

LeDeR Annual Report
Learning from
Lives and Deaths:
People with a
Learning Disability
and Autistic People

2023

LeDeR

Learning from lives and deaths – People with a learning disability and autistic people



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Learning from Lives and Deaths -
People with a learning disability and autistic people (LeDeR) report for 2023.
LeDeR Autism and Learning Disability partnership,
King's College London

Please be aware that this report discusses deaths by suicide and may be upsetting and distressing. If you or someone you know is affected by the content of this report, please call Samaritans for free on 116 123 (UK and ROI), email them at jo@samaritans.org, or visit [samaritans.org](https://www.samaritans.org) to find your nearest branch. Other sources of support are listed on the [NHS's help for suicidal thoughts webpage](#). Support is available round the clock, every single day of the year, providing a safe place for anyone struggling to cope, whoever they are, however they feel, whatever life has done to them.

Acknowledgements



These images are entrants to the Staying Alive and Well logo competition. 1. Tamsin, Milton Keynes, 2. Stacey, Wandsworth, 3. Peter, GRASSroots, 4. Louise, Darlington, 5. Charlie, Southwark, 6. Tonbridge and Tonbridge Wells day services.

We hope that this report does justice to the legacy of people who have died, and we dedicate this report to the people for whom this report is created; people with a learning disability, their families, friends, colleagues, carers, and all staff and service providers, whose lives are affected by this report.

We would like to thank the organisations who have been involved in this work; the learning disability and autism team at NHS England; the team at South Central and West Commissioning Support Unit (SCW) that had responsibility for processing and managing the data, the support and dedication of the many people and organisations across England, who have contributed to notifications of deaths of people with a learning disability and autistic people, Integrated Care Board (ICB) staff that conducted the reviews. Without them, the report would not have been possible.

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Working with people with a learning disability is a central part of LeDeR. Our work is informed by a team of people with a learning disability who meet on a regular basis (the Staying Alive and Well group). Their input is essential to raise awareness of the report's findings and to ensure the voices of people with a learning disability are being heard. Their dedication to this work is an inspiration to us all.

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Glossary of Abbreviations

<u>BRC</u>	Biomedical Research Centre.
<u>CI</u>	Confidence interval.
<u>CPR</u>	Cardio-Pulmonary Resuscitation.
<u>DNACPR</u>	Do Not Attempt Cardio-Pulmonary Resuscitation.
<u>GP</u>	General Practitioner.
<u>HR</u>	Hazard ratio.
<u>ICD-10</u>	International Classification of Diseases version 10.
<u>ICS</u>	Integrated Care System.
<u>IMD</u>	Index of Multiple Deprivation.
<u>IQR</u>	Inter-quartile range.
<u>KCL</u>	King's College London.
<u>LDLN</u>	Learning Disability Liaison Nurses.
<u>LeDeR</u>	Learning from lives and deaths - people with a learning disability and autistic people.
<u>MCA</u>	Mental Capacity Act.
<u>MCCD</u>	Medical Certificate of Cause of Death.
<u>MHA</u>	Mental Health Act.
<u>NICE</u>	National Institute for Health and Care Excellence.
<u>NIHR</u>	National Institute for Health and Care Research.
<u>NHS</u>	National Health Service.
<u>NHSE</u>	National Health Service England.
<u>OECD</u>	Organisation for Economic Cooperation and Development.
<u>ONS</u>	Office for National Statistics.
<u>OR</u>	Odds ratio.
<u>SCW</u>	South Central and West Commissioning Support Unit.
<u>SD</u>	Standard deviation.
<u>UCLan</u>	University of Central Lancashire.
<u>WHO</u>	World Health Organisation.

General notes for interpretation

Here we present some general notes to help understand the data in this report.

The protection of personal data

In this report, data for where there are fewer than 5 people (but more than 0) available we have suppressed the true number with “*”. This is to ensure that no individual can be identified from this report or data. In some instances, for example, when presenting a cause of death over different age groups, there were more than 5 data available for some groups but not for others. If we presented the numbers for the larger group, then it would be possible to identify individuals from the smaller group.

The use of hyperlinks

This report is primarily designed to be read as a digital document, with hyperlinks to relevant references and external sources highlighted throughout. A references page is included for further reference.

The use of colour-coded tables

This report uses a colour code on specific tables. This is designed to highlight differences in the data presented, making it easier to interpret. The key for the colour-coded tables can be found in [Appendix 0.6 to 0.8](#).

The use of median

Median is often understood as the “middle number” and is used to give readers the middle number of a range of numbers in this report. We use this primarily for age calculations to determine the average age.

Rounding of values

In this report, we use various rounding of numbers for clarity. In all chapters, when describing the overall LeDeR data, we have rounded to 1 decimal place for convenience. Where required, to provide more detailed figures when discussing statistics, we have used up to 2 decimal places, again as required, to provide full detailed statistical analysis.

The inclusion of data on the deaths of autistic people

In January 2022 LeDeR began collecting data on the deaths of autistic adults (aged 18 and over) who did not also have a diagnosis of a learning disability (please see [Chapter 4](#) for full details). In this report, the data available for autistic adults was relatively small. As such, we have taken the following steps:

- The data for autistic adults who do **not** also have a learning disability has been separated from the rest of the data and has been analysed in [Chapter 4](#). As such, all other chapters do **not** use review data which includes autistic adults who do not also have a learning disability for analysis. For [Chapter 1](#), notifications of autistic adults are only included in the first figure describing sources of notifications to LeDeR.
- Data for autistic adults with a learning disability is included in the overall learning disability data sample.

LeDeR Report 2023



Introduction and Foreword

Foreword from the Staying Alive and Well Group

Last year, we called the report the 'SPOT THE DIFFERENCE REPORT' because we have been saying the same things each year. We wanted to tell you what it is like to look at the numbers of people with a learning disability who die in England, and tell you about how it has made us feel.

This year, we feel the same and although there are changes, we still have a long way to go. We still feel upset when looking at the numbers in this report.

We have to keep going so that we are noticed, listened to and taken seriously.

There are lots of people who should be here. They should have been at birthdays, graduations, weddings and funerals. They should have heard their nephews or nieces' first words, played with them and shared a bedtime story.

We don't want to be an empty chair at Christmas. We do not want to be just a memory or a photograph on the wall. We want to be with you to tell you our dad jokes and share a glass of champagne at the New Year.

If we are valued and we are given the right support, we can live longer and healthier lives. If we are neglected, if we are not understood, if nobody notices we are unwell or unhappy – that can harm us, it can even kill us.

Little by little the tide is turning, and we are making an impact, but we can't do this on our own. We need help from people who are in charge. People are trying very hard to get things changed. Families and staff should be proud and, like us, you should keep trying your best because you are needed.

In other countries, people with a learning disability do not have a voice and less is done to learn from their deaths. We are leading the way and that is good, but we need to do more. We don't know how far we will get when we try to make things better.

Do not let our footsteps be washed away. Take action and make sure that we are included.



Foreword

LeDeR is a globally unique approach established in 2017 to learn from the deaths of people with a learning disability and autistic people in England. Funded by NHS England, the aim is to improve services by collating data on deaths, to identify improvements that should be made to reduce health inequalities and early deaths, for people with a learning disability and autistic people.

LeDeR is notified of deaths of adults with a learning disability or autistic adults through reports from family members, friends or professionals involved in a person's care. Details on the LeDeR review methodology can be found in [Appendix 0.4](#). This report is an independent analysis led by King's College London of the data collected through LeDeR notifications.

Changes for the 2023 report

We have made some changes to the format and focus of this year's report. We have shortened the main report so that the focus is on key findings, whilst underlying data can still be found in the appendices. In previous LeDeR annual reports, we detailed the deaths of people with a learning disability who were reported to LeDeR within a 12-month period (from January to December). However, this approach does not allow for a more detailed analysis of important but smaller subgroups of individuals who have died, such as those from ethnic minority groups. This year's report will, therefore, include the deaths of adults with a learning disability and autistic adults, from January 2021 through to December 2023, which were reviewed by LeDeR, using the new reporting format that was introduced in June 2021. We will combine data from these years where necessary, particularly when presenting data on specific aspects that require a larger dataset to avoid identification of individuals, while also presenting the 2023 data on its own where possible to allow for a comparison with previous years. We trust that this approach provides an opportunity to look into the data in different and deeper ways than previous reports and to comment on overall trends in the years after the COVID-19 pandemic.

In addition, we are adding a specific focus on people who had died and had a severe or profound learning disability ([Chapter 3](#)), as well as a chapter on deaths of people with a learning disability from ethnic minority backgrounds ([Chapter 2](#)). As in the 2022 report, we have included a chapter on the deaths of autistic people who did not have a learning disability, which have also been reported to LeDeR since the start of 2022 ([Chapter 4](#)). Finally, in chapter [Chapter 5](#), we have summarized the work we have been doing with NHS England on specific topics, known as "deep dives".

As in previous years, we acknowledge the limitations of the LeDeR dataset. Firstly, it is a mortality dataset and only includes data from people who have died. It is, therefore, not representative of living people with a learning disability or autistic people, and cannot be used to describe people who are currently alive in the community. This means we cannot estimate life expectancy or the number and nature of subgroups of individuals currently accessing services. A second limitation is that notifications of deaths to LeDeR is not compulsory, and data on deaths may therefore be incomplete, though the programme now has considerable reach and awareness, and there are indications that the majority of deaths are being notified, as is evidenced by the consistent numbers of deaths and findings across recent years. We have not included an analysis of the overall quality of care question in the 2023 report, because NHS England is currently reviewing the guidance and wording of this question to improve the reliability of the ratings. Finally, there are natural delays in completing reviews, such as when a death has been referred to a coroner. To ensure these deaths are ultimately included in our reports, we have added all available data from completed reviews, when making comparisons with previous years. This means that the number of deaths included may vary between annual reports as reviews become available. Notifications and reviews of the deaths of autistic people are, however, likely still not representative of the overall number of deaths, and caution is necessary when interpreting the findings we summarise in [Chapter 1](#).

This year, due to unforeseen pressures on the NHS, there have been somewhat fewer completed reviews than anticipated, affecting reviews during the latter part of 2023 in particular. This limitation may mean there are fewer completed reviews of deaths due to certain conditions, such as seasonal flu. Some findings should therefore be interpreted with caution – we have endeavoured to make readers aware of this when necessary.

Despite these limitations, LeDeR continues to have a high profile, with a crucial impact on NHS England's ongoing efforts to improve services for people with a learning disability and autistic people, through an expanding data cohort delivering new insights that inform decision-making.



KEY OVERALL DEMOGRAPHICS FROM THE LEDER REPORT

SEX

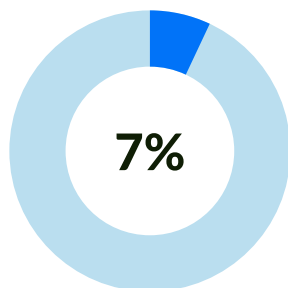
54.7% of adults notified with a learning disability who died in 2023 were male.



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

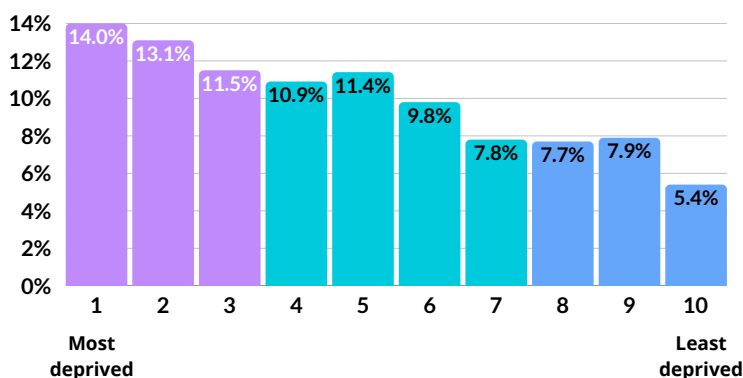
62.5

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

DEPRIVATION

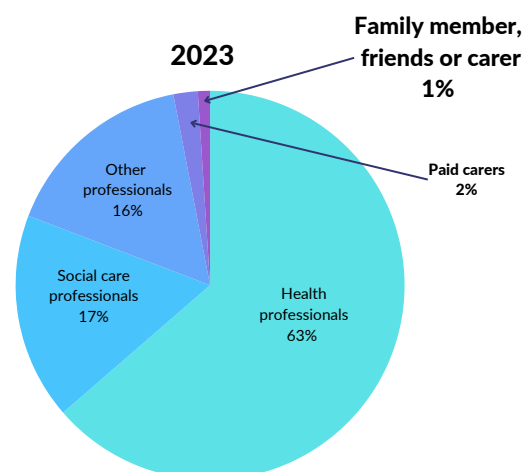
- 38.6% of adults who died lived in most deprived areas (1-3).
- 21% of adults who died lived in the least deprived areas (8-10).

2023



WHO NOTIFIED LeDeR?

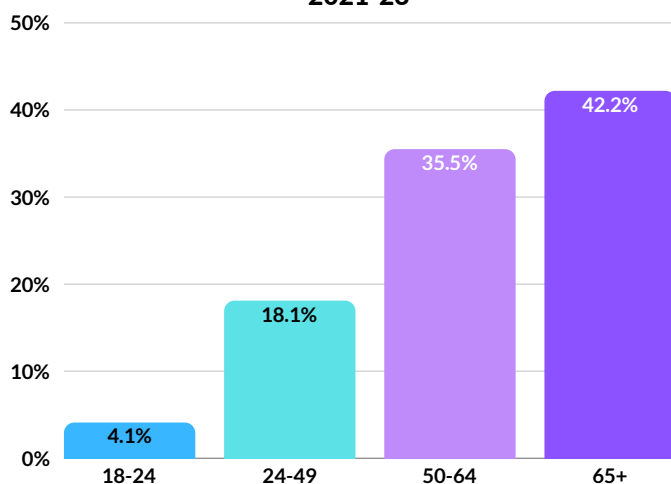
1% of deaths notified to LeDeR were made by a family member, friend or carer.



DEATHS BEFORE 65

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

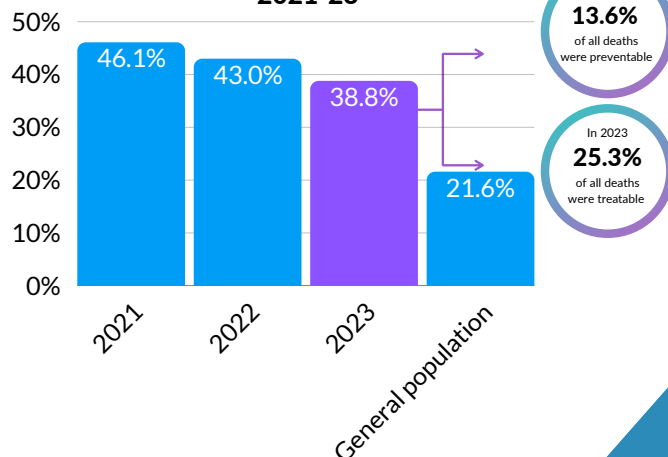
2021-23



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).

2021-23



Chapter 1

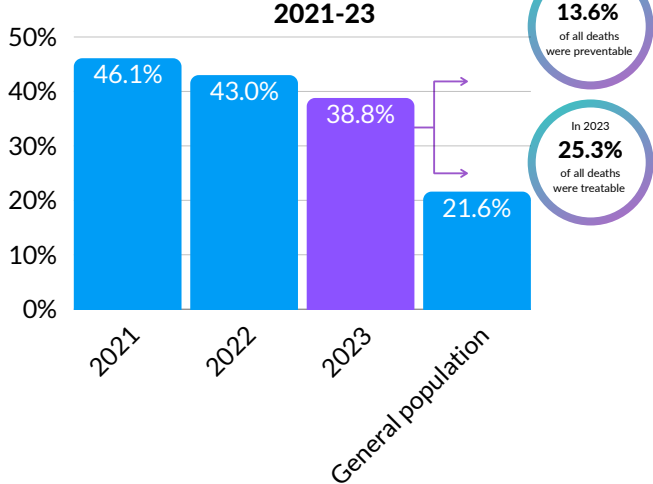


**Review of lives and deaths from
June 2021 to December 2023**

CHAPTER 1 - REVIEW OF THE LIVES AND DEATHS OF PEOPLE WHO DIED BETWEEN 2021 AND 2023 WHO HAD A LEDER REVIEW COMPLETED BETWEEN JUNE 2021 TO JULY 2024

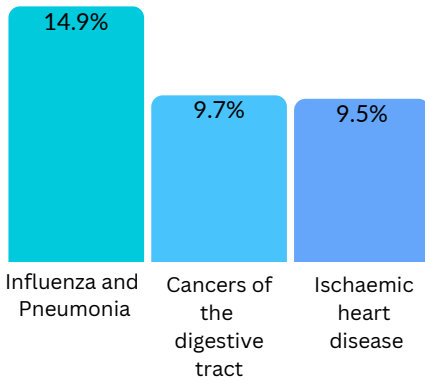
AVOIDABLE DEATHS

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).



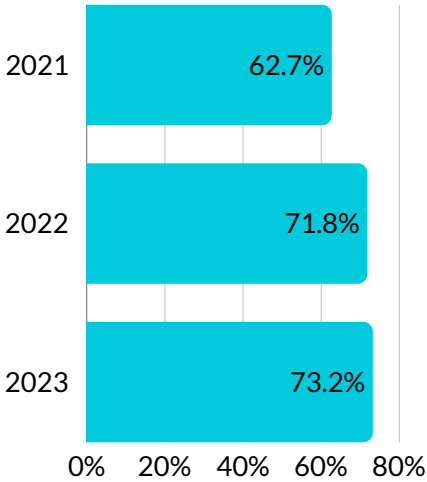
MOST COMMON AVOIDABLE DEATHS (2023)

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%)

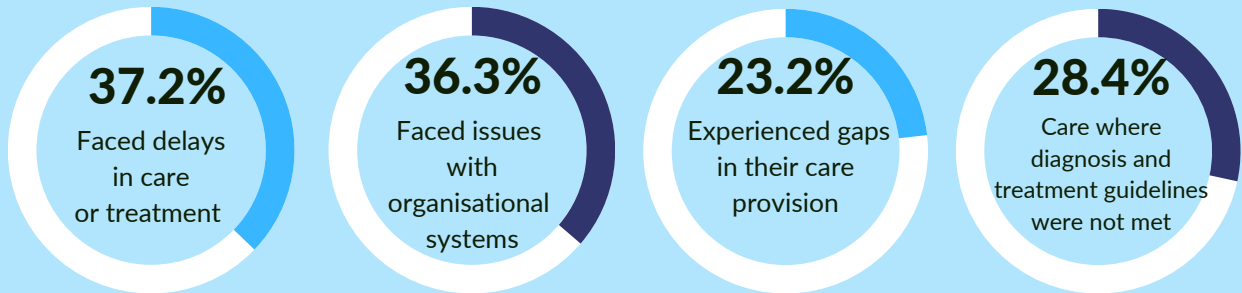


IMPROVEMENTS IN POSITIVE PRACTICE

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.**

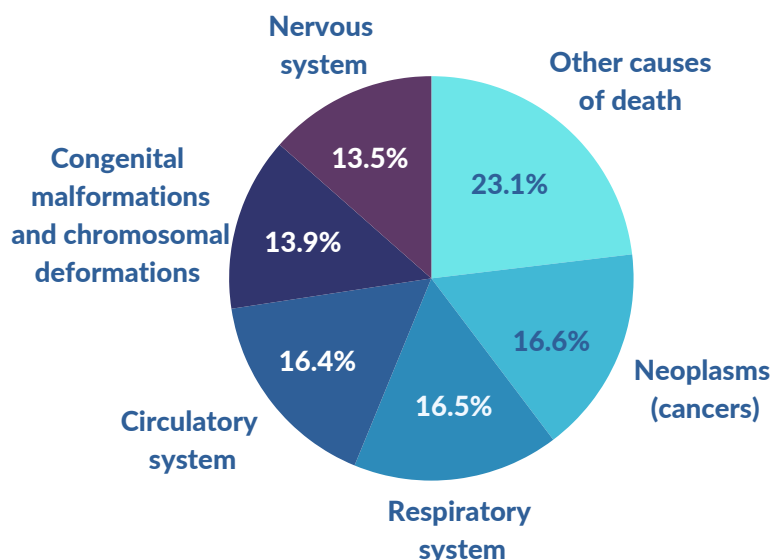
Year of death	Median age at death (years)	IQR
2018	61.8	52.2 to 71.1
2019	61.7	50.8 to 71.1
2020	63.0	53.3 to 72.3
2021	62.1	51.9 to 71.8
2022	62.2	51.4 to 71.8
2023	62.5	52.5 to 72.0

*note median age at death is not life expectancy.

CHAPTER 1 - REVIEW OF THE LIVES AND DEATHS OF PEOPLE WHO DIED BETWEEN 2021 AND 2023 WHO HAD A LECR REVIEW COMPLETED BETWEEN JUNE 2021 TO JULY 2024

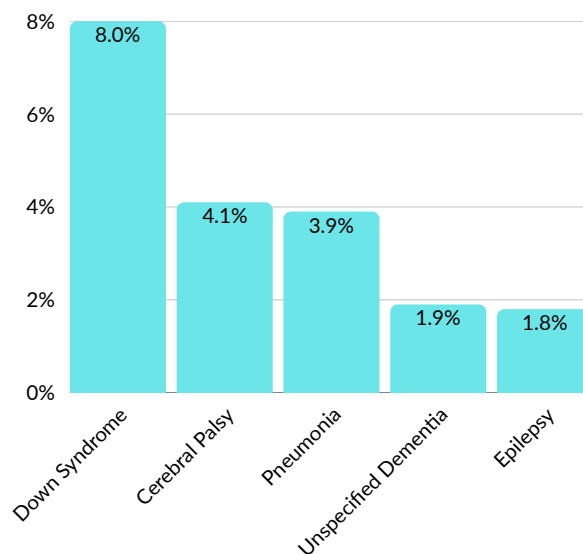
MOST COMMON ICD-10 CODE CAUSES OF DEATH IN 2023 OF ADULTS WITH A LEARNING DISABILITY WHOSE DEATHS WERE REVIEWED

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

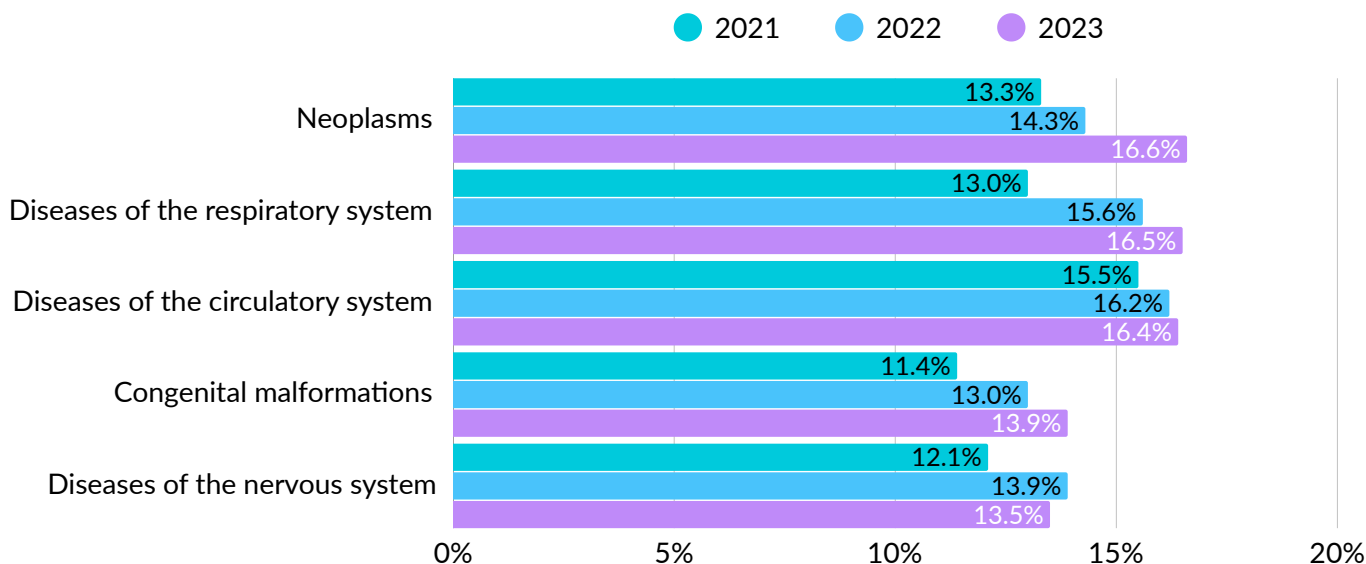
19.7% of deaths in 2023 occurred within 5 reported underlying ICD-10 causes of death..



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).



Review of lives and deaths from June 2021 to December 2023

Introduction

This chapter summarises the information collected in LeDeR reviews about adults with a learning disability who died in 2023. Data on the deaths of children and young people under the age of 18 can be found at [Deaths in children with learning disabilities and autistic children](#). As in previous reports, details of autistic people who did not have a learning disability are discussed separately in [Chapter 4](#).

The results for adults with a learning disability who died in 2023 are compared to adults with a learning disability who died in 2021 and 2022 to give an indication of changes over time. Where possible, the information about adults with a learning disability is compared to the information for the general population, provided by the Office for National Statistics (ONS). This sometimes involves comparisons with the whole population, including children. While helpful in exposing differences between groups, it is important to be aware, that this may not always be a like-for-like comparison. [Chapter 2](#) provides more information about adults with a learning disability from ethnic minority groups, and [Chapter 3](#) gives more detail about those with a severe or profound learning disability.

Information included in this chapter

In this chapter, information collected in the LeDeR notification form is summarised first (see [Appendix 0.3](#)). Notifications are the first point of contact for LeDeR, therefore notification data are available for all deaths reported to LeDeR. There were 10,600 notifications to LeDeR for adults with a learning disability who died between January 2021 and December 2023. This notifications analysis includes the total number of notifications each month, information about the notifier's relationship to the person who died, basic demographic information about the person who died, and their age at death.

The second part of this chapter includes a summary of the information collected in LeDeR reviews, to provide additional detail about the lives and deaths of adults with a learning disability. LeDeR introduced a new review system in May 2021, which changed the information that was available at each stage of the LeDeR process (see [Appendix 0.3](#)). A total of 8,082 reviews were completed using the new review format, detailing adults whose deaths were notified to LeDeR between June 2021 and December 2023. The review data are summarised to provide a further description of the demographics of the adults with a learning disability who died in 2023, their circumstances and causes of death, rates of avoidable mortality, and a summary of the care they received. The reviews analysed in this chapter differ in total from the notifications as the notifications cover January 2021 to December 2023 whilst the reviews span from June 2021 to July 2024.

LeDeR notifications in 2023

LeDeR was notified of the deaths of 3,556 adults with a learning disability in 2023. This compares with 3,451 deaths in 2021 and 3,593 deaths in 2022. Figure 1.1, below, shows the total number of deaths of adults with a learning disability, notified to LeDeR by month of death from January 2021 to December 2023[1].

There are three notable spikes in the notification of deaths across the period covered in Figure 1.1. The first, in January 2021, relates to a winter wave of COVID-19 and is also evident in national data from the general population. The second spike, in July 2022, relates to an extreme heatwave event in England during this month which was further discussed in the [LeDeR 2022 annual report](#). A third peak in December 2022 and January 2023 may be attributed to an exceptional level of seasonal infections (influenza and COVID-19) that winter. Similar spikes were noted in the general population, and the Office for National Statistics (ONS) has produced several reports in relation to this (ONS, 2023; UK Health and Security Agency, 2024).

Figure 1.1: Total number of deaths of adults with a learning disability notified by month of death from January 2021 to December 2023.

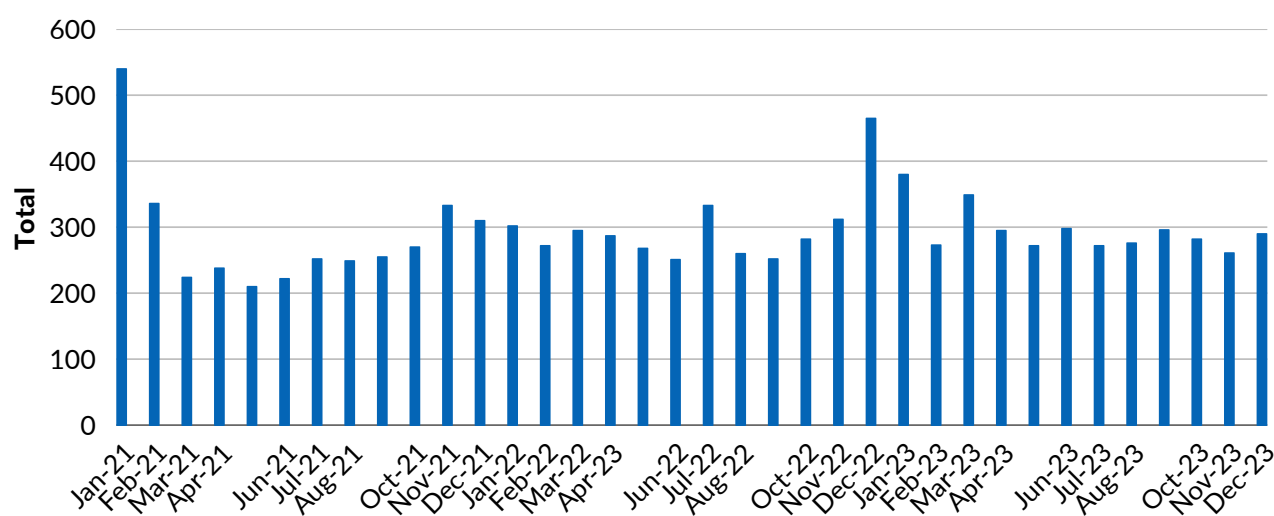
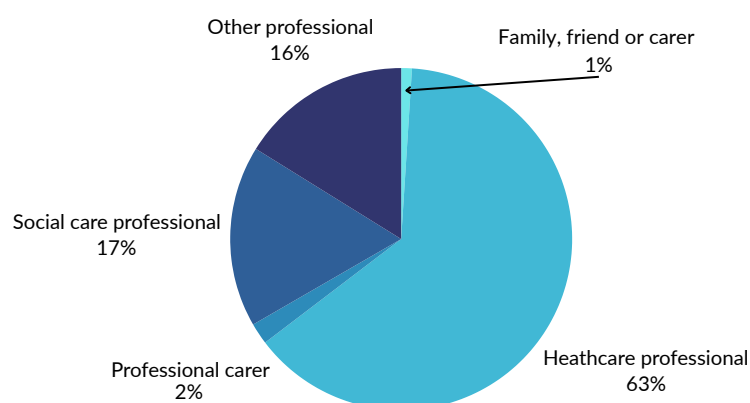


Figure 1.2 (right) shows that most notifications of deaths in 2023, were received from healthcare professionals. This is comparable to previous years.

Figure 1.2: Notifier relationship to the adult with a learning disability who died in 2023.



[1] This includes all notifications received during this interval to provide a yearly comparison, which also includes the previous LeDeR reporting system that was in place until April 2021. The rest of this chapter only includes information about deaths that were notified or reviewed as part of the new LeDeR system that was introduced in June 2021.

Demographics

Table 1.1 summarises the demographics of the 3,556 adults with a learning disability who died in 2023 and were notified to LeDeR, compared to those who died in 2021 and 2022. For a detailed breakdown of the notifications by age group please see [Appendix 1.1](#).

Table 1.1: Demographics for adults with a learning disability who died from January 2021 to December 2023 and were notified to LeDeR compared to the general population.

	2021 Number (%)	2022 Number (%)	2023 Number (%)	General adult population* 2022 Number (%)
Sex registered at birth				
Male	1900 (55.1%)	1,899 (52.9%)	1,946 (54.7%)	266,754 (49.4%)
Female	1,460 (42.3%)	1,533 (42.7%)	1,376 (38.7%)	273,579 (50.6%)
Not known	91 (2.6%)	161 (4.5%)	234 (6.6%)	±
Ethnic group**				
Asian or Asian British	84 (2.6%)	121 (3.7%)	93 (2.9%)	±
Black, Black British, Caribbean, or African	57 (1.8%)	70 (2.2%)	71 (2.2%)	±
Mixed ethnic group	63 (2.0%)	19 (0.6%)	25 (0.8%)	±
Other ethnic group	53 (1.7%)	21 (0.6%)	24 (0.8%)	±
White	2942 (92.0%)	3,014 (92.9%)	2,976 (93.3%)	±
Region***				
London	341 (9.9%)	379 (10.5%)	388 (10.9%)	52,014 (9.6%)
South West	346 (10.0%)	355 (9.9%)	329 (9.3%)	62,546 (11.5%)
South East	557 (16.1%)	541 (15.1%)	559 (15.7%)	88,237 (16.3%)
Midlands	707 (20.5%)	726 (20.2%)	699 (19.7%)	109,683 (20.2%)
East of England	430 (12.5%)	378 (10.5%)	401 (11.3%)	61,837 (11.4%)
North West	505 (14.6%)	568 (15.8%)	523 (14.7%)	78,626 (14.5%)
North East and Yorkshire	563 (16.3%)	646 (18.0%)	657 (18.5%)	87,390 (16.1%)
Total	3,451 (100%)	3,593 (100%)	3,556 (100%)	540,333 (100%)

± Comparable data not available

*Over the age of 20

**Note that unknown ethnic group and regional data has not been included in this total

***Regional data for the ONS differs slightly from the regions used by NHS England which are the regions used for LeDeR. The ONS regions are East, East Midlands, London, North East, North West, South East, South West, West Midlands, Yorkshire, and The Humber. For comparison, NHS England LeDeR data combines East and West Midlands together, and the North East and Yorkshire and The Humber. It should be noted that NHS England regions are of varying size and population, so we would not anticipate an equal number of notifications from each region. See [Appendix 0.3 Figure 0.1](#) for more detail on the regional breakdown.

Age at death

The median age at death for adults with a learning disability who died in 2023, and whose deaths were notified to LeDeR was 62.5 years (Inter quartile range (IQR) 52.5 to 72.0 years). Comparing to 2018, there has been a small increase in the median age at death, from 61.8 years (Table 1.2).

Table 1.2: Age at death for adults with a learning disability whose deaths were notified to LeDeR between January 2018, and December 2023.

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

Table 1.3 compares the age at death (grouped into age categories) of adults whose deaths were notified to LeDeR, compared to the general population. Nearly 60% of adults with a learning disability died before the age of 65 years, compared with less than 15% of adults in the general population. These data are represented graphically in Figure 1.3.

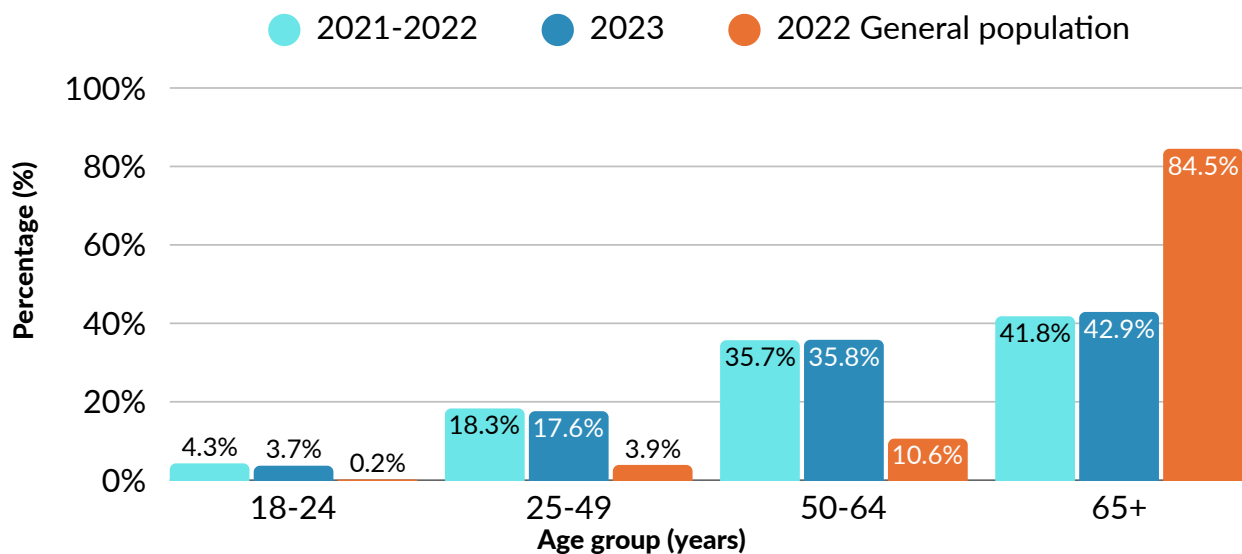
Table 1.3: Age groups for adults with a learning disability whose deaths were notified to LeDeR between January 2021 and December 2023 compared to the age at death for the general population.

Age group	2021 Number (%)	2022 Number (%)	2023 Number (%)	General adult population* 2022 Number (%)
18-24	143 (4.1%)	155 (4.3%)	133 (3.7%)	1,246 (0.2%)
25-49	632 (18.3%)	654 (18.2%)	626 (17.6%)	20,846 (3.9%)
50-64	1234 (35.8%)	1,283 (35.7%)	1,273 (35.8%)	57,484 (10.7%)
65+	1442 (41.8%)	1,501 (41.8%)	1,524 (42.9%)	456,735 (85.2%)

*Over the age of 20

[2] The 2018 LeDeR report is the first comprehensive report, and is used as a baseline year as previous years contained limited data.

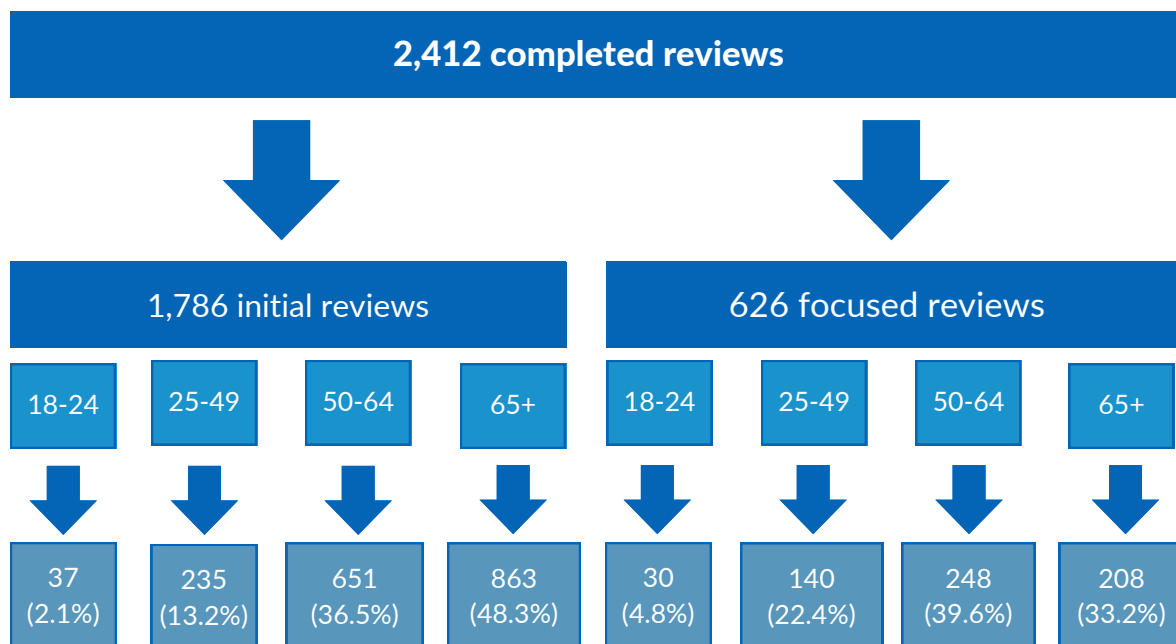
Figure 1.3: Bar chart showing the age at death for adults with a learning disability from January 2021 to December 2023 notified to LeDeR compared with the age at death for the general population.



LeDeR reviews during 2023

Of the 3,556 deaths that were notified to LeDeR in 2023, 2,412 LeDeR reviews were completed. This is similar to the number of reviews in 2021 (2,687) and 2022 (2,983). Of the reviews completed in 2023, 1,786 (74.0%) were initial reviews, and 626 (26.0%) were focused reviews[3]. In total, 1,071 (44.4%) were aged 65+ years, 899 (37.3%) were aged 50-64 years, 375 (15.6%) were aged 25-49 years, and 67 (2.8%) were aged 18-24 years. A breakdown of reviews by type and age group at death is shown in Figure 1.4. Note: All focused reviews start with an initial review.

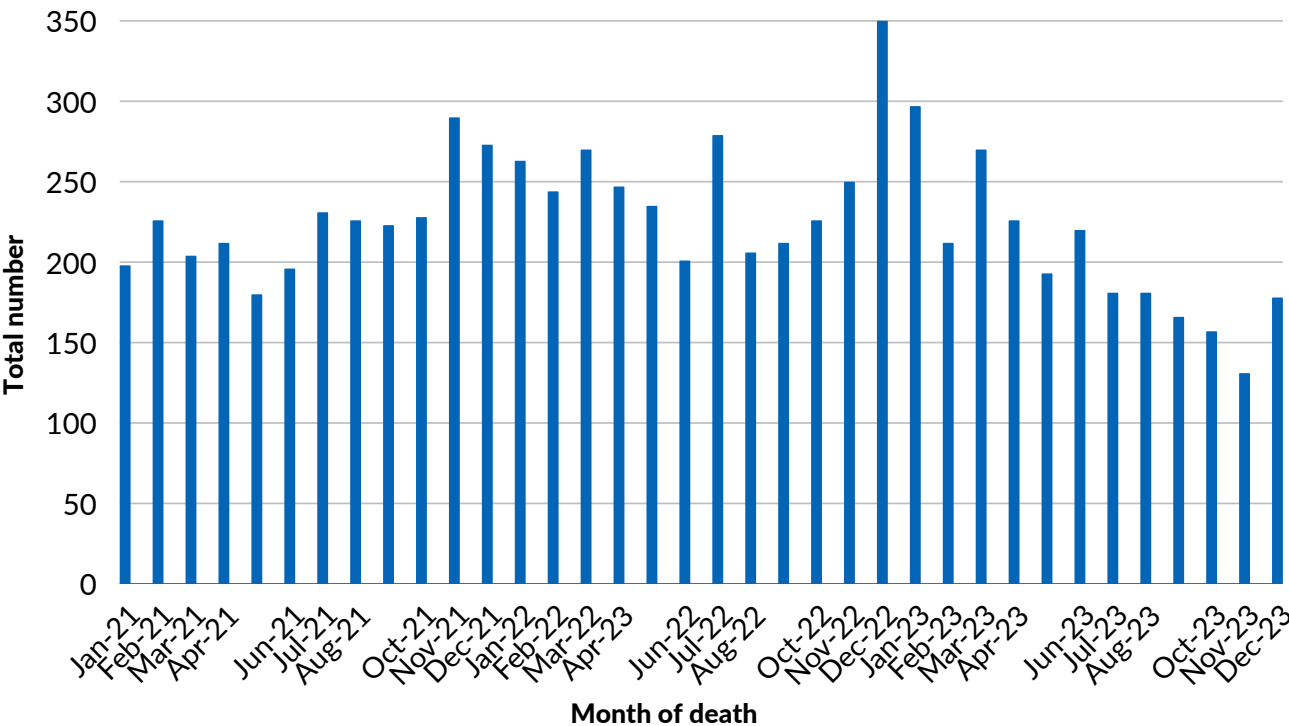
Figure 1.4: LeDeR reviews for adults with a learning disability who died in 2023 as either initial or focused reviews.



[3] See [Appendix 0.4](#) for an explanation of the LeDeR process and review types.

Figure 1.5 shows the total number of completed LeDeR reviews, by month of death between 2021, and 2023. This shows a decline in the number of completed reviews in the latter months of 2023[4]. As notifications have shown a consistent pattern across the months, this suggests that the data for 2023, whilst similar in total number compared to previous years, is not representative of the whole of 2023. These latter months typically have a reported increase in deaths due to seasonal illnesses which, therefore, may not have been fully captured in this 2023 data. This may impact various findings, such as reports of cause of death.

Figure 1.5: Total number of LeDeR reviews for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024, by month of death.



Demographics

Table 1.4 details the demographics of adults who died in 2023 and received a LeDeR review, compared with those who died during 2021 and 2022. In 2023 56.7% of all reviews were male. Similarly, 59.7% of deaths among 18-24 year olds were male. For a detailed breakdown of Table 1.4 by age group please see [Appendix 1.2](#). For demographic details on marital status, children, sexual orientation, and employment by year please see [Appendix 1.3](#).

The [Index of Multiple Deprivation \(IMD\)](#) is used to indicate the deprivation level of the areas where the adults who died lived. The IMD ranks areas based on multiple factors of deprivation, including income, employment, health, and education. The IMD ranks are divided into 10 equal groups and presented below. A greater proportion of adults with a learning disability who died in 2023 and had a LeDeR review lived in the most deprived areas (IMD levels 1 and 2; 27.1%), compared to the general population (20.8%).

4: Note that reviews can occur of deaths that happened prior to the rollout of the post April 2021 review system (i.e. in January – March)

Table 1.4: Demographic details of adults with a learning disability who died between January 2021 and December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024.

Demographic	2021 Number (%)	2022 Number (%)	2023 Number (%)	General adult population* 2022 Number (%)
Sex registered at birth				
Female	1,162 (43.2%)	1,324 (44.4%)	1,021 (42.3%)	266,754 (49.4%)
Male	1,507 (56.1%)	1,631 (54.7%)	1,368 (56.7%)	273,579 (50.6%)
Not known	18 (0.7%)	28 (0.9%)	23 (1.0%)	±
Ethnic group**				
Asian or Asian British	68 (2.5%)	108 (3.6%)	68 (2.8%)	±
Black African, Caribbean, or Black British	44 (1.6%)	63 (2.1%)	49 (2.0%)	±
Mixed ethnic group	34 (1.3%)	23 (0.8%)	12 (0.5%)	±
They preferred not to say	75 (2.8%)	107 (3.6%)	55 (2.3%)	±
Other ethnic group	12 (0.4%)	14 (0.5%)	10 (0.4%)	±
White	2,454 (91.3%)	2,668 (89.4%)	2,218 (92.0%)	±
Index of multiple deprivation decile				
1 (most deprived)	366 (13.6%)	394 (13.2%)	337 (14.0%)	56,197 (10.4%)
2	344 (12.8%)	383 (12.8%)	317 (13.1%)	53,506 (9.9%)
3	320 (11.9%)	338 (11.3%)	278 (11.5%)	52,404 (9.7%)
4	319 (11.9%)	339 (11.4%)	262 (10.9%)	54,709 (10.1%)
5	289 (10.8%)	342 (11.5%)	276 (11.4%)	55,203 (10.2%)
6	254 (9.5%)	294 (9.9%)	237 (9.8%)	55,892 (10.3%)
7	227 (8.4%)	312 (10.5%)	187 (7.8%)	55,729 (10.3%)
8	234 (8.7%)	243 (8.1%)	185 (7.7%)	54,359 (10.1%)
9	183 (6.8%)	193 (6.5%)	190 (7.9%)	52,667 (9.7%)
10 (least deprived)	139 (5.2%)	134 (4.5%)	131 (5.4%)	49,667 (9.2%)
Not known	12 (0.4%)	11 (0.4%)	12 (0.5%)	0 (0%)
Total number of reviews Number (%)	2,687 (100%)	2,983 (100%)	2,412 (100%)	Total number of deaths 540,333 (100%)

± Comparable data not available

*Over the age of 20

**Ethnic group data are discussed further in [Chapter 2](#).

Circumstances of death

Place of death

Over half (57.3%) of adults with a learning disability who died in 2023 and had a LeDeR review, died in hospital. 38.0% died in their usual place of residence, and 4.8% died in a place of residence categorised as 'other'. Comparable statistics for the general population of England for the most recent year available (2022), showed that 43.6% of adults died in hospital, 49.1% died in their usual place of residence, and 7.3% died in a place categorised as 'other'. Thus, adults with a learning disability were more likely to die in hospital compared to the general population, which is in line with findings in previous LeDeR annual reports. For a detailed breakdown of place of death by age group at death, please see [Appendix 1.4](#).

Table 1.5: *Place of death for adults with a learning disability who died from January 2021 to December 2023 and for whom a LeDeR review was completed between June 2021 and July 2024, compared to the general population.*

Place of death	2021 Number (%)	2022 Number (%)	2023 Number (%)	General adult population* 2022 Number (%)
Hospital**	1,585 (59.0%)	1743 (58.4%)	1,381 (57.3%)	235,588 (43.6%)
Usual place of residence	1,005 (37.4%)	1,102 (36.9%)	916 (38.0%)	265,070 (49.1%)
Other	97 (3.6%)	138 (4.6%)	115 (4.8%)	39,675 (7.3%)
Total number of reviews (%)	2,687 (100%)	2,983 (100%)	2,412 (100%)	540,333 (100%)

*Over the age of 20

** Hospital includes acute or community hospitals; Usual place of residence includes the person's home, the home of a friend or relative, or a residential nursing home; Other includes hospices, public places, secure units etc.

Deaths with DNACPR decisions

When completing an initial review, reviewers can indicate whether they identified evidence that a person had a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision in place at the time of death. All 2,412 adults with a learning disability who died in 2023 had a response to this question. Of these, 75.5% had a DNACPR decision in place at the time of death, and 24.5% did not. For comparison, 72.1% of adults with a learning disability who died in 2022 had a DNACPR decision in place at the time of death, and 72.5% in 2021. For a detailed breakdown of DNACPR by age group at death, please see [Appendix 1.5](#).

Table 1.6: Number of deaths where a DNACPR decision was in place for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024.

DNACPR decision at death	2021 Number (%)	2022 Number (%)	2023 Number (%)
Yes	1,947 (72.5%)	2,150 (72.1%)	1,821 (75.5%)
No	*	833 (27.9%)	591 (24.5%)
Not known	*	0 (0.0%)	0 (0.0%)
Total	2,687 (100%)	2,983 (100%)	2,412 (100%)

DNACPR documentation and processes

DNACPR documentation and processes are completed and followed correctly if the person's form was filled out properly, and healthcare professionals follow what was written on the form. For example, if Cardio-Pulmonary Resuscitation (CPR) is undertaken despite a DNACPR being in place, indicating that CPR should not be initiated in those circumstances, the DNACPR would be deemed to have not been followed correctly. Table 1.7 provides a breakdown of whether DNACPR documentation and processes were followed correctly.

Table 1.7: Whether DNACPR documentation was correctly completed and followed for adults with a learning disability with a DNACPR in place at death, who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024.

DNACPR documentation completed and followed correctly	2021 Number (%)	2022 Number (%)	2023 Number (%)
Completed and followed	1,182 (60.7%)	1,327 (61.7%)	1,140 (62.6%)
Completed but not followed correctly	21 (1.1%)	27 (1.3%)	11 (0.6%)
Incorrectly completed and followed	126 (6.5%)	163 (7.6%)	145 (8.0%)
Neither completed nor followed correctly	13 (0.7%)	16 (0.7%)	6 (0.3%)
Not known	605 (31.1%)	617 (28.7%)	519 (28.5%)
Total number of reviews (%)	1,947 (100%)	2,150 (100%)	1,821 (100%)

Deaths reported to a coroner

Certain deaths must be reported to a coroner. These include suspicious deaths, deaths of unknown cause, and deaths which have occurred under state detention (e.g. if the person was in prison or admitted to hospital under the Mental Health Act (MHA)). Whether a death was reported to the coroner is available in both initial and focused reviews; however, information about the outcome of any coroner's investigation may only be included in the focused review, and only if this has been available to the reviewer at the time of the focused review. Whether a death is reported to a coroner is not a reliable indicator of quality of care. Just over a third (36.4%) of LeDeR reviews for adults with a learning disability who died in 2023 were reported to a coroner, lower than deaths occurring in 2021 (40.5%) and 2022 (41.2%), and for the overall general population (38.6%). For a detailed breakdown of coroner reported deaths by age group at death please see [Appendix 1.6](#).

Table 1.8: Number of deaths reported to a coroner for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024, compared with the general population.

Death reported to a coroner?	2021 Number (%)	2022 Number (%)	2023 Number (%)	General adult population* 2022 Number (%)
Yes	242 (40.5%)	344 (41.2%)	223 (36.4%)	208,430 (38.6%)
No	355 (59.5%)	491 (58.8%)	389 (63.6%)	331,903 (61.4%)
Total	597 (100%)	835 (100%)	612 (100%)	540,333 (100%)

*Over the age of 20

Deaths with a police investigation

Certain deaths are reported to or investigated by the police. Similarly to deaths reported to a coroner, this may include suspicious deaths or deaths where criminal intent or negligence is suspected. Just over 2% (2.2%) of deaths of adults with a learning disability that occurred in 2023 and had a LeDeR focused review, were the subject of a police investigation, which is a decline from previous years (Table 1.9). Note that for the general population, comparative data were not available at the time of writing this report. For a detailed breakdown of police investigated deaths by age group please see [Appendix 1.7](#).

Table 1.9: Number of deaths that had a police investigation for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024.

Was there a police investigation?	2021 Number (%)	2022 Number (%)	2023 Number (%)
Yes	27 (4.4%)	33 (3.9%)	14 (2.2%)
No	584 (95.6%)	817 (96.1%)	612 (97.8%)
Total	611 (100%)	850 (100%)	626 (100%)

For a detailed summary of adults with a learning disability, who had a completed LeDeR review where there was a safeguarding enquiry please see [Appendix 1.8](#)

Causes of death

Medical Certificate of Cause of Death (MCCD) data were available for 1,887 (78.2%) of the 2,412 completed reviews for adults with a learning disability who died in 2023 (Table 1.10). Reasons for the MCCD not being available at the time of review include cases where a coroner's input was required, cases which involved a police investigation, or situations where the cause of death required further investigation. It is important to note that, due to the time required to complete LeDeR reviews, some of the latter months of the year may have less completed reviews than earlier months. This may therefore impact the number of seasonal causes of death (e.g. influenza).

The most common causes of death for adults with a learning disability by the [International Classification of Diseases, 10th edition](#) (ICD-10) chapter who died in 2023 and had a LeDeR review were: Neoplasms (cancers) (16.6% of deaths); diseases of the respiratory system (16.5% of deaths); and diseases of the circulatory system (16.4% of deaths). Congenital malformations, deformations and chromosomal abnormalities and diseases of the nervous system were the fourth and fifth most common causes of death, accounting for 13.9% and 13.5% of deaths for adults with a learning disability that occurred in 2023, respectively. For a full list of the ICD 10 chapters please see [Appendix 1.9](#).

Deaths due to congenital malformations, deformations, and chromosomal abnormalities (a category which includes conditions like Down syndrome, congenital heart defects, and other structural or genetic conditions) are much higher in those with a learning disability compared to the general population (13.9% vs 0.2%). The proportion of deaths due to diseases of the nervous system (a category which includes epilepsy) was also considerably higher than in the general population (13.5% vs 7.3%). In 2023 the most common grouped causes of death have all become more common (in terms of a proportion of overall deaths). However, it is important to consider that in 2021 many deaths were due to COVID-19, and thus the proportion due to other causes of death may be underrepresented. For a detailed breakdown of the most common grouped causes of death by age group please see [Appendix 1.10](#).

Table 1.11 shows the most common underlying causes of death of the MCCD data in LeDeR from 2021 to 2023. Apart from COVID-19, the same four underlying causes are commonly reported. These are Down Syndrome, Cerebral Palsy, Pneumonia, and Epilepsy. In 2021 and 2022 COVID-19 was the 1st and 3rd most common recorded underlying cause of death respectively. In 2023 it has fallen from the most common causes. U071 (COVID-19) appeared just 38 (1.5%) times in 2023.

Table 1.10: Most common ICD-10 chapter causes of death for adults with a learning disability who died from January 2021 to December 2023 and had a completed review between June 2021 and July 2024, compared with the general population.

ICD-10 chapter	2021 Number (%)	2022 Number (%)	2023 Number (%)	General adult population* 2022 (%)
Neoplasms (cancers)	352 (13.3%)	409 (14.3%)	313 (16.6%)	26.6%
Diseases of the respiratory system	345 (13.0%)	446 (15.6%)	311 (16.5%)	11.1%
Diseases of the circulatory system	409 (15.5%)	464 (16.2%)	309 (16.4%)	24.5%
Congenital malformations, deformations, and chromosomal abnormalities	302 (11.4%)	371 (13.0%)	263 (13.9%)	0.2%
Diseases of the nervous system	321 (12.1%)	398 (13.9%)	255 (13.5%)	7.3%

*Over the age of 20.

Table 1.11: Most common underlying ICD-10 code causes of death for adults with a learning disability who died from January 2021 to December 2023 and had a completed review between June 2021 and July 2024.

2021 ICD-10 code (Number (%))	2022 ICD-10 code (Number (%))	2023 ICD-10 code (Number (%))
U071: COVID-19 (316, 11.7%)	Q909: Down syndrome (277, 9.2%)	Q909: Down Syndrome (193, 8.0%)
Q909: Down syndrome (223, 8.2%)**	G809: Cerebral palsy (156, 5.2%)	G809: Cerebral Palsy (99, 4.1%)
G809: Cerebral palsy (113, 4.2%)**	U071: COVID-19 (150, 5.0%)	J189: Pneumonia (96, 3.9%)
J189: Pneumonia (95, 3.5%)	J189: Pneumonia (127, 4.2%)	F03: Unspecified dementia (48, 1.9%)
G409: Epilepsy (69, 2.5%)	G409: Epilepsy (88, 2.9%)	G409: Epilepsy (45, 1.8%)

*For Table colour key please see Appendix 0.7

**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).

Avoidable deaths

An internationally agreed list of causes of death that are considered avoidable is provided by the [Organisation for Economic Co-operation and Development \(OECD\)](#). An avoidable death is one that occurs in someone under 75 years of age, due to a condition deemed to be preventable or treatable or both. Preventable deaths are the deaths that could have been avoided through effective public health and primary prevention interventions (e.g. vaccinations or smoking cessation). Treatable deaths are the deaths that could have been avoided through timely and effective healthcare interventions, including secondary prevention and treatment (e.g., early cancer detection).

Using this definition, 733 (38.8%) of the 1,887 deaths of adults with a learning disability reviewed in 2023, that had a known cause of death were classed as avoidable. For comparison, 43.0% of adult deaths were classed as avoidable in 2022, and 46.1% in 2021. The proportion of avoidable deaths is highest in the 50-64 age group and comparable between males and females (unlike in the general population where males have higher rates (see Table 1.12).

The most common causes of avoidable death for adults with a learning disability who died in 2023 were influenza and pneumonia (14.9% of all deaths), malignant neoplasms (cancers) of the digestive organs (9.7% of all deaths), and ischaemic heart diseases (9.5% of all deaths). Please see Table 1.13 for the most common causes of avoidable death for adults who died in 2022 and 2021. The most common causes of avoidable death in males and females are presented in Table 1.14. Avoidable causes of death did not differ much by sex, except for ischaemic heart disease, which was more common in males. Avoidable causes of death by ethnic group are discussed in [Chapter 2](#).

In 2023, 13.6% of deaths were preventable. This compares to 22.8% of deaths in 2021 and 18.2% in 2022. However, this should be taken in the context of the COVID-19 pandemic, where in 2021, 266 (44%) of the preventable deaths were due to COVID-19. In addition, the data on latter month deaths for 2023 may be incomplete due to the delays in completing reviews (as discussed on page 18). As such, a direct comparison may not be possible and this data regarding preventable deaths should be interpreted with caution.

In 2023, 25.3% of deaths were treatable. For comparison, 23.3% of deaths in 2021 were treatable, and 24.8% in 2022. For a detailed breakdown of the most common avoidable causes of death by age group, please see [Appendix 1.11](#).

Table 1.12: Preventable and treatable deaths as a proportion of avoidable deaths for adults with a learning disability who died from January 2021 to December 2023 and for whom a LeDeR review was completed between June 2021 and July 2024, compared with the general population. Note: This refers to underlying causes of death on the MCCD [5].

Avoidable mortality	2021 Number (%)	2022 Number (%)	2023 Number (%)	General adult population* 2022 (%)
Preventable**	604 (22.8%)	521 (18.2%)	256.5 (13.6%)	14.1%
Treatable**	615 (23.3%)	709 (24.8%)	476.5 (25.3%)	7.5%
Total avoidable deaths (% of all deaths)	1,219 (46.1%)	1,230 (43.0%)	733 (38.8%)	21.6%
Avoidable deaths by age group (% of deaths by age group)				
18-24 years	38 (38.4%)	38 (34.2%)	15 (28.8%)	76.7%
25-49 years	239 (52.5%)	250 (53.9%)	121 (44.5%)	77.8%
50-64 years	532 (56.0%)	542 (51.5%)	334 (46.7%)	71.9%
65-74 years	410 (36.0%)	400 (32.4%)	263 (31.0%)	12.5%
Avoidable deaths by sex				
Female	522 (45.5%)	509 (40.1%)	307 (38.0%)	17.2%
Male	688 (46.5%)	709 (45.4%)	419 (39.5%)	25.8%

*Over the age of 20

**Causes of death are sometimes categorised as both preventable and treatable. For each death categorised as equally preventable and treatable, 0.5 was added to the total number of preventable and treatable deaths. There were 159 deaths in 2023 categorised as equally preventable and treatable.

Table 1.13: Most common avoidable causes of death for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024.

Rank	2021 (%)	2022 (%)	2023 (%)
First	COVID-19 (21.9%)	Influenza and pneumonia (14.1%)	Influenza and pneumonia (14.9%)
Second	Influenza and pneumonia (10.7%)	Ischaemic heart diseases (10.7%)	Malignant neoplasms of digestive organs (9.7%)
Third	Ischaemic heart diseases (9.2%)	COVID-19 (9.3%)	Ischaemic heart diseases (9.5%)

*For table colour key please see Appendix 0.8

[5] For a detailed breakdown of the most common avoidable causes of death by age group please see Appendix 1.11

Table 1.14: Most common avoidable causes of death for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024, by sex registered at birth.

Sex	Rank	2021 (%)	2022 (%)	2023 (%)
Female	First	COVID-19 (22.6%)	Influenza and pneumonia (14.1%)	Influenza and pneumonia (13.4%)
	Second	Influenza and pneumonia (11.3%)	COVID-19 (9.6%)	Chronic lower respiratory diseases (10.4%)
	Third	Cerebrovascular diseases (8.2%)	Ischaemic heart diseases (8.8%)	Malignant neoplasms of digestive organs (9.8%)
Male	First	COVID-19 (21.7%)	Influenza and pneumonia (14.0%)	Influenza and pneumonia (16.2%)
	Second	Ischaemic heart diseases (11.2%)	Ischaemic heart diseases (11.8%)	Ischaemic heart diseases (12.2%)
	Third	Influenza and pneumonia (10.5%)	COVID-19 (9.3%)	Malignant neoplasms of digestive organs (9.8%)

*For table colour key please see Appendix 0.8

Quality of Care Reviews that identified good practice

Good practice was identified in the reviews of 73.2% of adults with a learning disability who died in 2023, showing a slight increase over the recent years (Table 1.15).

Table 1.15: Number of deaths where the reviewer identified good practice for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024.

Good practice identified	2021 Number (%)	2022 Number (%)	2023 Number (%)
Yes	1,685 (62.7%)	2,141 (71.8%)	1,766 (73.2%)
No	1,002 (37.3)	842 (28.2%)	646 (26.8)
Total number (%)	2,687 (100.0%)	2,983 (100.0%)	2,412 (100%)

Reviews where concerns had been expressed

Reviewers were asked if anyone expressed concerns about the death during focused reviews. The concerns may have been expressed by anyone involved in the review process including the person who notified the death, the person's carers or the professionals involved in the person's care.

Concerns were identified in over one-quarter (26.5%) of focused reviews for adults who died in 2023, a reduction from previous years (Table 1.16). This could be due to the number of concerns raised during the COVID-19 pandemic; however, several factors could be contributing to this.

Table 1.16: Number of deaths where concerns were identified during the LeDeR review for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024.

Concerns identified*	2021 Number (%)	2022 Number (%)	2023 Number (%)
Yes	245 (40.1%)	261 (30.7%)	166 (26.5%)
No	286 (46.8%)	576 (67.8%)	454 (72.5%)
Not known	80 (13.1%)	13 (1.5%)	6 (1.0%)
Total number (%)	611 (100.0%)	850 (100.0%)	626 (100.0%)

*Note: in 2021, the question response was slightly different in that it asked “not to my knowledge,” whilst in 2022 and 2023, it was “not known”. This may explain the larger “not known” for 2021.

Social care package

Reviewers are asked to indicate whether the social care package appeared to have met the needs of the person who died. 74% of adults with a learning disability who died in 2023 were deemed by the reviewer to have had a care package that met their needs, similar to previous years (Table 1.17). However, in 25.6% (1 in 4) of 2023 reviews, reviewers noted that the social care package did not meet the needs of the person who died, suggesting that a significant proportion of the adults who died did not have adequate support. This is slightly lower than in 2021 (25.9%), but higher than in 2022 when just over 1 in 5 care packages were assessed as not meeting the needs of the adults with a learning disability.

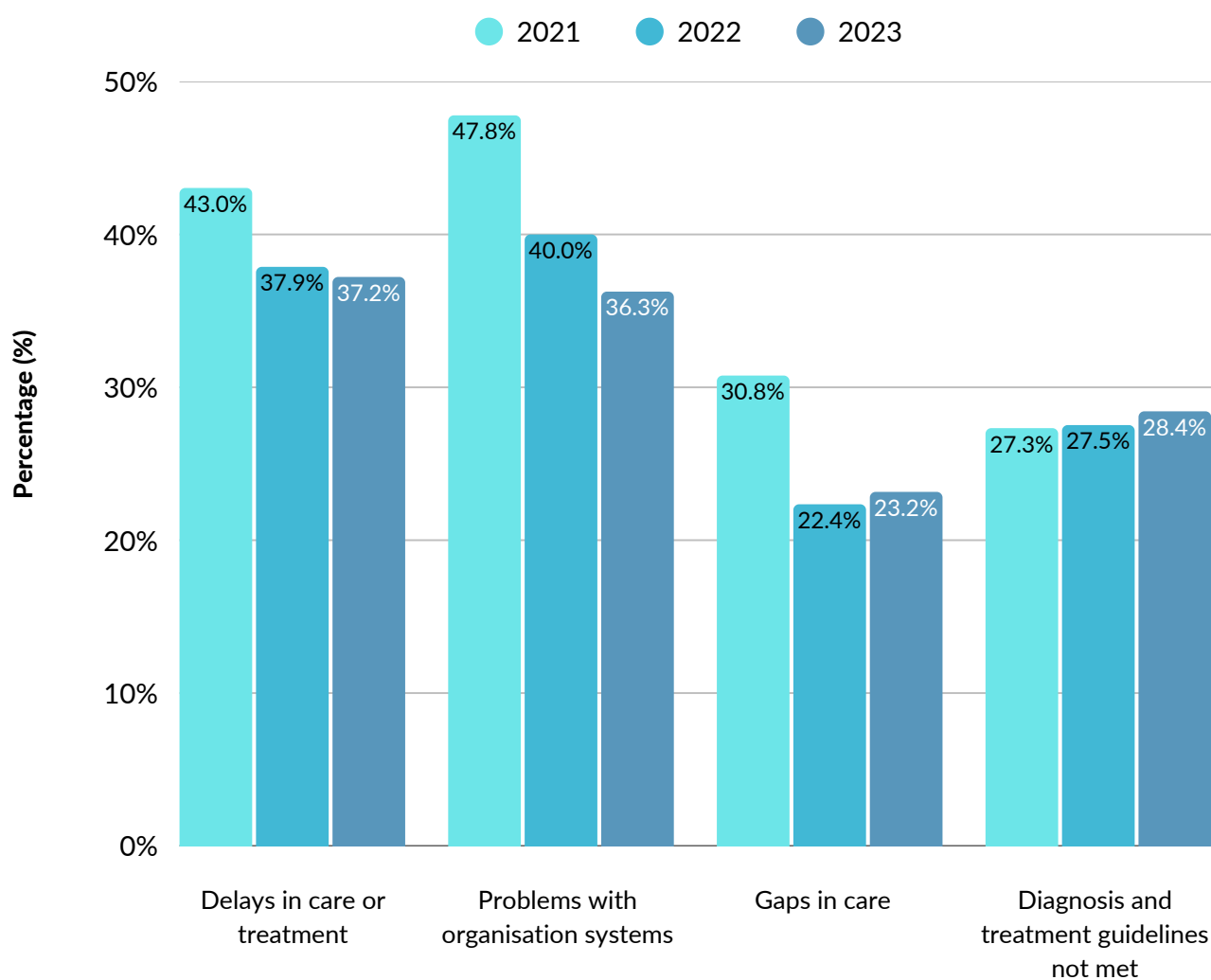
Table 1.17: Number of people whose care package met their needs for adults with a learning disability who died from January 2021 to December 2023, and received a LeDeR review between June 2021 and July 2024.

Care package met the needs of the person	2021 Number (%)	2022 Number (%)	2023 Number (%)
Yes	453 (74.1%)	671 (78.9%)	466 (74.4%)
No	158 (25.9%)	179 (21.1%)	160 (25.6%)
Total number (%)	611 (100.0%)	850 (100.0%)	626 (100.0%)

Reviews that identified specific problems in care

Reviewers are asked to report whether the adults who died with a learning disability had experienced any problems with specific aspects of their care. These include delays in care or treatment, problems with organisational systems and processes (including coordination of care), gaps in service provision, and diagnostic and treatment guidelines not being met. 37.2% of adults with a learning disability who died in 2023 experienced a delay in their care or treatment, a slight decrease when compared with deaths occurring in 2021, and 2022 (Figure 1.6). 36.3% experienced problems with organisational systems (a decrease from previous years) and 23.2% experienced gaps in their care, while 28.4% received a diagnosis or treatment that did not meet guidelines (comparable to previous years).

Figure 1.6: Proportion of reviews where specific problems of care were identified for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024.



Reasonable adjustments to care

72.7% of adults with a learning disability who died in 2023 were reported to have received the reasonable adjustments that they required when they accessed care. Conversely, 27.3% were reported to have needed at least one reasonable adjustment that they were not provided with.

Table 1.18: *Number of deaths where reasonable adjustments were provided for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024.*

Reasonable adjustments made	2021 Number (%)	2022 Number (%)	2023 Number (%)
All reasonable adjustments provided	404 (66.1%)	631 (74.2%)	455 (72.7%)
Reasonable adjustments should have been provided but were not	207 (33.9%)	219 (25.8%)	171 (27.3%)
Total number (%)	611 (100%)	850 (100%)	626 (100%)

Use of the Mental Capacity Act

In 2023 the Mental Capacity Act (MCA) was correctly followed for 68.2% of adults with a learning disability who died and had a capacity assessment in place (Table 1.19). This is a slight improvement from previous years (66.1% in 2022, and 65.2% in 2021).

Table 1.19: *Number of deaths where the Mental Capacity Act was followed for adults with a learning disability who had a capacity assessment in place, from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024.*

Use of the Mental Capacity Act	2021 Number (%)	2022 Number (%)	2023 Number (%)
Correctly followed	1754 (65.2%)	1974 (66.1%)	1645 (68.2%)
Not correctly followed	195 (7.2%)	219 (7.3%)	160 (7.6%)
Not known	738 (27.4%)	790 (26.4%)	607 (25.1%)

Summary and discussion

LeDeR continues to be well reported to following a reduction in notifications in 2022 (likely due to the COVID-19 pandemic), suggesting that healthcare partners are engaging with the process and the deaths of adults with a learning disability.

Analysis of deaths of adults with a learning disability who were notified to LeDeR in 2023 shows that they continue to die at a younger age compared to the general population. However, it is difficult to make direct comparisons, and we are not able to estimate the life expectancy of adults with a learning disability. Nonetheless, there has been a small increase in the age at death of those reported to LeDeR since 2018. The most common causes of death were the same for deaths that occurred in 2021, 2022 and 2023, though together they accounted for a larger proportion of deaths in 2023 in comparison to 2021. This may be due to a reduction in the proportion of deaths due to COVID-19 infection.

A relatively high proportion of deaths of adults with a learning disability are considered avoidable. However, this appears to have decreased over recent years, with 38.8% of deaths being considered avoidable in 2023, compared to 43.1% in 2021. It is still nearly twice as high as figures for the general population, where avoidable deaths accounted for 21.6% of all deaths, underlining the ongoing need to improve the health and care of people with a learning disability. There are indications of improvement in the proportion of reviews in which reviewers identified positive practice and a decline in the proportion of deaths where concerns were identified.

Reviews of deaths that indicated that the MCA was adhered to improved from 65.2% in 2021 to 68.2% in 2023. The provision of reasonable adjustments remained relatively static with reviewers reporting that just over one-quarter of adults who died in 2023, required reasonable adjustments that were not provided. Similarly, 1 in 4 adults who died in 2023 were rated by reviewers as not having a package of care that met all their needs. 37.2% of adults with a learning disability who died in 2023 experienced a delay in their care or treatment, and 36.3% experienced problems with organisational systems, a slight improvement from previous years. One in five experienced gaps in their care, while 28.4% received care that did not meet best-practice guidelines, which is comparable to previous years.

Looking forward

For health and care services:

- It is essential that deaths of people with a learning disability continue to be notified to LeDeR to ensure reliable data that can inform service improvements.
- It is important to continue to address the higher proportion of avoidable deaths of people with a learning disability.
- Improving access to screening programmes, awareness, and uptake of recommended vaccines (such as influenza, COVID-19, and pneumococcal vaccines).
- Robust Learning Disability Annual Health Checks should continue to be prioritised.
- Particular attention should be directed at treatable causes of avoidable mortality that account for a large proportion of deaths, including cancer and pneumonia.
- Improvements to social care services may be required. Improvements to care for adults with a learning disability can come from the social care sector as well as the NHS.
- The use of learning disability nurses and specialist physicians is associated with improved care (see [Chapter 3](#) for further discussion) and access to these should be enhanced.

For research:

- Further research is needed into issues surrounding the application of the Mental Capacity Act (MCA) in people with a learning disability, as well as potential inequalities in compliance. This aligns with recommendations made in the LeDeR reports from 2021 and 2022.
- Continue to report and evaluate where there are issues with care, as well as examples of good practice to identify areas where improvements could be made.

Chapter 2

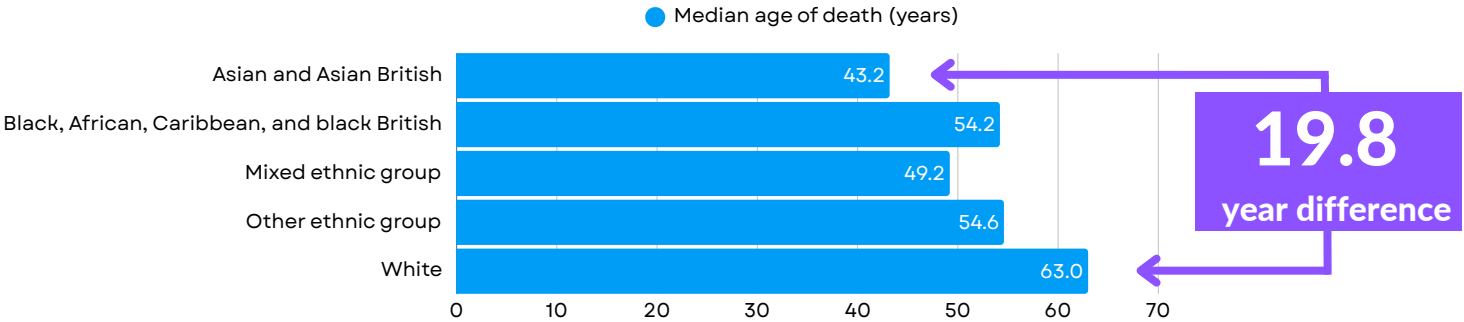


Ethnicity of adults who died with a learning disability and were notified to LeDeR

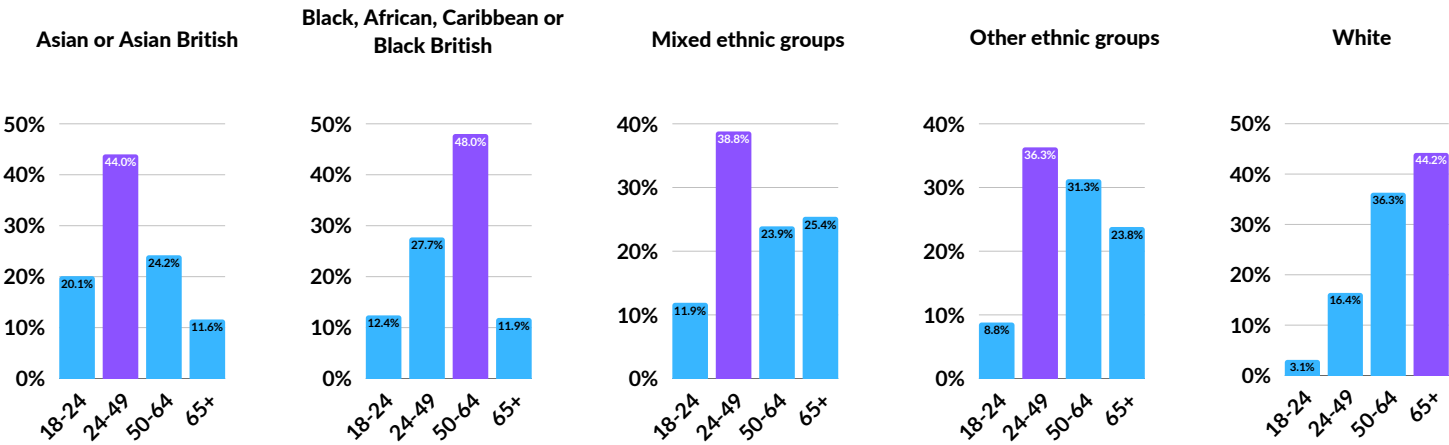
CHAPTER 2 - ETHNICITY OF PEOPLE WITH A LEARNING DISABILITY

AGE AT DEATH

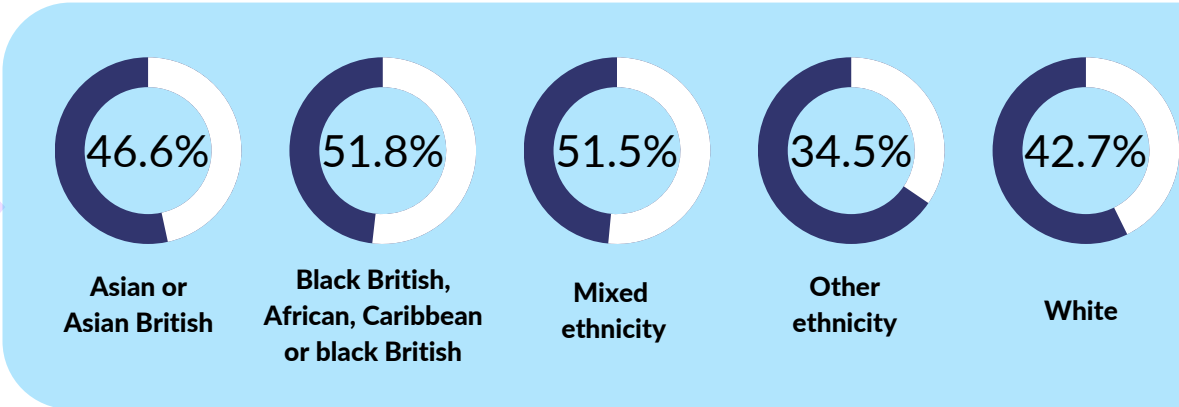
Adults from all ethnic groups who were notified to LeDeR from January 2021- December 2023 had a younger median age at death compared to White adults who died.



AGE GROUP AT DEATH 2021-2023



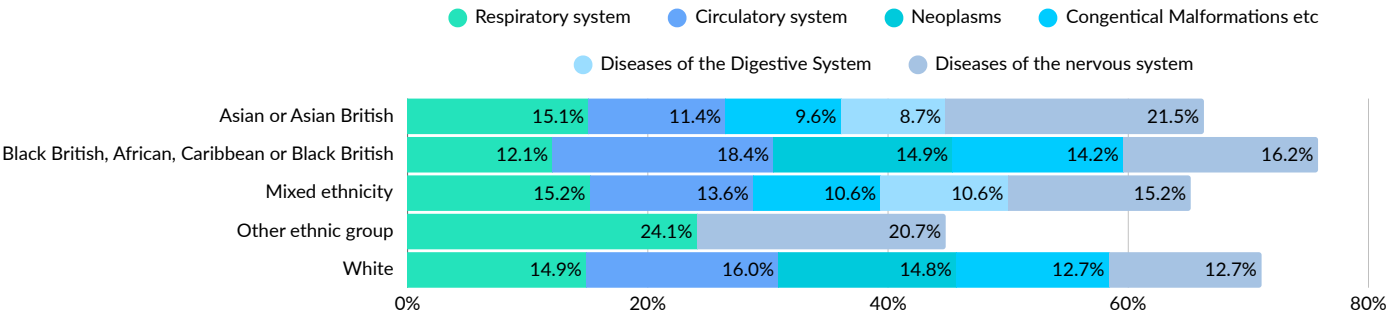
AVOIDABLE* DEATHS FOR 2021-23



*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

Ethnicity of adults who died with a learning disability and were notified to LeDeR

Introduction

People from ethnic minority groups with a learning disability continue to experience inequalities in terms of access, experience, and outcomes of care. LeDeR data provides a more detailed review of the differences in health outcomes and circumstances of death experienced by people with a learning disability from an ethnic minority group. Previous LeDeR data analyses have highlighted significant differences in age at death, with ethnic minority groups dying at a younger age, in comparison to those whose ethnic group was recorded as “White” (White et al., 2022; Umpleby et al., 2023).

This analysis focuses on explicit responses to the ethnic group questions in the LeDeR notifications and review process. It excludes responses of ‘prefer not to say’ and ‘not stated’, as well as cases where ethnic group questions were not completed by the notifier or reviewer. It should be noted that this approach may have excluded some individuals from ethnic minority groups. In addition, the small number of reported deaths for some groups in this chapter is likely an underestimation; therefore, the findings should be interpreted with caution.

Please note that the overall number of people denoted as “White” ethnicity is far larger than all other ethnicities. We will report on the data as is. However, it is important to be aware that with such smaller comparison numbers of those who are denoted as ethnic minority groups, further investigation with a larger sample size (if possible) is needed to draw firm conclusions. This chapter is therefore presented only as a guide detailing the data LeDeR has available to date.

LeDeR notifications by ethnic group: Demographics for ethnic groups

Ethnic group data for adults with a learning disability were available for 8,773 notifications of people who died from January 2021 to December 2023, who were notified to LeDeR from June 2021 to July 2024. This is the cohort used for the analysis in this chapter. Therefore, data presented here may be slightly different to the data in the previous chapter. Most people who died with a learning disability and were notified to LeDeR were “White” (93.0%), while 3.3% were “Asian or Asian British” and 2.0% were “Black, African, Caribbean, or Black British”. All ethnic groups other than “White” notified to LeDeR accounted for 7.0%[6].

Table 2.1: *Ethnic group for adults with a learning disability who died between January 2021 and December 2023 and were notified to LeDeR.*

Ethnic group	2021, Number (%)	2022, Number (%)	2023, Number (%)	Total, Number (%)
Asian or Asian British	79 (3.4%)	121 (3.7%)	93 (2.9%)	293 (3.3%)
Black, African, Caribbean, or Black British	36 (1.5%)	70 (2.2%)	71 (2.2%)	177 (2.0%)
Mixed ethnic group	23 (1.0%)	19 (0.6%)	25 (0.8%)	67 (0.8%)
Other ethnic group	35 (1.5%)	21 (0.6%)	24 (0.8%)	80 (0.9%)
White	2,166 (92.6%)	3,014 (92.9%)	2,976 (93.3%)	8,156 (93.0%)
Total number (% of all notified deaths)	2,339 (26.7%)	3,245 (37%)	3,189 (36.4%)	8,773 (100%)

The ONS (2023) lists 288 detailed ethnicities. Ethnic grouping covers a broad range of ethnicities. It is important to note that the ONS (2023) recognise that “Ethnic group, religion and national identity are self-identification measures reflecting how people define themselves”. Therefore, while Table 2.1 details the ethnic groups as referred to by LeDeR, the data shown in Table 2.2 (overleaf) uses the harmonised standard ethnicities[7]. All other data on the differences between ethnic groups use the aggregated categories.

Table 2.2 (overleaf) shows that the largest group of adults with a learning disability who died and were notified to LeDeR from an ethnic minority group from January 2021 to December 2023 were “Asian or Asian British”. The largest ethnic minority subgroup of “Asian or Asian British” adults were “Pakistani” (1.4% of all adults with a learning disability who died and were notified to LeDeR). The largest ethnic minority subgroup of “Black, African Caribbean or Black British” were “Caribbean” (1.1% of all adults with a learning disability and who were notified to LeDeR).

6: The option to include ethnic group can be made at any point when reporting to LeDeR therefore numbers may vary between notifications and reviews for specific ethnic groups.

7: [Ethnicity harmonised standard – Government Analysis Function \(civilservice.gov.uk\)](https://civilservice.gov.uk/government/publications/ethnicity-harmonised-standard).

Table 2.2. *Harmonised ethnic grouping for adults with a learning disability who died from January 2021 to December 2023, and were notified to LeDeR .*

Ethnic group	Harmonised ethnic group	Number	(%)
Asian or Asian British	Indian	89	1.0%
	Pakistani	122	1.4%
	Bangladeshi	22	0.3%
	Chinese	*	*
	Any other Asian background	58	0.7%
Black, African, Caribbean or Black British	African	43	0.5%
	Caribbean	96	1.1%
	Any other Black, Black British, or Caribbean background	30	0.3%
Mixed ethnic group	White and Black Caribbean	14	0.2%
	White and Black African	*	*
	White and Asian	*	*
	Any other mixed or multiple ethnic background	25	0.3%
Other ethnic group	Arab	*	*
	Any other ethnic background	77	0.9%
	Prefer not to say	50	0.6%
	Not stated	45	0.5%
White	White British	7,931	90.4%
	White Irish	48	0.5%
	Gypsy, Traveller or Irish Traveler	*	*
	Any other White background	98	1.1%
Total		8,773	

Sex registered at birth for ethnic groups

Male deaths were notified to LeDeR more often than females across all ethnic groups, except for adults who died who were notified as from the “Mixed” ethnic group, which were reported equally. Of the “Black, African, Caribbean, or Black British” adults who were notified to LeDeR, 58.8% were male. Among “Asian or Asian British” adults, 54.9% were male. For “White” adults, 53.9% were male, while those categorised as “Other,” 55.0% were male. This highlights a consistent trend of higher male-to-female notifications to LeDeR across all ethnic groups.

Table 2.3: Sex registered at birth of adults with a learning disability who died between January 2021 and December 2023 and were notified to LeDeR, by ethnic group.

Ethnic group	Female Number (%)	Male Number (%)	Not known Number (%)	Not stated Number (%)	Total Number (%)
Asian or Asian British	116 (35.9%)	161 (54.9%)	6 (2.0%)	10 (3.4%)	293 (3.3%)
Black, African, Caribbean, or Black British	67 (37.6%)	104 (58.8%)	*	*	177 (2.0%)
Mixed ethnic group	32 (47.8%)	32 (47.8%)	*	*	67 (0.8%)
Other ethnic group	31 (38.8%)	44 (55.0%)	*	*	80 (0.9%)
White	3,414 (41.9%)	4,397 (53.9%)	160 (2.0%)	185 (2.3%)	8,156 (93.0%)
Total number (%)	3,660 (41.7%)	4,738 (54.0%)	173 (2.0%)	202 (2.3%)	8,773 (100%)

Age at death for ethnic groups

Table 2.4 highlights some descriptive differences within the age at death categories across different ethnic groups. Those who were notified to LeDeR as “White” were older, with approximately 44% being in the 65+ age group, while the highest proportion of deaths for “Asian or Asian British” adults with a learning disability was in the 25–49 year age group (44% of all adults in this group). For “Black, African, Caribbean, or Black British” adults, the highest proportion of deaths was in the 50–64 year age group (48% of all adults in this group). “Mixed” and “Other” ethnic minority groups were more evenly distributed across the age groups.

Table 2.4: Age group for adults with a learning disability who died between January 2021 and December 2023 and were notified to LeDeR, by ethnicity.

Ethnic group	18-24 years Number (%)	25-49 years Number (%)	50-64 years Number (%)	65+ years Number (%)	Total Number (%)
Asian or Asian British	59 (20.1%)	129 (44%)	71 (24.2%)	34 (11.6%)	293
Black, African, Caribbean, or Black British	22 (12.4%)	49 (27.7%)	85 (48%)	21 (11.9%)	177
Mixed ethnic group	8 (11.9%)	26 (38.8%)	16 (23.9%)	17 (25.4%)	67
Other ethnic group	7 (8.8%)	29 (36.3%)	25 (31.3%)	19 (23.8%)	80
White	250 (3.1%)	1,341 (16.4%)	2,959 (36.3%)	3,606 (44.2%)	8,156
Total number (%)	346 (3.9%)	1,574 (17.9%)	3,156 (36.0%)	3,697 (42.1%)	8,773

Median age at death for ethnic minority groups

The LeDeR 2021 annual report identified ethnicity as one of the factors which was associated with the age at death (White et al., 2022). From January 2021 to December 2023, the median age at death for adults with a learning disability from ethnic minority groups, who were notified to LeDeR was 56.9 years (IQR 40.6 to 68.0) compared to 63.0 years (IQR 53.6 to 72.4) for the “White” ethnic group. Considering the significantly lower data for ethnic minority groups other than “White”, this area still requires further study and is therefore reported here. The age at death data in LeDeR reports should not be confused with life expectancy, as LeDeR only accounts for those who have died, without considering people still alive.

Table 2.5: Median age at death by ethnic group for adults who died from January 2021 to December 2023.

Ethnic group	Median age at death (years)	IQR
Asian or Asian British	43.2	27.0 to 55.1
Black British, African, Caribbean, or Black British	54.2	36.5 to 59.5
Mixed ethnic group	49.2	30.5 to 64.1
Other ethnic group	54.6	35.1 to 64.1
White	63.0	53.6 to 72.4

Region for ethnic groups

Table 2.6 presents the region of England and the ethnic group of adults with a learning disability who died from January 2021 to December 2023 and were notified to LeDeR. London had the highest proportions of notified deaths for adults from the “Black African, Caribbean, or Black British” (57.1%), “Mixed” (34.3%), and “Other” ethnic groups (45%). In comparison, London had the lowest proportion of deaths for “White” adults with a learning disability (8.6%). Additionally, London had the second largest proportion of deaths for “Asian or Asian British” adults with a learning disability (26.6%).

The Midlands region had the highest proportion of notified deaths for “Asian or Asian British” adults with a learning disability (27.3% of all deaths for this group) and the highest overall percentage of notified deaths for all ethnic groups, including those who died notified as “White” (20.9% of all notified deaths). The regions with the lowest proportions of notified deaths for adults with a learning disability from an ethnic group other than “White” were the East of England and the South west.

Table 2.6: *Region of England for adults with a learning disability who died from January 2021 to December 2023 and were notified to LeDeR, by ethnic group.*

Ethnic group	London	South West	South East	Midlands	East of England	North West	North east and Yorkshire	Total
Asian or Asian British	78 (26.6%)	8 (2.7%)	27 (9.2%)	80 (27.3%)	17 (5.8%)	43 (14.7%)	40 (13.7%)	293
Black African, Caribbean, or Black British	101 (57.1%)	*	19 (10.7%)	19 (10.7%)	15 (8.5%)	15 (8.5%)	*	177
Mixed ethnic group	23 (34.3%)	*	9 (13.4%)	20 (29.9%)	*	*	*	67
Other ethnic group	36 (45.0%)	5 (6.3%)	17 (21.3%)	10 (12.5%)	*	*	*	80
White	682 (8.6%)	828 (10.2%)	1,268 (15.6%)	1,661 (20.4%)	926 (11.4%)	1,254 (15.4%)	1,537 (18.8%)	8,156
Total number (% of all deaths)	920 (10.5%)	846 (9.6%)	1,340 (15.3%)	1,790 (20.4%)	965 (11.0%)	1,321 (15.1%)	1,571 (17.9%)	8,773

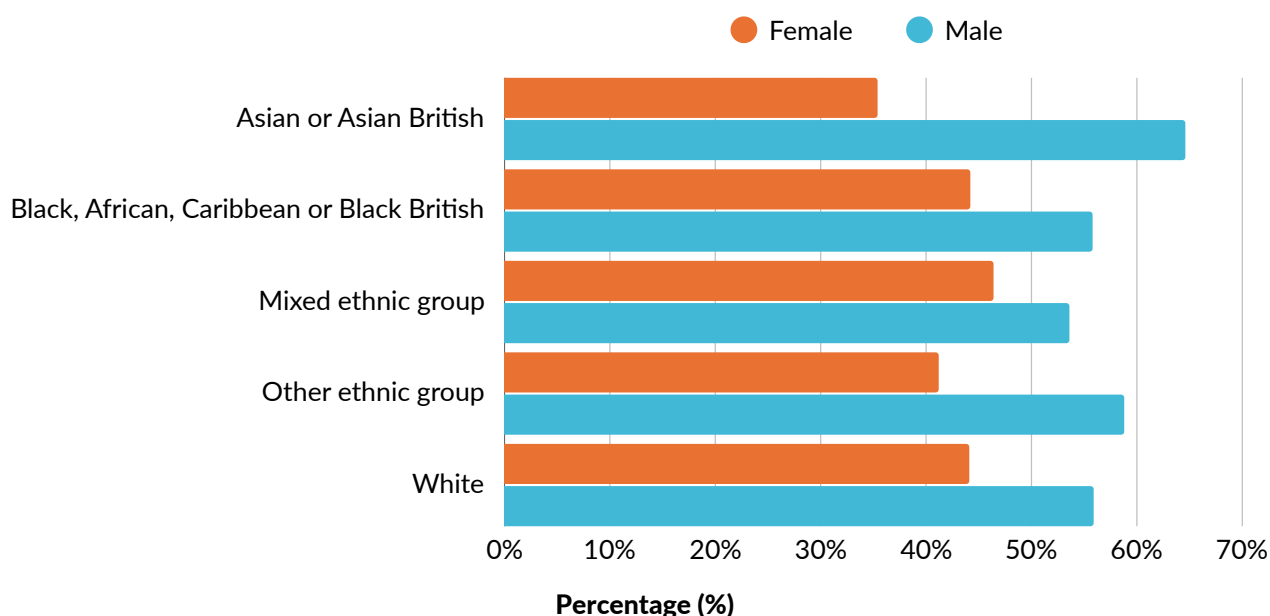
LeDeR reviews for ethnic groups

This part of the chapter includes a summary of the information collected in LeDeR reviews by ethnic group, providing additional detail about the lives and deaths of adults with a learning disability who died. Full data tables, which include detailed age breakdowns for reviews of the adults who died from an ethnic group, can be found in Appendix 2.1-2.6.

Sex registered at birth for ethnic groups

Figure 2.1 provides insights into the reported sex and ethnic group of the adults who had a review into their deaths and died between June 2021 and December 2023. Across all ethnic groups, males accounted for 55.7%, and females accounted for 43.5% of completed reviews. The largest difference is seen in the “Asian or Asian British” ethnic group, whereby males accounted for 64.6% of reviewed deaths, indicating that LeDeR reviewed a higher proportion of male deaths than females. For comparison, in mortality data for 2021, 2022 and 2023, for the general population across all ethnic groups (aged 20+ years), the male to female ratio is much more evenly distributed, with 50.8% of deaths being male and 49.2% being female (ONS, 2024b).

Figure 2.1: Sex registered at birth by ethnic group for adults with a learning disability who died from January 2021 to December 2023 and received a LeDeR review between June 2021 and July 2024, by ethnicity.



Place of death for ethnic groups

Over half (58.3%) of people with a learning disability across all ethnic groups died in hospital. 37.7% died in their usual place of residence and 4% died in 'other' locations (Table 2.7). Variations within specific ethnic groups can be seen, with higher proportions of deaths in hospitals in the "Asian or Asian British" ethnic group (69.3% of all deaths for this group) and the "Mixed" ethnic group (70.6% of all deaths for this group). There were fewer deaths in 'other' locations which, due to small numbers, we are not able to report by ethnic group.

Table 2.7: Place of death by ethnic group for adults with a learning disability who died from January 2021 to December 2023 and received a LeDeR review between June 2021 and July 2024.

Ethnicity	Hospital*	Usual place of residence**	Other***	Total
Asian or Asian British	169 (69.3%)	64 (26.2%)	11 (4.5%)	244
Black, African, Caribbean, or Black British	85 (54.5%)	*	*	156
Mixed ethnic group	48 (70.6%)	*	*	68
Other ethnic group	22 (61.1%)	*	*	36
White	4,202 (57.9%)	2,971 (38.1%)	290 (4.3%)	7,321
Total number (%)	4,564 (58.3%)	2,950 (37.7%)	311 (4.0%)	7,825

*Acute or community hospital

**Own home, home of a friend or relative, or residential nursing home

***Hospice, public, secure unit etc

Death with DNACPR decisions for ethnic groups

Table 2.8 (overleaf) provides a breakdown of the adults with a learning disability who had a review into their death and had a DNACPR decision in place by ethnic group. All ethnic minority groups had a lower percentage of adults with a learning disability with a DNACPR decision in place than the "White" ethnic group. Adults with an ethnic group denoted as "Other" and "Black, African, Caribbean, or Black British" had the lowest percentages of adults with a learning disability who died with a DNACPR decision in place at death (52.8% "Other"; 55.1% "Black, African, Caribbean, or Black British").

Table 2.8: Number of deaths where a DNACPR decision was in place at death by ethnic group for adults with a learning disability who died from January 2021 to December 2023, and received a LeDeR review between June 2021 and July 2024.

Ethnic group	Yes Number (%)	No Number (%)	Total Number (%)
Asian or Asian British	156 (63.9%)	88 (36.1%)	244
Black, African, Caribbean, or Black British	86 (55.1%)	70 (44.9%)	156
Mixed ethnic group	46 (66.7%)	23 (33.3%)	69
Other ethnic group	19 (52.8%)	17 (47.2%)	36
White	5,451 (74.3%)	1,888 (25.7%)	7,339
Total number (%)	5,758 (73.4%)	2,086 (26.6%)	7,844 (100%)

Referral to a coroner for ethnic groups

797 (40.1%) of deaths from ethnic groups were reported to a coroner. Table 2.9 shows that there is higher reporting in the “Other” ethnic minority group (56.7%) and the “Black, African, Caribbean, and Black British” ethnic group (49.3%).

Table 2.9: Number of deaths referred to a coroner by ethnic group for adults with a learning disability who died from January 2021 to December 2023 and for whom a LeDeR review was completed between June 2021 and July 2024.

Ethnic group	Yes Number (%)	No Number (%)	Total Number (%)
Asian or Asian British	86 (36.9%)	147 (63.1%)	233
Black, African, Caribbean, or Black British	74 (49.3%)	76 (50.7%)	150
Mixed ethnic group	13 (21.3%)	48 (78.7%)	61
Other ethnic group	17 (56.7%)	13 (43.3%)	30
White	607 (40.1%)	906 (59.9%)	1,513
Total Number (%)	797 (40.1%)	1,190 (59.9%)	1,987

Cause of death for ethnic groups

The cause of death for adults with a learning disability from an ethnic group were available for 7,392 reviews. The most common causes of death among those reviewed were conditions affecting the nervous, respiratory, and circulatory systems. In the “Asian or Asian British” ethnic group, diseases of the nervous system account for the largest proportion of deaths (21.5% of all deaths for this group) whilst in the “Black, African, Caribbean and Black British” ethnic group, diseases of the circulatory system were the most common (18.4% of all deaths for this group). The “Mixed” and “Other” ethnic groups varied in leading causes of death, including diseases of the respiratory and nervous system. For a detailed breakdown of the causes of death by ethnic group and age group please see [Appendix \(2.6\)](#).

Table 2.10: Most common ICD-10 chapter causes of death by ethnic group for adults with a learning disability who died from January 2021 to December 2023 and had a LeDeR review completed between June 2021 and July 2024.

Ethnic group*	First Number (%)	Second Number (%)	Third Number (%)	Fourth Number (%)	Fifth Number (%)
Asian or Asian British	Diseases of the nervous system 47 (21.5%)	Diseases of the respiratory system 33 (15.1%)	Diseases of the circulatory system 25 (11.4%)	Congenital malformations, deformations, and chromosomal abnormalities 21 (9.6%)	Diseases of the digestive system 19 (8.7%)
Black, African, Caribbean, or Black British	Diseases of the circulatory system 26 (18.4%)	Diseases of the nervous system 23 (16.3%)	Neoplasms (cancers) 21 (14.9%)	Congenital malformations, deformations, and chromosomal abnormalities 20 (14.2%)	Diseases of the respiratory system 17 (12.1%)
Mixed ethnic group	Others (Includes COVID-19) 12 (18.2%)	Diseases of the nervous system 10 (15.2%)	Diseases of the respiratory system 10 (15.2%)	Diseases of the circulatory system 9 (13.6%)	Congenital malformations, deformations and chromosomal abnormalities 7 (10.6%) Diseases of the digestive system 7 (10.6%)
Other ethnic group	Diseases of the respiratory system 7 (24.1%)	Diseases of the nervous system 6 (20.7%)	<5	<5	<5
White	Diseases of the circulatory system 1,076 (16.0%)	Diseases of the respiratory system 1,002 (14.9%)	Neoplasms (cancers) 992 (14.8%)	Congenital malformations, deformations, and chromosomal abnormalities 856 (12.7%)	Diseases of the nervous system 855 (12.7%)

Avoidable deaths for ethnic groups

An internationally agreed list of causes of death that are considered avoidable is provided by the [Organisation for Economic Co-operation and Development \(OECD\)](#). An avoidable death is one that occurs in someone under 75 years of age, due to a condition deemed to be preventable or treatable or both. Preventable deaths are the deaths that could have been avoided through effective public health and primary prevention interventions (e.g. vaccinations or smoking cessation). Treatable deaths are the deaths that could have been avoided through timely and effective healthcare interventions, including secondary prevention and treatment (e.g., early cancer detection).

Table 2.11 shows the rates of avoidable, preventable, and treatable deaths for adults with a learning disability from different ethnic groups. Variations in the proportions of avoidable, preventable, and treatable deaths can be seen for different ethnic groups. From June 2021 to December 2023, 43.1% of deaths reviewed by LeDeR among adults with a learning disability, where ethnic group was available, were classified as avoidable. The proportion of avoidable deaths was higher among individuals from “non-White” ethnic groups (“Asian or Asian British”, “Black, African, Caribbean, or Black British”, and “Mixed”) compared to those from “White” ethnic groups (48.1% versus 42.7%). Additionally, the percentage of avoidable deaths among adults with a learning disability was significantly higher than that of the 2022 general adult population data (43.1% versus 21.6%). Adults with a learning disability who were from the “Mixed” ethnic group had the highest rates of preventable mortality (28.8% of all deaths for this group were classed as preventable). “Black, African, Caribbean, or Black British” adults with a learning disability had the highest rates of treatable mortality (33.7% of all deaths for this group were classed as treatable).

Table 2.11: Avoidable mortality by ethnic group for adults with a learning disability who died from January 2021 to December 2023 and had a LeDeR review completed between June 2021 and July 2024.

Ethnic group	Avoidable, Number (% of all deaths)	Preventable*, Number (% of all deaths)	Treatable*, Number (% of all deaths)
Asian or Asian British	102 (46.6%)	44 (20.1%)	58 (26.5%)
Black, African, Caribbean, or Black British	73 (51.8%)	25.5 (18.1%)	47.5 (33.7%)
Mixed ethnic group	34 (51.5%)	19 (28.8%)	15 (22.7%)
Other ethnic group	10 (34.5%)	5 (17.2%)	5 (17.2%)
White	2,869 (42.7%)	1,250 (18.6%)	1,618.5 (24.1%)
Total	3,088 (43.1%)	1,344 (18.8%)	1,744 (24.3%)

*Causes of death are sometimes categorised as both preventable and treatable. For each death categorised as equally preventable and treatable, 0.5 was added to the total number of preventable as well as treatable deaths. 675 total deaths were categorised as equally preventable and treatable.

Avoidable causes of death for ethnic groups

Table 2.12 details the most common causes of avoidable deaths by ethnic group. For “Asian or Asian British” adults with a learning disability, the most common cause of avoidable death was diseases of the respiratory system, which accounted for 28.4% of the avoidable deaths in this group. Diseases of the circulatory system was the second most common cause of avoidable death for “Asian or Asian British” adults with a learning disability, both accounting for 16.7% of the avoidable deaths in this group. For “Black, African, Caribbean, and Black British” adults with a learning disability who died, the most common cause of avoidable death was diseases of the circulatory system, accounting for 24.7% of avoidable deaths in this group, followed by diseases of the respiratory system, which accounted for 21.9% of avoidable deaths in this group. There were low numbers of adults from the “Mixed” ethnic group in this sample, so their results should be interpreted with caution.

Table 2.12: Most common causes of avoidable death by ethnic group for adults with a learning disability who died from January 2021 to December 2023, and had a LeDeR review completed between June 2021 and July 2024.

Ethnic group*	First	Second	Third	Fourth	Fifth
Asian or Asian British	Diseases of the respiratory system (28.4%)	Diseases of the circulatory system (16.7%)	Others (includes COVID-19) (14.7%)	Neoplasms (Cancers) (8.8%)	Diseases of the nervous system (7.8%)
Black, African, Caribbean, or Black British	Diseases of the circulatory system (24.7%)	Diseases of the respiratory system (21.9%)	Neoplasms (cancers) (15.1%)	Diseases of the Nervous system (11.0%)	Others (includes COVID-19) (8.2%)
Mixed ethnic group	Others (includes COVID-19) (35.3%)	Diseases of the respiratory system (23.5%)	Diseases of the circulatory system (17.6%)	Diseases of the nervous system (14.7%)	Neoplasms (cancers) (5.9%)
Other ethnic group	Diseases of the respiratory system (30.0%)	Diseases of the Nervous system (20.0%)	Diseases of the circulatory system (20.0%)	Others (includes COVID-19) (20.0%)	Diseases of the digestive system (10.0%)
White	Diseases of the respiratory system (24.2%)	Diseases of the circulatory system (23.1%)	Neoplasms (cancers) (15.9%)	Others (includes COVID-19) (12.7%)	Diseases of the Nervous system (6.9%)

*For Table colour key please see Appendix 0.6

Summary and discussion

This chapter provides detailed information on the ethnic group of people who died and who were notified to LeDeR between June 2021 and December 2023. Of the 8,773 adult deaths notified which also had an ethnicity denoted, 617 (7.0%) were recorded as from an ethnic minority group other than “White”. While the proportion of people who were notified to LeDeR from ethnic minority groups is similar to previous years and may appear low, it is not clear whether this reflects an underrepresentation, as we lack reliable data on the ethnic composition of people with a learning disability in England.

Reporting of ethnic group to LeDeR became mandatory in 2021. Despite this, approximately one in ten notifications have missing or undisclosed ethnicity. This suggests there are still challenges to capturing complete demographic data. The missing information can make it harder to fully understand the care differences for people from ethnic minority groups with a learning disability. However, the rollout of the new Medical Examiners System in England from September 2024 now requires ethnicity to be recorded as part of the death certificate process (Department of Health and Social Care, 2024) and will allow a more accurate analysis of death certificate data.

The data highlights that there is a notable difference in the age at death for people from ethnic minority groups who were notified to LeDeR in 2023. The most noticeable difference was for the “Asian or Asian British” ethnic group, being 20 years lower than that of the “White” ethnic group. It must be noted that it is difficult to make direct comparisons, and we are not able to estimate the life expectancy of people with a learning disability.

Causes of death were seen to differ by ethnic group, with deaths due to diseases of the nervous system being more common in people with a learning disability from “Asian or Asian British” ethnic groups (21.5% of all deaths in this group), compared to the “White” ethnic group (12.7% of all deaths in this group). Deaths due to diseases of the circulatory system were the most common cause of death in people from “Black, African, Caribbean or Black British” ethnic groups (18.4%) whilst diseases of the circulatory system were most common for people in the “White” ethnic group (16.0%).

There are evident differences in avoidable causes of death. Over forty percent (43.1%, 3,088 out of 7,172 deaths) of all adults with a learning disability who died from January 2021 to December 2023 where the ethnic group was stated, were classed as avoidable. The most noticeable difference when accounting for ethnic groups can be seen in the “Black, African, Caribbean, and Black British” ethnic group (51.8% of all deaths in this group are classed as avoidable). The findings from this chapter highlight the need to provide healthcare that is inclusive and culturally appropriate to adults with a learning disability from ethnic minority groups. The apparent discrepancies in age at death and the higher rate of avoidable deaths among ethnic groups other than “White” are evident and concerning. Health and social care providers and policymakers should recognise the needs of people with a learning disability from ethnic minority groups and make efforts to address these.

Looking forward

Whilst the data are limited, some of the observable differences within the data could enable improvements to the care received for adults with a learning disability from an ethnic minority group. Listed below are the key points to consider on how services could implement improvements.

For health and care services:

- The analysis highlights data collection surrounding ethnicity and learning disability as a major limitation. This limitation makes it challenging to draw meaningful conclusions surrounding the cultural healthcare and social care needs of these groups. A centralised data recording system for both learning disability and ethnicity would significantly improve the overall ability to understand and improve the health outcomes for adults with a learning disability from ethnic minority groups.
- The data highlights a higher rate of avoidable deaths among adults who have a learning disability from ethnic groups other than “White”, especially among those who are “Black, African, Caribbean, or Black British”. Efforts should be made to further improve access to preventative healthcare and timely treatment that is appropriate.
- There are variations in the median age at death among all ethnic groups, with adults from the 'White' ethnic group having a higher median age at death than those from other ethnic groups. These variations may suggest that adults from ethnic minority groups face additional challenges at younger ages. These patterns could help shape policies regarding ageing, healthcare, and social care among different ethnic groups.
- The data suggests that there are varying regional patterns, with certain ethnic groups other than “White” being concentrated in areas such as London and the Midlands. Health and social care providers could use this information to understand the cultural needs of their local population.

For research:

- Future research should explore the factors contributing to the lower age at death seen in ethnic groups other than “White” with a learning disability, with a focus on avoidable causes of death and modifiable risk factors.
- Research should aim to identify specific healthcare interventions or policies that could reduce premature mortality in this population.
- Better quality data on the population of people with a learning disability from ethnic groups other than “White” are required to help interpret mortality findings.

Chapter 3



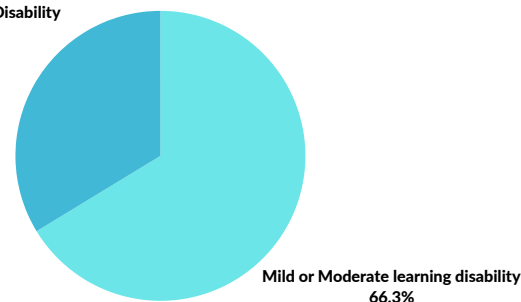
Deaths of People with Severe or Profound Learning Disability 2021-2023

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.

Severe or Profound learning Disability
33.7%



Median age at death

Mild or moderate

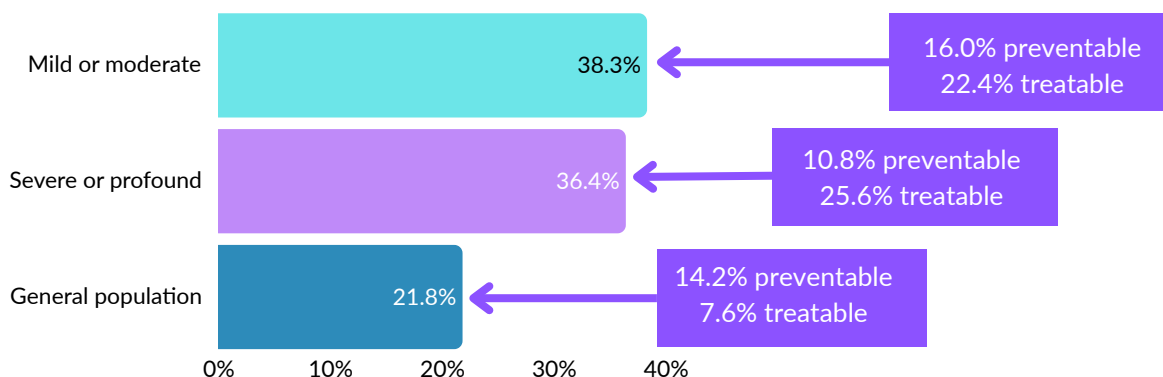
64.9
years

7.3
years
difference

57.6
years

Severe or profound

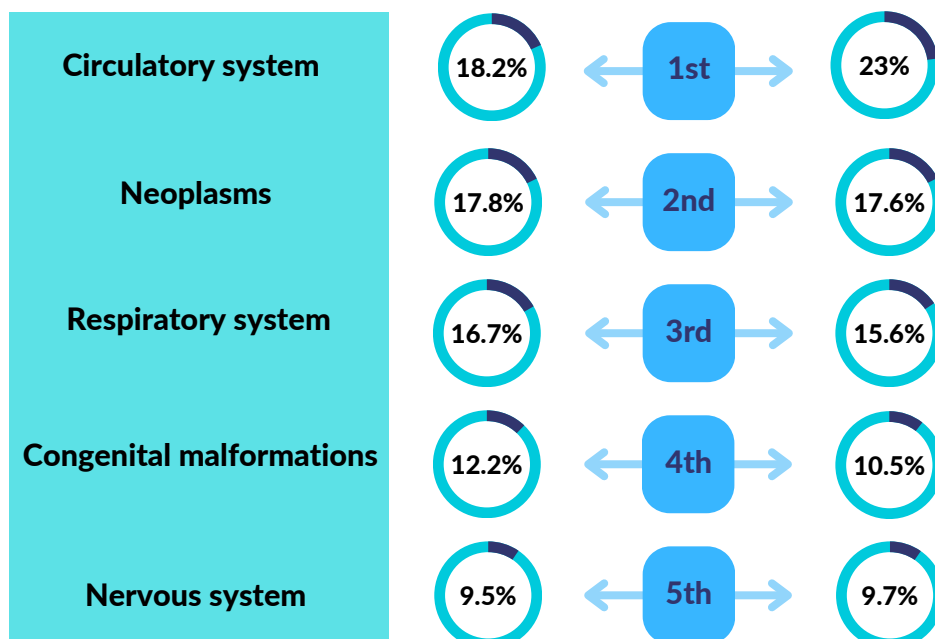
AVOIDABLE* DEATHS FOR 2021-23



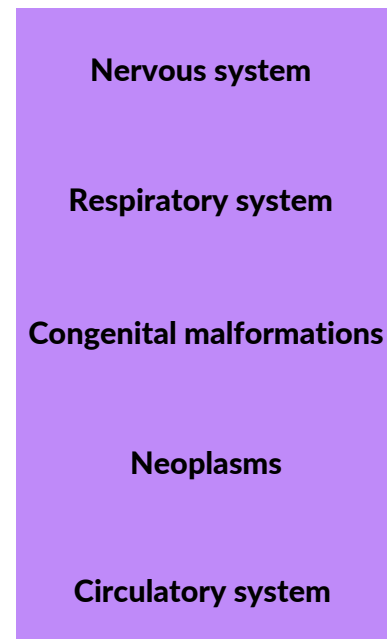
*This is based on the OECD preventable/treatable definition (see chapter 1).

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

MILD OR MODERATE



SEVERE OR PROFOUND



Deaths of People with Severe or Profound Learning Disability 2021-2023

Introduction

Learning disability is a broad condition that includes people with very varied levels of cognitive functioning, adaptive behaviour skills, and support needs (World Health Organisation, 2022). This is often classified as being mild, moderate, severe, or profound, based largely on results of standardised tests of intellectual functioning (measure with Intelligence Quotient, or IQ). Most people with a learning disability have a mild or moderate learning disability and a relatively small proportion, around 5%, have a severe or profound learning disability (Patel et al., 2020).

People with different level of learning disability often have different health and care needs related to differences in independent living skills, communication styles, and the presence of co-occurring genetic or other long-term health conditions. People with a severe or profound learning disability are often excluded from research, which mainly focuses on people with mild or moderate learning disability (Cluley, 2017). Existing research findings, therefore, may be less relevant to people with a severe or profound learning disability.

As the number of deaths reported to LeDeR has grown, so has the potential to investigate the circumstances of death and care of smaller groups of people with a learning disability. Based on feedback that we have received and a suggestion from both NHS England's independent advisory group and the academic collaboration advisory group, we have taken the opportunity in this year's report to look more closely into the completed LeDeR reviews of those with a severe or profound learning disability. We have taken the approach of comparing findings in this group with those with a mild and moderate learning disability to show specific areas of difference. Where possible, as in [Chapter 1](#), we also compare findings to those of adults from the general population in England.

Note: Adults with a learning disability who are autistic are included in this analysis. Autistic adults who do not have a learning disability are not included in this chapter.

Information included in this chapter.

Data sources by level of learning disability

The data we use in this chapter comes from the LeDeR reviews (initial and focused) of the deaths of people with a learning disability and the medical certificates of cause of death (MCCD) data which is supplied by the Office for National Statistics (see [Appendix 0.4](#)). For this analysis we have used the data from the latest version of the initial review form introduced in January 2023, as this was when a question about the level of learning disability was added (it was previously located in the focused review form).

This means that people who had died in 2021 and 2022 but had an initial review during 2023 are included in the analysis, whilst deaths reviewed using the earlier version of the initial review form before 2023 (that did not include the level of learning disability question) could not be included.

Analyses by level of learning disability

This chapter has two main parts. In the first, we present the demographics, circumstances of death, causes of death, and avoidable deaths in people with a severe or profound learning disability and compare this to those with a mild or moderate learning disability. In the second part of the chapter, we use data from focused reviews to explore the care received by people with severe or profound learning disability; again, we compare this to the care received by people with mild or moderate learning disability. We then summarise the free text comments made by reviewers in focused reviews, highlighting specific areas where there may have been issues with care for this group.

LeDeR reviews by level of learning disability

Of the people with a learning disability who died between 2021 and 2023 and for whom a LeDeR review had been completed, 3,970 adults with a learning disability had a level of learning disability recorded in their initial review form. Of these, approximately one-third (33.7%) were recorded as having a severe or profound learning disability and two-thirds (66.3%) were recorded as having a mild or moderate learning disability. 2,289 deaths occurred in 2023, 1,530 in 2022, and 151 deaths in 2021.

Table 3.1: Number and proportion of deaths occurring in each year by level of learning disability for adults who died from January 2021 to December 2023 and for whom a LeDeR review was completed using the latest version of the initial review form, by level of learning disability.

	2021, Number (%)	2022, Number (%)	2023, Number (%)
Level of learning disability			
Mild or moderate	100 (66.2%)	997 (65.2%)	1,536 (67.1%)
Severe or profound	51 (33.8%)	533 (34.8%)	753 (32.9%)
Total	151 (100%)	1,530 (100%)	2,289 (100%)

1,225 (30.9%) of the initial reviews progressed to a focused review. Of these, 463 (37.8%) were for adults with a severe or profound learning disability and 762 (62.2%) were for adults with a mild or moderate learning disability.

Demographics by level of learning disability

The demographic details of all adults who received an initial review and whose level of learning disability was recorded are presented in Table 3.2. The percentage of males and females was similar for adults who had a severe or profound learning disability and those who had a mild or moderate learning disability. Most people from the “Asian or Asian British” ethnic minority group who died and received a review had a severe or profound learning disability, whereas most adults denoted as “White” and “Black, African, Caribbean, and Black British” ethnic groups had a mild or moderate learning disability.

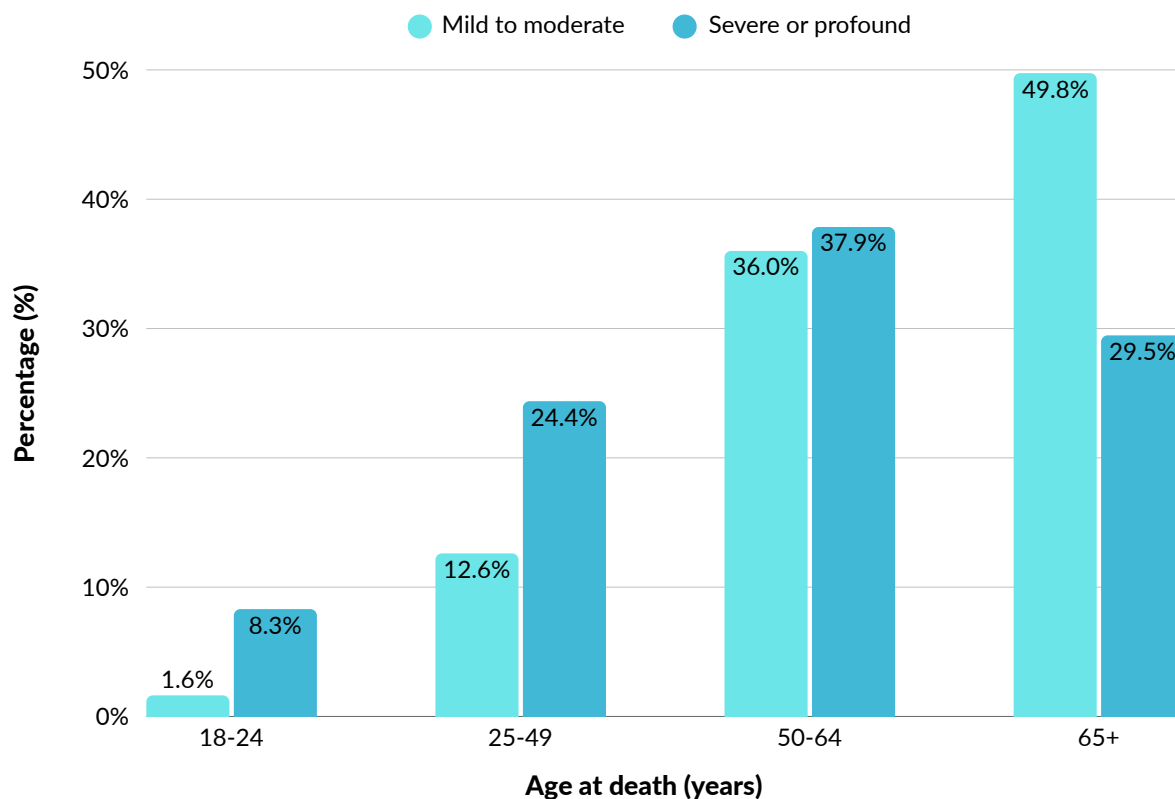
Table 3.2: *Demographics by the level of learning disability for adults who died from January 2021 to December 2023, and for whom a LeDeR review was completed using the latest version of the initial review form.*

	Mild and moderate, Number (%)	Severe or profound, Number (%)
Sex registered at birth		
Female	1,105 (42.0%)	609 (45.5%)
Male	1,508 (57.3%)	719 (53.8%)
Not known	20 (0.8%)	9 (0.7%)
Ethnic group		
Asian or Asian British	54 (2.1%)	90 (6.7%)
Black, African, Caribbean, or Black British	47 (1.8%)	37 (2.8%)
Mixed ethnic group	10 (0.4%)	16 (1.2%)
Other ethnic group	12 (0.5%)	8 (0.6%)
White	2,449 (93.0%)	1,155 (86.4%)
Preferred not to say	61 (2.3%)	31 (2.3%)
Total number of reviews (%)	2,633 (100%)	1,337 (100%)

Age at death by level of learning disability

The median age at death was 57.6 years (IQR 43.0 to 66.7) for those with a severe or profound learning disability and 64.9 years (IQR 56.3 to 73.7) for those with a mild or moderate learning disability. 32.7% of adults with a severe or profound learning disability died before the age of 50, and 14.2% of adults with a mild or moderate learning disability died before the age of 50 (Figure 3.1 overleaf).

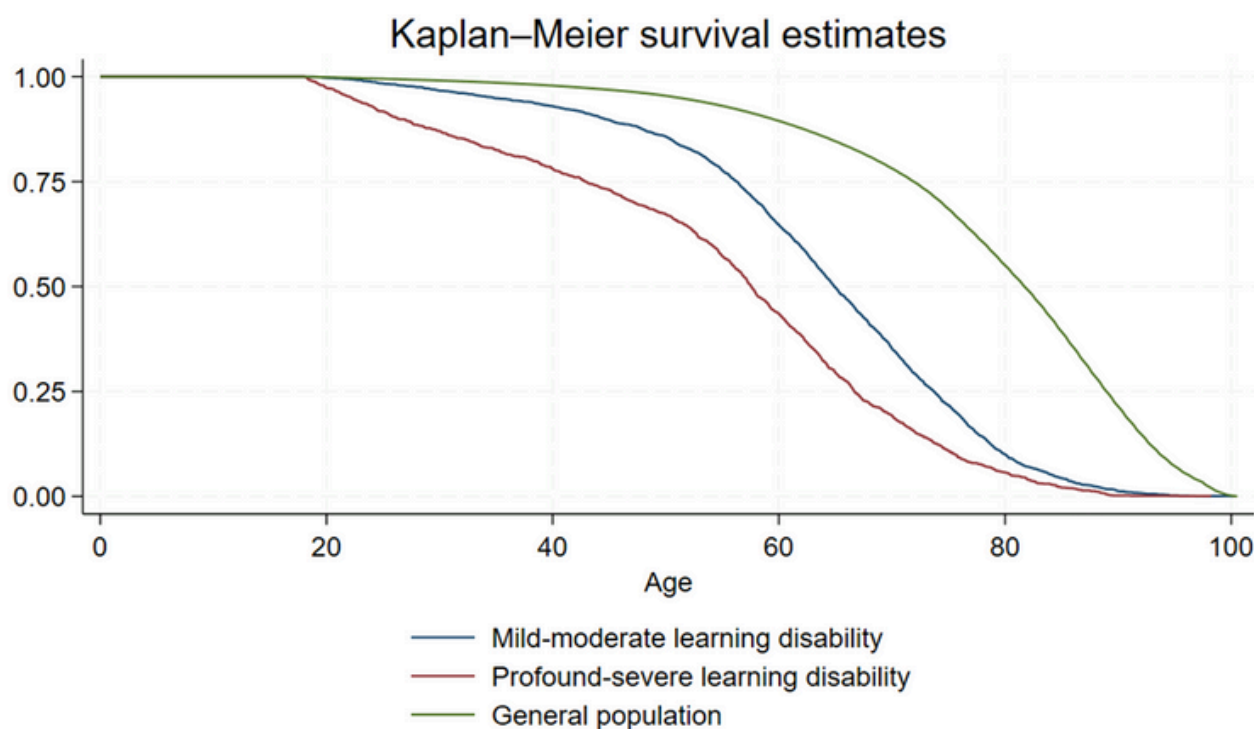
Figure 3.1: Age at death by level of learning disability for adults who died from January 2021 to December 2023 and for whom a LeDeR review was completed using the latest version of the initial review form by the level of learning disability.



We used a Cox proportional hazards model to estimate the effect of the level of learning disability on age at death. The unadjusted hazard of death for those with a severe or profound learning disability was 1.55 times (Hazard Ratio (HR) 1.55; 95% CI 1.45, 1.66) that of those with a mild or moderate learning disability. After adjusting for sex and ethnicity, the hazard of death for those with a severe or profound learning disability was 1.49 times (HR 1.49; 95% CI 1.39, 1.60) than for those with a mild or moderate learning disability. The hazard of death is roughly 50% higher for those with a severe or profound learning disability compared to those with mild or moderate learning disability, after adjusting for other factors that might be associated with age at death (sex and ethnic group).

Figure 3.2 (overleaf) is a survival curve which shows the proportion of adults with a learning disability who survive to different ages that were reported to LeDeR, separated by those from the general population, those with a mild or moderate learning disability, and those with a severe or profound learning disability. A greater number of deaths occur at younger ages in those with a severe or profound learning disability.

Figure 3.2: Survival curve showing the probability of survival over time by the level of learning disability.



Circumstances of death by level of learning disability

Place of death by level of learning disability

The proportion of deaths occurring in different settings was similar between those with a severe or profound learning disability compared with those with a mild or moderate learning disability, with most people dying in hospital settings (Table 3.3).

Table 3.3: Place of death by the level of learning disability for adults who died from January 2021 to December 2023 and for whom a LeDeR review was completed using the latest version of the initial review form.

	Mild or moderate, Number (%)	Severe or profound, Number (%)
Place of death		
Hospital	1,528 (58.0%)	787 (58.9%)
Usual place of residence	962 (36.5%)	490 (36.6%)
Other	143 (5.4%)	55 (4.1%)
Not known	0 (0)	* (<0.5%)
Total number of reviews (%)	2,633 (100%)	1,337 (100%)

Deaths with DNACPR by level of learning disability

Just over three-quarters of adults with a severe or profound learning disability had a DNACPR recommendation in place at the time of their death. This was higher than the figure for those with a mild or moderate learning disability (Table 3.4)

Table 3.4: Number of deaths where a DNACPR decision was in place at the time of death by level of learning disability for adults who died from January 2021 to December 2023 and for whom a LeDeR review was completed using the latest version of the initial review form.

	Mild or moderate, Number (%)	Severe or profound, Number (%)
DNACPR decision at death		
Yes	1,890 (71.8%)	1,028 (76.9%)
No	743 (28.2%)	309 (23.1%)
Total number of reviews (%)	2,633 (100%)	1,337 (100%)

Whether DNACPR documentation was completed and followed correctly

DNACPR documentation and processes were completed and followed correctly for similar percentages of adults with a severe or profound learning disability (60.6%) and adults with a mild or moderate learning disability (62.9%) (Table 3.5) (see [Chapter 1](#) for further explanation).

Table 3.5: Number of deaths where DNACPR documentation and processes were followed by the level of learning disability for adults who died from January 2021 to December 2023 and for whom a LeDeR review was completed using the latest version of the initial review form.

	Mild or moderate, Number (%)	Severe or profound, Number (%)
DNACPR documentation and processes followed		
Completed and followed	1174 (62.1%)	623 (60.6%)
Completed but not followed correctly	17 (0.9%)	8 (0.8%)
Incorrectly completed and followed	147 (7.8%)	93 (9.0%)
Neither completed nor followed correctly	6 (0.3%)	8 (0.8%)
Not known	546 (28.9%)	296 (28.8%)
Total number of reviews (%)	1,890 (100%)	1,028 (100%)

Deaths reported to a coroner by the level of learning disability

Deaths are reported to a coroner in certain circumstances (see Chapter 1). Whether the death was reported to a coroner is available only in focused reviews. The LeDeR review form may contain information on the reason for referral to a coroner and the outcome of the investigation, but there are no specific questions asking reviewers for this. Similar proportions of deaths were reported to a coroner for adults with a severe or profound learning disability and adults with a mild or moderate learning disability (Table 3.6).

Table 3.6: Number of deaths reported to a coroner by the level of learning disability for adults who died from January 2021 to December 2023 and for whom a LeDeR review was completed using the latest version of the initial review form.

	Mild or moderate, Number (%)	Severe or profound, Number (%)
Reported to a coroner		
Yes	46 (6.0%)	23 (5.0%)
No	713 (93.6%)	438 (94.6%)
No decision yet	* (<0.7%)	* (<1.1%)
Total number of focused reviews (%)	763 (100%)	463 (100%)

Causes of death by level of learning disability

The most common ICD-10 chapter underlying causes of death by level of learning disability are presented in Table 3.7 (see [Appendix 1.9](#) for details on ICD-10 chapters). The most common causes of death within each ICD-10 chapter are provided to add further detail.

Diseases of the nervous system (cerebral palsy and other paralytic syndromes (see note overleaf), epilepsy and congenital malformations, deformations and chromosomal abnormalities were more common underlying causes of death in adults with a severe or profound learning disability.

Cancer and diseases of the circulatory system (ischaemic heart diseases, cerebrovascular diseases, other forms of heart disease) accounted for a smaller proportion of deaths in adults with a severe or profound learning disability in comparison to adults with a mild or moderate learning disability.

Note: 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](#)).

Table 3.7: Most common ICD-10 chapter causes of death by the level of learning disability for adults who died from January 2021 to December 2023 and for whom a LeDeR review was completed, using the latest version of the initial review form (with additional detail about the most common conditions in each chapter).

Mild or moderate		Severe or profound		General adult population*	
ICD-10 chapter*	Number (%)	ICD-10 chapter	Number (%)	ICD-10 chapter	Number (%)
Diseases of the circulatory system	406 (18.2%)	Diseases of the nervous system	261 (23.0%)	Neoplasms (cancers)	26.6%
Ischaemic heart diseases	134 (6.0%)	Cerebral palsy and other paralytic syndromes	154 (13.6%)	Digestive organs	7.9%
Cerebrovascular diseases	105 (4.7%)	Epilepsy	60 (5.3%)		
Other forms of heart disease	70 (3.1%)				
Neoplasms (cancer)	398 (17.8%)	Diseases of the respiratory system	200 (17.6%)	Diseases of the circulatory system	24.5%
Digestive organs	146 (6.5%)	Influenza and pneumonia	102 (9.0%)	Ischaemic heart diseases	10.3%
		Chronic lower respiratory diseases	31 (2.7%)	Other forms of heart disease	5.5%
				Cerebrovascular diseases	5.1%
Diseases of the respiratory system	372 (16.7%)	Congenital malformations, deformations, and chromosomal abnormalities	177 (15.6%)	Diseases of the respiratory system	11.1%
Influenza and pneumonia	198 (8.9%)	Down syndrome	108 (9.5%)	Chronic lower respiratory diseases	5.2%
Chronic lower respiratory diseases	91 (4.1%)			Influenza and pneumonia	3.5%
Congenital malformations, deformations, and chromosomal abnormalities	273 (12.2%)	Neoplasms (cancers)	119 (10.5%)	Mental, behavioural, and neurodevelopmental disorders	7.7%
Down syndrome	220 (9.9%)	Digestive organs	48 (4.2%)	Dementia and Alzheimer's	7.4%
Diseases of the nervous system	211 (9.5%)	Diseases of the circulatory system	110 (9.7%)	Diseases of the nervous system	7.3%
Epilepsy	59 (2.6%)	Cerebrovascular diseases	44 (3.9%)	Other degenerative diseases of the nervous system	4.5%
Cerebral palsy and other paralytic syndromes	49 (2.2%)	Ischaemic heart diseases	30 (2.6%)		
		Other forms of heart disease	23 (2.0%)		
All causes	2,230 (100%)	All causes	1,136 (100%)		

*Over the age of 20

*For colour key please see Appendix 0.6

Avoidable mortality by level of learning disability

An internationally agreed list of causes of death that are considered avoidable is provided by the [Organisation for Economic Co-operation and Development \(OECD\)](#). An avoidable death is one that occurs in someone under 75 years of age, due to a condition deemed to be preventable or treatable or both. Preventable deaths are the deaths that could have been avoided through effective public health and primary prevention interventions (e.g. vaccinations or smoking cessation). Treatable deaths are the deaths that could have been avoided through timely and effective healthcare interventions, including secondary prevention and treatment (e.g., early cancer detection).

Similar percentages of adults with a severe or profound learning disability and adults with a mild or moderate learning disability died of an avoidable cause (38.3% mild or moderate learning disability, 36.4% severe or profound learning disability).

A higher percentage of deaths for adults with a severe or profound learning disability were from treatable causes of death in comparison to the percentage of deaths for adults with a mild or moderate learning disability. In contrast, a higher percentage of deaths for adults with a mild or moderate learning disability were from preventable causes of death in comparison to the percentage of deaths for adults with a severe or profound learning disability. 25.6% of the deaths of adults with a severe or profound learning disability were from treatable causes of death. 7.6% of deaths in the general population were from treatable causes of death (Table 3.8).

Table 3.8: *Avoidable mortality by the level of learning disability for adults who died from January 2021 to December 2023 and for whom a LeDeR review was completed using the latest version of the initial review form.*

	Mild or moderate Number (% of all deaths)	Severe or profound Number (% of all deaths)	General adult* population (% of all deaths)
Avoidable deaths (preventable and treatable)	855 (38.3%)	414 (36.4%)	21.8%
Preventable**	356.5 (16.0%)	123 (10.8%)	14.2%
Treatable**	498.5 (22.4%)	291 (25.6%)	7.6%

* Over the age of 20

**Causes of death classed as equally preventable and treatable have been counted as 0.5 in preventable and 0.5 in treatable. There were 60 deaths that were categorised as equally preventable and treatable for adults with a severe or profound learning disability. 195 deaths for adults with a mild or moderate learning disability were categorised as equally preventable and treatable.

Causes of avoidable mortality by level of learning disability

Influenza and pneumonia were the most common causes of avoidable death in adults with a severe or profound learning disability, accounting for more than a fifth of avoidable deaths. Influenza and pneumonia were also a common cause of death in people with a mild or moderate learning disability but accounted for a notably lower proportion (13.7%) of avoidable deaths. Epilepsy was the second most common cause of avoidable death in adults with a severe or profound learning disability. Ischaemic heart diseases were the second most common cause of avoidable death in adults with a mild or moderate learning disability. Cerebrovascular diseases were the third most common cause of avoidable death in adults with a severe or profound learning disability, whereas cancers of the digestive system were the third most common cause of avoidable death in adults with a mild or moderate learning disability (Table 3.9).

Table 3.9: Most common causes of avoidable mortality for adults with a learning disability by level of learning disability who died from January 2021 to December 2023 and for whom a LeDeR review was completed using the latest version of the initial review form.

Mild or moderate (% of avoidable deaths)		Severe or profound (% of avoidable deaths)	
Cause of avoidable death	Number (%)	Cause of avoidable death	Number (%)
Influenza and pneumonia	117 (13.7%)	Influenza and pneumonia	89 (21.5%)
Ischaemic heart diseases	98 (11.5%)	Epilepsy	54 (13.0%)
Cancer of the digestive organs	91 (10.6%)	Cerebrovascular diseases	30 (7.2%)

Quality of care by level of learning disability

The following data in this chapter are obtained from focused reviews only. Quality of care variables are not collected in initial reviews.

Reviews where concern about the death had been expressed by level of learning disability

Reviewers were asked if anyone expressed concerns about the death. The concerns may have been expressed by the person who notified the death, the reviewer, or an individual who provided information to the reviewer.

Concerns about the care the individual received were expressed for a slightly lower proportion of reviews for adults with a severe or profound learning disability (28.9%) than in adults with a mild or moderate learning disability (33.1%).

Table 3.10: *Number of deaths by level of learning disability where concerns were identified during the LeDeR review, for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed using the latest version of the initial review form.*

	Mild or moderate, Number (%)	Severe or profound, Number (%)
Concerns identified		
Yes	252 (33.1%)	134 (28.9%)
No/I don't know	510 (66.9%)	329 (71.1%)
Total number of focused reviews (%)	762 (100%)	463 (100%)

Reviews for adults who had a care package that met their needs by level of learning disability

In focused reviews, the reviewer is asked to judge whether the social care package that the person received met their needs. Over eight in ten (82.7%) of those with a severe or profound learning disability were deemed to have had a social care package that met their needs, compared to around seven in ten (72.4%) for those with a mild or moderate learning disability (Table 3.11).

Table 3.11: *Number of deaths where the person's care package met their needs by level of learning disability, for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed using the latest version of the initial review form.*

	Mild or moderate, Number (%)	Severe or profound, Number (%)
Care package deemed by reviewer to have met the needs of the adult		
Yes	552 (72.4%)	383 (82.7%)
No	210 (27.6%)	80 (17.3%)
Total number of focused reviews (%)	762 (100%)	463 (100%)

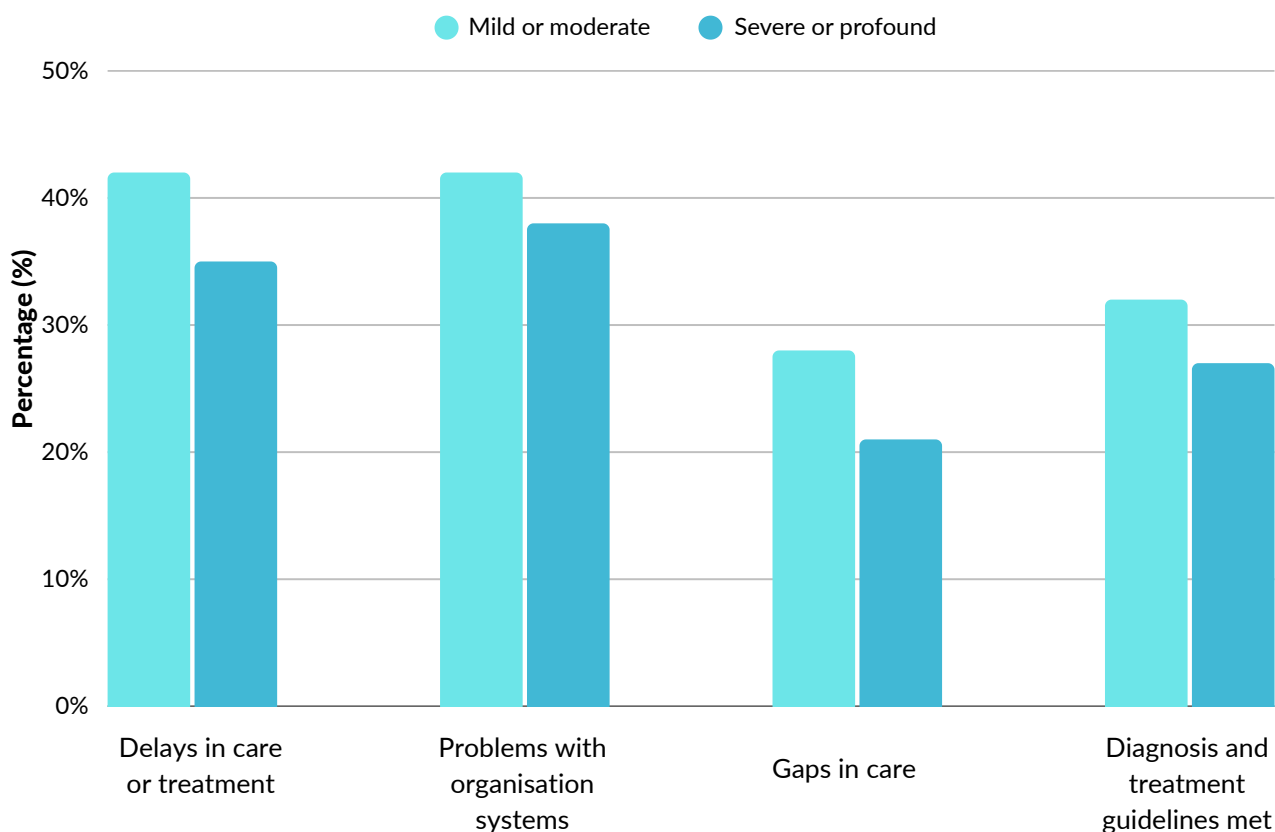
Reviews that identified specific problems in care by level of learning disability

Four questions in the LeDeR-focused review form enquire about specific issues with the care that a person received. They ask about delays in care, gaps in care, adherence to guidance around diagnosis and treatment, and organisational and systemic problems (including in the coordination of care).

Amongst people with a severe or profound learning disability, the most common areas in which there were problems with care were 'delays in care and treatment' and 'problems with organisational systems', which were determined to have been problematic in 41.3% and 41.1% of completed reviews, respectively. Diagnostic and treatment guidelines not being met and gaps in care were recorded less frequently.

Problems in specific aspects of care were less frequently reported in people with a severe and profound learning disability compared with people with a mild or moderate learning disability, although the differences between the groups were relatively small.

Figure 3.3: *Proportion of reviews where specific problems with care were identified by level of learning disability for adults with a learning disability who died from January 2021 to December 2023 and for whom a LeDeR review was completed, using the latest version of the initial review form.*



Where reviewers indicate that there was a problem with care in one of the above areas, they may elaborate on the issue in a corresponding free text box. We combined these comments into a single dataset and provide a summary of the common issues, with selected quotations to give a sense of the issues mentioned. In keeping with the focus of this chapter, this analysis uses data only from those focused reviews of people with a severe or profound learning disability.

Summary of problems with specific aspects of care by levels of disability

We identified common themes/issues and present a narrative summary of these below. The following summary relates only to reviews of people with a severe or profound learning disability and is drawn only from focused reviews (see above). We have included a selection of anonymised quotes from the reviews to give a deeper sense of the data.

Reactive rather than proactive care and “missed opportunities”

Reviewers reported a lack of preventative and proactive healthcare. This included the learning disability annual health check, which was mentioned by several as either not having occurred or having been limited and “a missed opportunity for a more thorough review.” There were instances of annual health checks being completed inadequately or involving only a conversation with a carer, thereby potentially missing important signs.

“2021 and 2022 annual health checks were not completed face to face but with a carer via telephone... other elements should have been taken into account.... such as her learning disability, not accessing usual service such as day centre, and mum being main carer as well as caring for other family members”

Some people had not received health screening in keeping with national programmes, which may have delayed the early identification of disease. Reviewers mentioned that screening was missed because of practical issues (such as transport to and from appointments), a lack of reasonable adjustments or alternatives (such as different examination or investigation methods), and a lack of proactive follow-up when screening appointments were missed.

“For a period of 10 years, the person missed out on breast screening without consideration of alternative, less restrictive, means.”

There was also felt to be a lack of regular routine review of existing long-term conditions and treatments, particularly reviews for epilepsy and reviews of antipsychotic medication, with reviewers noting that STOMP guidance was not always followed.

“[The person] did not have an annual asthma review... and there was no evidence that this condition was discussed at their learning disability annual health check”

“[the person] did not have a mental health diagnosis and it is clearly recorded it [psychotropic medication] was taken to support behaviour. Although STOMP was mentioned in the GP records in the Annual Health Check section there is nothing recorded, ... as to why prescribing continued for 15 years”

Investigation of early signs of illness and diagnostic overshadowing

Several reviewers highlighted delays in recognising and responding to undifferentiated symptoms that could represent early signs of illness, such as weight loss, declining mobility, or general malaise.

“[the person] had repeated chest infections and was not examined by his GP or assessed face to face... There is no evidence of any discussion regarding feeding position and sleeping position which may have identified risks for aspiration”

“There was no request for further investigation or referral to urology [upon admission to hospital with urinary retention]. The delayed diagnosis of metastatic prostate cancer was an incidental finding when [the person] was admitted to hospital 10 months later”

The reviewers expressed concerns about diagnostic overshadowing and said that people's symptoms were “not taken seriously” and there was “a lack of professional curiosity” in some cases.

“[the person] was unwell and his keyworker rang both the GP and 111 numerous times. Each passed him back to the other or on to mental health services because they maintained he was not physically ill. The GP felt that he was having a manic episode but carers who knew him well disputed this. An ambulance was called on the advice of 111 but the ambulance service called the GP who said he didn't need to go to hospital, so the carers were advised to take him to hospital themselves. However, it would appear that [the person] needed assessing and his carers needed support, but no one took responsibility for this. He did in fact have an infection and was prescribed antibiotics three days later”

Mental Capacity Act and Best Interest procedures

Reviewers gave examples that implied a lack of adherence to the Mental Capacity Act and Best Interest decision-making processes, resulting in gaps in the person's care.

“Inclusion of MCA in decision-making process missing. Appeared to be an assumption that [the person's] learning disability indicated a ‘poor quality of life’. Inclusion of care home manager or social worker in end-of-life decision not considered”

Reviewers also noted examples where distress was interpreted as the person “withdrawing consent”, rather than resulting from pain or discomfort.

In some instances, specialist advice around the MCA and independent advocacy was sought in medical emergencies, when it was not required.

“When [the person] was admitted to hospital his surgery was also delayed due to awaiting MCA input. However, an MCA was not required due to it being a medical emergency and the surgery could have been carried out earlier in [the person’s] best interests.”

Reasonable adjustments to care

The reviewers reported instances where a lack of reasonable adjustments led to delays and gaps in the person’s care. In some cases, there was “no consideration of the person’s learning disability” which meant the person did not receive any reasonable adjustments. Examples of reasonable adjustments that reviewers mentioned which should have been considered but were not included alternate options for performing medical procedures (e.g. screening and scans under anaesthetic), provision of suitable rooms and adapted environments in the hospital, and the provision of necessary equipment.

“Chest x-ray was not carried out because [the person] refused but there is no evidence of any reasonable adjustments that were attempted/provided”

In some cases, community and acute learning disability liaison nurses were not involved, or their input was delayed.

“There would also appear a lack of communication between GP services and the acute Trust with a missed opportunity to liaise with acute learning disability nurse regards reasonable adjustments to encourage earlier admission to hospital”

Co-ordination of care through a complex system

Navigating the health and social care system was sometimes difficult for professionals and people with a learning disability and their carers. These spanned referrals being “batted back and forth” and sometimes not referred to the community learning disability services, services in different regions or adult services.

“The requests by the medical teams to the GP practice to re-refer [the person] to gynaecology fast track rather than completing this internally whilst [the person] was an inpatient caused an additional delay.”

It was recognised that many people had multiple co-occurring health conditions which had caused difficulties as “no one person appeared to take overall responsibility” and “bring all the information together.” Professionals could be seen to be “working in silos” rather than as part of a connected, multi-disciplinary team.

“Different conditions with different treatments, arising from having [condition], required a collaborative process”

This was also seen where the person’s complex health conditions required referrals between different services or transfer of care between departments, with outstanding issues not being followed-up and completed.

Discharge from the hospital and failure to anticipate changing needs

Reviewers noted that people’s care and support needs were not always anticipated, and that advance care planning was not undertaken when a long-term decline was inevitable. This could be seen in discharges from hospitals being delayed due to inadequate planning and suitable care not being available in the community, particularly if the person’s needs had changed during their admission or if new equipment was needed (e.g. for hoisting or bathing).

“[Delayed discharge from hospital occurred] because [the person’s] needs had changed, and it was the view of the multi-disciplinary team that she required a higher level of support that could not be provided by her current placement.”

Responses to acute deteriorations in health

In some instances, problems had arisen due to a lack of recognition of an acute deterioration in health by carers and of the seriousness of a situation. Reviewers highlighted that staff turnover could contribute to a lack of trained staff and those who were familiar with the person.

“[the person’s] worsening constipation was not recognised or treated until he was very critically unwell, and his organs were failing.”

There were reports of delayed arrival of ambulances and transfer to the Emergency Department. This was noted as a “systemic concern” for one NHS trust that has been noted in “numerous” LeDeR reviews and has been flagged for further consideration.

“The safeguarding enquiry noted a delay in... receiving medical attention of approximately 12 hours. Although the call to the ambulance service was categorised as an urgent problem which requires transport and treatment in an acute setting within 2 hours, [the person] had to be taken to hospital by care staff on the advice of the ambulance service”

Feeding and nutrition in the hospital

Reviewers reported instances where people did not receive adequate feeding or nutrition support in the hospital. They mentioned cases where staff were “unaware” or “did not check” the person’s health action plan or hospital passport, leading to delays and increased risks of aspiration.

“The length of time in hospital to reinsert a Percutaneous endoscopic gastrostomy (known as PEG) feed took far too long and left the patient deteriorating unnecessarily.”

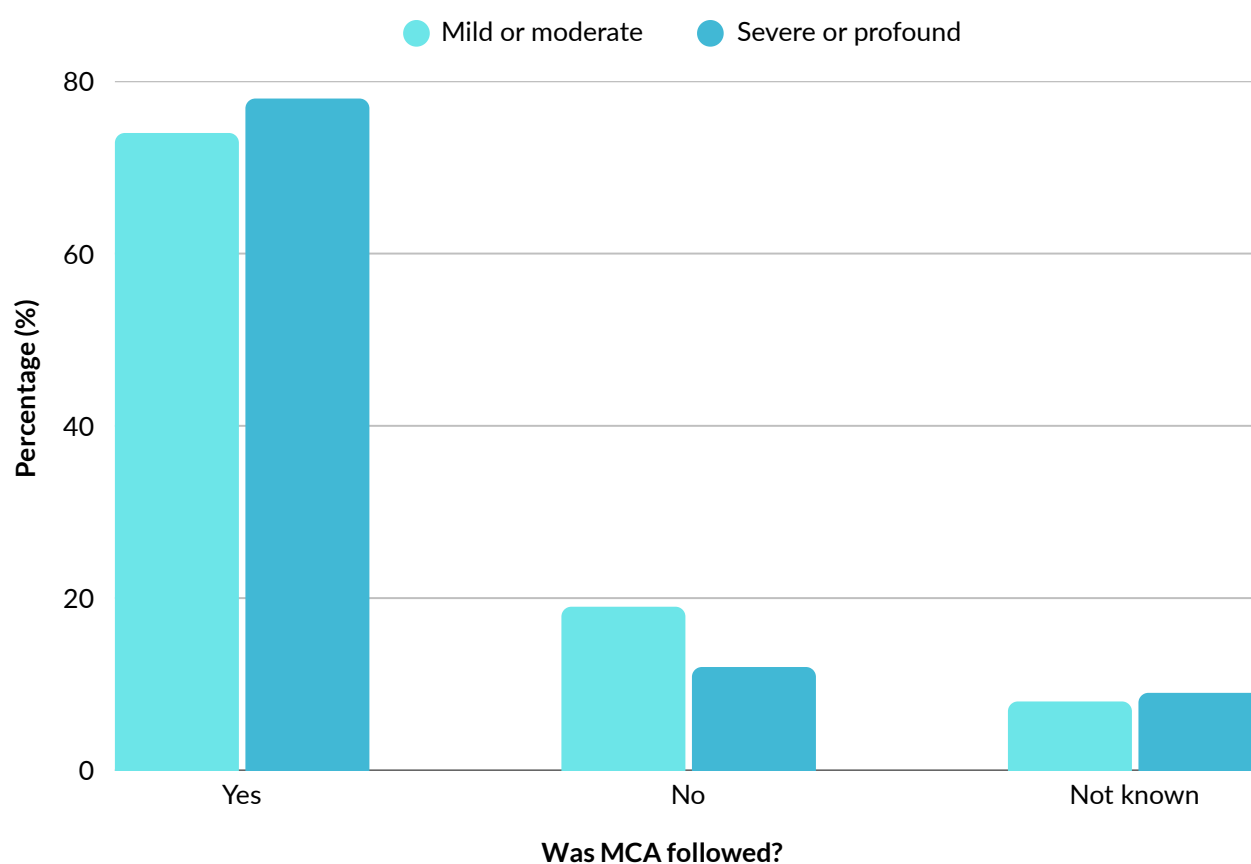
Adults who should have been provided with reasonable adjustments but were not

Reviewers are asked to report if the person should have been provided with reasonable adjustments to care but was not. Similar percentages of reviews of deaths of adults with a severe or profound learning disability (25.3%) and of reviews of deaths of adults with a mild or moderate learning disability (27.8%) indicated that reasonable adjustments were not provided where they should have been.

Application of the Mental Capacity Act

Reviewers reported that the MCA was followed in a higher proportion of reviews for adults with a severe or profound learning disability in comparison to the reviews for adults with a mild or moderate learning disability (78.0% severe or profound vs 74.6% mild or moderate) (Figure 3.4).

Figure 3.4: Proportion of reviews the Mental Capacity Act was adhered to for adults with a learning disability who died from January 2021 to December 2023 and for whom a LeDeR review was completed using the latest version of the initial review form by the level of learning disability.



Summary and discussion

People with a severe or profound learning disability may have different social and health care needs than people with mild or moderate learning disability. They may have greater rates of multi-morbidity, congenital abnormalities, limitations to mobility, communication difficulties, or life-limiting illnesses ([van Timmeren et al., 2017](#)). By definition, they have higher levels of support needs and are more likely to live with families or in high-support care settings. When people with a severe or profound learning disability are admitted to the hospital, they may need more reasonable adjustments to care. It is important that the characteristics and needs of this group are not overlooked despite them being a relatively smaller number of all of those with a learning disability.

The analysis in this chapter demonstrates that people with a severe or profound learning disability are more likely to die at a younger age than people with a mild or moderate learning disability. There are differences in the most common causes of death between those with a severe or profound learning disability and those with a mild or moderate learning disability, with a greater representation of deaths due to disorders of the nervous system (largely accounted for by cerebral palsy and epilepsy[8]) and due to genetic and congenital conditions in people with a severe or profound learning disability. The differences in leading causes of death may be partly attributed to lifestyle factors. Adults with mild or moderate learning disabilities may share similar lifestyle-related risks with the general population. For example, diseases of the circulatory system and neoplasms are among the leading causes of death in both groups. For more detailed insights, please refer to the circulatory disease deep dive ([Ding et al., 2024](#)).

Adults with a severe or profound learning disability are more likely to experience an avoidable death in comparison to the general population. Just over one-third of deaths of those with a severe or profound learning disability were classed as avoidable, slightly lower than the corresponding figure for those with a mild or moderate learning disability. Within this, people with a severe or profound learning disability were less likely to die from a preventable cause of death but more likely to die of a treatable cause than those with a mild or moderate learning disability. This might suggest that people with a severe or profound learning disability are at risk of later diagnosis and treatment or receive less effective care. However, the quality-of-care data did not reveal that this group was disadvantaged in the care they received in comparison to those with a mild or moderate learning disability, with quantitative indicators showing fewer identified concerns in care for those with a severe or profound learning disability. In contrast, the free text summary, which was drawn only from reviews of those with a severe or profound learning disability, revealed several issues. These issues concerned proactive care, diagnostic overshadowing, adherence to the MCA and Best Interest decision-making processes, reasonable adjustments, care coordination, planning the person's care (e.g., when discharged from the hospital), and responses to acute deteriorations in health and feeding and nutrition in the hospital.

[8] 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 it is likely that Down syndrome or cerebral palsy 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).

Looking forward

For health and care services:

- It is important to ensure that the health of adults with a severe or profound learning disability is monitored proactively. Caregivers (family or paid staff) should be supported to understand the need for proactive screening and prevention activities, including vaccination when required.
- Reasonable adjustments should be provided to enable access to monitoring and screening and any barriers should be escalated appropriately to ensure appropriate resolution. The reasonable adjustment digital flag should be used to support access to individualised reasonable adjustments.
- Care staff and healthcare professionals working with adults with a severe or profound learning disability should have increased awareness of the soft signs of deterioration and be aware of diagnostic overshadowing. Annual health checks could be an opportunity to identify potential soft signs of deterioration for inclusion in a health action plan, and tools such as [Restore2](#) can support caregivers in identifying and communicating concerns about deterioration.
- The focus to reduce avoidable death may need to be different for different groups: for those with a mild or moderate learning disability, more could be done to reduce preventable causes, whilst for those with a severe or profound learning disability, treatable causes need to be tackled.
- When people with severe or profound learning disability present with treatable conditions, care needs to be taken to provide appropriate treatment and monitoring, with timely response to deterioration to prevent avoidable deaths.
- People with a severe or profound learning disability may have multiple health conditions. Emphasis should be placed on care coordination to aid the navigation of complex healthcare systems. NHS managers should ensure that barriers to efficient care within the system are addressed, including ensuring efficient communication between services. In these settings, specialist Learning Disability Physicians and Learning Disability Nurses can support and assist people with comorbidities by helping them to navigate the system. This could potentially improve health outcomes and reduce hospital waiting times.

For research:

- Research should be conducted to determine how delays in recognising illness in adults with a severe or profound learning disability can be minimised.
- Research should aim to better understand the reasons for avoidable deaths due to treatable causes in individuals with a severe or profound learning disability and how this can be addressed.
- Research should be conducted to better understand the specific health needs and challenges associated with multimorbidity in adults with a severe or profound learning disability.

Chapter 4



Review of the lives and deaths of Autistic adults 2021-2023

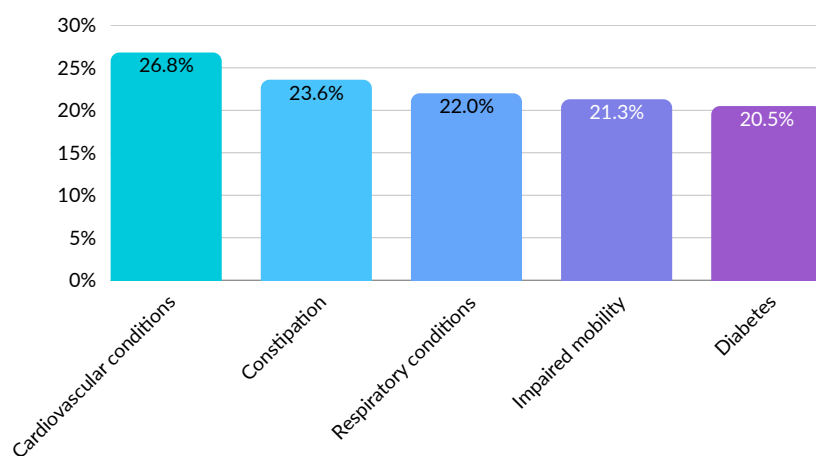
Please be aware that this chapter discusses deaths by suicide and may be upsetting and distressing. If you or someone you know is affected by the content of this report, please call Samaritans for free on 116 123 (UK and ROI), email them at jo@samaritans.org, or visit [samaritans.org](https://www.samaritans.org) to find your nearest branch. Other sources of support are listed on the [NHS's help for suicidal thoughts webpage](#). Support is available round the clock, every single day of the year, providing a safe place for anyone struggling to cope, whoever they are, however they feel, whatever life has done to them.

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

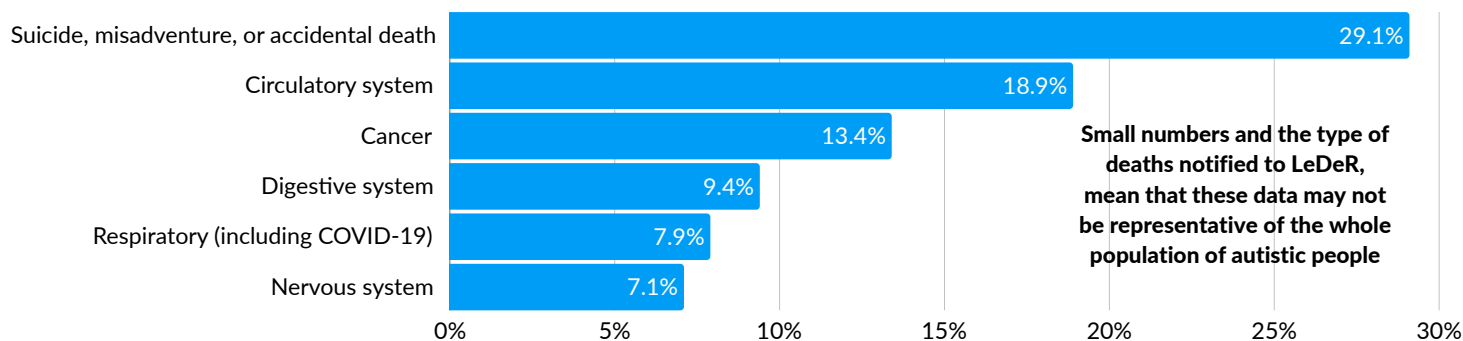
54.3%

Had a diagnosis of anxiety disorder

42.5%

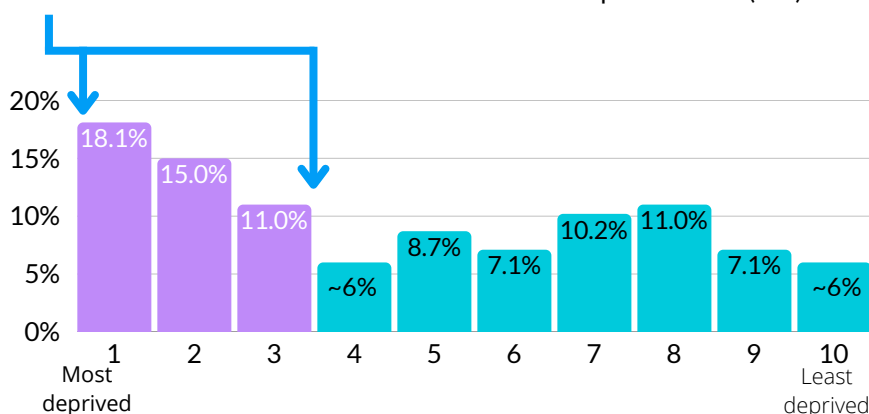
MOST COMMON CAUSES OF DEATH FOR AUTISTIC ADULTS WHO HAVE HAD A LeDeR REVIEW

2021-2023



INDEX OF MULTIPLE DEPRIVATION 2021-23

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



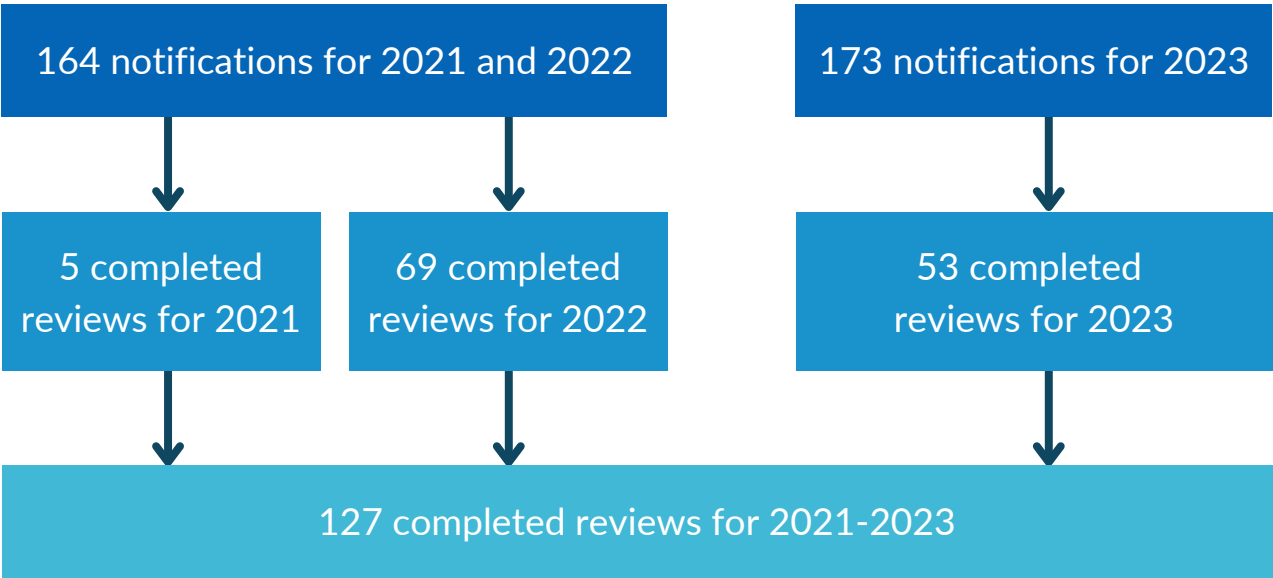
ISSUES WITH CARE

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

Introduction

In 2022, LeDeR began receiving notifications of deaths of adults (aged 18 and over) with a diagnosis of autism (without a learning disability) in England. Previously, autistic adults were only included where they had a learning disability. In this chapter, we report the data for autistic adults without a learning disability who died between 1st June 2021[9] and 31st December 2023, whose deaths were notified to LeDeR and had a completed review by the data drawdown date of 16th July 2024. It is important to note that all deaths of autistic adults notified to LeDeR receive a focused (in-depth) review rather than an initial review. See [Appendix 0.3](#) for a detailed explanation of the LeDeR reporting and reviewing process. In 2023, the deaths of 173 autistic adults without a learning disability were notified to LeDeR. Of these, 53 reviews were completed by 16th July 2024. For the 2022 report, 36 reviews had been completed by the date the report was written; the number of reviews completed for deaths occurring in 2022 has now increased to 69. There are 5 completed reviews of deaths of autistic adults that occurred in 2021. In total, LeDeR has received 337 notifications of deaths of autistic adults without a learning disability. Figure 4.1 shows the flow of notifications to completed reviews for autistic adults without a learning disability from 2021-2023.

Fig 4.1: Notifications to LeDeR and completed reviews of the deaths of autistic adults without a learning disability who died between January 2021 and December 2023.



9: Whilst deaths of autistic adults without a learning disability were not routinely collected by LeDeR until 2022, some deaths which occurred in 2021 were reported and reviewed in latter years. These deaths have been included in the analysis, although the number of deaths in 2021 that have been reported is small, and delayed notification of the deaths of autistic people, which happened prior to January 2022, were only accepted in exceptional circumstances.

Notifications to LeDeR of deaths of autistic adults without a learning disability combined across years are shown by region in Table 4.1. This suggests a relatively even spread of notifications from across English regions. It is important to note that the population size of NHS England regions varies significantly, and we would therefore not expect the number of notifications received for each region to be the same.

Table 4.1: *Region of England for autistic adults without a learning disability notified to LeDeR who died from January 2021 to December 2023.*

Notifications	London	South West	South East	Midlands	East of England	North West	North East and Yorkshire	Total
Deaths occurring in 2021-2023	26	37	58	69	22	75	50	337

ICB staff working on LeDeR have indicated to NHS England that reviews of the deaths of autistic adults without a learning disability have often taken longer than LeDeR reviews for adults with a learning disability, partly because many of the notified deaths have needed to go through police investigations and/or the coronial process. However, the number of notifications also suggests that only a minority of deaths of autistic adults are currently being reported to LeDeR. It is important to keep in mind that the LeDeR reviews of deaths of autistic adults reported here are unlikely to be fully representative of the deaths of autistic adults in England. Nonetheless, the data provide some insights into the causes and circumstances of death in a cohort of autistic adults and the care they received, which can be used for quality improvement efforts and to highlight areas where further research is needed.

In this chapter, we will report the combined data for 2021-2023. This has two purposes: 1) to provide a larger data set with which to draw conclusions from, and 2) to enable inclusion of the relatively small number of reviews from 2021 without the risk of identification.

Please note, to avoid small numbers which may place people at risk of identification, we will redact figures below five where necessary. Autistic adults who also had a learning disability are included in data in Chapters 1-3.

Deaths of autistic adults without a learning disability

Below is the breakdown of the data for the 127 completed focussed reviews between 2021 and 2023.

Demographics of the LeDeR data for autistic adults without a learning disability

Deaths of 101 (79.5%) autistic adults were reported as male and 26 (20.5%) as female. A small number of people were reported as neither male nor female-identifying. However, to protect anonymity and in keeping with the standard NHS protocol to suppress numbers below 5, we have reported sex only as assigned at birth.

For all years, the reported ethnicity of the deaths of autistic people reviewed by LeDeR were 110 (86.6%) recorded as “White”. Most people included were reported as being single at the time of their death. Just over a quarter of people who died were reported as having had children. Most people were reportedly not in work (either paid or voluntary) at the time of their death.

[The English Indices of Deprivation, 2019](#) (Index of Multiple Deprivation - (IMD) scale shows that most autistic adults whose deaths were reported to LeDeR lived in the most deprived areas of England, with just over one-third of those who died having lived in the 20% most deprived areas in the country.

The median age at which individuals received a diagnosis of autism was 33 years (mean 33.2 years), with a range of 0 – 80 years. This is a notable difference from research which suggests that the mean age of diagnosis for males in the UK is 12.3 years for females and 14.9 years for males (Russell et al., 2021), reflecting the known under-diagnosis in adults compared to children and may be part of a cohort effect reflecting changes in recognition of autism and diagnostic practices over the past decades. However, given the small sample size, these findings should not be overgeneralised and warrant further research.

The data in this report is not yet representative of the population of people who are autistic across England. The median age of diagnosis of those people whose deaths were received and analysed as part of this report is based on 127 deaths. These deaths themselves are not representative of the deaths of autistic people in England who died between 2021 and 2023. These deaths are likely of those who were more known to services, more likely to have had a traumatic death, and more likely to have had concerned others seeking a review into their death due to concerns about the care that they received. Therefore, caution must be taken regarding this data.

Table 4.2: Demographics of autistic adults without a learning disability who died from January 2021 to December 2023 and received a focused review by July 2024 by review type.

	Focused reviews for deaths that occurred from 2021-2023	Notifications
Demographic	2021-2023 combined, Number (%)	2021-23*, Number (%)
Sex registered at birth		
Male	101 (79.5%)	215 (63.8%)
Female	26 (20.5%)	69 (20.5%)
Not known/Other/preferred not to say	n/a	53 (15.7%)
Sexual Orientation		
Heterosexual	39 (30.7%)	n/a
Other than heterosexual	17 (13.4%)	n/a
Not recorded	71 (55.9%)	n/a
Marital status		
Single	79 (62.2%)	n/a
Married/Civil Partner	16 (12.6%)	n/a
Not Disclosed/Other**	32 (25.2%)	n/a
Children		
Yes	28 (22.0%)	n/a
No	70 (55.1%)	n/a
Unknown	29 (22.8%)	n/a
Employment		
Yes (paid or voluntary work)	12 (9.4%)	n/a
No	89 (70.4%)	n/a
Unknown	26 (20.5%)	n/a
Ethnic group		
White	110 (86.6%)	267 (79.2%)
Any other ethnic group than White	17 (13.4%)	70 (20.7%)
Median age at diagnosis of autism		
Male	33 years	n/a
Female	33 years	n/a
Overall	33 years	n/a
Index of Multiple Deprivation ***		
1 (most deprived areas)	23 (18.1%)	n/a
2	19 (15.0%)	n/a
3	14 (11.0%)	n/a
4	<10 (~6%)	n/a
5	11 (8.7%)	n/a
6	9 (7.1%)	n/a
7	13 (10.2%)	n/a
8	14 (11.0%)	n/a
9	9 (7.1%)	n/a
10 (least deprived areas)	<5 (~6%)	n/a

*Whilst sexual orientation and relationship status are asked of notifiers, we are not able to summarise responses here due to low numbers. Other demographic data are not available in notifications.

** "Other" includes those who are divorced, separated, or in a relationship not defined as either being single or in a marriage or civil partnership.

*** Note some postcodes were not matched in the IMD postcode system.

Age at death of autistic adults without a learning disability

As mentioned in the introduction, the data available in LeDeR is unlikely to be fully representative of the entire autistic population in England. The average age at death presented in the LeDeR report is not equivalent to life expectancy, as this requires data on living people as well as those who have died. Furthermore, there are several reasons why data on the age of the death of autistic people reported to LeDeR are not representative of the age at death of all autistic adults. Relatively small numbers of deaths of autistic adults have been reported to LeDeR. In addition, deaths of younger people who died due to events such as accidental death or suicide may be more likely to be reported to LeDeR than deaths due to other causes. There is also a known diagnostic skew for autism, with younger people being more likely to be diagnosed and underdiagnosis in older adults; as a result, there are fewer notifications of deaths of autistic older adults. This is due to an increased awareness and visibility of neurodiversity resulting in more children and young people being diagnosed than there has been in the past. For descriptive purposes, we summarise the median age at death of deaths of autistic adults reported to LeDeR between 2021 – 2023 in Table 4.3. The overall range at age for both males and females reported to LeDeR was 18-87 years.

For context, of the 337 notifications of deaths of autistic adults, the median age at death was 54 years, showing that estimates of age at death are likely to increase in future years as more data are collected.

Table 4.3: Median age at death for autistic adults without a learning disability who died from January 2021 to December 2023, by review type and sex.

Sex registered at birth	Age at death for focused reviews for deaths that occurred from 2021-2023*	Age at death for notifications*	Range
	2021-2023 (median years)	2021-2023 (median years)	2021-2023
Male	42	54	18-82
Female	40	53	18-87
Overall	42	54	18-87

*Age at death unlikely to be representative due to small numbers reported to LeDeR.

Causes of death of autistic adults without a learning disability

The cause of death is available from the MCCD for completed LeDeR reviews (please see Appendix 0.3 for details of the LeDeR process and data checks). The reviewers can also determine it based on several sources of evidence (such as discussions with the GP). We received completed MCCD data or reviewer-determined death information for 127 adults.

In this report, we have identified deaths that the reviewers have attributed to suicide, misadventure, or accidental death as a single group. This is due to the complex nature of determining suicidal intent (for example, with deaths involving an overdose of drugs or alcohol). As with last year's report, suicide, misadventure, or accidental death continues to be the most common cause of death for autistic adults, accounting for just under one-third of all deaths reviewed. However, the number of those deaths as a proportion of overall deaths has decreased slightly compared to the data available for the LeDeR 2022 annual report. Deaths from disorders of the circulatory system (e.g. cardiac arrest or stroke), cancers, and disorders of the digestive system (e.g. perforated bowel) are the next most commonly occurring causes of death. Comparisons with the general population are difficult due to the small number of reviews available, but the causes of death in the LeDeR data on deaths of autistic people should be compared to general population mortality data of a comparable age group. The completed review data of grouped causes of death for autistic adults in 2021, 2022 and 2023 are presented below in Table 4.4.

Table 4.4: *Grouped cause of death for autistic adults without a learning disability who died from January 2021 to December 2023 and received a focused review by July 2024.*

Grouped underlying cause of death	Totals 2021-2023, Number (%)
Suicide*, Misadventure, or Accidental Death[10]	37 (29.1%)
Circulatory system disorders and diseases	24 (18.9%)
Cancer	17 (13.4%)
Digestive system disorders and diseases	12 (9.4%)
Respiratory conditions (including COVID-19)	10 (7.9%)
Diseases of the nervous system	9 (7.1%)
Other[11]	18 (14.2%)

*Note: Suicide as defined by the ONS definition and by reviewers' judgement. The vast majority (32) were coded by coroners or reviewers as suicide, the remainder were coded as either drug or alcohol-related deaths (either with uncertain intentions or those not directly believed to be suicidal ideation) or falls of both accidental and undetermined intent (either with or without drugs or alcohol involvement).

[10] In this report, we have grouped suicide, misadventure, and accidental death due to the method of reporting on the MCCD by coroners. This may be in relation to changes in the standard of proof used by coroners to determine whether a death is a suicide or not. For more details, see the [ONS website](#).

[11] "other" refers to conditions that are not in the most common group. These can be singular instances or a small number of occurrences. When added together, however, they become a large number but are not representative of one distinct condition, so they are removed for ease of understanding the data.

Circumstances of deaths of autistic adults without a learning disability

Below, we detail some of the circumstances of the death of autistic adults without a learning disability reported to LeDeR between 2021 and 2023. Due to the nature of many of these deaths, police investigations, serious incident reviews, and coroner inquests are much more likely to have occurred than for adults with a learning disability (see [Chapter 1](#) for comparable figures). Note that in Table 4.5 where appropriate when a blank response was inputted, this has been added to the “no” total.

Table 4.5: *Circumstances of death for autistic adults without a learning disability who died from January 2021 to December 2023 and for whom a LeDeR review was completed between June 2021 and July 2024 by review type and sex for autistic adults.*

	Safeguarding Enquiry, Number (%)	Police investigation of the death, Number (%)	Serious incident review of the death, Number (%)	Coroner Inquest, Number (%)	Postmortem, Number (%)
Yes	6 (4.7%)	14 (11.0%)	25 (19.7%)	36 (28.3%)	54 (42.5%)
No	121 (95.3%)	113 (89.0%)	102 (80.3%)	91 (71.7%)	73 (57.5%)

The use of the MCA and DNACPRs recommendations is less frequent for autistic adults without a learning disability than for adults with a learning disability (see [Chapter 1](#)). Sixty-seven (53%) of autistic adults without a learning disability had a capacity assessment, and 52 (41%) had a DNACPR decision at death. Reviewers indicated that for autistic adults, the use of the MCA and DNACPRs recommendations are more likely to be correctly applied and followed than not (where reviewers were able to find evidence).

Table 4.6: MCA use in autistic adults without a learning disability who died from January 2021 to December 2023 and received a LeDeR review between by July 2024, for autistic adults who had a capacity assessment.

	Was the MCA correctly followed in those that had a capacity assessment? Number (%)
Yes	55 (82.1%)
No	7 (10.4%)
Not known	5 (7.5%)

Table 4.7: Number of deaths where DNACPR documentation was completed and followed correctly for autistic adults without a learning disability who died from January 2021 to December 2023, and received a LeDeR review by July 2024.

DNACPR documentation	2021 – 2023, Number (%)
Completed and followed	38 (73.1%)
Completed but not followed	*
Completed but incorrectly followed	*
Incorrectly completed and followed	0 (0.0%)
Don't know	12 (23.1%)

Most deaths of autistic adults occurred in acute settings (i.e. hospitals), or at their homes. Few occurred in a residential nursing home. The 'Other' category includes places such as public places, or in a building other than a care facility or home.

Table 4.8: Place of death for autistic adults without a learning disability who died from January 2021 to December 2023, and received a LeDeR review by July 2024.

Place of death	2021 – 2023, Number (%)
Hospital	60 (47.2%)
Home of the person who died or friend or relative*	41 (32.3%)
Residential nursing home	6 (4.7%)
Other	20 (15.7%)

*To avoid small numbers and potential identification, both home of the person who died and home of a friend or relative have been merged.

A breakdown of the recorded physical health conditions for autistic adults is presented in Table 4.9. The most commonly occurring physical health conditions were cardiovascular conditions, constipation, respiratory conditions, impaired mobility, and diabetes.

Table 4.9: *Physical health comorbidities for autistic adults without a learning disability who died from January 2021 to December 2023, and received a LeDeR review by July 2024.*

Physical health condition	2021 – 2023, Number (%)
Cardiovascular conditions	34 (26.8%)
Constipation	30 (23.6%)
Respiratory conditions (including COVID-19)	28 (22.0%)
Impaired mobility	27 (21.3%)
Diabetes	26 (20.5%)
Smoker (yes/previous)*	Yes = 25 (19.7%) previous = 16 (12.6%)
Sensory impairment (vision or hearing problems)	21 (16.5%)
Sleep disorders**	19 (15.0%)
Renal conditions	18 (14.2%)
Cancer	17 (13.4%)
Epilepsy	17 (13.4%)
Endocrine conditions	15 (11.8%)
Swallowing issues	14 (11.0%)
Aspiration pneumonia	10 (7.9%)
Dementia	8 (6.3%)
Dental problems	*
Parkinson's disease	0 (0%)

*Whilst smoking is not a physical health comorbidity itself it is known to be linked to several physical health conditions and is therefore presented here for reference.

** Sleep disorders can refer to any disorder related to sleep, e.g. insomnia, sleep apnoea, etc. Grouped for low numbers.

Mental health conditions for autistic adults

Mental health conditions and the use of medications for mental health were frequently reported, with depression (54.3%) and anxiety (42.5%) being the most commonly occurring. Rates of anti-depressant and anti-anxiety medication prescriptions were in keeping with the rate of diagnoses of these conditions. Note: these are mental health conditions listed by the LeDeR reviewers based on the medical history of the person. They can therefore have been present at the time of death or, if not experienced at the time of death, were in the recent medical history.

Table 4.10: *Mental health conditions and medication treatments for autistic adults without a learning disability who died from January 2021 to December 2023, and received a LeDeR review by July 2024.*

Mental health condition	2021- 2023, Number (%)
Depression	69 (54.3%)
History of anti-depressant prescription*	66 (52.0%)
Anxiety	54 (42.5%)
History of anti-psychotic prescription	38 (29.9%)
History of anti-anxiety prescription*	36 (28.3%)
Behaviour disorders	30 (23.6%)
History of suicide attempts	27 (21.3%)
History of self-harm	19 (14.9%)
Psychosis	18 (14.2%)
Bipolar disorder	8 (6.3%)
Eating disorder	6 (4.7%)

*Note that some anti-depressants (e.g. SSRIs) can also be used to treat anxiety with or without depression and may have been recorded as either an anti-depressant or anti-anxiety medication in the LeDeR review.

Mental health support – Talking Therapies for autistic adults.

Overall, 56% of the autistic adults without a learning disability who died and for whom a LeDeR review was completed had access to talking therapy support (e.g. CBT, group therapy, or access to a therapist/psychologist providing psychotherapy or clinical counselling) (Table 4.11). For those autistic adults who died by suicide in the LeDeR data, the majority had access to talking therapy support within the 12 months before their deaths. However, it is not clear whether the talking therapy was adapted to meet the needs of autistic adults, and therefore, its suitability or efficacy cannot be determined by this data alone. Further discussion on this and whether talking therapy adaptations which are being provided to autistic adults are sufficient can be found in the quality of care section below. Note that Table 4.11 only includes data where evidence of talking therapy provision was definitely evident or not evident.

Table 4.11: *The provision of talking therapies for autistic adults without a learning disability who died from January 2021 to December 2023, by cause of death, and received a LeDeR review by July 2024.*

	All deaths, Number (%)*	Deaths by suicide, Number (%)*
Yes	51 (56.0%)	26 (83.9%)
No	40 (44.0%)	5 (16.1%)

*Note that due to small number for deaths by suicide, all "not known/blank" have been removed from calculation to ensure deidentification.

Quality of care

A review of the free text data on these deaths and comments on the quality of care can provide insight into emergent themes that may be of value in highlighting gaps in care and directing improvement efforts. We reviewed the free text data across the reviews of 44 reviews where reviewers indicated care fell short of acceptable standards. Emergent themes are similar to those found last year.

1. There is a recurring theme of a lack of high-quality training, awareness, or understanding of the specific needs of autistic people. In several instances, available services were reported to have been unable to provide adequate care, and this was related to the behaviour or engagement ability of the autistic person. Support for both services and for the autistic person to better manage these situations was sometimes unavailable.
2. In some cases, there was a lack of services specifically tailored to the needs of an autistic adult, or a lack of support to access services. Examples include offering only group therapy when individual therapy would be less challenging for the individual, autistic people being placed on the learning disability register by their GP when they do not have a learning disability, or a failure to refer an autistic client to specialist care services for autism.
3. Failing to recognise that significant changes to an individual's situation can prove more challenging for an autistic individual than for someone who is not autistic. This includes the potential impact of a relationship status change for autistic adults who may require support to manage significant life events and changes.
4. In some cases, difficulties transitioning from child to adult services was noted. Greater support for navigating this change, and for other significant life changes, could be needed for autistic adults.

5. A lack of crisis escalation plans, and/or a lack of an awareness of suicidality risk for autistic adults.

6. A lack of communication between support networks and a lack of multidisciplinary collaboration. This was particularly noted for those with mental health support needs, and in some instances, there was a noted failure of communication between private and NHS provided care.

7. Missed or delayed diagnosis of physical health conditions due to wrongly attributing symptoms to autism (diagnostic overshadowing). Examples include missing cancer diagnoses due to a lack of reasonable adjustments for accessing screening and a lack of specialist autism care. In other cases, autism was overshadowed by other mental health conditions, resulting in delays in accessing appropriate care.

Similarly, we reviewed the free text reviewer comments on LeDeR reviewers where reviewers had not identified any issues with care. Emergent themes were:

- An awareness of autism and efforts to make reasonable adjustments for service users.
- Communication between agencies, individuals, and services providing care. This includes good communication between private and public services, as well as between families and professional carers.
- Reasonable plans being put in place for crisis and escalation supports, and where appropriate including suicidality assessments using recognised frameworks.
- Supports were offered and explained to the individual, specifically tailored to the needs of the individual.
- Reasonable adjustments were made to support people's involvement in their care decisions.

In essence, good care was found to be that which considered and understood the specific needs of the autistic adult, whilst poorer care was found to be less responsive and understanding of autism. Throughout the reviews, comments on the awareness of the specific needs of autistic adults, and how these may differ from the needs of adults who are not autistic, were seen in both evidence good practice and issues with care. These continue to remain a theme in the care of autistic adults and offer examples of where care and training can be improved upon in the future.

Summary and discussion

The demographic characteristics of autistic adults whose deaths were reported to LeDeR showed that this group were largely male and “White” with an average age at death in their mid-to late-40s. Whilst we must be cautious in our interpretations due to the under-reporting of deaths of autistic adults to LeDeR, we do know from other research that more males than females are diagnosed with autism, and that an autism diagnosis is less likely to have been made in older adults (Russell et al., 2022). Because of the demographics of people who have received a diagnosis of autism, the average age at death of adults who were included in this sample may be skewed to a younger age and, in the future, this may change as awareness improves and more diagnoses are made in adults (O’Nions et al., 2023).

The data continues to show relatively high numbers of deaths by suicide, misadventure, or accident in autistic adults whose deaths were reported to LeDeR. The data we have available in this report supports other work that shows deaths by suicide are more common among autistic people without a learning disability than among the general population (Hirvikoski et al., 2020). Deaths by suicide are routinely investigated by a coroner and therefore, may be more likely to be reported to LeDeR than other causes of death. A recent systematic review by Santomauro et al (2024) found that, globally, autistic people without a learning disability were more than five times more likely to die by suicide than people who are not autistic. They also noted that the suicide risk for autistic females, relative to females from the general population, was significantly larger than the risk for autistic males compared to peers from the general population.

Physical health conditions such as cardiovascular conditions, diabetes, and epilepsy were commonly reported, though given the relatively small number of deaths reported to LeDeR it is not yet possible to make comparisons with the general population.

The number of deaths of autistic adults reported to LeDeR is likely to increase as awareness of the need to collect data on autistic people’s deaths improves. This will help to identify areas where care can be improved, inform service developments, and guide policy with the aim of improving health outcomes and reducing health inequalities. NHS England continues to work with partners such as the [National Autistic Society](#) and [Autistica](#) to raise awareness of the inclusion of autistic adults in LeDeR. Increased data in future years will likely strengthen the findings.

Looking forward

For health and care services:

- Emergent themes in the reviews suggest that services need to ensure a good understanding by staff of the needs of autistic people to identify those at risk, ensure adequate provision of support tailored to the needs of the person, and provide personalised crisis plans.
- Reasonable adjustments for autistic adults who access care, and person-centred care plans that factor in the individual's autism diagnosis, should continue to be implemented and strengthened.
- Care providers should be aware of the increased risk of suicide for autistic adults and where necessary factor this into crisis and support plans.

For research:

- There is an ongoing need to better understand the health conditions experienced by autistic adults and the extent to which they face health inequalities in the NHS. This data are not yet available in LeDeR, but further improvements to notification and data collection of health outcomes for autistic adults are warranted.
- There continues to be a high proportion of deaths by suicide in autistic adults reported to LeDeR compared to both people with a learning disability and the general population. This is concerning and requires further investigation using other data sources such as the [National Confidential Inquiry into Suicide and Safety in Mental Health](#), to confirm the extent and nature of this issue.
- Research into the ways in which autistic people who experience suicidal thoughts can be better supported is required.
- Further research into talking therapy adaptations for autistic adults who seek support through the NHS is warranted.
- The age at death for autistic adults and reasons for differences with the general population should be investigated further with larger, representative sample sizes.

Chapter 5



**Deep Dives and Publications that
have arisen from LeDeR**

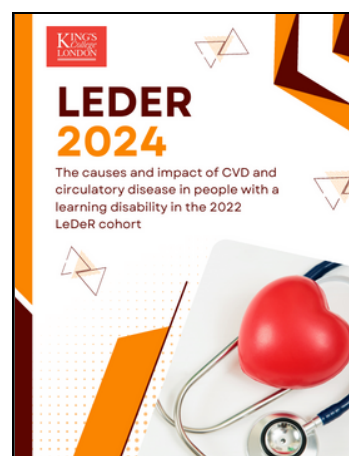
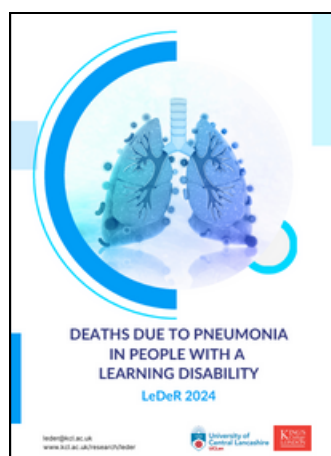
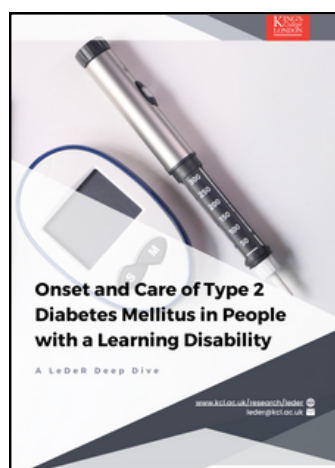
Deep Dives and Publications that have arisen from LeDeR

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.

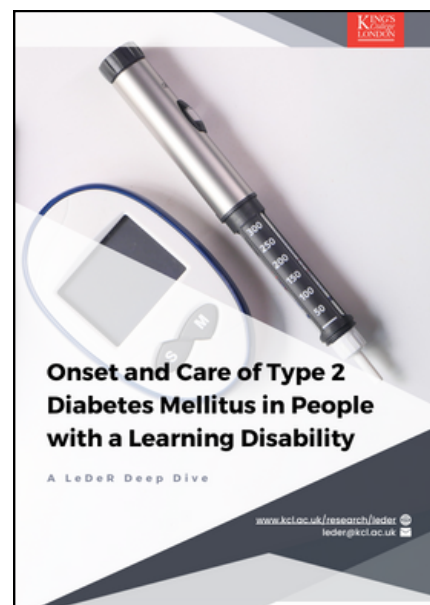
Much of this work uses LeDeR data directly. Some, however, use LeDeR findings as a starting point for further investigation and may use other datasets or gather new information to explore specific questions regarding the health and care of people with a learning disability or autistic people further. 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.**



Diabetes

Objective: Previous research has found that people with a learning disability are around two and a half times more likely to be diagnosed with diabetes than the general population and that approximately 8.5% of people with a learning disability have diabetes. [The National Diabetes Audit](#) previously reported in 2017 that people with a learning disability and type 2 diabetes are less likely to receive appropriate diabetes care, including regular check-ups, blood glucose monitoring, and medication management. This can lead to poor blood sugar control and a greater risk of diabetes-related complications. This deep dive aimed to 1) determine the new onset (incidence) rate of type 2 diabetes, 2) examine the quality of care related to the management of type 2 diabetes and 3) investigate the health issues and demographic factors associated with a type 2 diabetes diagnosis in people with a learning disability compared to the general population in England, using data from a large primary care dataset (Data Resource Profile: Clinical Practice Research Datalink (CPRD) - PMC)



Findings: People with a learning disability in England have higher rates of new onset of type 2 diabetes compared to the general population. The findings revealed that people with a learning disability are more likely to have the onset of type 2 diabetes approximately 10-15 years earlier than the general population. LeDeR data demonstrated that people with a learning disability who had type 2 diabetes, were less likely to have eye and foot checks than the general population. In addition, screening for type 2 diabetes was not always included as part of annual health checks even with the known higher risk factors for people with a learning disability. Regarding the management of conditions associated with diabetes, our analyses support the application of existing NHS guidance for the management of obesity, hypertension, and cardiovascular health, and for reducing or monitoring the long-term impact of antipsychotic medication in people with a learning disability.

These findings suggest several opportunities for improved diabetes care. Healthcare providers and caregivers should be aware of the increased risk of type 2 diabetes and take steps to ensure that appropriate screening and management strategies are in place for people with a learning disability, including eye and foot health checks. Alongside this, better health education around diabetes for caregivers and people with a learning disability could help to prevent and manage the condition more effectively.

Impact: This work resulted in a deep dive report and a submitted academic paper. The findings will contribute to planning for improvements in the monitoring and screening for type 2 diabetes in people with a learning disability. Taken together with the findings of another report on diabetes in people with [Down syndrome](#) which demonstrated that a higher risk for type 2 diabetes at younger ages was associated with obesity, there is a need for earlier intervention with preventative lifestyle interventions.

Take-home messages:

- People with a learning disability are more likely to be diagnosed with type 2 diabetes around 10-15 years earlier than those without a learning disability.
- People with a learning disability are less likely to have eye and foot checks as part of their annual health checks than the general population, which can be important in the management of type 2 diabetes.
- Education should be provided to support people with a learning disability and their carers to help better prevent and manage type 2 diabetes.
- Lifestyle interventions should be recommended at an earlier stage (in teenagers and young adults) to prevent type 2 diabetes.

References and Resources

For further information and tools for improving care for people with diabetes and a learning disability please see: [Improving care for people with diabetes and a learning disability | Diabetes UK](#)

Deep dive report: Baksh, R.A. et al (2022). Onset and care of type 2 diabetes mellitus in people with a learning disability [Diabetes deep dive](#)

Aslam AA, Baksh RA, Pape SE, Strydom A, Gulliford MC, Chan LF; GO-DS21 Consortium. Diabetes and Obesity in Down Syndrome Across the Lifespan: A Retrospective Cohort Study Using U.K. Electronic Health Records. *Diabetes Care*. 2022 Sep 30;45(12):2892–9. doi: 10.2337/dc22-0482. Epub ahead of print. PMID: 36178378; PMCID: PMC7613880.

Video by the Staying Alive and Well group on what kind of information people need about diabetes: [How to make accessible health information for people with a learning disability](#)

Bowel Cancer

Objective: Previous annual LeDeR reports, as well as other published work globally, have found that people with a learning disability have an increased risk of developing and subsequently dying from bowel cancer than the general population. The [national bowel cancer screening programme](#) is currently lowering the screening age for everyone from 54 to 50 years old and aims to complete this by 2025. This deep dive asked: is this screening age low enough for people with a learning disability?

Findings: Analysis of the LeDeR data from 2017 to 2022, found that 15% of people with a learning disability, who died from bowel cancer were under the age of 50, with almost all these people being over 40 years old. A review of the screening program eligibility across 40 countries revealed that some, like Austria and Japan, begin screening at age 40 or 45, while the U.S. and Australia suggest lowering the screening age. However, no specific screening exists for individuals with a learning disability. LeDeR data shows these individuals are at higher risk for bowel cancer and often die before the recommended screening age of 50. Thus, it is suggested that in England, those with a learning disability be recognised as an at-risk group and offered bowel cancer screening starting at age 40.

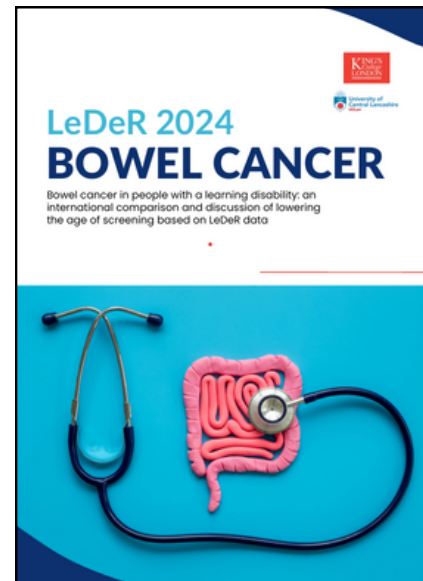
Impact: The [NHS England National Learning Disability and Autism Programme](#), with support from King's College London, has submitted a proposal for consideration to the [UK National Screening Committee](#) demonstrating the value of reducing the age of bowel cancer screening to 40 years for people with a learning disability.

Take-home messages:

- People with a learning disability are at increased risk compared to the general population of developing and dying from bowel cancer.
- Bowel cancer accounts for approximately 18% of deaths of people with a learning disability each year (compared to approximately 10% in the general population), and 15% of these are of people below the age of 50 years.
- Several countries are already offering screening for people from 40 or 45 years of age.
- The bowel cancer screening programme in England has been asked to consider lowering the age of screening for people with a learning disability to 40 years of age.

References and Resources:

Deep Dive report: White, A. et al (2024). Bowel cancer in people with a learning disability: an international comparison and discussion of lowering the age of screening based on LeDeR data.
<https://www.kcl.ac.uk/ioppn/leder/bowel-cancer-deep-dive.pdf>



The coverage and impact of Learning Disability Liaison Nurses

Objective: Learning Disability Liaison Nurses work in primary, acute and secondary care settings to provide a range of clinical expertise, advocate for people with a learning disability including their families and care teams, advise professionals providing care, and provide training and education to staff. There is some evidence from small studies that Learning Disability Liaison Nurses are highly valued and impactful. However, not all NHS hospitals in England have Learning Disability Liaison nurses. We sought to better understand the potential impact of learning disability liaison nurses on the care of people with a learning disability admitted to acute hospitals.

Findings: 4,742 LeDeR reviews (2017-2021) revealed that one-third of people with a learning disability who died in hospitals in England received care from Learning Disability Liaison Nurses (LDLNs). Their involvement correlated with a higher likelihood of reasonable adjustments in care and best practices identified by reviewers. However, access to LDLNs varied regionally, being less common in the North East and North West, and more frequent among cancer patients.

Impact: This work resulted in a paper published in the BMJ Open as well as presentations at international conferences, including the IASSIDD conference in Chicago in 2024.

Take-home messages:

- Few learning-disabled patients in England's hospitals receive LDLN support, as not all hospitals offer this service.
- LDLN involvement improves care quality and highlights the importance of these roles.
- Further research is needed on effective LDLN models and their impact on patients and caregivers.
- NHS England is developing a new competency framework for LDLNs to enhance care delivery.

References and Resources:

Sheehan, R., Ding, J., White, A., Magill, N., Chauhan, U., Marshall-Tate, K., & Strydom, A. (2024). Specialist intellectual disability liaison nurses in general hospitals in England: cohort study using a large mortality dataset. *BMJ open*, 14(8), e077124. [Specialist intellectual disability liaison nurses in general hospitals in England: cohort study using a large mortality dataset | BMJ Open](#)



Constipation

Objective: Constipation is a common issue for people with a learning disability. This work sought to understand the use of medications (and laxatives) for people with a learning disability who also have constipation. What is the prevalence of constipation and could prescribed medications be contributing to this? What learning is there from the LeDeR data about those people who died with a diagnosis of constipation?

Findings: This deep dive explored constipation in people with a learning disability using a sample of 97 people who died in 2021 and had a LeDeR review. We reported the prevalence of constipation amongst those who had died, medications that were prescribed where constipation was a known side-effect, and the frequency of laxative prescriptions. We then calculate a risk score for constipation due to side effects of medication. Analysis of the people sampled within this deep dive found that over 50% had a risk score of being prescribed two or more medications that commonly or very commonly have constipation as a side effect. Rates of laxative prescriptions for people with a learning disability were high, with 40% of the people included in this deep dive prescribed at least one laxative before they died. Constipation itself did not appear on any part of the death certificate of any of the people who died in the sample, but 13% of those with constipation died of causes of death such as bowel perforation which may be caused by or be related to constipation. Very few people were recorded to understand what constitutes normal bowel function or to have received education on normal bowel habits.

Impact: This deep dive linked to the development of a risk tool for risk for constipation associated with [prescribed medication](#), which is now included in the [Medichec](#) app developed by the NIHR Maudsley Biomedical Research Centre (BRC). This is a practical, free tool that can be used by both clinicians and the public alike to understand the constipation risk of combinations of different medications. This deep dive also resulted in a peer-reviewed publication for scientific dissemination and several presentations at national conferences, raising awareness of the risks of constipation and mortality for people with a learning disability.



Take-home messages

- Regular medication reviews should be completed to mitigate the effects of constipating medications, particularly for individuals with complex conditions and polypharmacy.
- The NIHR Maudsley BRC has developed an app which can be used to identify medications with a high risk of causing constipation. The app could be used routinely in decisions about prescribing.
- Accessible advice and education about constipation should be offered to people with a learning disability and their caregivers, particularly those with or at risk of developing constipation, such as people on several medications that can have a constipating effect. NHS England has made available information to help with this which can be found here: [NHS England » Constipation resources for people with a learning disability](#)
- Bowel monitoring is essential for those at high risk for developing constipation to ensure it is identified and treated early.
- Clinicians should keep in mind the risk factors people with a learning disability may be predisposed to (such as obesity, hypothyroidism, mobility problems and multimorbidity) when prescribing medications that have constipation as a side effect.

Reference and resources:

Deep dive report: Roberts, C. et al (2023). CONSTIPATION: Premature death, the side effects of medications, and the use of laxatives, for people with a learning disability in England.

<https://www.kcl.ac.uk/ioppn/leder/copy-of-constipation-5.pdf>

Deep dive key findings: <https://www.kcl.ac.uk/ioppn/leder/constipation-takehome.pdf>

Roberts C, Ding J, Bishara D, Riaz S, Sheehan R, White A, Strydom A, Chauhan U. Constipation prevalence and risk from prescribed medications in people with intellectual disability: Findings from an English mortality programme. *J Intellect Disabil*. 2024 Jul 19:17446295241267085. doi: 10.1177/17446295241267085. Epub ahead of print. PMID: 39030671.

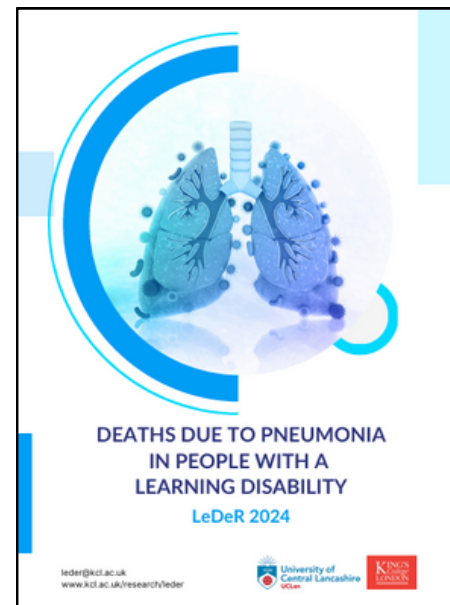
Bishara D, Riaz S, Sauer J, Mueller C, Gee S, Taylor D, Wilcha RJ, Edwards M, Beehuspoteea N, Mallia AMB, Brook J, Balasundaram B, Harwood D, Funnell N, Strydom A, Stewart R. A tool for safer prescribing in vulnerable adults: the continuing development of the Medichech app and website. *BJPsych Bull*. 2023 Sep 6:1-7. doi: 10.1192/bjb.2023.71. Epub ahead of print. PMID: 37671832.

Medichech app for reviewing constipation as a side effect of medication: <https://medichech.com/>

NHS England constipation resources for people with a learning disability: <https://www.england.nhs.uk/publication/constipation-resources-for-people-with-a-learning-disability/>

Pneumonia

Objective: Respiratory conditions including pneumonia are common causes of preventable death in people with learning disability. Pneumonia accounted for over one-third of all deaths due to respiratory conditions reported in the LeDeR 2022 annual report (White et al., 2023). In this deep dive, we first conducted a literature review which focussed on risk factors for poor outcomes of community-acquired pneumonia in adults with a learning disability. We then investigated the presence of risk factors for pneumonia in a sample of 100 adults with a learning disability who died from pneumonia and whose deaths were reviewed by LeDeR. We then reviewed the quality of care received before their deaths to highlight areas for potential improvement.



Findings: The review of the literature identified several risk factors for poor outcomes of community-acquired pneumonia in people with a learning disability. These included having more severe disabilities and greater support needs, certain genetic conditions (such as Down syndrome), existing physical health conditions (heart disease, asthma, dysphagia), and advancing age. However, good quality evidence in this area is lacking, highlighting the need for future large-scale studies. Our analysis of deaths due to pneumonia reviewed by LeDeR showed that impaired airway clearance, postural problems, and swallowing difficulties were all more common in people with a learning disability who died of pneumonia compared with those dying of other causes.

Impact: This work is being used to further inform pneumonia care for people with a learning disability and has been presented at international conferences.

Take-home messages:

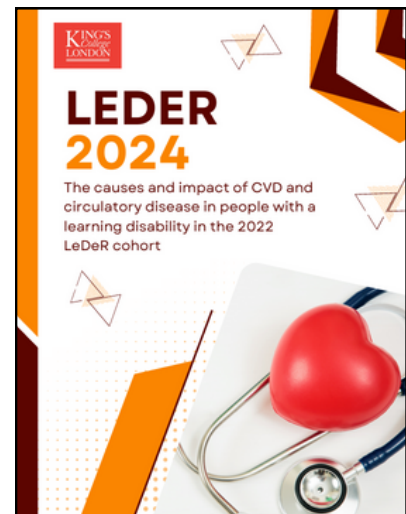
- People with a learning disability with respiratory infections who have risk factors that make them especially vulnerable to poor outcomes should be identified and managed proactively.
- People at risk for pneumonia and respiratory infections should have access to preventative care (e.g. pneumococcal vaccination programmes) and should be offered more pro-active acute care.
- Appropriate training for carers is necessary to help them to recognise the signs and symptoms of pneumonia and of deterioration in physical health.

References and Resources:

Deep dive report: White, A., et al (2024) Deaths due to pneumonia in people with a learning disability: kcl.ac.uk/ioppn/assets/fans-dept/deaths-due-to-pneumonia-in-people-with-a-learning-disability-leder-report-2024.pdf

Cardiovascular disease

Objective: This deep dive has four objectives: To identify the most common cardiovascular causes of death in adults with a learning disability and compare them with the general population. To identify the conditions associated with death from a cardio-vascular condition for adults with a learning disability. To understand the demographics of adults with a learning disability who had a focused review in LeDeR and who died from cardiovascular conditions. To explore the management of common cardiovascular conditions in adults with a learning disability who died from cardiovascular diseases.



Findings: The most common cardiovascular causes of death in adults with a learning disability are ischaemic heart diseases, cerebrovascular diseases, and heart failure. Other conditions identified in people with a learning disability who had a cardio-vascular condition listed in part one of their death certificate were: aspiration pneumonia, influenza and pneumonia, diabetes, obesity, epilepsy, hypertension, and Down syndrome. The findings indicated that adults with a mild learning disability may be at particular risk of dying from a cardiovascular condition. A small percentage of people were recorded by LeDeR reviewers as not having received care that aligned with NICE guidance or local care pathways. Increased awareness of the risk factors and causes of death from cardiovascular conditions among health providers and carers could help improve the health of adults with a learning disability and ensure that appropriate time and resources are allocated to prevention and treatment interventions.

Impact: This work is being used to further inform cardiovascular care for people with a learning disability.

Take-home messages:

- Cardiovascular conditions are a major cause of death for adults with a learning disability, accounting for around 20% of all deaths each year.
- Adults with a learning disability are more likely than the general population to be obese, have reduced mobility, have co-occurring conditions that increase the risk of pulmonary embolism, and have other co-occurring conditions that are treated with medications that may increase the risk of pulmonary embolism.
- Appropriate training for carers to help them recognise the risks of cardiovascular conditions is important so that appropriate treatment and support can be provided rapidly. This may include dietary, fitness, and mobility supports.

References and Resources

Deep dive report: [Ding, J; et al. \(2024\) The causes and impact of CVD and circulatory disease in people with a learning disability in the 2022 LeDeR cohort](#)

Appendices



LeDeR

Annual Report 2023

Learning from lives and deaths
– People with a learning
disability and autistic people

2023 LeDeR Appendix

Appendix 0.1: Updates to the report – 2023

Following consultation and feedback from stakeholders, the advice of our independent advisory group, and in discussion with NHS England, we have made some changes to the format of the 2023 annual report. A summary of these changes is given below.

- We have opted to look at all available LeDeR review data from the start of the revised LeDeR review forms (from 1st June 2021). As this is our third annual report it is a timely opportunity for us to consider the work over the three year period however, it should be noted that due to challenges identified in our foreword, there is limited data for the latter part of 2023. A summary of the data relating to deaths occurring in 2023 is provided for context along with comparisons with reviews of deaths occurring in 2021 and 2022.
- Changes have also been made to the format of the accessible report to ensure that it is more suited to a wider range of people. These include:
- Greater use of video to explain both the LeDeR process, and the foreword of the 2023 report.
- Shorter summaries of only the most important information.
- Dividing the accessible report into smaller, easier to understand sections.

Changes have also been made to the format of the accessible report to ensure that it is more suited to a wider range of people.

Appendix 0.2: The Staying Alive and Well Group

Working with people with a learning disability is a central part of LeDeR. Our work is informed by a team of people with a learning disability who meet on a regular basis. The group are keen to increase connections with the wider community of people with a learning disability and autism to raise awareness of the report's findings, to ensure that people with a learning disability have opportunities to engage with LeDeR and empower people with a learning disability to advocate for change

“It is about time we speak up for ourselves and not let other people speak up for us”

Frankie, member of Staying Alive and Well

The group chose to name themselves the ‘Staying Alive and Well’ group and ran an art project, open to all people with a learning disability in England, to develop a group logo and artwork to feature in annual reports, deep dives, and research digests. The members of the Staying Alive and Well group had the difficult choice of selecting the winners.

“As we are speaking up for ourselves, we are not just doing it for ourselves, we are doing it for everyone else”

Lee, member of Staying Alive and Well

Appendix 0.2. Continued.

The Staying Alive and Well group is also assisted by several stakeholder groups and organisations. These are: the [Estia Centre](#), [Pathways Associates](#), the [Foundation for People with Learning Disabilities](#), and the [Baked Bean Theatre Company](#). The contributions of people with a learning disability are fundamental to our work on the LeDeR project, and, without their contribution, this report would not be possible

Appendix 0.3: 2023 LeDeR process summarised.

Deaths of autistic adults (aged 18 and over), adults with a learning disability, and autistic adults with a diagnosis of a learning disability are eligible for a LeDeR review. It is important to note that reporting a death to LeDeR is not mandatory, but it is strongly encouraged. Therefore, LeDeR is unlikely to be a complete record of all deaths of people with a learning disability or autism diagnosis in England.

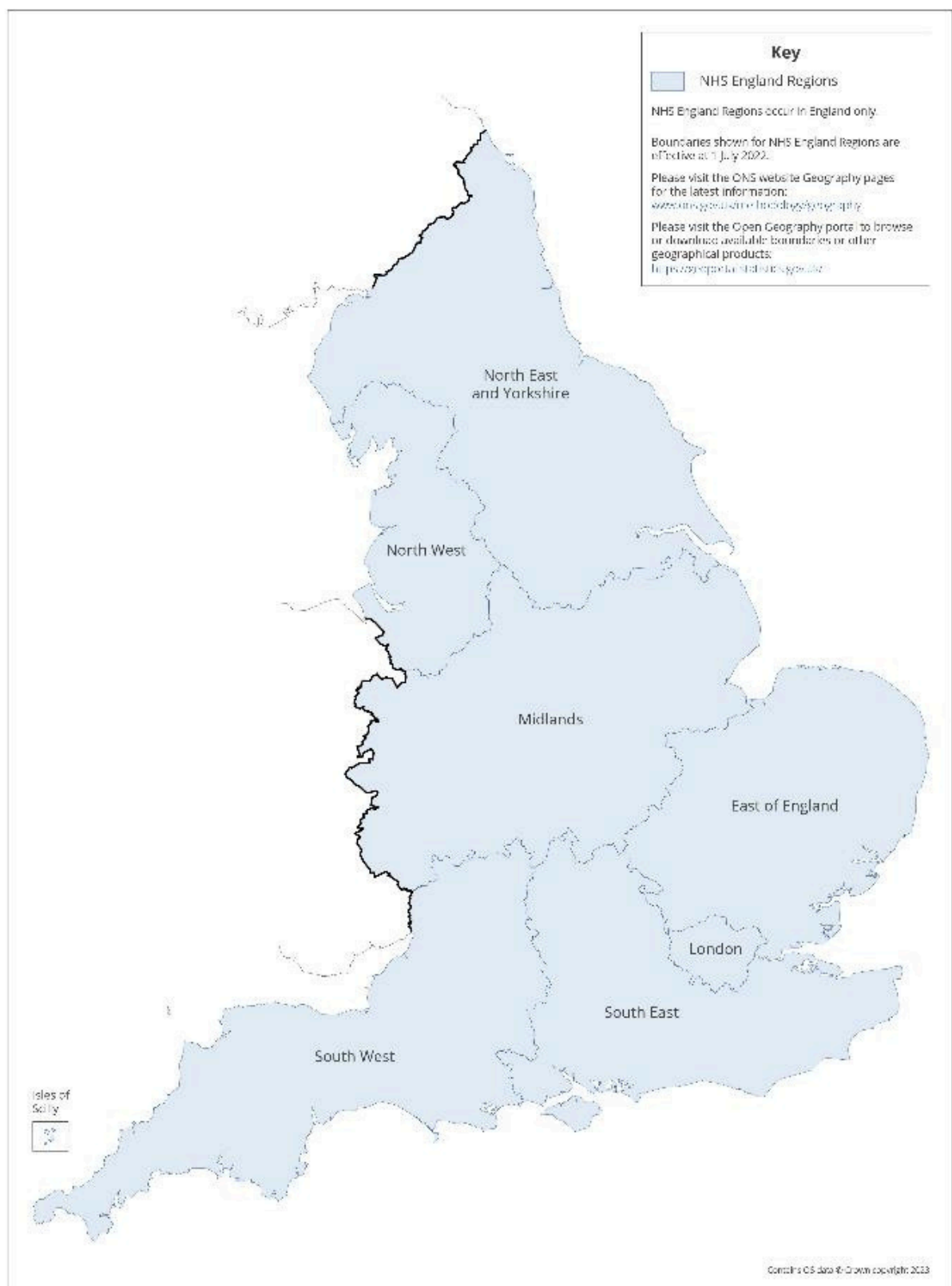
Following a notification of a death to LeDeR via the [website](#), the first step is to check that the notification is within the scope of the LeDeR process (that is, the person was over 18 years of age, lived in England and they had a learning disability or had a diagnosis of being autistic). Following confirmation that the death is within scope, one of the local Integrated Care Board's trained LeDeR reviewers will then gather details on the death from several sources, such as the medical records, the professionals involved in the deceased's care, and by speaking with carers, family members, and loved ones. They will then start the initial review process. The target for the initial review to be completed is within 6 months of starting the review, but there are cases which are more complex, such as those that require a coroner's report, which may be paused while statutory reviews are completed. The review process looks at many aspects of the person's life and death, such as their cause of death, where they lived, and, by using a process called a "pen portrait", creates a detailed story about who this person was and why they died.

For some reviews, this initial review will lead to a more comprehensive "focused" review, which looks even more closely at the person's life and circumstances of death. These focused reviews, once completed, are then considered by the Integrated Care Board's local governance group and detail areas of good practice, areas of concern, and wider areas of learning that can be taken from the persons' death. The governance group will identify actions which can be taken across the ICS to improve services locally to prevent premature and avoidable mortality in the future. Certain groups, such as autistic people, and people from ethnic minority groups, will always receive a focused review. The process is outlined in detail on the website <https://leder.nhs.uk/about>.

Scan to find out
more about
LeDeR



Fig 0.1 shows the NHS regions defined in the LeDeR data. Source: Office For National Statistics (2022)



Appendix 0.4: LeDeR data used in this report.

In the annual LeDeR reports, we use pseudonymised data which reflect the different stages of the LeDeR review process. In this report, we include:

- All notified deaths of people (aged 18+) with a learning disability with or without a diagnosis of autism.
- All completed review data (both initial and focused reviews) for people who died between January 2021 and December 2023 and who had a LeDeR review completed between June 2021 and July 2024.
- For the chapter on deaths of autistic adults we use data about anyone with a clinical diagnosis of autism without a learning disability who died between January 2022 and December 2023 and who had a LeDeR review completed before July 2024 (it also includes a small number of deaths of autistic people who died in 2021 for whom notifications were accepted due to exceptional circumstances).
- Our primary focus is on the completed review data, and this forms most of our analyses and reporting. In each chapter, we explain from which data set (notification, initial reviews, focused reviews) the analysis is drawn. Notification data are used for providing an overview of the type and scope of data, whilst the review data offers more detailed information about a person's life and death health conditions and care and treatment.

Notification data

Anyone, whether they are a doctor, nurse, social worker, family member, or a friend, can report the death of an autistic person or someone with a learning disability by submitting a notification to LeDeR via the LeDeR website at

<https://leder.nhs.uk/report>. The notification form includes basic demographic information about the person who died, such as their name, NHS number (if known), address, date of birth, sex, and ethnic group. The person submitting the form is also asked to provide information about the circumstances of the death of the person who died, including where the death occurred, what they thought caused the death, and whether they had any concerns about the care of the person. During this process, it may become apparent that the notification is not suitable for LeDeR. For example, on further examination, it may be that the deceased person did not have a learning disability or a diagnosis of autism. In these cases, a LeDeR review is not completed, no further data are requested, and the notification is then removed from the dataset.

Initial Review Data

If the notification is found to be eligible for a LeDeR review after initial checks (that is, it is in scope, has not already been reviewed, and is of a person who meets the LeDeR review criteria), it is then passed to the relevant Integrated Care Board (ICB) which allocates the review to a trained reviewer for further information gathering. The reviewer gains more information through talking with people who knew or were involved in the care of the person who died, which includes the family of the person who died and the deceased's clinicians (or viewing their clinical records). The reviewers also look to speak to at least one other person involved in the care of the person who died to build a clear picture of the person's life and their health and care leading up to the time of their death.

The review data are also added to and supported by linkage with other available data, such as the Medical Certificate of Cause of Death (MCCD) data provided by the Office of National Statistics (ONS) and NHS England. This helps to create an overall review of this person's life and the reasons for their death.

Focused Review Data

Focused reviews explore in more detail the life and death of the person and lessons that can be learnt from their care. Only a sample of deaths progress to a focused review. Deaths only receive a focused review in cases where the reviewer feels that there is learning to be gained from the death based on the initial review or if the family of the deceased request a focused review, where the person has been in contact with the criminal justice system in the 5 years prior to death, or if the person is from an ethnic minority group. LeDeR has been reviewing the deaths of people with a diagnosis of autism and no learning disability since 2022. Focused reviews are carried out for all autistic people who did not have a learning disability and whose deaths were reported to LeDeR. In a focused review, reviewers add to data that was already available from the initial review by looking further into the health and social care of the person who died, and the circumstances surrounding their death. More detailed information about the deceased persons' medical history, care, treatment, and their social care arrangements are obtained by working closely with the professionals involved in their care and by accessing additional records, such as coroner's reports (when these are available). Judgements are also made about the quality of care a person received and the reviewer provides explicit learning points to be taken from the review.

Old LeDeR process

King's College London (KCL) and the academic partnership who currently author the LeDeR report began doing so with the 2020 data, with the first report published by them in 2021. This report was the first to use the new system as described above. Prior to this, the University of Bristol team who authored the reports from 2017-2019 were responsible for their own data collection and data management. As such, there are some slight differences between the two datasets.

Appendix 0.5: Medical Certificate of Cause of Death (MCCD) data

MCCDs are usually completed by a doctor involved in the care of the person who died. MCCDs contain the sequence of events or conditions which led to the person's death, including conditions that indirectly contributed to the person's death. Details from the MCCD are matched to initial review data where possible, although in some cases, MCCD data are not available (e.g. if a death is reported to a coroner and there is a delay in the MCCD being completed). MCCDs are split into two parts. Part one contains the sequence of events or conditions that lead directly to death and part two contains conditions which contributed to the person's death that were not on the direct causal pathway.

Underlying causes of death are reported in this chapter. The World Health Organisation (WHO) has defined the [underlying causes of death](#) as the disease or injury that initiates the sequence of events or conditions which led to death. Underlying causes of death can be found anywhere on the death certificate (either in part one or two). The underlying cause of death has been grouped by chapter of the 10th edition of the International Classification of Diseases (ICD-10) to enable easier interpretation and comparison of the most common causes of death.

Appendix 0.6: ICD 10 Chapter colour key

ICD-10 codes and colour key to be used for the following tables and appendices: Table 1.10, Table 2.10, Table 2.12, Table 3.7, Appendix 1.10 and Appendix 2.6.

Code	Chapter	Colour	Code	Chapter	Colour
K00-K95	Diseases of the digestive system	Green	U00-U49 U82-U85	Others (includes COVID-19)	Yellow
Q00-Q99	Congenital malformations, deformations, and chromosomal abnormalities	Light Green	E00-E89	Endocrine, Nutritional, and metabolic	Orange
J00-J99	Diseases of the respiratory system	Cyan	C00-D49	Neoplasms (Cancers)	Pink
I00-I99	Diseases of the circulatory system	Blue	V00-Y98	External causes of morbidity	Dark Blue
F01-F99	Mental and behavioural	Olive	G00-G99	Diseases of the nervous system	Light Purple
D50-D89	Diseases of the blood	Red	This is intentionally blank		

Appendix 0.7: Most common underlying causes of death (ICD-10 codes) and colour Key

ICD-10 codes and colour key to be used for Table 1.11.

Code	Description	Colour
Q909	Down syndrome	Light Green
G809	Cerebral palsy	Yellow
J189	Pneumonia	Cyan
G409	Epilepsy	Light Purple
U071	COVID-19	Red
F03	Unspecified dementia	Orange

Appendix 0.8: Avoidable death causes of death (ICD-10 codes) and colour Key

Colour key to be used for the following tables and appendices: Table 1.13, Table 1.14, Table 3.7, and Appendix 1.11.

Code	Description	Colour
G40-G41	Epilepsy	Light Green
U07.1-U07.2	COVID-19	Orange
J09-J18	Influenza and pneumonia	Cyan
I60-I69	Cerebrovascular diseases	Light Purple
I20-I25	Ischaemic heart diseases	Dark Blue
C15-C16, C18-C22	Malignant neoplasms of digestive organs	Pink
A00-A09, A15-A19, B90, J65, A33, A34, A35, A36, A37, A39, A40, (excl. A40.3), A41 (excl. A41.3), A46, L03, A48.1, A49.1, A49.2, A50-A60, A63, A64, G00.0, G00.1, G00.2, G00.3, G00.8, G00.9, G03, J13, J14, J15, J00-J06, J20-J22, K35-K38, K81, N34.1, N70-N73, N75.0, N75.1, N76.4, N76.6	Other bacterial diseases	Red
J40-J44	Chronic lower respiratory diseases	Blue
C81, C91.0, C91.1	Malignant neoplasms of lymphoid, haematopoietic and related tissue	Olive Green
Q00, Q01, Q05	Certain congenital malformations (neural tube defects)	Green
Q20-Q28	Congenital malformations of the circulatory system (heart defects)	Brown
D10-D36	Benign neoplasms	Purple

Chapter 1

Appendix 1.1: LeDeR notification demographics by age group

Demographic details of adults with a learning disability who died in 2023 and whose deaths were notified to LeDeR by age range compared to adults with a learning disability who died in 2021 and 2022 and the general population[1].

LeDeR notifications								
	Total 2021 Number (%)	Total 2022 Number (%)	Age group 2023 Number (%)				Total 2023 Number (%)	General adult population* 2022 Number (%)
			18 to 24	25 to 49	50 to 64	65+		
Sex registered at birth								
Male	1900 (55.1%)	1,899 (52.8%)	75 (56.3%)	343 (54.8%)	703 (55.2%)	825 (54.1%)	1,946 (54.7%)	266,754 (49.4%)
Female	1460 (42.3%)	1,533 (42.6%)	47 (35.3%)	237 (37.9%)	483 (37.9%)	609 (39.9%)	1,376 (38.6%)	273,579 (50.6%)
Not known	91 (2.6%)	161 (4.4%)	11 (8.2%)	45 (7.3%)	87 (6.8%)	190 (5.9%)	233 (6.5%)	±
Ethnic group*								
Asian or Asian British	84 (2.6%)	121 (3.37%)	20 (17.5%)	41 (7.4%)	23 (2.0%)	9 (0.7%)	93 (2.9%)	±
Black, African, Caribbean, or Black British	57 (1.8%)	70 (1.95%)	6 (5.3%)	21 (3.8%)	35 (3.0%)	9 (0.7%)	71 (2.2%)	±
Mixed ethnic group	63 (2.0%)	19 (0.53%)	*	*	8 (0.7%)	8 (0.6%)	25 (0.8%)	±
Other ethnic group	53 (1.7%)	21 (0.58%)	*	*	11 (1.0%)	6 (0.4%)	24 (0.8%)	±
White	2,942 (92.0%)	3,014 (92.8%)	85 (74.6%)	480 (86.5%)	1,074 (93.3%)	1,337 (97.7%)	2,976 (93.3%)	±
Region***								
London	341 (9.9%)	379 (10.5%)	16 (12.0%)	63 (10.1%)	147 (11.5%)	162 (10.6%)	388 (10.9%)	52,014 (9.6%)
South West	346 (10.0%)	355 (9.8%)	8 (6.0%)	55 (8.8%)	113 (8.9%)	153 (10.0%)	329 (9.3%)	62,546 (11.5%)
South East	557 (16.1%)	541 (15%)	23 (17.3%)	97 (15.5%)	191 (15.0%)	248 (16.3%)	559 (15.7%)	88,237 (16.3%)
Midlands	707 (20.5%)	726 (20.2%)	31 (23.3%)	112 (17.9%)	263 (20.7%)	293 (19.2%)	699 (19.7%)	109,683 (20.2%)
East of England	430 (12.5%)	378 (10.5%)	11 (8.3%)	74 (11.8%)	148 (11.6%)	168 (11.0%)	401 (11.3%)	61,837 (11.4%)
North West	505 (14.6%)	568 (15.8%)	20 (15.0%)	106 (16.9%)	181 (14.2%)	216 (14.2%)	523 (14.7%)	78,626 (14.5%)
North East and Yorkshire	563 (16.3%)	646 (17.9%)	24 (18.0%)	119 (19.0%)	230 (18.1%)	284 (18.6%)	657 (18.5%)	87,390 (16.1%)
Total Number (%)	3,451 (100%)	3,593 (100%)	133 (3.7%)	626 (17.6%)	1,273 (35.8%)	1,524 (42.9%)	3,556 (100%)	540,333 (100%)

± Comparable data not available

*Over the age of 20

**Ethnic group data are discussed further in Chapter 2.

*** Regional data for the ONS differs slightly to the regions used in LeDeR. The ONS regions are East, East Midlands, London, North East, North West, South East, South West, West Midlands, Yorkshire and The Humber. For comparison to LeDeR, East and West Midlands were combined as were the North East and Yorkshire and The Humber.

1 Not all notifications will have a completed review analysed in this report however, a review will be completed over time provided they are in scope.

Appendix 1.2: LeDeR review demographics by age group

Demographic details of adults with a learning disability who died in 2023 for whom a LeDeR review was completed by age range, compared to adults with a learning disability who died in 2021 and 2022, and for whom a LeDeR review was completed, and the general population.

LeDeR Reviews								
	Total 2021 Number (%)	Total 2022 Number (%)	Age group 2023 Number (%)				Total 2023 Number (%)	General adult population* 2022 Number (%)
			18 to 24	25 to 49	50 to 64	65+		
Sex registered at birth								
Female	1,162 (43.2%)	1,334 (44.7%)	25 (37.3%)	170 (45.3%)	368 (40.9%)	458 (42.8%)	1,021 (42.3%)	266,754 (49.4%)
Male	1,507 (56%)	1,631 (54.6%)	40 (59.7%)	201 (53.6%)	523 (58.2%)	604 (56.4%)	1,368 (56.7%)	273,579 (50.6%)
Not known	18 (0.6%)	29 (0.9%)	*	*	8 (0.9%)	9 (0.8%)	23 (1.0%)	±
Ethnic group**								
Asian or Asian British	68 (2.5%)	108 (3.6%)	11 (16.4%)	28 (7.5%)	19 (2.1%)	10 (0.9%)	68 (2.8%)	±
Black African Caribbean or Black British	44 (1.6%)	63 (2.2%)	0 (0.0%)	16 (4.3%)	28 (3.1%)	5 (0.5%)	49 (2.0%)	±
Mixed ethnic group	34 (1.3%)	23 (0.8%)	*	*	5 (0.6%)	*	12 (0.5%)	±
Other ethnic group	12 (0.4%)	14 (0.5%)	*	*	*	*	10 (0.4%)	±
White	2,454 (91.3%)	2,668 (89.4%)	50 (74.6%)	313 (83.5%)	823 (91.5%)	1032 (96.4%)	2,218 (92.0%)	±
Region***								
London	230 (8.5%)	309 (10.3%)	8 (11.9%)	35 (9.3%)	101 (11.2%)	112 (10.5%)	256 (10.6%)	52,014 (9.6%)
South West	263 (9.7%)	311 (10.4%)	*	*	78 (8.7%)	109 (10.2%)	223 (9.2%)	62,546 (11.5%)
South East	426 (15.8%)	481 (16.1%)	10 (14.9%)	60 (16.0%)	125 (13.9%)	159 (14.8%)	354 (14.7%)	88,237 (16.3%)
Midlands	544 (20.2%)	625 (20.9%)	21 (31.3%)	89 (23.7%)	218 (24.2%)	243 (22.7%)	571 (23.7%)	109,683 (20.2%)
East of England	351 (13%)	331 (11%)	7 (10.4%)	43 (11.5%)	112 (12.5%)	117 (10.9%)	279 (11.6%)	61,837 (11.4%)
North West	404 (15%)	424 (14.2%)	8 (11.9%)	48 (12.8%)	101 (11.2%)	125 (11.7%)	282 (11.7%)	78,626 (14.5%)
North East and Yorkshire	469 (17.4%)	502 (16.8%)	9 (13.4%)	68 (18.1%)	164 (18.2%)	206 (19.2%)	447 (18.5%)	87,390 (16.1%)

Appendix 1.2: Continued

LeDeR Reviews								
	Total 2021 Number (%)	Total 2022 Number (%)	Age group 2023 Number (%)				Total 2023 Number (%)	General adult population* 2022 Number (%)
			18 to 24	25 to 49	50 to 64	65+		
Index of multiple deprivation decile								
1 (most deprived)	366 (13.7%)	394 (13.3%)	9 (13.6%)	59 (15.8%)	125 (14.0%)	144 (13.5%)	337 (14.0%)	56,197 (10.9%)
2	344 (12.9%)	383 (12.9%)	.12 (18.2%)	40 (10.7%)	137 (15.3%)	128 (12.0%)	317 (13.2%)	53,506 (9.9%)
3	320 (12.0%)	338 (11.4%)	5 (7.6%)	37 (9.9%)	116 (12.9%)	120 (11.3%)	278 (11.6%)	52,404 (9.6%)
4	319 (11.9%)	339 (11.4%)	9 (13.6%)	36 (9.7%)	93 (10.4%)	124 (11.6%)	262 (10.9%)	54,709 (10.1%)
5	289 (10.8%)	342 (11.5%)	7 (10.6%)	36 (9.7%)	110 (12.3%)	123 (11.5%)	276 (11.5%)	55,203 (10.2%)
6	254 (9.5%)	294 (9.9%)	*	*	94 (10.5%)	102 (9.6%)	237 (9.9%)	55,892 (10.3%)
7	227 (8.5%)	312 (10.5%)	*	*	65 (7.3%)	82 (7.7%)	187 (7.8%)	55,729 (10.3%)
8	234 (8.7%)	243 (8.2%)	8 (12.1%)	28 (7.5%)	62 (6.9%)	87 (8.2%)	185 (7.7%)	54,359 (10%)
9	183 (6.8%)	193 (6.5%)	6 (9.1%)	40 (10.7%)	52 (5.8%)	92 (8.6%)	190 (7.9%)	52,667 (9.7%)
10 (least deprived)	139 (5.2%)	134 (4.5%)	*	*	42 (4.7%)	63 (5.9%)	131 (5.5%)	49,667 (9.2%)
Total number of reviews (%)	2,687 (100%)	2,983 (100%)	67 (2.8%)	375 (15.5%)	899 (37.3%)	1071 (44.4%)	2,412 (100.0%)	Total number of deaths 540,333 (100%)

± Comparable data not available

*Over the age of 20

**Ethnic group data are discussed further in Chapter 2.

*** Regional data for the ONS differs slightly to the regions used in LeDeR. The ONS regions are East, East Midlands, London, North East, North West, South East, South West, West Midlands, Yorkshire, and The Humber. For comparison to LeDeR, East and West Midlands were combined as were the North East and Yorkshire and The Humber.

Appendix 1.3: Marital status, children, employment, and sexual orientation by age group

Marital status, children, sexual orientation, and employment for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024, by year.

	Total 2021 Number (%)	Total 2022 Number (%)	Total 2023 Number (%)	General adult population* 2022 Number (%)
Marital status				
Single	2,028 (94.1%)	2,527 (94.0%)	2,082 (94.9%)	±
Married or civil partner	54 (2.5%)	74 (2.8%)	59 (2.7%)	±
Separated	8 (0.3%)	10 (0.4%)	8 (0.4%)	±
Divorced	29 (1.3%)	32 (1.2%)	14 (0.6%)	±
Widowed	37 (1.7%)	45 (1.7%)	30 (1.4%)	±
Did the person have children?				
No	2029 (95.9%)	2,357 (95.0%)	1,910 (95.4%)	±
Yes	87 (4.1%)	125 (5.0%)	92 (4.6%)	±
Sexual orientation**				
Heterosexual	46 (65.7%)	558 (72.5%)	794 (71.3%)	±
Gay or lesbian	*	*	*	±
Bisexual	*	*	*	±
Other	*	*	8 (0.7%)	±
Not known	*~34%	*~27%	*~27%	
Employment				
No	2,183 (98.2%)	2,509 (98.2%)	2,048 (98.4%)	±
Employed (paid)	17 (0.8%)	19 (0.7%)	14 (0.7%)	±
Employed (voluntary)	22 (1.0%)	27 (1.1%)	19 (0.9%)	±

± Comparable data not available

*Over the age of 20

**Sexuality was not directly asked until 2022. For the row "does not know" reviewers had the option of inputting either "asked and does not know or is not sure" or "person asked but declined to provide a response." For this report both options have been combined.

Appendix 1.4: Place of death

Place of death details for adults with a learning disability who died in from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024, by age range and the general population.

	Total 2021 Number (%)	Total 2022 Number (%)	Age group 2023 Number (%)				Total 2023 Number (%)	General adult population* 2022 Number (%)
			18 to 24	25 to 49	50 to 64	65+		
Place of death								
Hospital	1585 (58.9%)	1743 (58.4%)	43 (64.2%)	221 (58.9%)	511 (56.8%)	606 (56.6%)	1381 (57.3%)	235,588 (43.6%)
Usual place of residence	1005 (37.4%)	1102 (36.9%)	*	*	334 (37.2%)	423 (39.5%)	900 (37.3%)	365,070 (49.1%)
Other	97 (3.6%)	138 (4.6%)	*	*	52 (5.8%)	41 (3.8%)	128 (5.3%)	39,675 (7.3%)
Total Number (%)	2687 (100%)	2983 (100%)	67 (2.8%)	375 (15.5%)	899 (37.3%)	1071 (44.4%)	2412 (100%)	540,333 (100%)

Over the age of 20

**Hospital includes acute or community hospitals; Usual place of residence includes the person's home, the home of a friend or relative, or a residential nursing home; Other includes hospices, public places, secure units etc.

Appendix 1.5: DNACPR

Number of people with a DNACPR decision in place for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024, by age range.

	Total 2021 Number (%)	Total 2022 Number (%)	Age group 2023 Number (%)				Total 2023 Number (%)
			18 to 24	25 to 49	50 to 64	65+	
Yes	1947 (72.5%)	2150 (72.1%)	47 (70.1%)	230 (61.3%)	665 (74.0%)	879 (82.9%)	1821 (75.5%)
No	739 (27.5%)	833 (27.9%)	20 (29.9%)	145 (38.7%)	234 (26.0%)	192 (17.9%)	591 (24.5%)
Total Number (%)	2,686 (100%)	2,983 (100%)	67 (100%)	375 (100%)	899 (100%)	1071 (100%)	2412 (100%)

Appendix 1.6: Coroner reporting

Number of deaths reported to the coroner for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024.

	Total 2021 Number (%)	Total 2022 Number (%)	Age group 2023 Number (%)				Total for 2023 Number (%)	General adult population* 2022 Number (%)
			18 to 24	25 to 49	50 to 64	65+		
Death reported to a coroner								
Yes	242 (40.5%)	344 (41.1%)	17 (58.6%)	64 (48.1%)	88 (35.9%)	54 (26.3%)	223 (36.4%)	208,430 (38.6%)
No	355 (59.4%)	491 (58.8%)	12 (41.3%)	69 (51.8%)	157 (67.0%)	151 (73.6%)	389 (63.5%)	331,903 (61.4%)
Total Number (%)	597 (100%)	835 (100%)	29 (4.7%)	133 (21.7%)	245 (40.0%)	205 (33.4%)	612 (100%)	540,333 (100%)

Appendix 1.7: Police investigation

Number of deaths that had a Police investigation for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024.

	Total 2021 Number (%)	Total 2022 Number (%)	Age group 2023 Number (%)				Total for 2023 Number (%)
			18 to 24	25 to 49	50 to 64	65+	
Was there a police investigation?							
Yes	27 (4.4%)	33 (3.8%)	*	*	5 (2.0%)	5 (2.4%)	14 (2.2%)
No	584 (95.5%)	817 (96.1%)	*	*	243 (98.0%)	203 (97.6%)	612 (97.8%)
Total Number (%)	611 (100%)	850 (100%)	30 (4.8%)	140 (22.4%)	248 (39.6%)	208 (33.2%)	626 (100%)

*

Appendix 1.8: Safeguarding enquiry

Number of safeguarding enquiries for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024.

	Total 2021 Number (%)	Total 2022 Number (%)	Age group 2023 Number (%)				Total for 2023 Number (%)
			18 to 24	25 to 49	50 to 64	65+	
Was there a safeguarding enquiry?							
Yes	101 (16.5%)	79 (9.2%)	*	*	22 (8.9%)	17 (8.2%)	44 (7.0%)
No	510 (83.4%)	771 (90.7%)	*	*	226 (91.1%)	191 (91.8%)	582 (93.0%)
Total Number (%)	611 (100%)	850 (100%)	30 (4.8%)	140 (22.4%)	248 (39.6%)	208 (33.2%)	626 (100%)

Appendix 1.9: ICD 10 chapters, codes, and descriptions

Chapter	Code range	Description
1	A00-B99	Certain infectious and parasitic diseases
2	C00-D49	Neoplasms
3	D50-D89	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism
4	E00-E89	Endocrine, nutritional, and metabolic diseases
5	F01-F99	Mental, Behavioral and Neurodevelopmental disorders
6	G00-G99	Diseases of the nervous system
7	H00-H59	Diseases of the eye and adnexa
8	H60-H95	Diseases of the ear and mastoid process
9	I00-I99	Diseases of the circulatory system
10	J00-J99	Diseases of the respiratory system
11	K00-K95	Diseases of the digestive system
12	L00-L99	Diseases of the skin and subcutaneous tissue
13	M00-M99	Diseases of the musculoskeletal system and connective tissue
14	N00-N99	Diseases of the genitourinary system
15	O00-O9A	Pregnancy, childbirth, and the puerperium
16	P00-P96	Certain conditions originating in the perinatal period
17	Q00-Q99	Congenital malformations, deformations, and chromosomal abnormalities
18	R00-R99	Symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified
19	S00-T88	Injury, poisoning and certain other consequences of external causes
20	V00-Y99	External causes of morbidity
21	Z00-Z99	Factors influencing health status and contact with health services

Appendix 1.10: Most common causes of death

The most common causes of death by age range for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024 (overleaf).

Appendix 1.10: Continued

Year of Death	Ranking	Total (%) 2021	Total (%) 2022	Total (%) 2023
Age group				
18-24	First	Diseases of the nervous system (38.4%)	Diseases of the nervous system (35.7%)	Diseases of the nervous system (50.0%)
	Second	Congenital malformations, deformations, and chromosomal abnormalities (15.2%)	Congenital malformations, deformations, and chromosomal abnormalities (14.3%)	Congenital malformations, deformations, and chromosomal abnormalities (9.6%)
				Neoplasms (9.6%)
	Third	Diseases of the respiratory system (8.1%)	Diseases of the respiratory system (10.8%)	Mental, behavioral, and neurodevelopmental disorders (7.7%)
	Fourth	Others (incl. COVID-19) (7.1%)	Neoplasms (6.3%)	Diseases of the circulatory system (5.8%)
			Diseases of the circulatory system (6.3%)	
			Diseases of the digestive system (6.3%)	
	Fifth	Endocrine, nutritional & metabolic (6.1%)	Others (incl. COVID-19) (5.4%)	Diseases of the respiratory system (3.8%)
		External causes of morbidity (6.1%)		Endocrine, nutritional, and metabolic (3.8%)
25-49	First	Diseases of the nervous system (23.3%)	Diseases of the nervous system (23.9%)	Diseases of the nervous system (23.9%)
	Second	Diseases of the circulatory system (13.0%)	Congenital malformations, deformations, and chromosomal abnormalities (12.1%)	Neoplasms (16.9%)
	Third	Congenital malformations, deformations, and chromosomal abnormalities (11.9%)	Neoplasms (11.9%)	Congenital malformations, deformations, and chromosomal abnormalities (15.4%)
	Fourth	Others (incl. COVID-19) (11.7%)	Diseases of the circulatory system (11.6%)	Diseases of the circulatory system (11.0%)
	Fifth	Neoplasms (10.3%)	Diseases of the respiratory system (9.5%)	Diseases of the respiratory system (9.6%)
50-64	First	Congenital malformations, deformations, and chromosomal abnormalities (19.1%)	Congenital malformations, deformations, and chromosomal abnormalities (21.5%)	Congenital malformations, deformations, and chromosomal abnormalities (23.1%)

*For colour key please see Appendix 0.6

Appendix 1.10: Continued

Year of Death	Ranking	Total (%) 2021	Total (%) 2022	Total (%) 2023
50-64	Second	Diseases of the circulatory system (15.9%)	Diseases of the circulatory system (16.5%)	Neoplasms (17.9%)
	Third	Neoplasms (15.0%)	Neoplasms (14.1%)	Diseases of the circulatory system (14.4%) Diseases of the respiratory system (14.4%)
	Fifth	Others (incl. COVID-19) (10.8%)	Diseases of the respiratory system (12.7%)	Diseases of the digestive system (5.6%)
65+	First	Diseases of the circulatory system (17.1%)	Diseases of the respiratory system (20.8%)	Diseases of the respiratory system (21.2%)
	Second	Diseases of the respiratory system (16.4%)	Diseases of the circulatory system (18.6%)	Diseases of the circulatory system (20.4%)
	Third	Neoplasms (13.9%)	Neoplasms (16.1%)	Neoplasms (15.8%)
	Fourth	Others (incl. COVID-19) (13.5%)	Diseases of the nervous system (8.8%)	Diseases of the nervous system (9.7%)
	Fifth	Mental, behavioural, and neurodevelopmental disorders (8.5%)	Diseases of the digestive system (7.5%)	Mental, behavioural, and neurodevelopmental disorders (7.1%)
Sex registered at birth				
Female	First	Neoplasms (14.2%)	Neoplasms (15.2%)	Neoplasms (17.5%)
	Second	Diseases of the circulatory system (13.8%)	Diseases of the circulatory system (15.0%)	Diseases of the respiratory system (15.8%)
	Third	Diseases of the respiratory system (12.9%)	Diseases of the nervous system (14.3%)	Congenital malformations, deformations, and chromosomal abnormalities (14.9%)
	Fourth	Others (incl. COVID-19) (11.9%)	Diseases of the respiratory system (14.1%)	Diseases of the circulatory system (14.1%)
	Fifth	Congenital malformations, deformations, and chromosomal abnormalities (11.7%)	Congenital malformations, deformations, and chromosomal abnormalities (13.5%)	Diseases of the nervous system (13.0%)

*For colour key please see Appendix 0.6

Appendix 1.10: Continued

Year of Death	Ranking	Total (%) 2021	Total (%) 2022	Total (%) 2023
Male	First	Diseases of the circulatory system (16.8%)	Diseases of the circulatory system (16.9%)	Diseases of the circulatory system (18.1%)
	Second	Diseases of the respiratory system (13.1%)	Diseases of the respiratory system (16.7%)	Diseases of the respiratory system (17.1%)
	Third	Neoplasms (12.6%)	Neoplasms (13.8%)	Neoplasms (16.1%)
	Fourth	Diseases of the nervous system (12.6%)	Diseases of the nervous system (13.6%)	Diseases of the nervous system (13.9%)
	Fifth	Others (incl. COVID-19) (12.2%)	Congenital malformations, deformations, and chromosomal abnormalities (12.6%)	Congenital malformations, deformations, and chromosomal abnormalities (13.3%)

Appendix 1.11: Most common avoidable causes of death

The most common causes of avoidable death by age range for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024.

Age group	Rank	Total 2021 Number (%)	Total 2022 Number (%)	Total 2023 Number (%)
18-24	First	Epilepsy (21.1%)	Epilepsy (29.0%)	Epilepsy (46.7%)
	Second	COVID-19 (18.4%)	Influenza and pneumonia (15.8%)	Chronic lower respiratory diseases (13.3%)
	Third	Congenital malformations of the circulatory system (7.9%)	COVID-19 (15.8%)	Benign neoplasms (6.7%)
				Cerebrovascular diseases (6.7%)
				Congenital malformations of the nervous system (6.7%)
				Malignant neoplasms of lymphoid, haematopoietic and related tissue (6.7%)
				Other bacterial diseases (6.7%)
				COVID-19 (6.7%)
25-49	First	COVID-19 (22.2%)	Epilepsy (29.0%)	Epilepsy (11.6%)
	Second	Epilepsy (14.6%)	COVID-19 (12.0%)	Malignant neoplasms of digestive organs (9.1%)
	Third	Influenza and pneumonia (7.1%)	Influenza and pneumonia (11.2%)	Influenza and pneumonia (8.3%)
50-64	First	COVID-19 (19.4%)	Influenza and pneumonia (13.7%)	Influenza and pneumonia (15.9%)
	Second	Influenza and pneumonia (11.5%)	Ischaemic heart diseases (10.9%)	Malignant neoplasms of digestive organs (10.5%)
	Third	Ischaemic heart diseases (11.1%)	COVID-19 (8.5%)	Ischaemic heart disease (10.2%)
65+	First	COVID-19 (25.4%)	Influenza and pneumonia (16.5%)	Influenza and pneumonia (17.5%)
	Second	Influenza and pneumonia (12.4%)	Ischaemic heart diseases (13.3%)	Cerebrovascular diseases (11.4%)
	Third	Ischaemic heart diseases (10.2%)	Cerebrovascular diseases (10.0%)	Ischaemic heart diseases (11.4%)

*For Table colour key please see Appendix 0.8

Chapter 2

Appendix 2.1: Marital status by ethnic group

Marital status by ethnic group for adults with a learning disability who died from January 2021 to December 2023 and for whom a LeDeR review was completed between June 2021 and July 2024.

Ethnic group*	Married – Civil partnership	Divorced	Single	Not disclosed	Separated	Widowed	Total
Asian or Asian British	12 (7.8%)	*	203 (83.9%)	21 (8.7%)	*	*	242
Black, African, Caribbean, or Black British	*	*	138 (90.2%)	12 (7.8%)	*	*	153
Mixed ethnic group	*	*	50 (75.8%)	13 (19.7%)	*	*	66
Other ethnic group	*	*	29 (80.6%)	6 (16.7%)	*	*	36
White	164 (2.3%)	71 (1.0%)	6,077 (84.8%)	725 (10.1%)	24 (0.3%)	109 (1.5%)	7,170
Total number (%)	182 (2.4%)	74 (1.0%)	6497 (84.7%)	777 (10.1%)	26 (0.3%)	111 (1.4%)	7,667

*Ethnic group and marital status were available for 7,667 out of 8,082 reviews.

Appendix 2.2: Sexual orientation by ethnic group

Sexual orientation* by ethnic group for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024.

Ethnic group**	Heterosexual	Gay or Lesbian	Bisexual	Other	Not known***	Total
Asian or Asian British	46 (71.9%)	*	*	*	*	64
Black, African, Caribbean, or Black British	33 (73.3%)	*	*	*	*	45
Mixed ethnic group	8 (80%)	*	*	*	*	10
Other ethnic group	9 (81.8%)	*	*	*	*	11
White	1,286 (71.5%)	*	*	*	491 (27.3%)	1,799
Total number (%)	1,382 (71.6%)	*	*	*	523 (27.1%)	1,929

*Sexual orientation was not directly asked until 2022.

**Sexual orientation and ethnic group data were available for 1,929 out of 8,082 reviews.

***Reviewers had the option of selecting "I do not know" or leaving the section blank for sexual orientation. For this table, these have been combined.

Appendix 2.3: Employment by ethnic group

Employment status by ethnic group for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024.

Ethnic group*	Yes – Paid	Yes – Volunteer	No	I don't know**	Total
Asian or Asian British	*	*	217 (88.9%)	*	244
Black, African, Caribbean, or Black British	*	*	138 (88.5%)	*	156
Mixed ethnic group	*	*	58 (84.1%)	*	69
Other ethnic group	*	*	*	*	36
White	50 (0.7%)	64 (0.9%)	6,148 (83.3%)	1078 (14.7%)	7,340
Total number (%)	50 (0.6%)	67 (0.9%)	6,596 (84.1%)	1132 (14.4%)	7,845

*Employment and ethnic group data were available for 7,845 out of 8,082 reviews.

**Reviewers had the option of selecting 'I do not know' or leaving the question blank. For this table, these have been combined.

Appendix 2.4: Police investigation by ethnic group

Police investigation by ethnic group for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024.

Ethnic group*	Yes	No	Total
Asian or Asian British	8 (3.4%)	230 (96.6%)	238
Black, African, Caribbean, or Black British	*	*	*
Mixed ethnic group	*	*	*
Other ethnic group	*	*	*
White	59 (3.8%)	1,482 (96.2%)	1,541
Total number (%)	74 (3.7%)	1,953 (96.3%)	2,027

*Ethnic group and police investigation data were available for 2,027 reviews

Appendix 2.5: Safeguarding enquiry by ethnic group

Safeguarding enquiries by ethnic group for adults with a learning disability who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024.

Ethnic group*	Yes	No	Total
Asian or Asian British	16 (6.7%)	222 (93.3%)	238
Black, African, Caribbean, or Black British	6 (3.9%)	149 (96.1%)	155
Mixed ethnic group	*	*	*
Other ethnic group	*	*	*
White	191 (12.4%)	1350 (87.6%)	1541
Total number (%)	219 (10.8%)	1808 (89.2%)	2027

*Ethnic group and safeguarding enquiry data were available for 2,027 of the 8082 reviews.

Appendix 2.6: Most common causes of death by ethnic group

The most common ICD-10 chapter causes of death by ethnic group and age group for adults with a learning disability, who died from January 2021 to December 2023, and for whom a LeDeR review was completed between June 2021 and July 2024.

Rank	First	Second	Third	Fourth	Fifth
Age group	Asian or Asian British				
18-24	Diseases of the nervous system (31.8%)	Congenital malformations, deformations, and chromosomal abnormalities (22.7%)	Endocrine, Nutritional, and metabolic (13.6%)	Diseases of the digestive system (6.8%)	Diseases of the respiratory system (6.8%)
25-49	Diseases of the nervous system (25.3%)	Diseases of the respiratory system (19.8%)	Diseases of the circulatory system (9.9%)	Diseases of the digestive system (8.8%)	Neoplasms (7.7%)
50-64	Neoplasms (14.5%)	Diseases of the circulatory system (14.5%)	Diseases of the nervous system (12.7%)	Others (including Covid 19) (12.7%)	Diseases of the respiratory system (10.9%)
					Congenital malformations (10.9%)
65+	Diseases of the circulatory system (20.7%)	Diseases of the respiratory system (20.7%)	Mental, Behavioural and Neurodevelopmental disorders (13.8%)	Diseases of the nervous system (10.0%)	Diseases of the digestive system (10.3%)

*For Table colour key please see Appendix 0.6

Appendix 2.6: Continued

Rank	First	Second	Third	Fourth	Fifth
Age group	Black, African, Caribbean or Black British				
18-24	Diseases of the nervous system (62.5%)	Diseases of the blood (18.8%)	Congenital malformations, deformations, and chromosomal abnormalities (6.3%)	Others (including Covid 19) (6.3%)	External causes of morbidity (6.3%)
25-49	Diseases of the circulatory system (23.5%)	Neoplasms (17.6%)	Diseases of the nervous system (11.8%)	Diseases of the digestive system (11.8%)	Congenital malformations, deformations, and chromosomal abnormalities (8.8%)
50-64	Diseases of the circulatory system (22.1%)	Neoplasms (18.2%)	Congenital malformations, deformations, and chromosomal abnormalities (18.2%)	Diseases of the respiratory system (15.6%)	Diseases of the nervous system (10.4%)
65+	Diseases of the respiratory system (21.4%)	Congenital malformations, deformations, and chromosomal abnormalities (14.3%)	Diseases of the digestive system (14.3%)	Endocrine, nutritional, and metabolic (14.3%)	Neoplasms (7.1%)
					Diseases of the nervous system (7.1%)
					Others (including Covid 19) (7.1%)
					External causes of morbidity (7.1%)

*For Table colour key please see Appendix 0.6

Appendix 2.6: Continued

Rank	First	Second	Thrid	Fourth	Fifth
Age group	Mixed ethnic group				
18-24	Diseases of the nervous system (33.3%)	Others (including Covid 19) (33.3%)	Neoplasms (11.1%)	Diseases of the digestive system (11.1%)	Diseases of the respiratory system (11.1%)
25-49	Others (including Covid 19) (20.8%)	Congenital malformations, deformations, and chromosomal abnormalities (12.5%)	Diseases of the circulatory system (12.5%)	Diseases of the digestive system (12.5%)	Neoplasms (12.5%)
50-64	Diseases of the circulatory system (28.6%)	Others (including Covid 19) (14.3%)	Congenital malformations, deformations, and chromosomal abnormalities (14.3%)	Diseases of the nervous system (14.3%)	Diseases of the respiratory system (14.3%)
65+	Diseases of the respiratory system (33.3%)	Neoplasms (16.7%)	Diseases of the nervous system (16.7%)	Others (including Covid 19) (8.3%)	Endocrine, nutritional, and metabolic (8.3%)
					Congenital malformations, deformations, and chromosomal abnormalities (8.3%)
					Diseases of the digestive system (8.3%)

*For Table colour key please see Appendix 0.6

Appendix 2.6: Continued

Rank	First	Second	Third	Fourth	Fifth
Age group	Other ethnic group				
18-24	Diseases of the nervous system (33.3%)	Congenital malformations, deformations, and chromosomal abnormalities (33.3%)	Other (including Covid 19) (16.7%)	Diseases of the respiratory system (16.7%)	<5
25-49	Diseases of the digestive system (25.0%)	Mental, Behavioural and Neurodevelopmental disorders (25.0%)	Others (including Covid 19) (12.5%)	Diseases of the nervous system (12.5%)	Diseases of the respiratory system (12.5%)
					Neoplasms (12.5%)
50-64	Diseases of the nervous system (37.5%)	Diseases of the respiratory system (25%)	Others (including Covid 19) (12.5%)	Diseases of the circulatory system (12.5%)	Neoplasms (12.5%)
65+	Neoplasms (42.9%)	Diseases of the circulatory system (28.6%)	Others (including Covid 19) (14.3%)	Diseases of the digestive system (14.3%)	<5

<5 – Less than 5

*For Table colour key please see Appendix 0.6

Appendix 2.6: Continued

Rank	First	Second	Third	Fourth	Fifth
Age group	White				
18-24	Diseases of the nervous system (40.3%)	Congenital malformations, deformations, and chromosomal abnormalities (12.2%)	Diseases of the respiratory system (9.4%)	Neoplasms (7.2%)	Diseases of the circulatory system (6.6%)
24-49	Diseases of the nervous system (24.6%)	Congenital malformations, deformations, and chromosomal abnormalities (13.4%)	Neoplasms (12.7%)	Diseases of the circulatory system (11.9%)	Diseases of the digestive system (8.2%)
50-64	Congenital malformations, deformations, and chromosomal abnormalities (21.7%)	Neoplasms (15.5%)	Diseases of the circulatory system (15.3%)	Diseases of the respiratory system (12.9%)	Diseases of the nervous system (11.4%)
65+	Diseases of the respiratory system (19.3%)	Diseases of the circulatory system (18.5%)	Neoplasms (15.3%)	Diseases of the nervous system (8.4%)	Others (including Covid 19) (7.7%)

*For Table colour key please see Appendix 0.6

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