% (n=<5) |
| Old Age | 3% (n=<5) |
| Other | 3% (n=<5) |

Additionally, the causes of death for the additional 48 completed reviews from notifications prior to the reporting period (pre) 2022/23 are as follows:

*Table 11: Causes of Death for 48 Additional Completed Reviews notified Pre 2022/23 (Rounded Up or Down)*

| Cause of Death | Number of Causes of Death |
|---|---|
| Aspiration | 44% (n=21) |
| Heart Related Causes | 13% (n=6) |
| Sepsis | 13% (n=6) |
| COVID-19 | 6% (n=<5) |
| Gastrointestinal | 6% (n=<5) |
| Multiple Organ Failure | 4% (n=<5) |
| Renal Related Causes | 4% (n=<5) |
| Not Stated | 4% (n=<5) |
| Cancer | 4% (n=<5) |
| Old Age | 2% (n=<5) |

As you will see from both sets of data there are similarities in that aspiration is still the main cause of death for all completed review within the reporting period with heart related causes the second cause of death. Aspiration, sepsis, gastrointestinal, COVID-19, cancer and brain related all featuring in the top 6 causes of death. The 2021/22 LeDeR annual report identified the most common 6 causes of death as:

Chest Infection, Aspiration, Covid-19, heart disease/Failure, Gastrointestinal conditions, Sepsis.

We now have cancer highlighted as a cause of death which differs from the previous year however only a total of 4% completed reviews attribute to this cause of death data.

## 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 33 Closed Reviews in 2022/23*

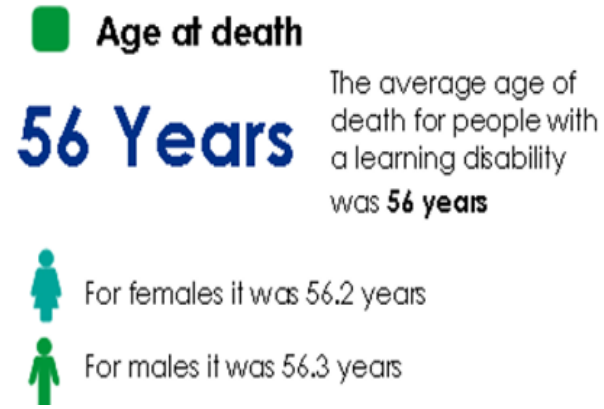
| | Number from LeDeR Notifications |
|---|---|
| 2+ Health Conditions | 56% (n=18) |
| 5+ Health Conditions | 41% (n=13) |
| No | 3% (n=<5) |

Furthermore, additional health conditions can be seen for the 48 closed reviews pre-2022:

*Table 13: Other Health Conditions for 48 Closed Reviews notified Pre 2022/23*

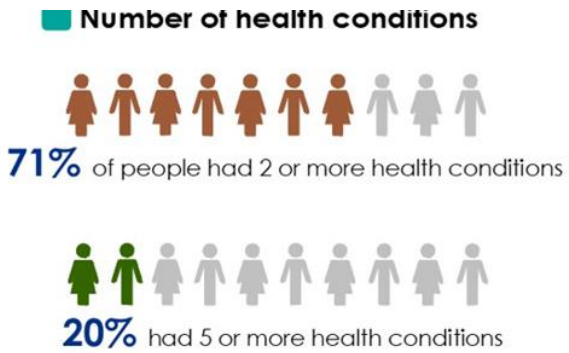
| | Number from LeDeR Notifications |
|---|---|
| 2+ Health Conditions | 42% (n=20) |
| 5+ Health Conditions | 52% (n=25) |
| No | 6% (n=<5) |

## Below highlights some of the significant differences in the data from 2021/22 LeDeR Annual Report



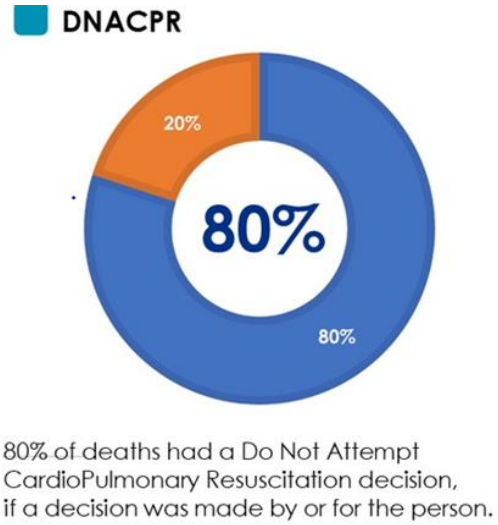

**2022/23 comparisons of data Age of death for the total 81 completed reviews was:**
**Females - 61 years**
**Males - 56 years**

**Data from the 33 notified and completed within 2022/23:**
**Females - 52 years**
**Males - 54 years**




**2022/23 comparisons of data regarding health conditions for the total 81 completed reviews:**
**2 or more 47% 5 or more 48%**

**Data from the 33 notified and completed within 2022/23:**
**2 or more 56% 5 or more 41%**




**2022/23 comparisons of data regarding DNAPCR for the total 81 completed reviews:**
**72% of people had a DNACPR decision in place.**

**Data from the 33 notified and completed within 2022/23:**
**70% of people had a DNACPR decision in place.**

**Where people died**

**60%**

**60% of people died in hospital**

(47% of the general population die in hospital)

- 35% died where they usually lived
- 4% died in a hospice
- 1% died away from home

**2022/23 comparisons of data on place of death been in hospital for the total 81 completed reviews was: 56% of people dies in hospital.**

**Data from the 33 notified and completed within 2022/23: 42% of people died in hospital.**

## Good Practice examples highlighted by the Reviewers

- ✓ Good communication and involvement of family during hospital admission recognising when family needed support due to English not being their first language.
- ✓ Co-ordination of care by Learning Disability Community Matron.
- ✓ Evidence of professional and family discussion in mortality review documents.
- ✓ Evidence of good communication with mum and multi-agency involvement in care.
- ✓ Involvement of specialist services appropriate to diagnosis and treatment.
- ✓ Swift recognition that a patient required end of life care with promotion of comfort and dignity.
- ✓ Effective communication between acute and community Learning Disability teams.
- ✓ Discharge co-ordination and provision of support on release from prison was excellent.
- ✓ Learning Disability Community team were responsive and knew her and her family well. Sister stated carers names and said, '*they were a God send we don't know what we would have done without them*'.
- ✓ Responsive involved community team.
- ✓ Staff know tenants really well. Staff retention is excellent 85% of staff have worked in same home for 15 years or more.
- ✓ ReSPECT was done and documentation was clear that preferred place of care and death was home. Care home were well supported facilitating preference of patient and family.
- ✓ Responsive Learning Disability involvement. Relationship between hospice and Learning Disability team was good which was beneficial for all concerned.
- ✓ MDT working and communication led to excellent care. Input from Learning Disability Facilitation Nurses ensured holistic care for patient and her Mum.
- ✓ Swift response from GP when condition deteriorated in ascertaining family wishes regarding ceiling of care.

## Summary

These are excellent examples of professionals providing responsive patient centred care and communicating and involving families. The use of end of life care planning, appropriate specialist involvement providing the right care at the right time highlighting the value of relationships in knowing the person well to best meet their individual holistic needs.

## Improvement Measures in place for the LeDeR Programme

- ✓ We have introduced a quality assurance tool adapted from the tool that NHSE use to provide scrutiny on dip samples of completed reviews nationally. This tool supports supervision between the Senior Reviewer and the Reviewers and provides a means of audit to assure quality improvement is ongoing. We received some positive feedback from our last review audit by NHSE *"Concise and recording of most relevant issues relating to the care and life of the person. Respectful of sisters wishes in relation to post-mortem and didn't wish to be involved with LEDER review."* The panel also commented that the pen portrait was the best they had seen in the Quality Improvement forum. The panel provided some areas for further improvement for the Reviewing Team to embed.

- ✓ We now have three established Focused Review Governance Panels chaired by the LAC where completed focused reviews are presented by the Reviewers to a Panel consisting of place-based partners and people with lived experience representative of our ICS. These Panels take place for Leeds, Bradford and a combined Calderdale, Kirklees and Wakefield once the team have completed 2 focused reviews for place.

- ✓ A LeDeR quarterly update is now 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.

- ✓ The introduction of additional criteria for an automatic Focused Reviews for people with a dual diagnosis of learning disability and autism. This is to gain understanding of having a dual diagnosis and living within our communities may present difficulties in accessing services, health care and specialist care to meet their needs in relation to autism and their learning disability.

- ✓ 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 referrals into the national NHSE database. As well as ensuring it is known that LeDeR now includes people with a diagnosis of autism over the age of 18 years without a diagnosis of a learning disability also. The following feedback was received from a Learning Disabilities and Transitions Services Manger "*Thanks so much for taking the time to come and present to our service time out session it was so appreciated, and the*

*information shared was so relevant and valuable. I received positive feedback from staff about the session. I have circulated your presentation across the service. Thanks again".*

- ✓ The LeDeR Programme now has an action plan to address the recommendations from the 2021/22 Annual Report and the ICB's must do's document has been updated to ensure the programme is on track and operating within the NHSE LeDeR Policy to fulfil the ICB's statutory responsibilities. A meeting of the West Yorkshire and LeDeR place leads has been established and has four key workstreams – Reviewer capacity; Reporting; Learning into action; and Governance.

- ✓ We have extended the teams current fixed term contracts until March 2024 to make recruitment more attractive and mitigate workforce turnover and vacancies and the team are proactively filling the bank reviewers post to create more resilience within the team.

## Oliver McGowan Training

To read about Oliver McGowan's Story please click on the links below;

Oliver McGowan Mandatory Training

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

Following a long campaign led by Oliver McGowan's mother Paula McGowan OBE, Health Education England, the Department of Health and Social Care, NHS England and Skills for Care launched The Oliver McGowan Mandatory Training on Learning Disability and Autism e-learning.

Oliver's death shone a light on the need for health and social care staff to have better training and aims to provide the health and care workforce with the right skills and knowledge to provide safe, compassionate, and informed care to autistic people and people with a learning disability. This requirement is set out in the Health and Care Act 2022 for all CQC regulated service providers.

The Oliver McGowan Mandatory Training on Learning Disability and Autism is co-delivered by trainers with lived experience of learning disability and autism who are paid for their time.

The Oliver McGowan Mandatory Training is a standardised package that is delivered by trained and approved trainers.

The consistent content and delivery mean it is transferable between employers. It is the government's preferred and recommended training and is recognised by national bodies advising on standards for the health and care sector.

A frequently asked questions link can be found about the Oliver McGowan Mandatory Training for your information.

https://www.hee.nhs.uk/our-work/learning-disability/current-projects/oliver-mcgowan-mandatory-training-learning-disability-autism/faqs-oliver-mcgowan-mandatory-training

NHS West Yorkshire ICB is contracting with two external providers Cloverleaf and Inclusion North who are setting up their Trios. The Trio's from these two external providers are attending in the Summer 2023 a 4 hour train the trainers course so that they become approved Tier 1 – 60 Minute Webinar trainers for the Oliver McGowan Mandatory Training. Looking for the contract to start around end of September 2023 to deliver the Tier 1 – 60 Minute Webinar.

## Oliver McGowan Mandatory Training Tier 1 60 Minute Webinar

The following organisations have agreed to accept the small offer of training during this pilot year for up to 180 staff to receive this training with 30 staff joining a 60 minute webinar per session. All of these staff will need to have undertaken the e-learning module prior to attending the 60 minute webinar. The Tier 1 60 minute webinar is for staff who do not have direct contact with patient/service users.

A Data Processing Impact Assessment has been developed and has been shared with the above organisations own information governance leads to comment on with a view to take this forward for sign off within their own organisations. The data that is being shared with the external training companies is the staff members work email address and full name who are to be identified to receive this training during this pilot year.

| | |
|---|---|
| Leeds & York Partnership NHS Foundation Trust | Leeds City Council |
| Bradford Teaching Hospital NHS Trust | Wakefield Metropolitan District Council |
| Mid Yorkshire Hospital NHS Trust | Calderdale Metropolitan District Council |
| Calderdale & Huddersfield NHS Trust | Bradford District Care NHS Foundation Trust |
| South West Yorkshire Partnership NHS Foundation Trust | Bradford Council |

The code of practice is now out for consultation (see link below). A joint response from the ICB and organisations is being developed through the West Yorkshire Working Group.

Government seeks views on learning disability and autism training - GOV.UK (www.gov.uk)

## The Mental Health, Learning Disabilities and Autism Programme

To support the learning through the LeDeR programme, we launched our Learning Disability Challenge in 2022. 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.

The WY ICB Partnership has 10 Big Ambitions and one of those is to reduce the gap in life expectancy between people with mental health conditions, learning disabilities, autism and other neurodiverse conditions, and the rest of the population by 10% by 2024. Achieving this ambition will make life better for more than 200,000 people living in West Yorkshire.

The focus of the Learning Disability Challenge is to share information about a range of projects happening across our five places and hospital trusts to ensure people with Learning Disabilities and/or Autism (LDA) receive the health support they need. This includes Emergency Care Bags, identification of people with LDA on elective care waiting list, training and careers and inclusive employment and supporting people with learning disabilities in the criminal justice system. As mentioned above we are currently undertaking a procurement exercise to work with a broker organisation to oversee the implementation of the Oliver McGowen training across our health and care partnership.

## Examples of actions to address Health Inequalities Across our System

### Calderdale

The weekly learning disability action group meeting is something that is hugely beneficial and positive in enabling partnership working and supporting one another to reduce health inequalities. This has facilitated a joined up approach to be taken that has led to real positive changes.

The work with the Calderdale self-advocacy network to create a top tips poster for health action plans and a poster around reasonable adjustments "think learning disabilities" has been produced. The Calderdale self-advocacy network had previously created a poster for top tips for annual health checks and we agreed these 3 posters would be widely shared to help improve the quality and number of annual health checks. The Calderdale self-advocacy network had been involved in the work to introduce "think learning disabilities" within Calderdale and Huddersfield NHS Trust (CHFT) and wanted the same message to be shared within primary care to support a consistent approach.

Learning disability awareness training was offered to all GP practices in Calderdale. 13 training sessions were delivered to 12 GP practices. This was delivered in partnership with Lead the Way, Cloverleaf advocacy. By working with Calderdale and Huddersfield NHS Foundation Trust (CHFT) we were able to share local data to explore what actions we could take to have a positive impact upon the appropriate health issues. After the session each practice was provided with a resource pack which included, information on local services, national reports, easy read information resources and posters and advice devised by or with the Calderdale Self-Advocacy network such as the posters mentioned above. Feedback forms were completed after each session, it was clear that hearing from a person with a lived experience of a learning disability was extremely powerful and beneficial for the staff working within GP practices.

Quotes from staff feedback:

*"Resources really helpful, personal experience"*

*"Great reminder of the "gold" standard we should be offering to all patients,*

*"Really enjoyable and good to hear real life experiences".*

Presentations were delivered at the Practice Nurse Forums, these included:

- The role of the Calderdale leaning disability community health team.
- Understanding of health inequalities faced by people with learning disabilities.
- The importance of “was not brought” and enquiring why people may not have attended health appointments.
- Reasonable adjustments, hospital passports and information about the Mental Capacity Act.
- How general practice can support bowel management for people with learning disabilities.

Partner organisations, including the Calderdale Learning Disability Health Team, Calderdale Cares, West Yorkshire Cancer alliance, GP Practices and Primary Care Networks worked together to establish and implement a process for learning disability flagging for bowel screening. Training was provided which included, reasonable adjustments, diagnostic overshadowing, and the Mental Capacity Act. This was to ensure staff were confident in implementing the process and ensured that resources and support that is available was widely shared.

**Learning Disability Flagging for Bowel Screening Invitations** Calderdale have worked closely with North East and Cumbria NHS Bowel Screening to share the GP practice learning disability register which identifies patients with a learning disability aged 50+. On receipt of the age appropriate register, the bowel screening team flag their patient records that the patient has a learning disability. The age limit of 50+ is used for the registers, to ensure all patients are picked up within the gradual change in age eligibility for bowel screening.

When a flagged patient is sent the usual bowel screening invite letter and kit, an additional easy read version is sent out. The bowel screening team then share a list of the patients they have invited who were flagged with a learning disability each quarter, so the GP practices can offer them more support. Primary Care Network Care Co-ordinators based within the GP practices currently manage these registers. Training and resources were shared on how to access additional support for their patients from our Strategic Health Facilitator and where necessary, make a referral to the community learning disability team. Patients with a positive result would be referred for further investigations and the care coordinators are aware of how to share the reasonable adjustments that may be needed for the patient.

The registers are refreshed on an annual basis. Data will be shared after the first year from the bowel screening team and we hope to see an uptake in bowel screening for patients with a learning disability.

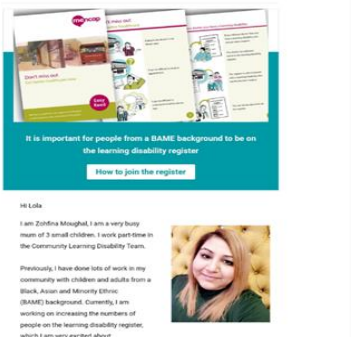
## Wakefield

**The ACE programme - Achieving Change through Engagement** Informative webinar sessions were facilitated by the strategic health facilitator and Conexus (GP Federation) for all members of the general practice clinical teams providing interactive, and relevant topics to enhance the care of learning disability patients within practice. These masterclass sessions have been developed by learning disability experts as well as patients with lived experience and their carers, to provide essential skills and knowledge in a friendly, interactive environment.

**The VIP Red Bag Scheme** was developed to tackle health inequalities faced by people with learning disabilities, when accessing acute hospitals. The scheme was launched in Wakefield in 2022. Funding was secured through, Mencap Treat Me Well campaign, Morrisons Community Fund and Wakefield CCG/NHS England. This has enabled everyone in Wakefield on the learning disability register, to have a bag for free. They are also available to autistic people. The aim is to highlight to hospital staff that the person with the Red Bag requires additional support and may need reasonable adjustments during their appointment or hospital admission. The project has gone from strength-to-strength, with over 1200 bags distributed. Advise on translation was given, and they are now able to work in collaboration with the whole diverse community.

**Don't Miss Out** Following the previous LeDeR Report we approached Mencap to ask if they had the 'Don't Miss Out' poster campaign in Urdu, but they did not. The publisher of the poster provided permission to produce it in Urdu, we worked with Language Empire who translated the poster in Urdu. We reviewed the number of people from a black, Asian, minority ethnic background on the learning disability register. We were asked to promote the work, Zohfina Moughal a Senior Health Support Worker wrote an email which was called Zohfina's email signature. This email had a great response with over 4,000 people nationally, nurses from other areas of the country wanting further information. Mencap informed us that from the initial work they have seen in Wakefield they would develop it into a national campaign and funding was granted. We worked to connect local leaders in Wakefield, GPs, and the local community. We met with the local elected councillors to share LeDeR findings and shared the work we were doing within the community. The Local leaders shared the LeDeR report on social media platforms with connections with over 200+ people from black, Asian, minority ethnic background. They also agreed after Jumma prayers leaders would present our work on video, to raise

awareness of the importance of being on a GP learning disability Register. We shared our work and case study of a black, Asian, minority ethnic dedicated Health Café with Mencap as background for their campaign.




**One Stop Shops** Brings together services in community venues to promote a holistic approach with inclusion of the whole MDT and representation from services to show case provision that may be required throughout the person's life. The events promote reasonable adjustments, enabling greater choice, desensitising and demedicalising access to health services, promoting health, and addressing carer's needs. They support creation of a patient held personalised care and support plan, as well as offering Covid booster / Flu vaccines.

The One Stop Shop Team consists of Physiotherapy and Occupational Therapy, cancer screening, sexual health, carer awareness and support, Community Learning Disabilities team, healthy eating and physical activity, Social Prescribers, Care Coordinators, Health and Wellbeing Coaches, Pharmacist and Practice Nurses.

**Service user feedback**

*"Everyone friendly, breast and testicle care were fun"*

*"Nice to meet people from the practice, good to see what's happening around here"*

*"Very friendly and approachable, great opportunities, plenty of leaflets and free gifts, good advice"*

*"I am really glad I came I spoke to someone from my general practice, I am really happy she is going to come and see my husband at home, I am caring for my husband.*

The following outcomes have been achieved:

- Increase in referrals to a range of services including social prescribing, age related screening, dementia screening, care link, stop smoking, HIV testing, sexual health services, dentist, Carer registration within GP.

- Numerous red bags were given out including the Mid Yorkshire Hospital Trust VIP passport.
- Contact details were recorded to ensure that the reasonable adjustment flag could be added to clinical notes.
- Covid vaccinations were administered, alongside information giving, health promotion and myth busting to allay fears and worries.
- LD register accuracy was addressed,
- New participants were recruited to join the Patient Engagement Group (PEG).
- Complete and partial Annual Health Reviews were undertaken during the event.
- Structured medication reviews.
- Completion of the Health Action Plans (HAP).
- There was also a high uptake of physical monitoring and health promotion.

## Bradford

**Respiratory Pathway and Keeping My Chest Healthy Digital Hub** In response to the high rates of respiratory issues for people with learning disabilities highlighted by LeDeR, Bradford District Care Trust (BDCT) clinicians supported by the Working Academy at the University of Bradford, worked in partnership with people with learning disabilities, their families and carers to co-produce a digital resource.

The respiratory pathway and website will support people to manage their respiratory health at home by providing of suite of accessible videos and text guidance available in multiple languages. The site is enabled for use on both tablets and phones and can be accessed by scanning the QR code that is embedded in an individual's Keeping My Chest Healthy care plan.

The Keeping My Chest Healthy digital hub is due to launch on the 11th September 2023. The development of the digital hub has followed on from the Respiratory pathway and screening work that has been done in the learning disability health support team, BDCFT.

**Red Bag work** Bradford Teaching Hospitals Trust (BTHT) and Bradford District Care Foundation Trust (BDCFT) have both received additional funding via Lottery & Hospital Charities to provide over 500 Red Bags to adults with learning disability across the Bradford district to help improve people's care whilst they are in hospital. Airedale hospital is also exploring if they can get some additional funding to implement this. Both the acute hospital trusts and the community trust have worked closely with the local self advocacy groups Bradford

People First, Keighley & Craven People First and Exclusively Inclusive to ensure that people with learning disabilities have been closely involved in the roll out of this work. This has also increased the promotion of VIP Hospital Passports across the district.

**Pharmacy support** The LeDeR reports have highlighted the issues about poly pharmacy for people with learning disabilities and so we have now got pharmacy support in our learning disability multidisciplinary team at BDCFT. This has supported clinicians, people with learning disabilities and carers to ensure that they receive better support when thinking about medications.

**STOMP-**stopping over medication for adults with learning disabilities and **STAMP-**stopping over medication in paediatrics BDCFT provide free STOMP/STAMP training across the Bradford district to anyone supporting people with learning disabilities to find out more about STOMP, side effects of medications and alternatives such as Positive Behavioural Support. We also have a district wide all age multi agency STOMP steering group to discuss issues around medication which has raised awareness across services.

## Leeds

Leeds Learning Disability and Neurodivergence took over management of LeDeR at place in April 2022, the team has focused on establishing the Leeds LeDeR group, embedding quality processes and developing its membership to ensure cross sector system representation. The team have also embedded lived experience by co-producing a LeDeR engagement plan with third sector organisation Forum Central, ensuring people are involved in a meaningful way and influence actions taken.

### Ongoing health equality interventions include:

- Working with health and care organisations to increase the number and quality of Learning Disability Annual Health check, flu and covid vaccinations. Work with Business Intelligence to develop dashboards to identify practices with low uptake so this can be addressed and to reduce data variance.
- Joining Leeds Dying Matters Partnership to support wider and earlier conversations around end of life and end of life planning.
- Implementing actions for regional themes identified at the Learning Disability Health Inequality Challenge meeting.

Leeds Mental Capacity Act (MCA) Lead has implemented several interventions to increase practitioners' understanding of the Mental Capacity Act to improve health and care outcomes, including:

- Establishing a COVID-19 Vaccination Advisory Group to advise and support practitioners managing complex cases to avoid delays in care delivery, improving health outcomes. This has resulted in correct Best Interest Decision making in situations where family have refused COVID-19 vaccinations on behalf of a family member, sometimes requiring resolution at the Court of Protection
- Establishing the Mental Capacity Act Local Integrated Network for Leeds to share good practice and co-produce an MCA Strategy. The network works with the Local Safeguarding Adults Board to use the MCA to improve the safety and quality of health and care of vulnerable adults.

Leeds Joint Care Management Team sought LeDeR awareness training from the WY LAC to increase their understanding of LeDeR, the importance of information sharing and the referral process. This will improve reviews undertaken in Leeds and increase referrals to LeDeR. Team Managers also now have dedicated time to monitor the progress of learning actions from future focused reviews.

In response to identified themes, the Adult Commissioning Team has adapted the annual provider submission to include dental care to improve oral health and reduce aspiration pneumonia. This submission already ensures providers support individuals to receive Annual Health Checks and a variety of health and cancer screenings. Other interventions to promote health include:

- sharing the NHS constipation campaign toolkit with providers via email
- continued promotion of the Restore 2 mini training and training dates to improve staff's ability to recognise health deterioration or report this to GP Practices effectively so people receive appropriate health interventions in a timely manner.
- implementation of a bowel monitoring chart in one provider setting as a result of a specific LeDeR case and subsequently shared with all providers to embed across the system to reduce the likelihood of constipation.

Public Health lead a multi-agency Learning Disability Cancer Screening Task Group which is implementing plans increasing the uptake of Bowel Screening:

- Working with the Bowel Cancer Screening Hub (BCSH) in Gateshead to develop and implement a pathway to flag people in their records so they can support individuals and their primary care teams to increase uptake of screening.
- Over 85% of GP Practices are signed up to the scheme and prior notifications are being sent to practices for eligible patients on the learning disability registers.
- This has led to an increase of 45% uptake of bowel screening in the (flagged) learning disability population.

Similar work for breast and cervical cancer programmes is currently underway.

Leeds Community Healthcare NHS Trust (LCH) receives increasing requests from services to make their services more accessible. Case example: In partnership with another NHS Trust and Social Services, a woman's learning disability was identified, and her capacity assessed regarding her health needs. This led to her accessing a placement in a specialist home with support, where she is now able to access activity and social events.

## Other health equality interventions implemented include:

- Support to the Long Covid Team to adapt their pathway to include appropriate reasonable adjustments, enabling people with a learning disability to be seen sooner. Accessible information has been produced to support this.
- A clear approach and template in Dental Services for when a reasonable adjustment is required, ensuring a co-ordinated and holistic approach across organisations and the use of least restrictive practices. This will improve oral health and reduce the risk of aspiration pneumonia - identified as a key cause of death for people with a learning disability in Leeds.

Leeds and York Partnership NHS Foundation (LYPFT) has introduced Learning Disability and Autism Champions in each service who will explore any issues people face when accessing mainstream mental health services. Recommendations are then disseminated and implemented across services. Their Health Facilitation Team (HFT) is part of the Cancer Screening Task Group and produced the easy read information used to improve uptake in Bowel Screening. As a member of the Leeds Palliative Care Network they ensure learning disability is considered is all aspects of their work. This engagement has led to the completion of an easy read My Future Wishes booklet which support people to make their own decisions about end of life planning.

The Learning Disability and Autism Team marked Autism Acceptance week with the launch of a new Autism Health Passport, co-produced by the Autism Subgroup and partners across the city. This new passport has received extremely positive feedback from patients and Leeds Teaching Hospitals Trust (LTHT) staff. Learning Disability and autism flagged inpatients are seen within two working days of admission and receive a range of support to ensure their individual needs are met.

### Recent examples of improvements include:

- Emergency Department Care Bags: each eligible patient receives a bag containing information, sensory supports and items for occupation to help them to cope with appointments better. Thirteen other Trusts are now replicating this initiative and NHS England have created a film about the care bags as an example of excellent practice.
- An Endoscopy Pathway has been implemented to ensure patients achieve endoscopy on the first attempt without previously identified complications.
- over 75 co-produced accessible leaflets produced.

## Kirklees

### Project to support the Identification and reporting of any change/deterioration in the physical health of individuals with Learning Disabilities:

Building on the implementation of the Framework published in March 2021 which provided guidance for primary care and community health services to ensure that people living in care homes receive the same level of access to healthcare and support as they were when living in their own home; and moved towards proactive care that is centred on the needs of individual residents, their families and care home staff.

A workshop has been held for all health & social care providers, supported by experts by experience with focus on AHCs and how system partners can support individuals to access and prioritise these. The sessions also covered information on how to embed details into individuals Health Action Plans and individuals care and support plans.

Partners from Kirklees's community assets programme, along with identified community champions are working with professionals and Primary Care Networks to support vulnerable, unengaged individuals to access AHCs and to support professionals make reasonable adjustments.

The Continuing Health Care teams review template includes a specific section for individuals with a recorded learning disability to ensure that up to date AHCs, Health Action Plans and screening tests have been completed, specifically for those placed in out of district placements. Issues identified are then escalated back to the individuals' temporary GP as well as recorded with their registered GP for action.

Digital technology, including electronic Health Action Plans has been piloted within 1 Primary care networks in Kirklees. Alongside this, additional medical devices have been purchased to facilitate the review of known respiratory and cardiovascular conditions to support earlier recognition of any changes in an individuals' condition or any deterioration to ensure rapid Multidisciplinary team review.

Following learning from the Covid 19 Pandemic and the commencement of the virtual ward model, patient, carers and care staff have undertaken additional training around the appropriate use Oxygen.

Supportive training sessions to Care homes across Kirklees has been implemented, through Multidisciplinary teams from both our acute and Mental health providers, supported by experts by experience and carers. The Learning Disabilities homes and domiciliary care providers have been receptive to this training. Sessions have included:

- How to recognise signs of deterioration in their residents using 'Soft signs'. (Soft signs can be assessed by carers who know an individual well & is able to recognise subtle changes to usual behaviours which would indicate that the individual is becoming unwell).
- Also how to provide concise, clear communication of any concerns/changes in an individuals' presentation to relevant healthcare professionals, to ensure access to early clinical review.

Both the main Acute trust providers, covering the Kirklees footprint, have ensured the full roll out of the learning disability dashboard to monitor presentations of individuals with a learning disability. Through funding allocated as part of the Core20 plus 5 programme, information and data are now collated on those individuals presenting for elective clinics and procedures including:

- did not attend rates for Outpatient clinics
- time individuals are on waiting lists
- In-patient data
- if reasonable adjustments are required/made

Recent developments during 2022 include:

- Emergency Department attendances
- Length of waiting time

- Themes for attendances

**Project to support Reasonable Adjustments:**

There is a programme of joint training between the ICB, Community Learning Disability Team and Kirklees community involvement with Primary Care Networks regarding understanding of and the implementation of reasonable adjustments.

An example of the work has been through the estates programme and changes that have been made in practice premises: For example, adaptations to make external doors more accessible at one of the practices; Another has identified a quiet area for those suffering from Neuro developmental disorders.

Our community champions and experts by experience are working to support vulnerable patients access appointment and to support professionals to make reasonable adjustments to appointment slots including double length appointments, easy read information prior to the appointment or where required a home visit.

Work has been undertaken with providers to ensure their knowledge of individuals is shared with other key professionals. Hospital via VIP passport and an agreed flagging process on electronic patient records. This ensures that key detailed information about communication needs, support preferences and other reasonable adjustments required, is readily available without individuals relatedly asking.

**Project to review application of 'Do not attempt cardiopulmonary resuscitation (DNACPR) policy where learning disability is identified:**

Following learning from previous LeDeR annual reports and national patient feedback following with Covid 19 Pandemic, Primary Care Networks and GP practices have been reviewing all DNACPRs that are in place for people with a learning disability and to confirm that they were determined appropriately and continue to be clinically appropriate. This is a specific field as a requirement within the Annual health check documentation.

All our provider trusts are in the process of undertaking audits of all DNACPR forms to ensure accurate usage, an additional question included to the audit is specifically in relation to the reasonable adjustments made to support the application of DNACPR.

## Some examples of issues/learning identified by Reviewers


In reviewing all of the identified learning from the 81 reviews completed which consisted of 56 initial and 25 focused reviews the following recurring themes were evident and should be considered by all working with adults with learning disabilities and or autism in service improvement initiatives, resourses and training packages;

| Mental Capacity Act | End of Life (EOL) | Communication and involvement of family/carers |
|---|---|---|
| Whilst acknowledging there has been a vast amount of work to date around education and implementing processes 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 was involved.<br><br>Resource: What is The Mental Capacity Act? \| Mencap | Some concerns regarding lack of referrals to EOL support in a timely manner.<br>Families not feeling fully aware of what to expect when patients are discharged home to die. Concerns that care homes may not be equipped to meet the patient's palliative and EOL care needs.<br>Some cases where advanced care planning has not taken place.<br><br>Resource: Implementation: getting started \| Care of dying adults in the last days of life \| Guidance \| NICE | We have seen cases where families have reported to not have felt listened to or included in decision making.<br>Conversations with health professionals and families regarding death have only taken place when death is imminent.<br>Families have reported not to have been aware of what services and support they could access.<br><br>Resource: Recommendations \| Care and support of people growing older with learning disabilities \| Guidance \| NICE |

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

This report showcases some of the fantastic 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 utilise 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.

As you will see from the data provided within this report that we have some distinct differences across our places which reflects the diversity of our West Yorkshire communities. We do also have some similarities which provide an opportunity to work in collaboration and do something once. We have a consistant picture across all five places within West Yorkshire in relation to respiritory 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 will host later in the year the first West Yorkshire learning event which will have a focus on these cases of respiritory related deaths. It is important to acknowledge that aspiration pneumonia and risk factors for aspiration pneumonia, are reported to be common particularly in people with a learning disability as well as in older people and in patients with neurological or upper gastrointestinal conditions. According to the British Thorasic Society:

- Prevention, identification and treatment requires a multidisciplinary team approach.
- Every hospital and care home should have at least one oral health 'champion' promoting good oral healthcare BTS clinical statement on aspiration pneumonia | Thorax (bmj.com)

By exploring these cases further to inform our learning and reviewing interventions already put in place or in development some of which are highlighted within the place examples we will have an opportunity to identify best practices and take these forward and implement within services across our system.

Cardiac related was the second highest cause of death with the exception of Leeds where it was their third highest cause, attributing to 13.6% of the overs all completed reviews. Leeds differs from the other 4 places within West Yorkshire in that cancer was the second biggest cause of death from the completed reviews. More detail is required to be captured from future reviews to better understand the umbrella term of cardiac related. Risk factors for cardiovascular disease are common in people with learning disabilities and are associated with some genetic causes of learning disabilities. Therefore we need to be able to highlight known risk factors of our population.

## LeDeR key priorities for 2023/24

- The findings of the audit into the DNACPR decisions highlighted in the 2021/22 LeDeR Annual Report from completed focused reviews to be presented to System Quality Group and wider dissemination and consideration of recomendations.

- Grading of care to be completed in the reviews and recorded on the LeDeR spreadsheet for ongoing system monitoring**.**

- AHC and Health Action Plans to be requested if not automatically provided by the GP. The recording of whether this was done in person or virtual/telephone to be recorded on the spreadsheet. The review to record the months between the last AHC and the person's death. Also the number of times the patient was invited for an AHC if not responded before their death.

- DNACPR documentation to be requested when not provided to the Reviewers or a conversation with an acute Trust link where applicable to gain assurance of the quality of this process, e.g patient/family/carer involvement in decision making.

- Long term conditions, the recording of what these conditions were within the reviews highlighting when related to the cause of death and the recording of these on the LeDeR spreadsheet.

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

- Embed findings from LeDeR within quality and relevant programmes of work in order to suport 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 adverage age of death continue to be highlighted.

- Continue to raise awareness of the LeDeR Programme, ensuring the reporting/referral 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 relevent 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.

- The ensure the LeDeR team recruitment challenges are addressed and the team can reach a full compliment. The ICB to secure funding post March 2024 with an aim to make all roles within LeDeR substantive contracts to provide stability of the workforce.

- To establish a LeDeR place leads forum with a learning and best practice focus to allow collaboration across West Yorkshire to address themes from the LeDeR findings that are presenting as either West Yorkshire wide or impacting on people living in more than one area within West Yorkshire.

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

- The regular reporting of specific long term conditions to be shared with place for local information to support targeted preventative and health promotional programmes of work accordingly.

- The ICB to priorities implementing the recommendations from the July 2023 published NHS Race and Health Obsevatory Report We deserve better: Ethnic minorities with learning disabilities and access to healthcare We deserve better: Ethnic minorities with a learning disability and access to healthcare - NHS - Race and Health Observatory NHS – Race and Health Observatory (nhsrho.org)

- Await the publication due autum 2023 of the NHSE National LeDeR Report in order to make some national and regional comparrisons with our West Yorkshire data.

## Place infographic fact sheets data from completed reviews

# LeDeR Reviews Fact Sheet - Wakefield 2022-23 - Completed Reviews

(Completed Reviews: 14)

NHS West Yorkshire Integrated Care Board

### Sex Demographics

50% of the population in the data were female while 50% were male.

### Age of Death

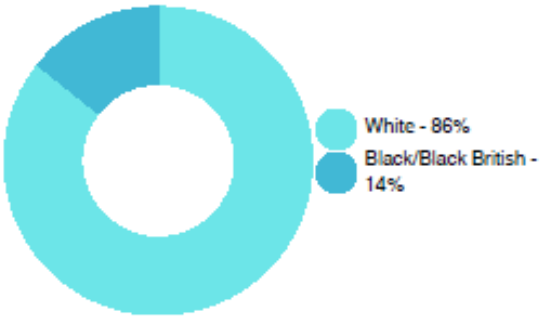
**62 Yrs**

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

**For females it was 65 years**

**For males it was 60 years**

### Ethnicity Demographics




### Early Death

**50%** of people with a learning disability died before they were 65.
Only **10%** of the general population die before they are 65.

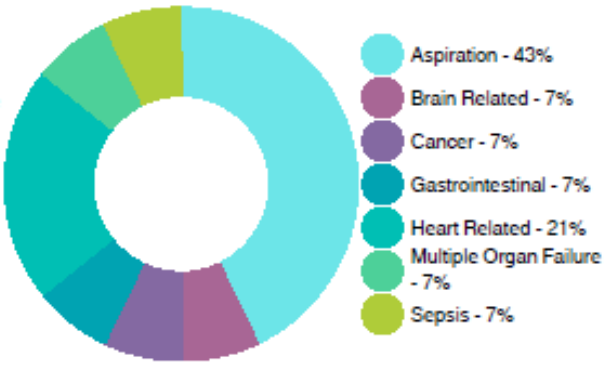
### Cause Demographics

**43%**

43% of people died from aspiration-related causes - this was mostly made up of pneumonia.

The top 5 causes of death were:

- Aspiration
- Heart Related
- Brain Related
- Cancer
- Gastrointestinal



# LeDeR Reviews Fact Sheet - Wakefield 2022-23 - All Reviews

(Completed Reviews: 14)

NHS West Yorkshire Integrated Care Board

## COVID-19 Statistics

**79%**

of people in our closed review population pool had at least 1 COVID-19 vaccination

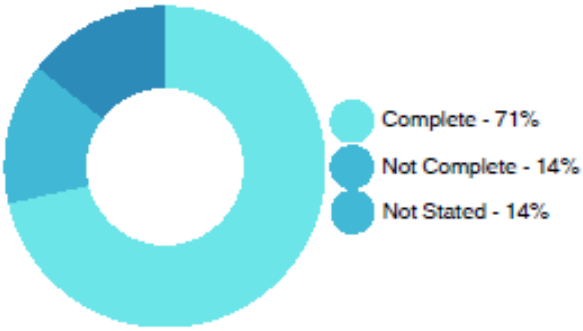
There were no people in these closed reviews who died from COVID-19.

## Number of Health Conditions

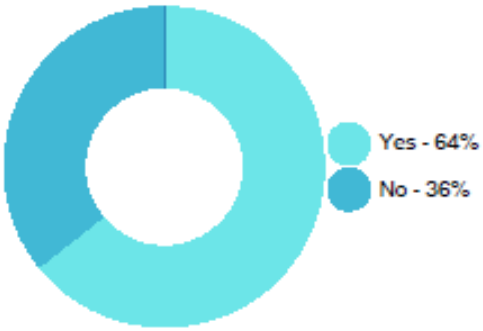
50% of people had 2 or more health conditions

43% of people had 5 or more health conditions

## Annual Health Checks




## DNACPR




64% of deaths had a Do Not Attempt CardioPulomary Resuscitation decision if a decision was made by or for the person.

## Place of Death

**29%**

**29% of people died in hospital**

(47% of the general population die in hospital)

- 14% died where they usually live
- 29% died in a residential/nursing home
- 14% died in a hospice

# LeDeR Reviews Fact Sheet - Kirklees 2022-23 - Completed Reviews

NHS West Yorkshire Integrated Care Board

(Completed Reviews: 10)

## Sex Demographics

40% of the population in the data were female while 60% were male.

## Age of Death

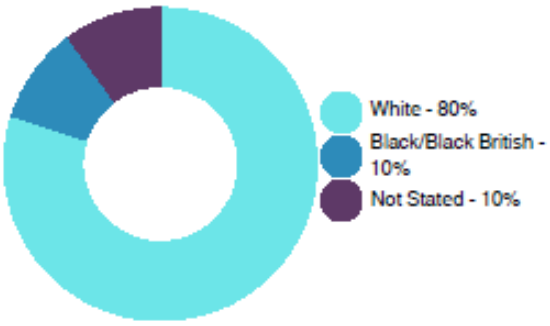
**60 Yrs**

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

**For females it was 57 years**

**For males it was 62 years**

## Ethnicity Demographics




## Early Death

**40%** of people with a learning disability died before they were 65.
Only **10%** of the general population die before they are 65.

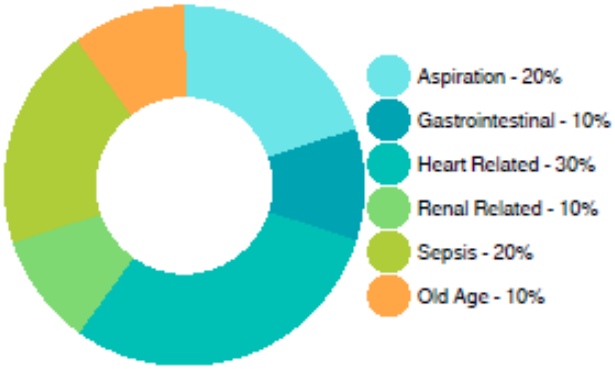
## Cause Demographics

**30%**

30% of people died from heart-related causes, this was closely followed by aspiration-related and sepsis.

The top 5 causes of death were:

- Heart Related
- Aspiration
- Sepsis
- Gastrointestinal
- Renal Related



# LeDeR Reviews Fact Sheet - Kirklees 2022-23 - All Reviews

(Completed Reviews: 10)

NHS West Yorkshire Integrated Care Board

## COVID-19 Statistics

**60%**

of people in our closed review population pool had at least 1 COVID-19 vaccination

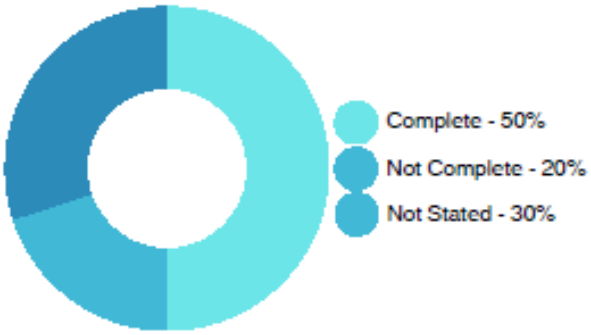
There were no people in these closed reviews who died from COVID-19.

## Number of Health Conditions

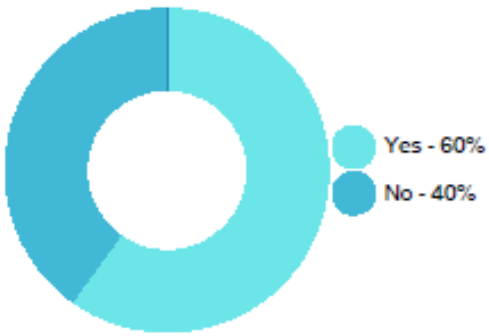
60% of people had 2 or more health conditions

30% of people had 5 or more health conditions

## Annual Health Checks




## DNACPR




60% of deaths had a Do Not Attempt CardioPulomary Resuscitation decision if a decision was made by or for the person.

## Place of Death

**60%**

**60% of people died in hospital**

(47% of the general population die in hospital)

- 30% died where they usually live
- 10% died in a residential/nursing home
- 0% died in a hospice

# LeDeR Reviews Fact Sheet - Calderdale 2022-23 - Completed Reviews

(Completed Reviews: 6)

NHS West Yorkshire Integrated Care Board

## Sex Demographics

50% of the population in the data were female while 50% were male.

## Age of Death

**62 Yrs**

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

**For females it was 68 years**

**For males it was 55 years**

## Ethnicity Demographics


## Early Death

**50%** of people with a learning disability died before they were 65.
Only **10%** of the general population die before they are 65.

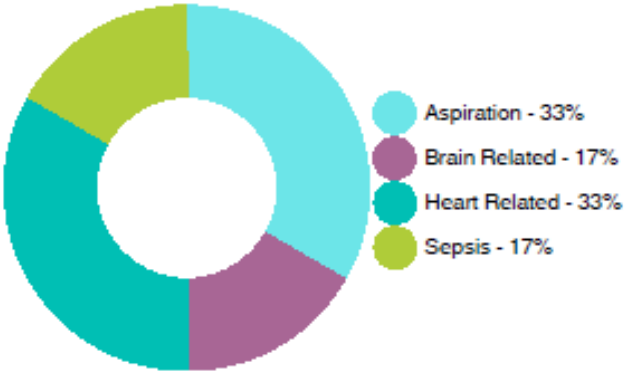
## Cause Demographics

**33%**

33% of people died from respiratory-related causes and or heart-related causes.

The top 5 causes of death were:

- Aspiration
- Heart Related
- Brain Related
- Sepsis



# LeDeR Reviews Fact Sheet - Calderdale 2022-23 - Completed Reviews

(Completed Reviews: 6)

NHS West Yorkshire Integrated Care Board

## COVID-19 Statistics

**67%**

of people in our closed review population pool had at least 1 COVID-19 vaccination

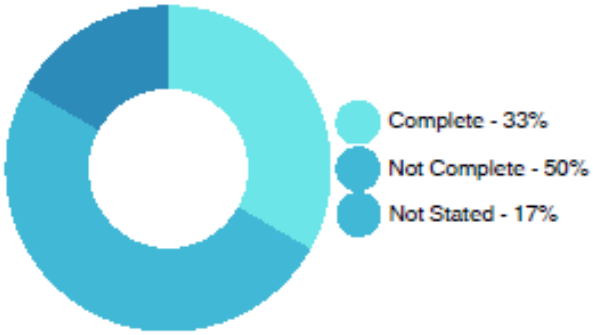
There were no people in these closed reviews who died from COVID-19.

## Number of Health Conditions

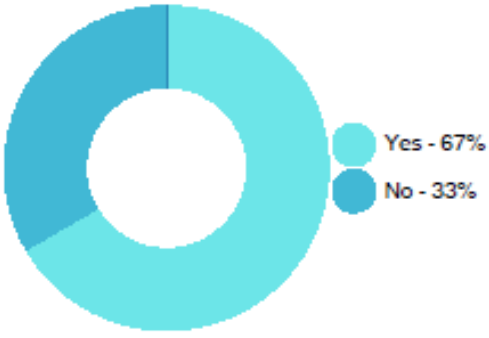
67% of people had 2 or more health conditions

33% of people had 5 or more health conditions

## Annual Health Checks




## DNACPR




67% of deaths had a Do Not Attempt CardioPulomary Resuscitation decision if a decision was made by or for the person.

## Place of Death

**50%**

**50% of people died in hospital**

(47% of the general population die in hospital)

- 17% died where they usually live
- 33% died in a residential/nursing home
- 0% died in a hospice

# LeDeR Reviews Fact Sheet - Leeds 2022-23 - Completed Reviews

(Completed Reviews: 22)

NHS West Yorkshire Integrated Care Board

## Sex Demographics

32% of the population in the data were female while 68% were male.

## Age of Death

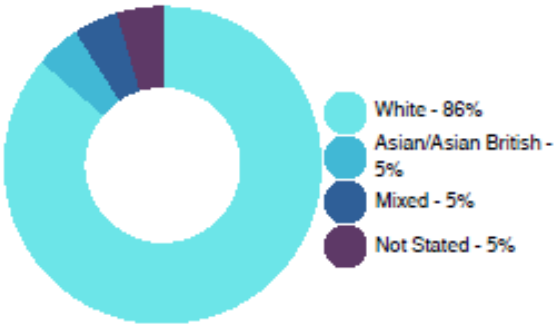
**54 Yrs**

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

**For females it was 54 years**

**For males it was 54 years**

## Ethnicity Demographics




## Early Death

59% of people with a learning disability died before they were 65.
Only 10% of the general population die before they are 65.

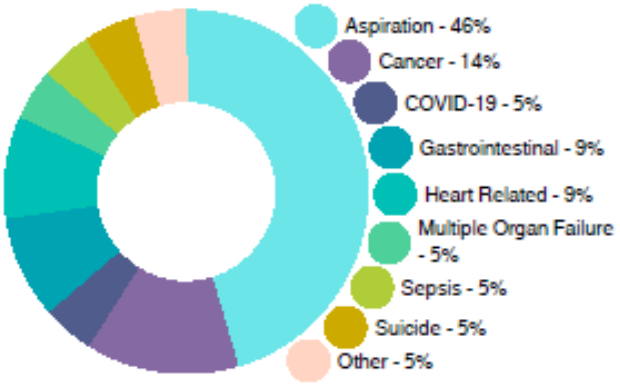
## Cause Demographics

**46%**

46% of people died from aspiration-related causes - the majority of this being made up of pneumonia.

The top 5 causes of death were:

- Aspiration
- Cancer
- Gastrointestinal
- Heart Related
- COVID-19



# LeDeR Reviews Fact Sheet - Leeds 2022-23 - All Reviews

(Completed Reviews: 22)

NHS West Yorkshire Integrated Care Board

## COVID-19 Statistics

(1 case of COVID-19)

**77%**

of people in our closed review population pool had at least 1 COVID-19 vaccination

0% of people who died of COVID-19 had a vaccination.

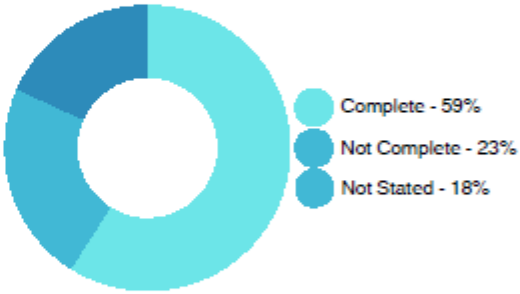
100% of people who died of COVID-19 did not have a vaccination.

## Number of Health Conditions

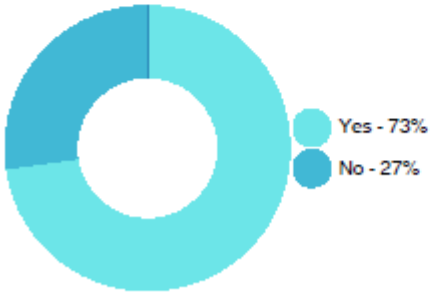
41% of people had 2 or more health conditions

55% of people had 5 or more health conditions

## Annual Health Checks




## DNACPR




73% of deaths had a Do Not Attempt CardioPulomary Resuscitation decision if a decision was made by or for the person.

## Place of Death

**64%**

**64% of people died in hospital**

(47% of the general population die in hospital)

- 27% died where they usually live
- 5% died in a residential/nursing home
- 5% died in a hospice

# LeDeR Reviews Fact Sheet - Bradford 2022-23 - Completed Reviews

(Completed Reviews: 29)

NHS West Yorkshire Integrated Care Board

## Sex Demographics

34% of the population in the data were female while 66% were male.

## Age of Death

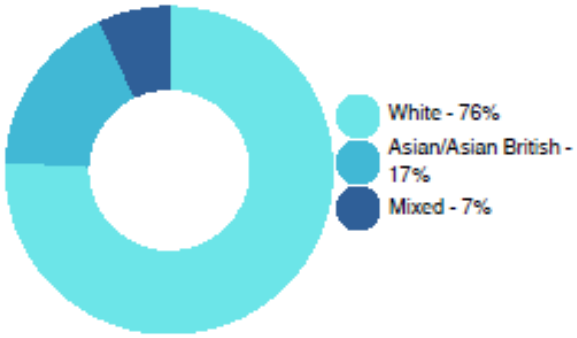
**55 Yrs**

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

**For females it was 61 years**

**For males it was 52 years**

## Ethnicity Demographics




## Early Death

**62%** of people with a learning disability died before they were 65.
Only **10%** of the general population die before they are 65.

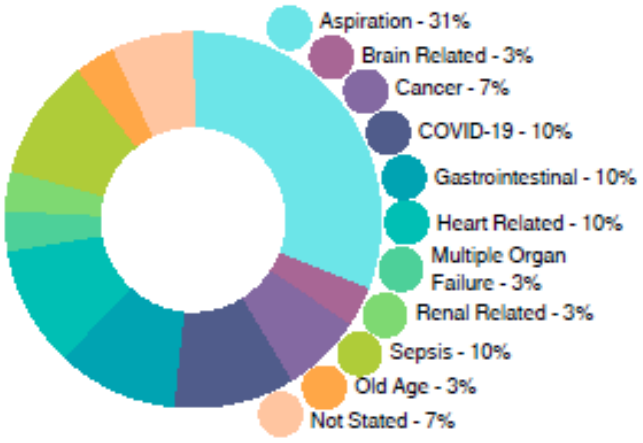
## Cause Demographics

**31%**

31% of people died from respiratory-related causes - the majority of this was due to pneumonia.

The top 5 causes of death were:

- Aspiration
- COVID-19
- Gastrointestinal
- Heart Related
- Sepsis



# LeDeR Reviews Fact Sheet - Bradford 2022-23 - Completed Reviews

(Completed Reviews: 29)

NHS West Yorkshire Integrated Care Board

## COVID-19 Statistics

(3 cases of COVID-19)

**62%**

of people in our closed review population pool had at least 1 COVID-19 vaccination

33.3% of people who died of COVID-19 had a vaccination.

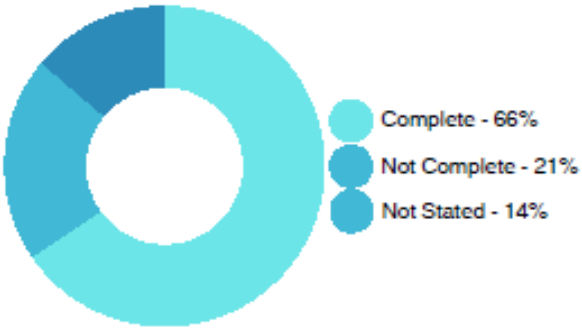
66.6% of people who died of COVID-19 did not have a vaccination.

## Number of Health Conditions

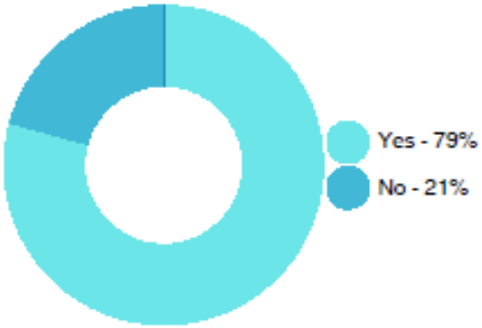
47% of people had 2 or more health conditions

48% of people had 5 or more health conditions

## Annual Health Checks




## DNACPR




79% of deaths had a Do Not Attempt CardioPulomary Resuscitation decision if a decision was made by or for the person.

## Place of Death

**55%**

**55% of people died in hospital**

(47% of the general population die in hospital)

- 21% died where they usually live
- 14% died in a residential/nursing home
- 7% died in a hospice

## 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%. |
| CCG | Clinical Commissioning Group were created following the Health and Social Care Act in 2012. They were clinically led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area. |
| 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. |
| HIV | Human immunodeficiency virus is a virus that damages the cells in the immune system and weakens your ability to fight everyday infections and disease. |
| ICB | Intergrated Care Board is a statutory NHS organisation that plans and delivers health services in a geographical area. |
| ICS | Intergrated 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 Authroity 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. |
| LeDeR | Learing from the lives and death of people with a learning disability and or autism |
| 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. |
| LTC | Long Term Condition are conditions for which there is currently no cure, and which are managed with drugs and other treatment. |
| 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. |
| 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. |
| STAMP | Stopping over medication in paediatrics**.** |
| STOMP | Stopping over medication for adults with learning disabilities**.** |
| TBC | To be confirmed as this information is not yet known. |
| Q4 | Quarter four is a term within a year that covers a 3 month period. |
| 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. |