Appendicies

LeDeR

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.
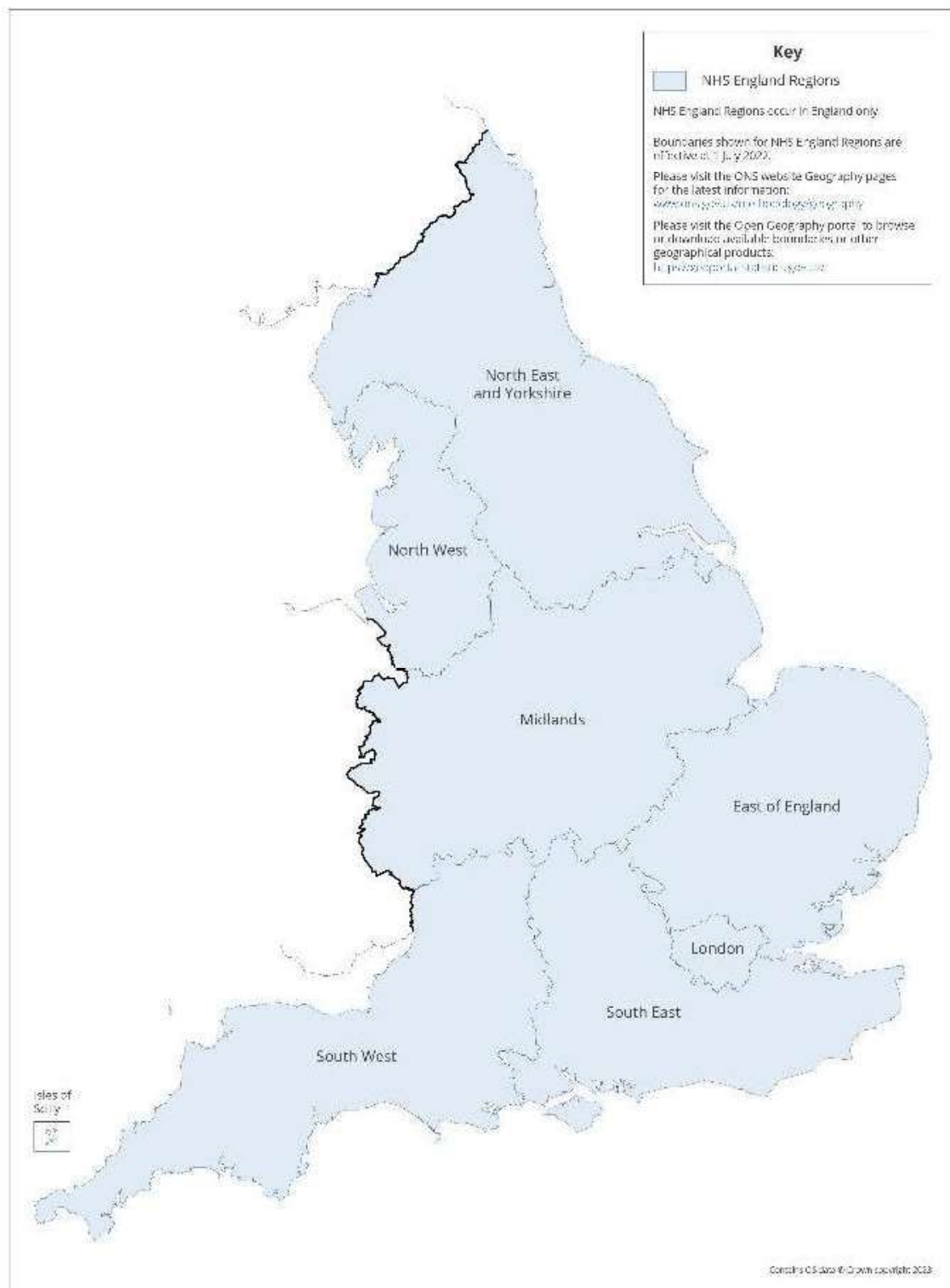
Following a notification of a death to LeDeR via the website, the first step is to check that the notification is within the scope of the LeDeR process (that is, the person was over 18 years of age, lived in England and they had a learning disability or had a diagnosis of being autistic). Following confirmation 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		U00-U49 U82-U85	Others (includes COVID-19)	
Q00-Q99	Congenital malformations, deformations, and chromosomal abnormalities		E00-E89	Endocrine, Nutritional, and metabolic	
J00-J99	Diseases of the respiratory system		C00-D49	Neoplasms (Cancers)	
I00-I99	Diseases of the circulatory system		V00-Y98	External causes of morbidity	
F01-F99	Mental and behavioural		G00-G99	Diseases of the nervous system	
D50-D89	Diseases of the blood		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	
G809	Cerebral palsy	
J189	Pneumonia	
G409	Epilepsy	
U071	COVID-19	
F03	Unspecified demetia	

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	
U07.1-U07.2	COVID-19	
J09-J18	Influenza and pneumonia	
I60-I69	Cerebrovascular diseases	
I20-I25	Ischaemic heart diseases	
C15-C16, C18-C22	Malignant neoplasms of digestive organs	
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	
J40-J44	Chronic lower respiratory diseases	
C81, C91.0, C91.1	Malignant neoplasms of lymphoid, haematopoietic and related tissue	
Q00, Q01, Q05	Certain congenital malformations (neural tube defects)	
Q20-Q28	Congenital malformations of the circulatory system (heart defects)	
D10-D36	Benign neoplasms	

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.

	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

	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+		
LeDeR Reviews								
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 (6.3%) / Diseases of the digestive system (6.3%)	Diseases of the circulatory system (5.8%)
	Fifth	Endocrine, nutritional & metabolic (6.1%) / External causes of morbidity (6.1%)	Others (incl. COVID-19) (5.4%)	Diseases of the respiratory system (3.8%) / 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

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

125