Public Board of Directors
Item number: 11
Date: 24 September 2025

Private/ public paper:	Public
Report Title:	**Mortality Quarter 1 Report 2025/26**
Author(s)	Vin Lewin, Head of clinical quality
Accountable Director:	Prof Helen Crimlisk, Interim executive medical director
Presented by:	Prof Helen Crimlisk, Interim executive medical director
Vision and values:	The Mortality Review Team supports the Trust to deliver on the vision of the people in our communities by: • **Working with and advocating for the local population** • **Refocusing our services towards prevention and early intervention** • **Continuous improvement of our services** • **Developing a confident and skilled workforce** • **Ensuring excellent and sustainable services**
Purpose:	This report provides the Board of Directors with an overview of SHSC's mortality processes and any learning from mortality discussed in the Mortality Review Group (MRG). 100% of deaths reported through SHSC's incident management system (Ulysses) were subject to review and due diligence.
Executive summary:	During quarter 1 2025/26, SHSC was fully compliant with the 2017 National Quality Board (NQB) standards for learning from deaths. 63 deaths (2 of which were learning disability deaths) were incident reported and reviewed via mortality processes. This report analyses the deaths that have occurred by service/team, age, ethnicity and gender, in line with the National Quality Board guidance. Appendices: Appendix 1 - Deaths reported by service area/team, broken down by quarter and causes of death Appendix 2 - NCISH characteristics of SHSC suicides Appendix 3 - Mortality Dashboard Appendix 4 – LeDeR report take home facts infographic published September 2025

Which strategic objective does the item primarily contribute to:					
Effective Use of Resources	***Yes***		*No*		
Deliver Outstanding Care	***Yes***		*No*		
Great Place to Work	***Yes***		*No*		
Reducing Inequalities	*Yes*		***No***		

What is the contribution to the delivery of standards, legal obligations and/or wider system and partnership working.	
This report is relevant to compliance with the following key standards: • CQC Regulation 18: Notification of other incidents • CQC's Review of Learning from Deaths • Learning Disabilities Mortality Review (LeDeR) Project • NHS Sheffield Integrated Care Board Quality Schedule (part of NHS Contract) • NHS England's Patient Safety Incident Response Framework • SHSC's Patient Safety Incident Response Framework and Patient Safety Incident Response Plan • SHSC's Duty of Candour/Being Open Policy • SHSC's Learning from Deaths Policy • National Quality Board Guidance on Learning from Deaths (2017)	
BAF and corporate risk/s:	There is currently 1 risk associated with this item: **BAF 0024** Risk of failing to meet fundamental standards of care caused by lack of appropriate systems and auditing of compliance with standards, resulting in avoidable harm and negative impact on service user outcomes and experience, staff wellbeing, development of closed cultures, reputation, future sustainability of particular services which could result in potential for regulatory action.
Any background papers/ items previously considered:	This report covers quarter 1 2025/26. This report was presented to the Quality Assurance Committee on 10 September 2025.
Recommendation:	The Board of Directors are asked to: • Be **assured** that SHSC has robust mortality and learning from deaths review processes in place

Mortality Report Quarter 1 2025/26

1. Purpose

This report provides the Board of Directors with an overview of SHSC's mortality processes and any learning from mortality discussed in the Mortality Review Group (MRG).
100% of deaths reported through SHSC's incident management system (Ulysses) were subject to review and due diligence.

For each death reviewed, the mortality processes aim to determine and understand:

- What was the cause of death?
- Who certified the death?
- Whether family/carers or staff had any questions/concerns in connection with the death?
- The setting the person was in in at the time of death, e.g., an inpatient, residential setting or own home?
- Whether the patient had a Learning Disability or Autism Spectrum Disorder?
- Whether the person had a diagnosis of psychosis or eating disorder during their last episode of care?
- Whether the person was prescribed antipsychotic medication at the time of their death?
- Whether there was any other indicator that they may not have received good care including inequalities markers?

2. Background

2.1 The Five Year Forward View for Mental Health identified that people with severe and prolonged mental illness are at risk of dying on average 15 to 20 years earlier than other people.

2.2. Reports and case studies have consistently highlighted that in England, people with learning disabilities die younger than people without learning disabilities.

2.3. The findings of the Care Quality Commission (CQC) report "Learning, candour and accountability: A review of the way NHS trusts review and investigate the deaths of patients in England", found that learning from deaths was not being given sufficient priority in some organisations and consequently valuable opportunities for improvements were being missed.

National Quality Board (NQB)

The NQB guidance outlines that all providers should have a policy in place setting out how they respond to the deaths of patients who die under their management and care, including how we will:

- Determine which patients are considered to be under our care and included for case record review if they die (also stating which patients are specifically excluded)
- Report the death within our organisation and to other organisations who may have an interest (including the deceased person's GP)
- Respond to the death of an individual with a learning disability, autism or mental health needs
- Review the care provided to patients who we do not consider having been under our care at the time of death, but where another organisation suggests we should review the care SHSC provided to the patient in the past
- Review the care provided to patients whose death may have been expected, for example those receiving end of life care

- Record the outcome of our decision whether or not to review or investigate the death, informed by the views of bereaved families and carers
- Engage meaningfully and compassionately with bereaved families and carers.

National Mortality and Learning from Deaths

2.4 Understanding mortality in mental health settings can be complex and extracting learning may mean that exploration of co-morbidities is necessary. A priority for the Mortality Review Group (MRG) was to continue to engage with the national Better Tomorrow project in order to improve and strengthen our learning from deaths.

2.5 The Better Tomorrow project came to an end, however, SHSC remains an active member of the National Mortality and Learning from Deaths group, which is a legacy of the Better Tomorrow project. Members of the mortality group have attended the National and Learning from Deaths Group, national LeDeR and national Structured Judgement Review (SJR) meetings as well as local mortality groups. This enables members to remain updated for both national and Integrated Care Board perspectives. This is a valuable learning experience about trends in deaths which informs the focus of the SJRs undertaken. This informs our focus which is currently around end-of-life care in regard for SJRs.

3. Mortality Data

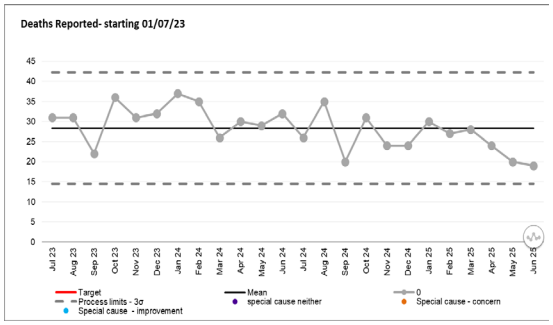
100% of deaths reported through SHSC's incident management system (Ulysses) were reviewed at the weekly MRG. Within quarter 1 2025/26, the MRG reviewed a combined total of 63 deaths individually.

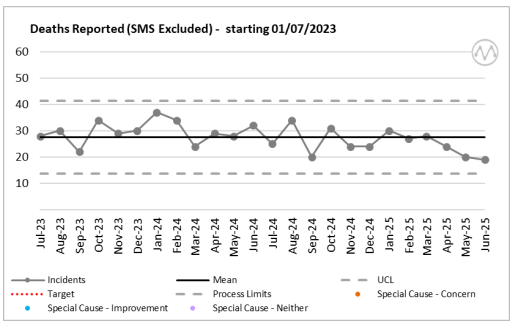
The table below shows the number and type of deaths reviewed by MRG during the period.

Reporting Period	Source	Number of Deaths
2025/26	NHS Spine (National Death Reporting Process)	*0
	Incident Report (excluding LD Deaths)	61
	Learning Disability Deaths	2
	Total	63

The low number during this period reflects the disruption to Spine access as a result of RIO implementation and is expected to be reflected in next quarter's figures.

The statistical process chart below shows the number of deaths reported as an incident on a monthly basis from April 2023 to June 2025. The charts below show the number of deaths reported across all teams as well as the number of deaths recorded (excluding substance misuse services). This is to confirm, or otherwise, whether the downward trend is simply a legacy effect of the loss of substance misuse services. We will continue to monitor this going forwards and may reduce the upper control limits, if this reduction is sustained.





Analysis of All Death Incidents Reported (Including Learning Disabilities)

Deaths reported as incidents during 2025/26 are classified in the table below, broken down by reporting quarter:

	No. of deaths per month			
Death Classification	**April 2025**	**May 2025**	**June 2025**	**Quarter 1 Totals**
Expected Death (Information Only)	5	8	4	17
Expected Death (Reportable to HM Coroner)			1	1
Suspected Suicide – Community	3	2	1	6
Unexpected Death - SHSC Community	4	3	3	10
Unexpected Death (Suspected Natural Causes)	12	7	10	29
Total	**24**	**20**	**19**	**63**

The table below show the age breakdown for deaths that were incident reported (including Learning Disability deaths):

	No. of deaths per month			
Age Range	**April 2025**	**May 2025**	**June 2025**	**Quarter 1 Totals**
30 – 35	2		1	3
36 – 39		3	1	4
40 – 49			2	2
50 - 59	2	3	1	6
60 – 69	3	2	5	10
70 - 79	8	5	5	18
80 – 89	7	7	3	17
90+	2		1	3
Grand Total	**24**	**20**	**19**	**63**

The table above shows that the highest number of deaths reported in quarter 1 2025/26 were service users aged between 70-79 years of age, followed by people in the 80– 89 age range.

Analysis of Learning Disability Deaths Reported

Learning disability Deaths reported as incidents during 2024/26 are classified in the table below, broken down by reporting quarter:

Death Classification (LD only)	**Q2**	**Q3**	**Q4**	**Q1**
Expected Death (Information Only)	0	1	3	1
Expected Death (Reportable to HM Coroner)	0	0	0	0
Suspected Suicide – Community	0	0	0	0
Unexpected Death - SHSC Community	0	1	1	0
Unexpected Death - SHSC Inpatient/Residential	0	0	0	0
Unexpected Death (Suspected Natural Causes)	1	4	2	1
Suspected Homicide	0	0	0	0
Total	1	6	6	2

The chart/table below shows the age breakdown for learning disability deaths that were incident reported in 2024/26:

Age Range	Q2	Q3	Q4	Q1	Total
0*	0	2	2	0	***4**
16-17	0	0	0	0	**0**
18-24	0	0	1	0	**1**
25-34	0	0	0	0	**0**
35-44	0	0	0	0	**0**
45-54	0	0	0	0	**0**
55-64	1	0	1	2	**4**
65-74	0	2	1	0	**3**
75-84	0	1	0	0	**1**
85-94	0	1	1	0	**2**

* *These deaths have no age recorded on Ulysses. This is due to the patient information not being pulled from Insight (or Rio), eg the service user may have been under such teams as LTNC, which use SystmOne instead of Insight/Rio.*

The above shows that the highest number of deaths reported in 2024/26 were service users aged between 55-64 years of age, followed by people in the 65-74 age range. This illustrates what previous studies (including LeDeR reviews) have found that typically, people with a learning disability die approximately 20 years younger than people without a learning disability.

Breakdown by Service Area/Team

A detailed breakdown for deaths reported as incidents during 2025/26 per service area/team is provided in Appendix 1.

The table below provides a summary of which services were providing the care (or the most recent care episode) at the time of death, as a percentage of the total number of deaths.

	No. of deaths per month			
Service/Team	**April 2025**	**May 2025**	**June 2025**	**Quarter 1 Totals**
CERT		1		1
CMHT North			1	1
CMHT South		1	1	2
CRHTT	1		1	2
Dovedale	1			1
Early Intervention Service	1			1
Gender Identity Service		1		1
Liaison Psychiatry	4	2	3	9
LTNC	2	3	3	8
Neuro Enablement Service			1	1
OA CMHT North	2	2	5	9
OA CMHT South East	4	1	2	7
OA CMHT South West	3	1	1	5
OA CMHT West	2	5		7
OA Home Treatment		1	1	2
Specialist Community Learning Disabilities Service (SCLDS)	1	1		2
Urgent & Crisis Service	1			1

Woodland View | Willow Cottage	2	1		3
Grand Total	**24**	**20**	**19**	**63**

This shows that 53% (n=34) of all deaths reported were service users who were open to older adult services (including community and residential). The second highest number of deaths were of service users open to our psychiatric liaison service with 14% (n=9) deaths reported in the year.

Conclusion

Out of the 63 deaths that were incident reported during quarter 1 2025/26, 79% (n=49) were deemed to have been due to natural causes (this determination may have been following initial Coronial enquiries, such as a postmortem).

Examples of the natural cause deaths recorded during 2025/26 include:

- Dementia (including Alzheimer's Dementia, Lewy Body Dementia etc)
- Motor Neurone Disease
- Chronic Obstructive Pulmonary Disease (COPD)
- Huntington's Disease
- Bronchopneumonia / Pneumonia / Aspiration Pneumonia
- Frailty
- Progressive Supranuclear Palsy
- Cancer (some examples are Metastatic Bowel Cancer, Pancreatic Cancer, Metastatic Squamous Cell Lung Cancer, Basal Cell Carcinoma, Chorea/Cell lymphoma)
- Myocardial Infarction
- Sepsis
- Parkinson's Disease

Key Demographics

Age breakdown

	No. of deaths per month			
Age Range	**April 2025**	**May 2025**	**June 2025**	**Quarter 1 Totals**
30 – 35	2		1	3
36 – 39		3	1	4
40 – 49			2	2
50 - 59	2	3	1	6
60 – 69	3	2	5	10
70 - 79	8	5	5	18
80 – 89	7	7	3	17
90+	2		1	3
Grand Total	**24**	**20**	**19**	**63**

Gender breakdown

	No. of deaths per month			
Service User Gender	**April 2025**	**May 2025**	**June 2025**	**Quarter 1 Totals**
F	7	11	4	22
M	17	9	15	41
Grand Total	**24**	**20**	**19**	**63**

Ethnicity breakdown

	No. of deaths per month			
Ethnicity	**April 2025**	**May 2025**	**June 2025**	**Quarter 1 Totals**
White British	12	10	13	35
White Irish	1			1
Asian or Asian British Bangladeshi			1	1
Black or Black British African	1			1
Not Stated	5	6	5	16
(blank)	5	4		9
Grand Total	**24**	**20**	**19**	**63**

65% (n=41) of all deaths reported were male service users. 35% (n=22) were female and all individuals had their gender recorded on the Ulysses system.

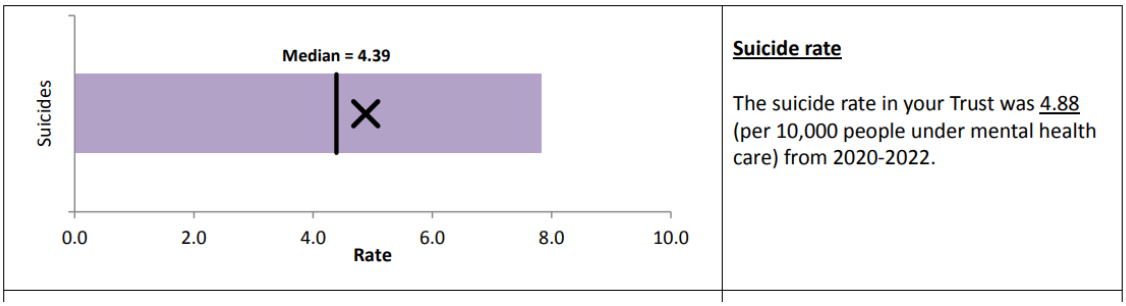
56% (n36) of all deaths reported during quarter 1 2025/26 were of white British service users. The full ethnicity breakdown can be seen in Appendix 1. 25 service users' ethnicity is 'not stated' or 'blank'. This prohibits more detailed analysis and a fuller understanding of the ethnicity of 40% of those that died. Work is underway in SHSC to improve the demographics and protected characteristics reporting across all teams and as this becomes available, further analysis based on inequalities flags will be undertaken. A series of SJRs are currently being undertaken to further interrogate learning from any deaths identified in people from ethnic minorities, however it is acknowledged that without baseline data being identified, this has the potential to be misleading.

4. Benchmarking

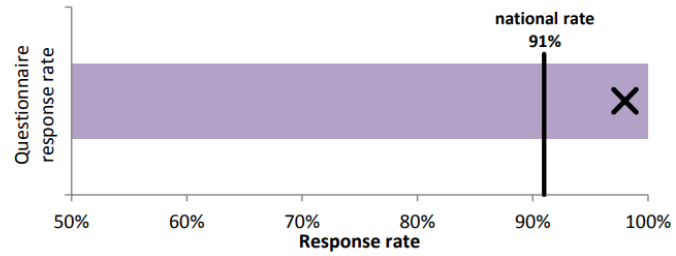
4.1 Following the Covid-19 outbreak, regional benchmarking processes, available via the Northern Alliance for mortality review were unavailable. In early 2024/25 the Northern Alliance Group was re-formed and the Trust re-engaged with this group.

4.2 Learning from Deaths was subject to wider clinical audit in 2022/2023 and will be subject to repeat audits as per the trust-wide annual audit programme.

4.3 Our safety scorecard for 2025 (covering a 3-year period from 2020-22) has recently been received from the National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH). This shows that our suicide rate is higher than the median for mental health trusts in the UK.



The Trust has also returned 98% of the NCISH questionnaire's, which is one of the highest rates of questionnaire returns.



NCISH questionnaire response rate

You have returned 98% of NCISH questionnaires between January 2022 and September 2024.

The key characteristics of service users who died by suicide between 2012-2022 has also been provided by NCISH and is attached at Appendix 2. This shows SHSC's results compared with regional and national statistics. SHSC's deaths show that we have more service users who live alone, who take their lives by suicide, than both the region and England and less service users who are unemployed, that complete suicide. This information also shows that we have a higher percentage of service users diagnosed with a personality disorder, who take their own lives, than regionally and nationally and a higher proportion of service users with a substance dependence.

Quarter 1 suspected suicide demographics

	No. of deaths per month			
Team/ Age Range / Gender	**April 2025**	**May 2025**	**June 2025**	**Quarter 1 Totals**
CRHTT	Male - 30 yrs			1
Liaison		Male – 37 yrs		1
CMHT South		Male - 38 yrs		1
CRHTT			Female - 39 yrs	1
Urgent & Crisis	Female – 58 yrs			1
Liaison	Male – 64 yrs			1
			Total	**6**

This correlates with national data that indicates men are significantly more at risk, and highest rates are seen in those aged 30 to 64. Work is ongoing to ensure that demographic details of these service users are more visible in future reports.

4.5 Learning from the Lives and Deaths of People with a learning disability and autistic people (LeDeR) Annual Report 2023/24

SHSC has a well-established mortality pathway, where a team will review each death that is identified to the trust (via incident reporting etc), in both the daily incident huddle and as part of a weekly mortality meeting. Part of this process would be to identify if any person has a learning disability or autism, which is done via an electronic record check. This is done for each reported death. When a person has a confirmed learning disability or autism, there is a requirement to report this death to the National LeDeR platform. Any reportable LeDeR death will then be reviewed, and various actions can be taken as part of the learning from deaths pathway. SHSC will then receive a completed LeDeR review that will be discussed through the mortality pathway and then disseminated to local teams for any actions or wider learning. Data from these reviews is then shared in wider mortality reporting.

Findings from the Annual LeDeR Report

As this was the first ever combined report across South Yorkshire, this highlight report mainly focuses on key points including anything from a physical health perspective.

- Sheffield submitted 60 notifications for time period, South Yorkshire received 127 overall.
- 52/60 were completed in 2023/24 (including 6 focused reviews)
- Most common causes of death were noted to be related to; Respiratory Illness, Cancer, Sepsis, Cardiac, Digestive System, Neurology, System Failure, Covid, Epilepsy & Frailty.
- 31 deaths were also associated with having a genetic condition – the most common being Down Syndrome.
- Screening uptake for bowel, breast, cervical and abdominal aortic aneurysm (AAA) was low in all areas.
- Annual Health Checks were noted to be at an 80% completion rate during the time period of review of LeDeR deaths.
- Only 12% of people reviewed during this period had an EOL pathway documented. ·
- Carers assessments were extremely low – only 2 people recorded as having received a carers assessment.

The national LeDeR report for 2023 was published in September 2025 and can be found at LeDeR Report 2023 - Main Report. The take home facts in infographic style can be found at Appendix 4.

Next steps for SHSC

- Screening awareness across all domains to be publicised and encouraged.
- Record keeping – work taking place currently on looking at effective documentation and how staff can better demonstrate patient care (including work on collaborative care plans).
- End Of Life policy is currently being developed to offer supportive guidance for staff in all areas.
- Continue to monitor, review and report any learning Disability/Autism deaths via systems already in place.
- Continue to learn from and share findings from completed LeDeR reviews.

Number of LeDeR reports reviewed by MRG in Q1 2025/26

Q1 2025/26			
April 2025	**May 2025**	**June 2025**	**Quarter 1 Totals**
4	1	1	6

There were no specific learning points identified for SHSC during quarter 1, however all returned reports are shared with the Community Learning Disability team for dissemination.

5. Triangulation

5.1 The outcomes from the learning from deaths processes, is outlined in the separate Patient Safety Learning Report that the Quality Assurance Committee receives on a quarterly basis. This report brings together all the various elements, eg incident reporting, patient safety investigations, learning responses, safeguarding concerns, Freedom to Speak Up concerns, mortality processes and Coronial procedures to establish themes and to outline what work is being undertaken to address these themes. A thematic review of unexpected deaths is also currently underway in line with SHSC's Patient Safety Incident Response Plan.

6. Engagement with Families

6.1 The current process for reviewing deaths reported within SHSC includes contact with bereaved relatives and carers to express the Trust condolences and ask for feedback on the quality of the service provided to their family member.

6.2 The Structured Judgement Review process requires that all completed reviews and the learning from those reviews is presented to the individual teams that provided care to the deceased patient. Structured Judgement Reviews will be completed by a growing pool of clinical staff across SHSC and all reviews will be presented to the Patient Safety Oversight Panel, before final review at the Mortality Review Group.

7. Public Reporting of Death Statistics

7.1 National Quality Board Guidance states that Trusts must report their mortality figures to a public Board meeting on a quarterly basis. The current dashboard attached at Appendix 3 was developed by the Northern Alliance for this purpose and contains information from the SHSC's risk management system (Ulysses) as well as information from our patient administration system (Insight/RIO). The learning points recorded in the dashboard are actions arising from patient safety incident investigations, structured judgement reviews, or LeDeR reviews, that result in changes in practice. The dashboard attached covers information across all four quarters for 2024/25 and will be updated as and when processes are completed and additional learning is identified.

8. Recommendations

The Board of Directors are asked to:

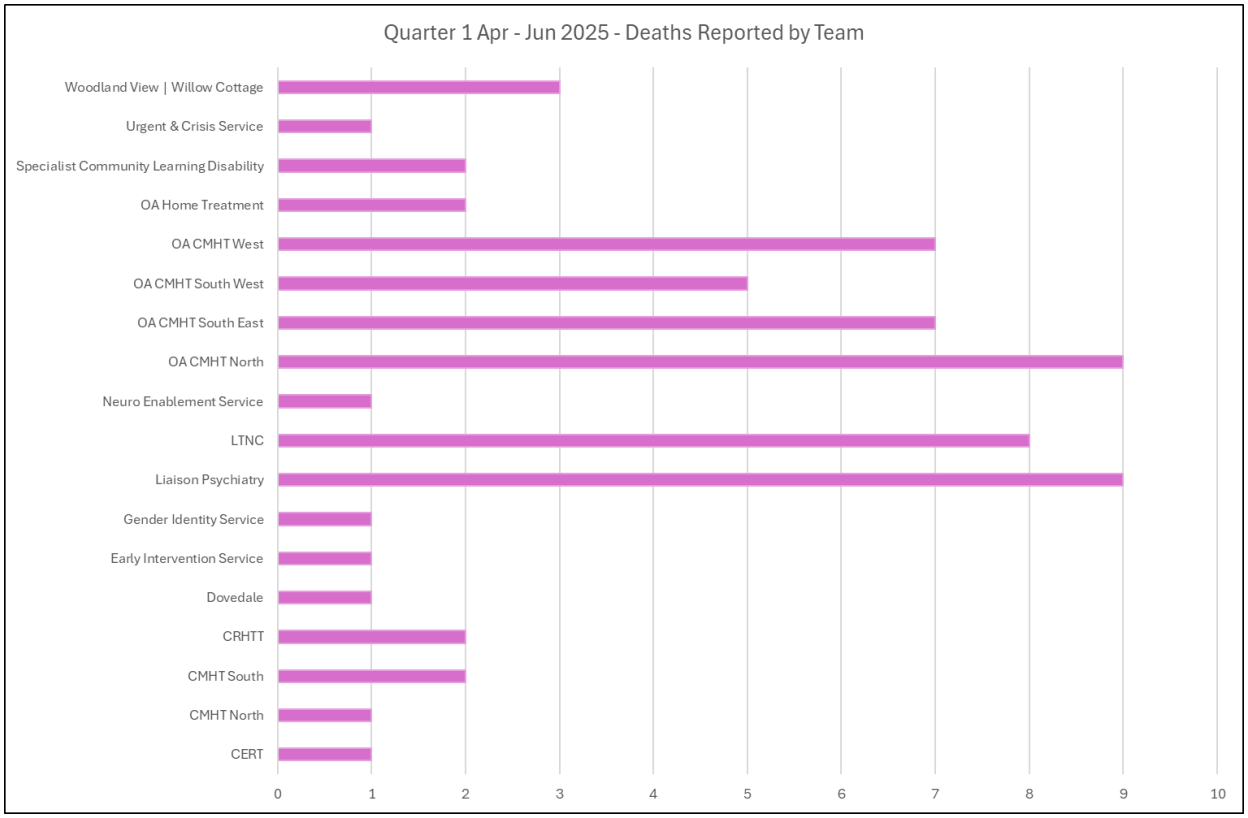
- Be **assured** that SHSC has robust mortality and learning from deaths review processes in place

Appendices:

Appendix 1 - Deaths reported by service area/team, broken down by quarter and causes of death
Appendix 2 - NCISH characteristics of SHSC suicides
Appendix 3 - Mortality Dashboard
Appendix 4 – LeDeR report take home facts infographic published September 2025

Appendix 1

Deaths reported Q1 2025/26 - broken down by Service Area/Team



Causes of Death (where known – may include preliminary causes of death)

Causes of Death Recorded
Other significant conditions contributing to death - frailty of old age, dementia
1a Frailty due to Colorectal Cancer & Pneumonia
1a Motor Neurone Disease
1a) Alzheimer's Dementia
2) Pneumonia
1a) Aspiration Pneumonia
1b) Paralytic Ileus
2) Type 2 Diabetes mellitus
1b) Downs Syndrome Dementia
1a) Astrocytoma
1a) Brain Tumour (Palliative Care)
1a) Bronchopneumonia
2) Huntingdon's Disease
2) Myocardial infarction, vascular dementia, type 2 diabetes mellitus
1a) Congestive cardiac failure
2) Frailty due to dementia, Chronic Kidney Disease
1a) Dementia
1a) Frailty due to Alzheimer's disease
2) Cerebrovascular disease
1a) Heart Failure
2) Dementia
1a) Lung cancer
2) Encephalopathy
(Palliative care)
1a) Metastatic Squamous Cell Carcinoma of the Bladder
2) Chronic Kidney Disease
1a) Motor Neurone Disease
1a) Multiple System Atrophy (MSA)
1a) Old Age & Frailty
2) Likely Dementia
1a) Parkinson's
1a) Pneumonia
2) Metastatic Melanoma, Cor Pulmonale, Chronic Obstructive Pulmonary Disease
1a) Pulmonary Fibrosis
1a) Squamous Cell Cancer
1a) Subdural Haemorrhage
1a) Upper Gastrointestinal Haemorrhage
1b) Gastric Ulcer
2) Heart Failure, Hypertension, Chronic Kidney Disease
1a) Urosepsis
Brain Tumour
1a - Congestive heart failure
1b Tricuspid regurgitation, pulmonary hypertension
1b) - Pharyngeal Dysphagia
Covid 19 infection
Other significant conditions contributing to death:
metastatic malignancy of unknown primary , fronto temporal dementia

Heart Block
Heart Failure
Other significant conditions contributing to death - Proctocolitis
1a) - Community Acquired Pneumonia
Other significant conditions contributing to death
Frailty due to Old Age, Stroke, Alzheimer's Disease
1a- Community Acquired Pneumonia
Spontaneous Upper Gastrointestinal Bleed
Other significant conditions contributing to death
Frailty due to Old Age & Dementia, Peripheral Vascular Disease
Intra-cranial meningioma

Grand Total 63

Appendix 2

Characteristics of patients who died by suicide in SHSC compared with regional and national data

Year	2012 - 2022		
	Sheffield Health & Social Care NHS Foundation Trust	Yorkshire and the Humber	ENGLAND
Percentages given are valid percentages	N=173	N=1,310	N=13,893
Sociodemographic:			
Age Median (Min-Max)	44 (16-87)	45 (14-95)	46 (12-100)
Male	117 (67.6%)	886 (67.6%)	9,061 (65.2%)
Female	56 (32.4%)	424 (32.4%)	4,832 (34.8%)
Living alone	83 (54.2%)	577 (47.6%)	6,026 (46.7%)
Unemployed	58 (38.7%)	510 (43.5%)	5,738 (45.6%)
Clinical:			
In-patient at time of suicide	4 (2.3%)	77 (5.9%)	743 (5.4%)
Died within 3 months of discharge from in-patient care	18 (10.7%)	140 (11.5%)	1,667 (12.8%)
Primary diagnosis:			
Schizophrenia & other primary psychotic disorders	26 (15.7%)	183 (14.5%)	2,100 (15.5%)
Affective disorders	63 (38.0%)	512 (40.5%)	5,609 (41.5%)
Alcohol dependence/misuse	5 (3.0%)	69 (5.5%)	737 (5.5%)
Drug dependence/misuse	17 (10.2%)↑	61 (4.8%)	499 (3.7%)
Personality disorder	25 (15.1%)	130 (10.3%)	1,492 (11.0%)
Other diagnosis	27 (16.3%)	247 (19.5%)	2,635 (19.5%)
Any comorbid diagnosis	94 (57.3%)	649 (51.7%)	7,323 (54.6%)
History of self-harm	108 (66.3%)	743 (60.1%)	8,058 (60.8%)
History of alcohol misuse	77 (48.1%)	565 (46.3%)	5,768 (44.0%)
History of drug misuse	61 (37.7%)	438 (35.6%)	4,642 (35.1%)
Risk:			
Short-term risk low or none	90 (73.2%)	914 (83.2%)	9,285 (79.9%)

↑significantly higher compared to national data (England)

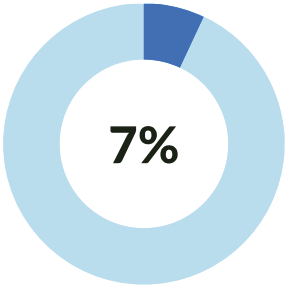
KEY OVERALL DEMOGRAPHICS FROM THE LEDER REPORT

SEX

54.7% of adults notified with a learning disability who died in 2023 were male.

79.5% of autistic adults who died in 2021-2023 were male.

ETHNICITY



7% of adults notified to LeDeR in 2023 were from an ethnic minority group.

AGE AT DEATH

In 2023, adults with a learning disability on average die 19.5 years younger than the general population.

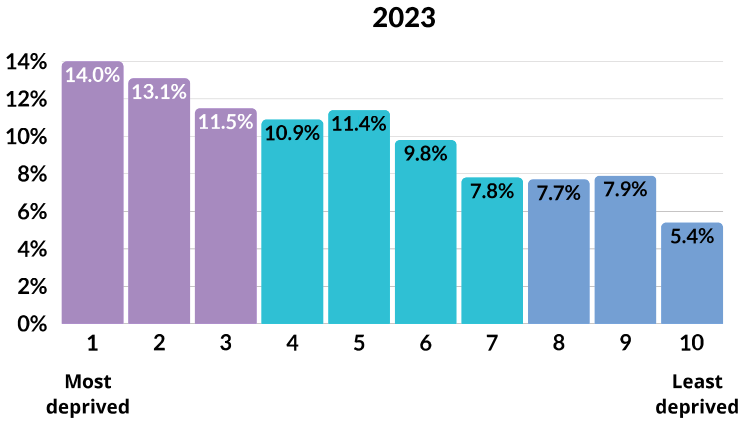
MEDIAN AGE AT DEATH OF ADULTS WITH A LEARNING DISABILITY WHOSE DEATH WERE NOTIFIED TO LEDER BETWEEN 2018 - 2023

62.5

*Note: Age at death is not the same as life expectancy.

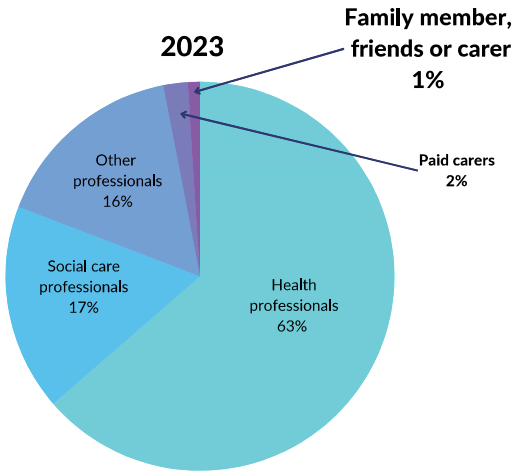
DEPRIVATION

- **38.6%** of adults who died lived in most deprived areas (1-3).
- **21%** of adults who died lived in the least deprived areas (8-10).



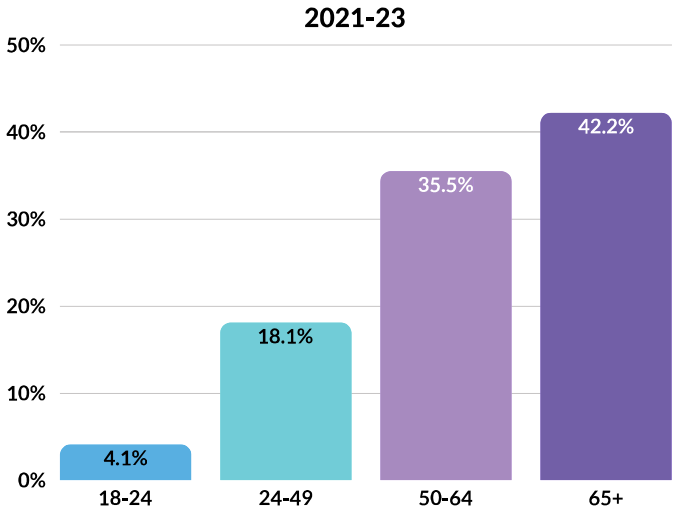
WHO NOTIFIED LeDeR?

1% of deaths notified to LeDeR were made by a family member, friend or carer.



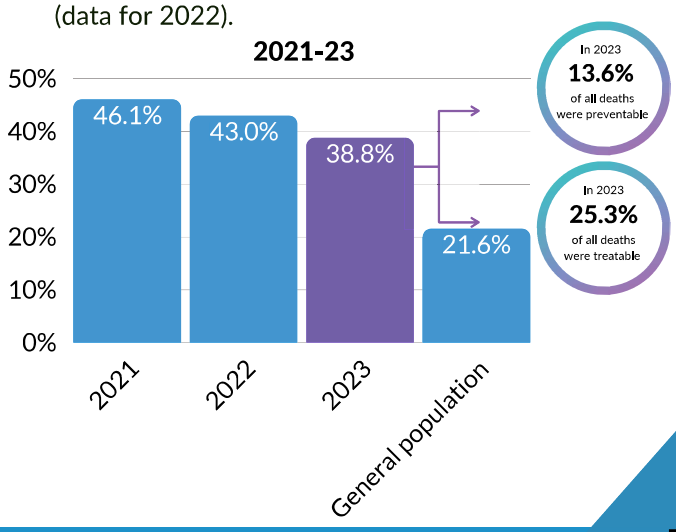
DEATHS BEFORE 65

Nearly **60%** of adults with a learning disability who had a LeDeR review died before the age of 65 years.



AVOIDABLE DEATHS

Avoidable deaths have declined since 2021, however, the rate for adults with a learning disability who died in 2023 is still nearly **double the rate compared to the general population** (data for 2022).



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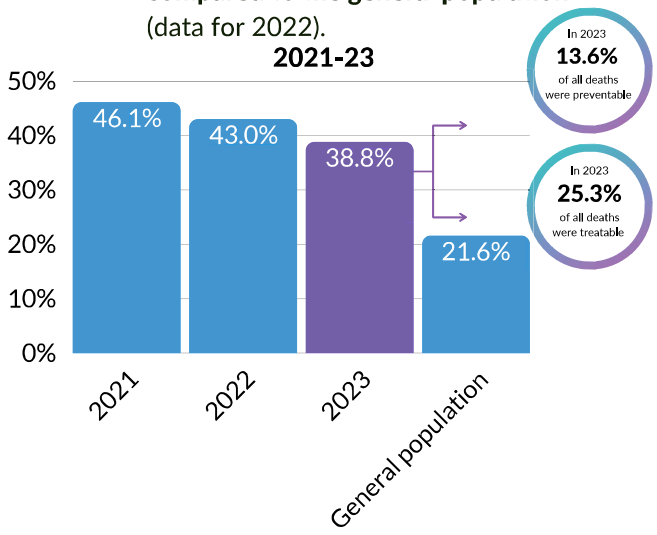
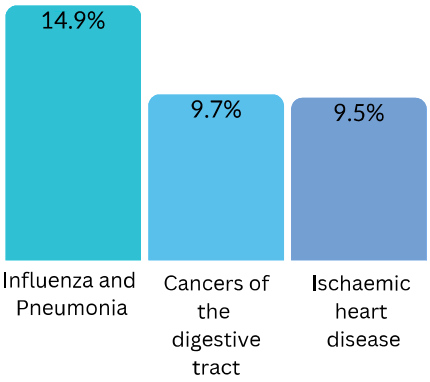


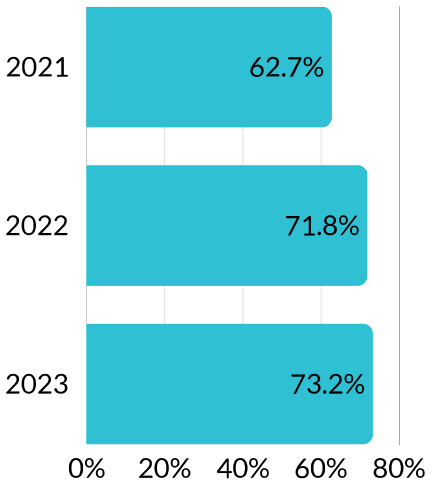
MOST COMMON AVOIDABLE DEATHS (2023)

The 3 most common causes of avoidable deaths are influenza and pneumonia (14.9%), cancers of the digestive tract (9.7%) and ischemic heart disease (9.5%)

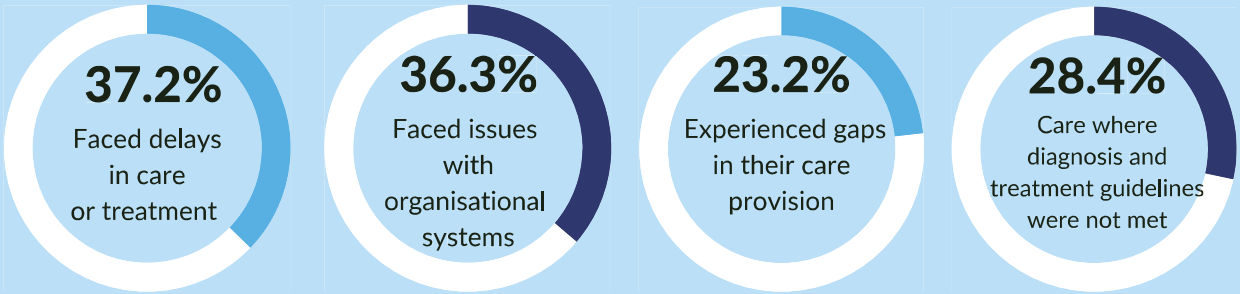


IMPROVEMENTS IN POSITIVE PRACTICE

The % of reviews identified with good practice has increased year on year.



KEY CARE FINDINGS OF 2023



MEDIAN AGE AT DEATH

The median age at death has remained similar since 2021. The median age peaked in 2020 to 63.0 years, and was lowest in 2019 at 61.7 years.

When comparing 2018 to 2023 the median age at death has increased by 7 months.

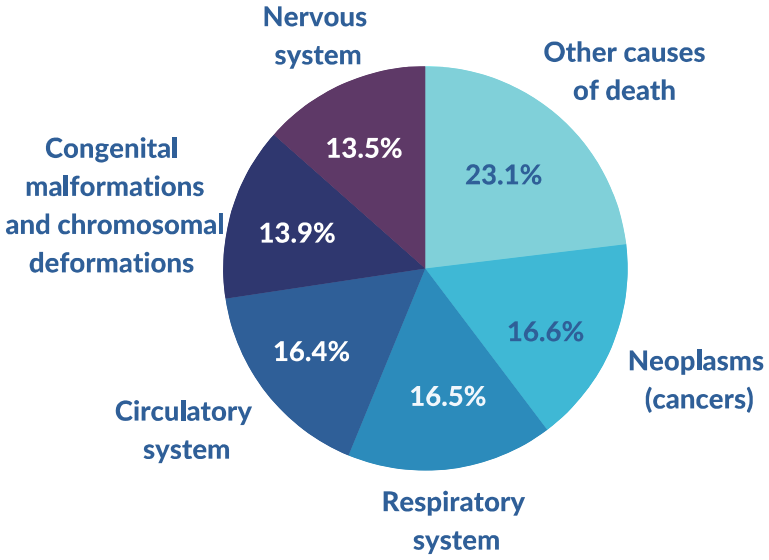
The median age at death for people with a learning disability who were reported to LeDeR is around **20 years lower than for the general population.**

*note median age at death is not life expectancy.

Year of death	Median age at death (years)	IQR
2018	61.8	52.2 to 71.1
2019	61.7	50.8 to 71.1
2020	63.0	53.3 to 72.3
2021	62.1	51.9 to 71.8
2022	62.2	51.4 to 71.8
2023	62.5	52.5 to 72.0

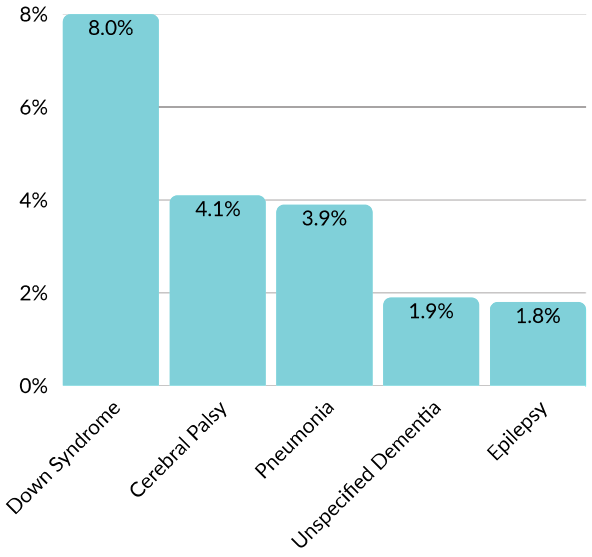
MOST COMMON ICD-10 CODE CAUSES OF DEATH IN 2023 OF ADULTS WITH A LEARNING DISABILITY WHOSE DEATHS WERE REVIEWED

76.9% of deaths in 2023 occurred within 5 ICD-10 groupings.



MOST COMMON UNDERLYING CAUSES OF DEATH IN 2023 OF ADULTS WITH A LEARNING DISABILITY WHOSE DEATHS WERE REVIEWED

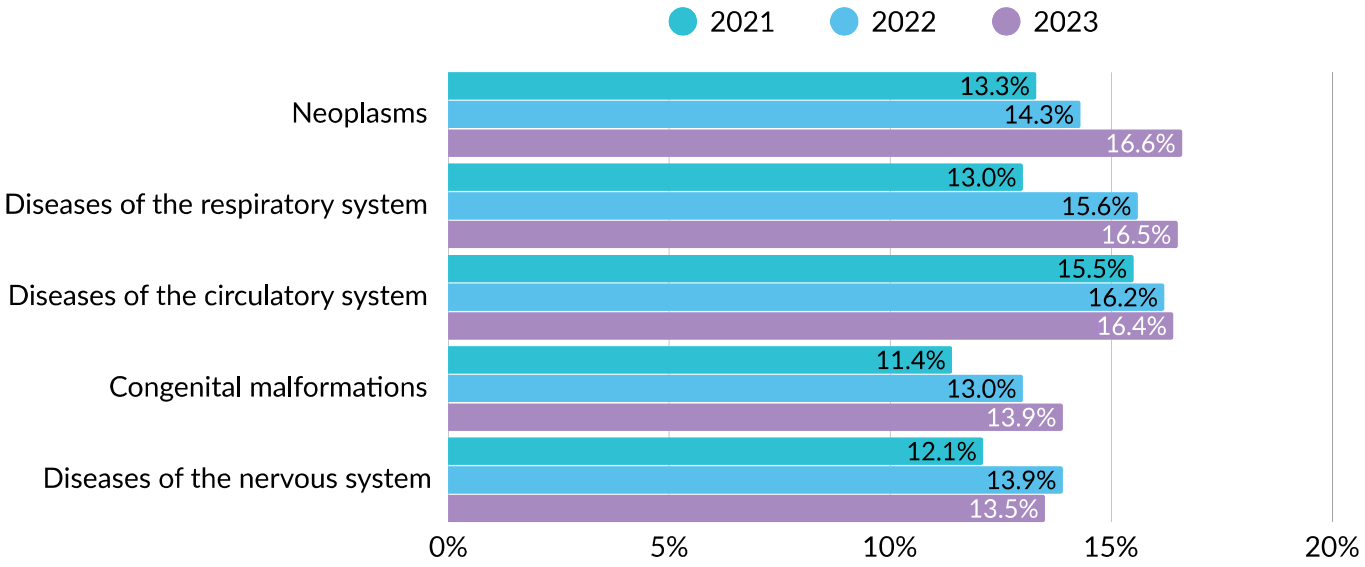
19.7% of deaths in 2023 occurred within 5 reported underlying ICD-10 causes of death..



Although Down syndrome and cerebral palsy should not be listed as the only cause of death on the MCCD, it may be appropriate for them to be listed as the underlying cause of death if the sequence of events or conditions that lead to death is fully recorded, and Down syndrome or cerebral palsy likely resulted in the condition (e.g., if the death was due to a congenital heart defect associated with Down syndrome) (see guidance for completing death certificates).

MOST COMMON GROUPED CAUSES OF DEATH SINCE 2021

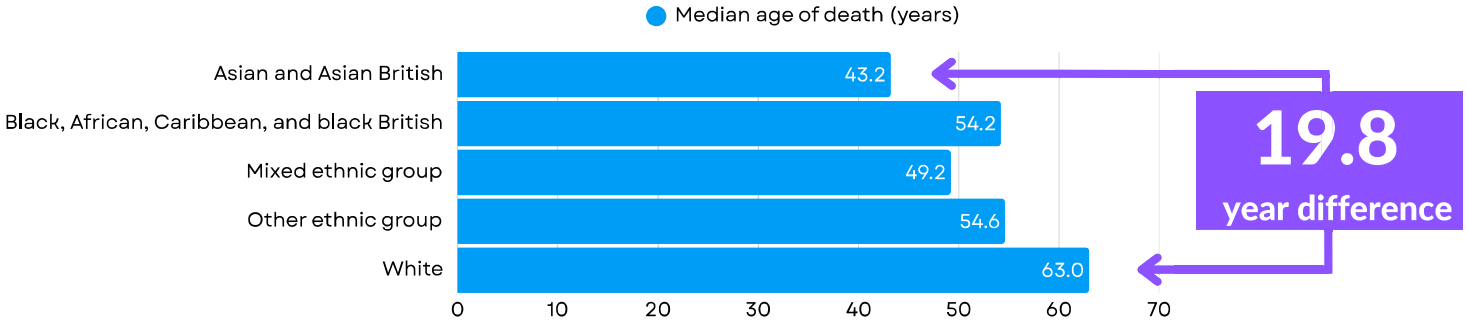
The % of deaths among adults with a learning disability has increased since 2021 for all of the most common causes (except circulatory diseases).



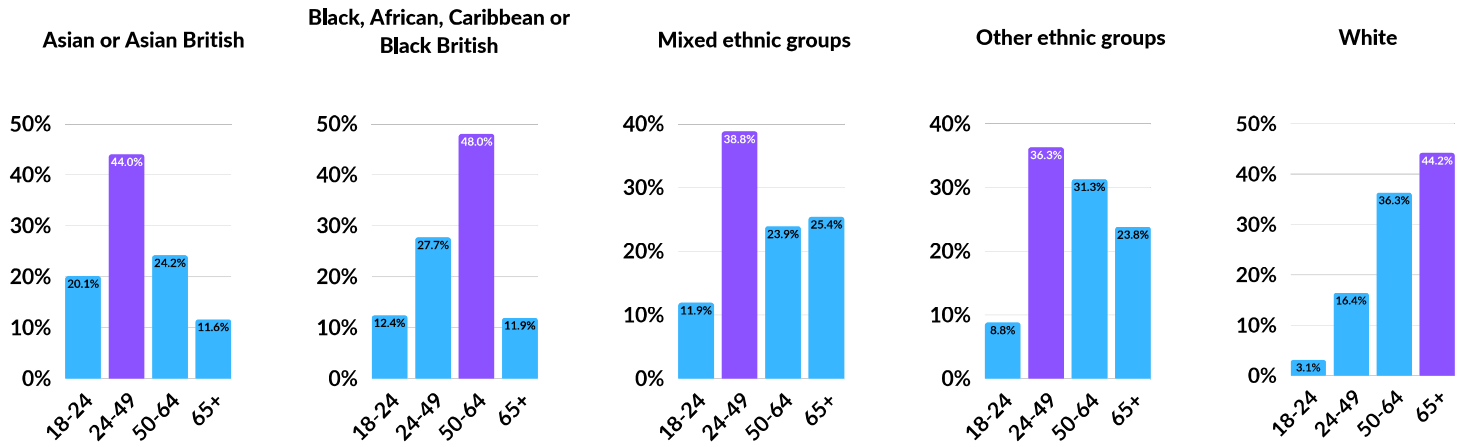
CHAPTER 2 - ETHNICITY OF PEOPLE WITH A LEARNING DISABILITY

AGE AT DEATH

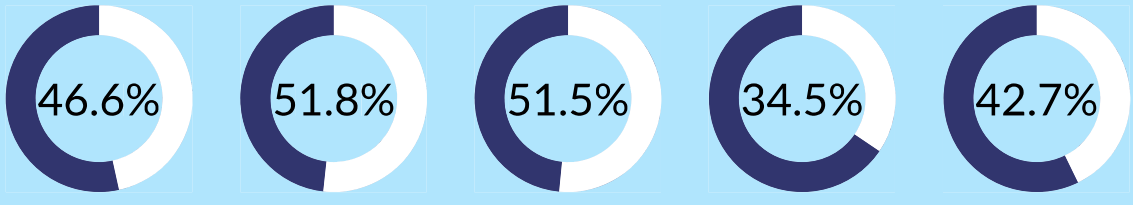
Adults from all ethnic groups who were notified to LeDeR from January 2021- December 2023 had a younger median age at death compared to White adults who died.



AGE GROUP AT DEATH 2021-2023



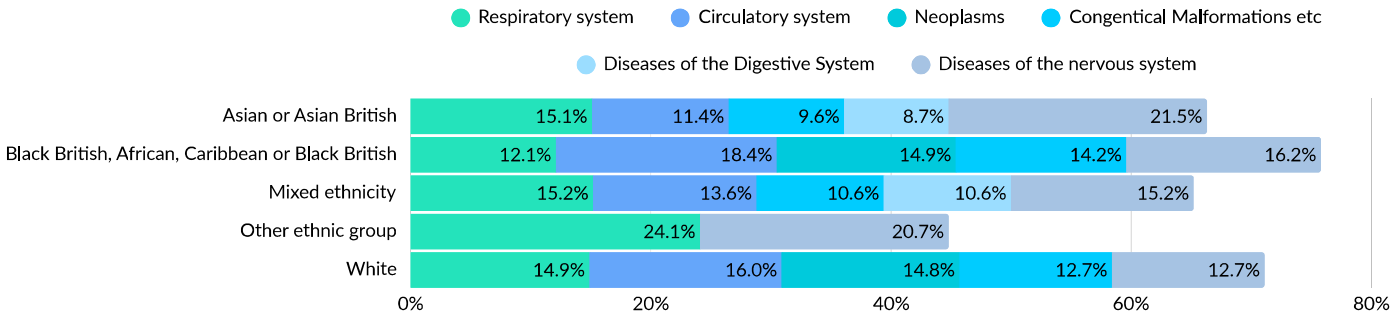
AVOIDABLE* DEATHS FOR 2021-23



*This is based on the OECD preventable/treatable definition (see chapter 1).

MOST COMMON CAUSE OF DEATH BY ETHNICITY 2021-2023

The 5* most common causes of death for adults with a learning disability an by ethnic group.

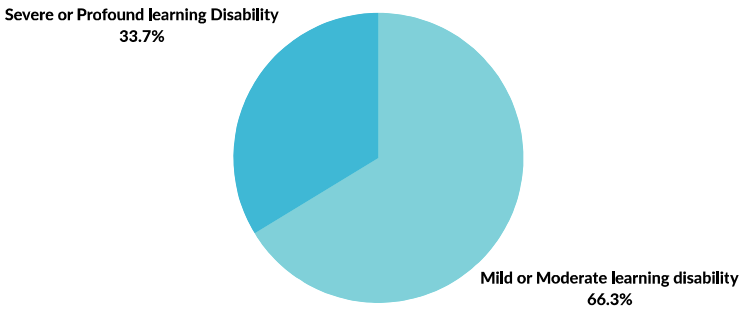


*5 available only when possible to avoid deidentification due to small numbers

CHAPTER 3 - PEOPLE WITH A SEVERE OR PROFOUND LEARNING DISABILITY

LEVEL OF LEARNING DISABILITY IN THE LeDeR DATA BETWEEN 2021-2023

Of the 3,970 adults with learning disability who had a level of learning disability recorded in their initial review form, over two thirds were recorded as having a mild to moderate learning disability, and one third a severe or profound learning disability.



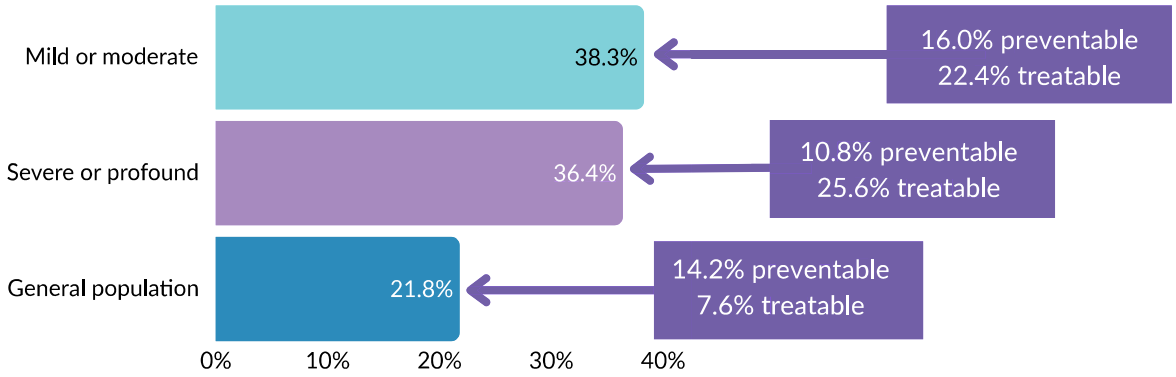
Median age at death

Mild or moderate **64.9 years**

7.3 years difference

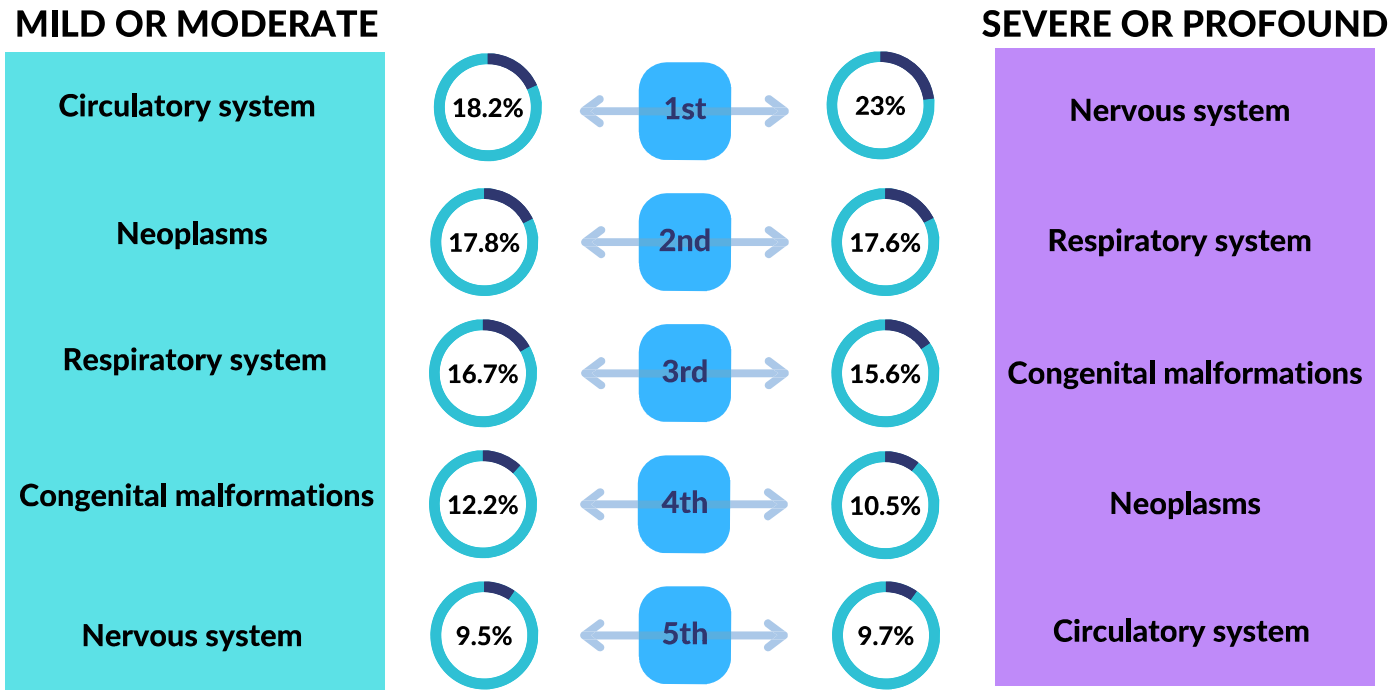
57.6 years Severe or profound

AVOIDABLE* DEATHS FOR 2021-23



*This is based on the OECD preventable/treatable definition (see chapter 1).

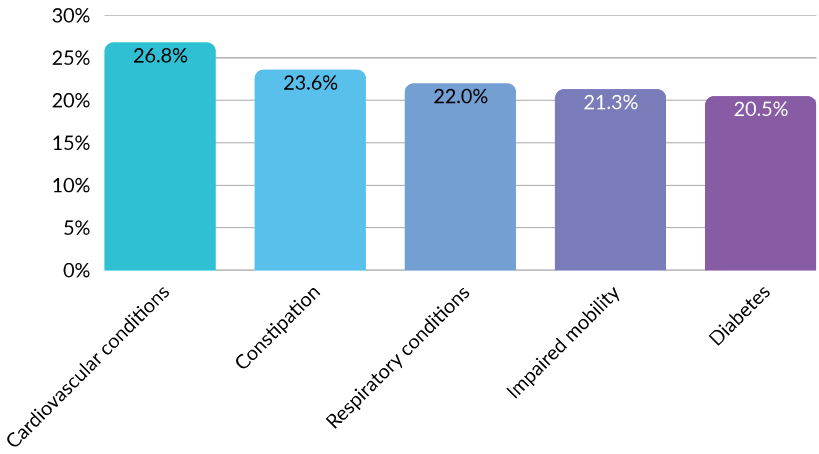
MOST COMMON ICD-10 GROUPED CAUSE OF DEATH BY LEVEL OF LEARNING DISABILITY



CHAPTER 4 - AUTISTIC ADULTS WITHOUT A LEARNING DISABILITY WHO WERE NOTIFIED TO LeDeR

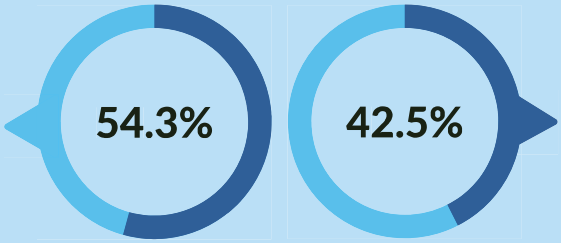
KEY DEMOGRAPHICS OF AUTISTIC ADULTS WHO HAD A LeDeR REVIEW BETWEEN 2021 - 2023

TOP 5 COMORBID REPORTED PHYSICAL HEALTH CONDITIONS (2021-2023)



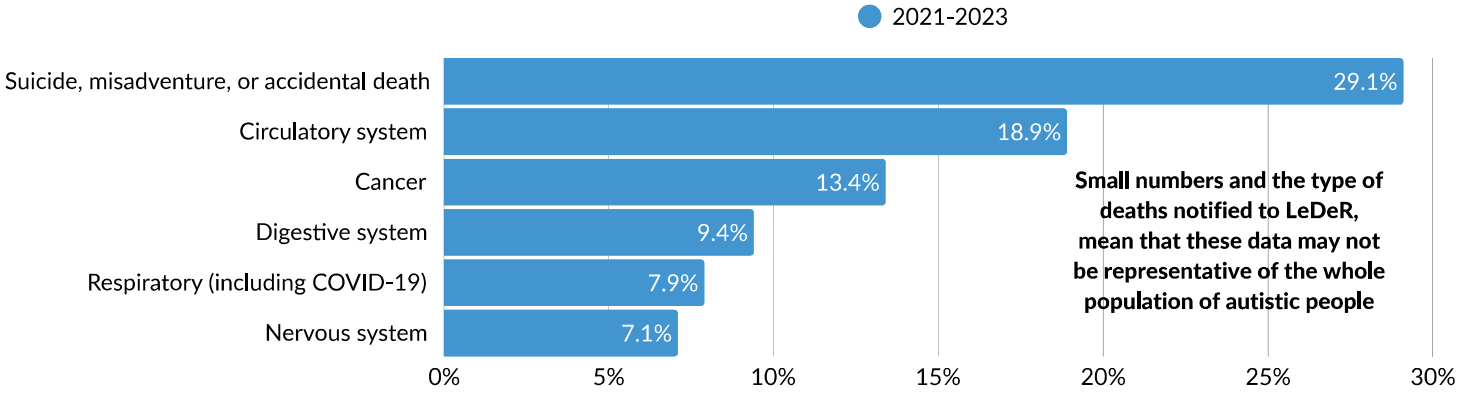
MENTAL HEALTH 2021-23

Had a diagnosis of depression



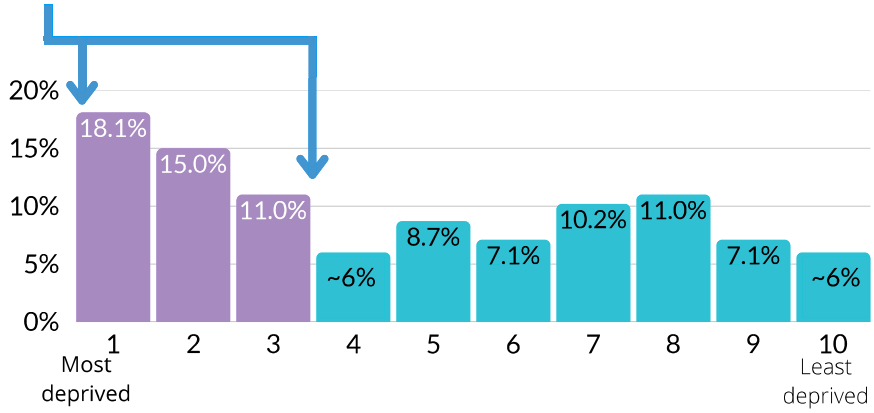
Had a diagnosis of anxiety disorder

MOST COMMON CAUSES OF DEATH FOR AUTISTIC ADULTS WHO HAVE HAD A LeDeR REVIEW



INDEX OF MULTIPLE DEPRIVATION 2021-23

44.1% of autistic adults who died lived in most deprived areas (1-3).



ISSUES WITH CARE

- Inadequate training for staff around autistic adults needs.
- Lack of awareness of autistic adults' needs.
- Insufficient referrals to autistic specialist services.

Deep Dives and Publications that have arisen from LeDeR

Introduction

The LeDeR academic partnership led by KCL regularly undertakes more in-depth and extensive investigations ("deep dives") to gain insights into key areas to improve our understanding of the health needs and service improvements needed for people with a learning disability and autistic people. Working in collaboration with NHS England, the academic partnership has investigated several different topic areas that have impacted policy, guidance, and service provision across England. Recently published works are summarised here.

Much of this work uses LeDeR data directly. Some, however, use LeDeR findings as a starting point for further investigation and may use other datasets or gather new information to explore specific questions regarding the health and care of people with a learning disability or autistic people further. The published reports, known as **deep dives**, can be found in full on our website at Learning from Lives and Deaths - people with a learning disability and autistic people (LeDeR) | King's College London

In this section, we will summarise the findings from 6 deep dives completed during the past three years covering. These are: **Diabetes, Bowel Cancer, Impact of Learning Disability Liaison Nurses, Constipation, Pneumonia, and Cardiovascular diseases.**