Appendicies

LeDeR

Annual Report 2022

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

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Chapter 1 – Descriptive and Demographic Data

Table A1.1. LeDeR notifications by sex for 2018-2022, compared to ONS data of deaths from the general population.

Children and adults combined.	**2018**	**2019**	**2020**	**2021**	**2022**	**General Population (2020)**
Males	58%	57%	57%	56%	55%	51%
Females	42%	43%	43%	44%	45%	49%
Total No.	2,613	2,825	3,652	3,304	3,328	607,922
Adults (18+)						
Males	58%	57%	57%	56%	55%	51%
Females	42%	43%	43%	44%	45%	49%
Total No.	2,416	2,595	3,442	3,096	3,044	604,406
Children (4-17)						
Males	54%	57%	61%	50%	59%	60%
Females	46%	43%	39%	50%	41%	40%
Total No.	197	230	210	208	284	865

https://www.ons.gov.uk/releases/deathsregisteredinenglandandwales2020

Note: Reporting to LeDeR is not mandatory. In 2022 the LeDeR started to collect data on autistic adults without a learning disability in addition to people with a learning disability.

Table A1.2. LeDeR notifications by ethnicity for 2018-2022, compared to ONS data of deaths from the general population in England and Wales.

Children and adults	**2018**	**2019**	**2020**	**2021**	**2022**	**General Population (2017-2019)**
Asian or Asian British	2%	1%	1%	3%	5%	2%
Black, black British, Caribbean or African	2%	2%	2%	2%	2%	1%
Mixed ethnic group	3%	4%	5%	3%	<1%	<1%
Other	1%	2%	2%	1%	<1%	<1%
White	92%	91%	90%	91%	90%	96%
Total No.	2,528	2,745	3,522	3,104	3,189	2,884,017

Mortality from leading causes of death by ethnic group, England and Wales - Office for National Statistics (ons.gov.uk) Note, general population data is for adults 10 years and above who died in England and Wales between 2017-2019.

Chapter 2 – Circumstances and causes of death

Table A2.1: Place of death for adults with a learning disability who died between 2018 and 2022 and had a completed LeDeR review, with comparison data from the general population.

	Adults with a learning disability			General population
Place of death	**2018 and 2019**	**2020 and 2021**	**2022**	**2021**
Hospital	58.0%	60.1%	57.4%	45%
Usual place of residence	33.0%	34.0%	38.8%	44%
Other	5.7%	4.1%	3.6%	11%
Not recorded	3.3%	1.8%	0.1%	-
Total number of adults	4,844	6,391	2,084	-

A2.2: When are deaths reported to a coroner?

A death should be notified to a coroner in the following circumstances:

- Where the cause of death is unknown
- Where there was no attending registered medical practitioner and there was no other medical practitioner available to sign the cause of death certificate.
- The registered medical practitioner suspects that the death has taken place while in custody or state detention (e.g. prison, police custody, immigration detention centre, when someone is held under mental health legislation).
- The identity of the deceased person is unknown

Deaths should also be reported if caused by:

- poisoning
- exposure to, or contact with a toxic substance
- the use of a medicinal product, the use of a controlled drug or psychoactive substance
- violence, trauma or injury
- self-harm
- neglect, including self-neglect
- undergoing any treatment or procedure of a medical or similar nature
- injury or disease related to any employment held by the person during the person's lifetime
- any other unnatural cause that does not fall within the above circumstance

A2.3: Which leading causes of death were presented in this report?

This report presents the 10 (including COVID-19) leading causes of death of adults with a learning disability who died between 2018 and 2022 and had a review completed by LeDeR before July 13th, 2023. COVID-19 was included using the following ICD-10 codes: U.071, U.072 and U10.9.

Presenting the top 10 leading causes of death meant that more than 55% of the total number of deaths for each time period were included across all of the analyses for this chapter.

Table A2.4.1: Top 10 leading causes of death for all adults with a learning disability who received a LeDeR review (2018-2022).

2018 and 2019			2020 and 2021			2022		
Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%
Congenital malformations, deformations and chromosomal abnormalities	655	14.2%	COVID-19	1,293	21.4%	Congenital malformations, deformations and chromosomal abnormalities	274	13.3%
Influenza and pneumonia	535	11.6%	Congenital malformations, deformations and chromosomal abnormalities	610	10.1%	Malignant neoplasms	227	11.1%
Malignant neoplasms	525	11.4%	Malignant neoplasms	535	8.9%	Influenza and pneumonia	154	7.5%
Ischaemic heart diseases	241	5.2%	Influenza and pneumonia	400	6.6%	Cerebral palsy and other paralytic syndromes	123	6.0%
Cerebrovascular diseases	226	4.9%	Ischaemic heart diseases	281	4.7%	Ischaemic heart diseases	121	5.9%
Cerebral palsy and other paralytic syndromes	205	4.4%	Cerebral palsy and other paralytic syndromes	260	4.3%	COVID-19	118	5.7%
Dementia and Alzheimer disease	202	4.4%	Cerebrovascular diseases	249	4.1%	Cerebrovascular diseases	95	4.6%
Epilepsy and status epilepticus	174	3.8%	Dementia and Alzheimer disease	233	3.9%	Dementia and Alzheimer disease	80	3.9%
Chronic lower respiratory diseases	145	3.1%	Epilepsy and status epilepticus	160	2.7%	Epilepsy and status epilepticus	62	3.0%
Appendicitis, hernia and intestinal obstruction	106	2.3%	Chronic lower respiratory diseases	156	2.6%	Chronic lower respiratory diseases	60	2.9%
Total number of deaths	4,844	100%	Total number of deaths	6,391	100%	Total number of deaths	2,054	100%

Table 2.4.2: The most frequently reported ICD-10 chapter causes of death, by year of death, for all adults with a learning disability reviewed by LeDeR (2018-2022).

ICD-10 chapter	2018 and 2019		2020 and 2021		2022	
	M	F	M	F	M	F
Diseases of the circulatory system	16.3%	15.1%	14.7%	13.1%	17.6%	15.6%
Diseases of the respiratory system	20.4%	21.1%	12.9%	13.2%	15.7%	13.2%
Neoplasms	14.1%	16.0%	11.0%	13.0%	14.2%	14.9%
Diseases of the nervous system	11.8%	11.3%	11.0%	9.7%	13.7%	13.5%
Congenital malformations, deformations and chromosomal abnormalities	14.7%	13.6%	9.9%	10.4%	12.7%	14.1%
Diseases of the digestive system	7.7%	6.2%	6.0%	5.6%	7.6%	6.3%
Codes for special purposes (COVID-19)	0.1%	0.0%	22.6%	19.9%	6.1%	5.4%
Mental and behavioural disorders*	4.4%	5.4%	3.3%	5.3%	3.0%	4.6%
Diseases of the genitourinary system	2.2%	2.3%	2.6%	2.5%	2.2%	2.9%
Endocrine, nutritional and metabolic diseases	1.8%	2.4%	1.5%	2.2%	1.7%	2.7%
External causes of morbidity and mortality	3.4%	2.3%	1.9%	1.6%	2.3%	1.6%
Certain infectious and parasitic diseases	1.3%	1.7%	1.3%	1.0%	1.6%	1.4%
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	0.5%	0.9%	0.4%	0.9%	0.8%	1.3%
Diseases of the skin and subcutaneous tissue	0.4%	0.5%	0.3%	0.5%	*	1.0%
Diseases of the musculoskeletal system and connective tissue	0.5%	0.9%	0.4%	0.6%	*	0.7%
Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	0.3%	0.5%	0.1%	0.4%	*	*
Certain conditions originating in the perinatal period	*	0.0%	*	*	*	*
Total number of deaths	4,614	100%	6,030	100%	2,054	100%

* Includes dementia and delirium

Table A2.5.1: The most frequently reported leading causes of death in adults with a learning disability reviewed by LeDeR (2018-2022) (18- to 64-year-olds).

2018 and 2019			2020 and 2021			2022		
Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%
Congenital malformations, deformations and chromosomal abnormalities	512	18.9%	COVID-19	669	19.8%	Congenital malformations, deformations and chromosomal abnormalities	219	19.0%
Malignant neoplasms	302	11.1%	Congenital malformations, deformations and chromosomal abnormalities	497	14.7%	Malignant neoplasms	120	10.4%
Influenza and pneumonia	281	10.4%	Malignant neoplasms	295	8.7%	Cerebral palsy and other paralytic syndromes	94	8.2%
Cerebral palsy and other paralytic syndromes	169	6.2%	Cerebral palsy and other paralytic syndromes	214	6.3%	COVID-19	68	5.9%
Epilepsy and status epilepticus	146	5.4%	Influenza and pneumonia	186	5.5%	Influenza and pneumonia	68	5.9%
Ischaemic heart diseases	107	3.9%	Epilepsy and status epilepticus	136	4.0%	Ischaemic heart diseases	60	5.2%
Cerebrovascular diseases	94	3.5%	Ischaemic heart diseases	133	3.9%	Epilepsy and status epilepticus	47	4.1%
Chronic lower respiratory diseases	61	2.2%	Cerebrovascular diseases	115	3.4%	Cerebrovascular diseases	42	3.7%

2018 and 2019			2020 and 2021			2022		
Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%
Dementia and Alzheimer disease	60	2.2%	Appendicitis, hernia and intestinal obstruction	88	2.6%	Appendicitis, hernia and intestinal obstruction	23	2.0%
Appendicitis, hernia and intestinal obstruction	57	2.1%	Chronic lower respiratory diseases	65	1.9%	Diseases of the urinary system	22	1.9%
Total number of deaths	2,714	100%	Total number of deaths	3,375	100%	Total number of deaths	1,150	100%

Table A2.5.2: The most frequently reported ICD-10 chapter causes of death, by year of death, 18-64-year-olds with a learning disability reviewed by LeDeR (2018-2022)

ICD-10 chapter	2018 and 2019		2020 and 2021		2022	
	M	F	M	F	M	F
Congenital malformations, deformations and chromosomal abnormalities	18.9%	18.9%	14.1%	15.6%	18.2%	20.1%
Diseases of the nervous system	16.2%	14.5%	14.8%	12.8%	16.9%	17.6%
Diseases of the circulatory system	14.5%	11.2%	14.7%	11.1%	17.2%	13.0%
Neoplasms	13.3%	17.3%	10.4%	13.2%	12.8%	13.9%
Diseases of the respiratory system	15.9%	18.9%	9.6%	10.7%	11.2%	10.1%
Diseases of the digestive system	7.5%	5.9%	6.8%	6.1%	7.4%	4.8%
Codes for special purposes (COVID-19)	-	-	19.9%	19.7%	6.2%	5.6%
Endocrine, nutritional and metabolic diseases	2.2%	2.6%	1.6%	2.5%	2.1%	3.1%
External causes of morbidity and mortality	4.2%	2.7%	2.3%	1.7%	2.7%	1.7%
Mental and behavioural disorders*	2.6%	2.6%	1.6%	2.3%	1.7%	2.3%
Diseases of the genitourinary system	1.7%	2.0%	1.9%	1.4%	1.1%	3.1%
Certain infectious and parasitic diseases	1.4%	1.5%	1.2%	0.9%	1.4%	1.4%
Diseases of the skin and subcutaneous tissue	0.4%	0.4%	*	0.4%	*	1.0%
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	*	*	0.3%	*	*	*

ICD-10 chapter	2018 and 2019		2020 and 2021		2022	
	M	F	M	F	M	F
Diseases of the blood and blood forming organs and certain disorders involving the immune mechanism	0.5%	0.5%	*	0.5%	*	*
Certain conditions originating in the perinatal period	*	*	*	*	*	*
Diseases of the musculoskeletal system and connective tissue	0.5%	0.8%	0.4%	0.7%	*	*
Total numbers of deaths	1,526	1,188	1,879	1,496	633	517

* Includes dementia and delirium

Table A2.6.1: The most frequently reported leading causes of death for adults with a learning disability who died aged 65+ reviewed by LeDeR (2018-2022).

2018 and 2019			2020 and 2021			2022		
Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%
Influenza and pneumonia	254	13.4%	COVID-19	624	23.5%	Malignant neoplasms	107	11.8%
Malignant neoplasms	223	11.7%	Malignant neoplasms	240	9.0%	Influenza and pneumonia	86	9.5%
Congenital malformations, deformations and chromosomal abnormalities	143	7.5%	Influenza and pneumonia	214	8.1%	Ischaemic heart diseases	61	6.7%
Dementia and Alzheimer disease	142	7.5%	Dementia and Alzheimer disease	172	6.5%	Dementia and Alzheimer disease	60	6.6%
Ischaemic heart diseases	134	7.1%	Ischaemic heart diseases	148	5.6%	Congenital malformations, deformations and chromosomal abnormalities	55	6.1%
Cerebrovascular diseases	132	6.9%	Cerebrovascular diseases	134	5.0%	Cerebrovascular diseases	53	5.9%
Chronic lower respiratory diseases	84	4.4%	Congenital malformations, deformations and chromosomal abnormalities	113	4.3%	COVID-19	50	5.5%
Diseases of the urinary system	53	2.8%	Diseases of the urinary system	94	3.5%	Chronic lower respiratory diseases	43	4.8%

2018 and 2019			2020 and 2021			2022		
Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%
Appendicitis, hernia and intestinal obstruction	49	2.6%	Chronic lower respiratory diseases	91	3.4%	Cerebral palsy and other paralytic syndromes	29	3.2%
Cerebral palsy and other paralytic syndromes	36	1.9%	Appendicitis, hernia and intestinal obstruction	55	2.1%	Diseases of the urinary system	28	3.1%
Accidents	35	1.8%	Cerebral palsy and other paralytic syndromes	46	1.7%	Appendicitis, hernia and intestinal obstruction	26	2.9%
Total number of deaths	1,900	100%	Total number of deaths	2,655	100%	Total number of deaths	904	100%

Table A2.6.2: The most frequently reported ICD-10 chapter causes of death, by year of death, adults with a learning disability aged 65+ reviewed by LeDeR (2018-2022).

	2018 and 2019		2020 and 2021		2022	
ICD-10 chapter	M	F	M	F	M	F
Diseases of the respiratory system	26.7%	24.4%	17.0%	16.5%	21.6%	17.0%
Diseases of the circulatory system	18.8%	20.9%	14.6%	15.8%	18.1%	18.9%
Neoplasms	15.3%	14.1%	11.9%	12.7%	16.0%	16.1%
Diseases of the nervous system	5.7%	6.6%	6.2%	5.7%	9.4%	8.4%
Diseases of the digestive system	8.0%	6.6%	5.0%	4.9%	7.8%	8.2%
Congenital malformations, deformations and chromosomal abnormalities	8.8%	5.7%	4.8%	3.5%	5.5%	6.7%
Mental and behavioural disorders*	6.9%	9.5%	5.5%	9.2%	4.7%	7.4%
Codes for special purposes (COVID-19)	-	-	26.0%	20.1%	6.0%	5.0%
Diseases of the genitourinary system	3.0%	2.6%	3.5%	3.9%	3.7%	2.6%
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	0.9%	1.9%	0.5%	2.0%	1.4%	2.2%
External causes of morbidity and mortality	2.2%	1.7%	1.4%	1.5%	1.8%	1.4%
Endocrine, nutritional and metabolic diseases	1.2%	2.0%	1.4%	1.9%	1.2%	2.2%
Certain infectious and parasitic diseases	1.2%	2.0%	1.4%	1.2%	1.8%	1.4%
Diseases of the musculoskeletal system and connective tissue	0.6%	1.0%	0.4%	0.4%	*	1.2%
Diseases of the skin and subcutaneous tissue	*	0.6%	0.5%	0.6%	*	*
Diseases of the blood and blood forming organs and certain disorders involving the immune mechanism	*	*	*	*	*	*
Certain conditions originating in the perinatal period	0.0%	0.0%	0.0%	0.0%	*	0.0%
Total number of deaths	1,097	803	1,527	1,128	487	417

* Includes dementia and delirium

Table A2.7: Most common leading causes of death in males with a learning disability reviewed by LeDeR (2018-2022)

2018 and 2019			2020 and 2021			2022		
Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%
Males aged 18-64								
Congenital malformations, deformations and chromosomal abnormalities	288	18.9%	COVID-19	374	19.9%	Congenital malformations, deformations and chromosomal abnormalities	115	18.2%
Malignant neoplasms	157	10.3%	Congenital malformations, deformations and chromosomal abnormalities	264	14.1%	Malignant neoplasms	62	9.8%
Influenza and pneumonia	139	9.1%	Malignant neoplasms	149	7.9%	Cerebral palsy and other paralytic syndromes	53	8.4%
Cerebral palsy and other paralytic syndromes	99	6.5%	Cerebral palsy and other paralytic syndromes	131	7.0%	COVID-19	39	6.2%
Epilepsy and status epilepticus	88	5.8%	Influenza and pneumonia	96	5.1%	Influenza and pneumonia	38	6.0%
Ischaemic heart diseases	78	5.1%	Ischaemic heart diseases	93	4.9%	Ischaemic heart diseases	38	6.0%
Cerebrovascular diseases	57	3.7%	Epilepsy and status epilepticus	69	3.7%	Cerebrovascular diseases	28	4.4%
Appendicitis, hernia and intestinal obstruction	37	2.4%	Cerebrovascular diseases	67	3.6%	Epilepsy and status epilepticus	23	3.6%
Chronic lower respiratory diseases	37	2.4%	Appendicitis, hernia and intestinal obstruction	55	2.9%	Appendicitis, hernia and intestinal obstruction	14	2.2%

2018 and 2019			2020 and 2021			2022		
Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%
Dementia and Alzheimer disease	34	2.2%	Chronic lower respiratory diseases	40	2.1%	Dementia and Alzheimer disease	10	1.6%
			Dementia and Alzheimer disease	33	1.8%	Chronic lower respiratory diseases	10	1.6%
Total number of deaths	1,526	100%	Total number of deaths	1,879	100%	Total number of deaths	633	100%
Males aged 65+								
Influenza and pneumonia	145	13.2%	COVID-19	397	26.0%	Malignant neoplasms	63	12.9%
Malignant neoplasms	135	12.3%	Malignant neoplasms	137	9.0%	Influenza and pneumonia	56	11.5%
Congenital malformations, deformations and chromosomal abnormalities	97	8.8%	Influenza and pneumonia	134	8.8%	Ischaemic heart diseases	34	7.0%
Ischaemic heart diseases	88	8.0%	Ischaemic heart diseases	99	6.5%	COVID-19	29	6.0%
Dementia and Alzheimer disease	69	6.3%	Dementia and Alzheimer disease	82	5.4%	Dementia and Alzheimer disease	28	5.7%
Cerebrovascular diseases	66	6.0%	Congenital malformations, deformations and chromosomal abnormalities	73	4.8%	Congenital malformations, deformations and chromosomal abnormalities	27	5.5%
Chronic lower respiratory diseases	58	5.3%	Cerebrovascular diseases	65	4.3%	Cerebrovascular diseases	26	5.3%
Diseases of the urinary system	33	3.0%	Chronic lower respiratory diseases	57	3.7%	Chronic lower respiratory diseases	24	4.9%

2018 and 2019			2020 and 2021			2022		
Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%
Appendicitis, hernia and intestinal obstruction	30	2.7%	Diseases of the urinary system	51	3.3%	Diseases of the urinary system	18	3.7%
Total number of deaths	1,097	100%	Total number of deaths	1,527	100%	Total number of deaths	487	100%

Table A2.8: Most common leading causes of death in females with a learning disability reviewed by LeDeR (2018-2022)

2018 and 2019			2020 and 2021			2022		
Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%
Females aged 18-64								
Congenital malformations, deformations and chromosomal abnormalities	224	18.9%	COVID-19	295	19.7%	Congenital malformations, deformations and chromosomal abnormalities	104	20.1%
Malignant neoplasms	145	12.2%	Congenital malformations, deformations and chromosomal abnormalities	233	15.6%	Malignant neoplasms	58	11.2%
Influenza and pneumonia	142	12.0%	Malignant neoplasms	146	9.8%	Cerebral palsy and other paralytic syndromes	41	7.9%
Cerebral palsy and other paralytic syndromes	70	5.9%	Influenza and pneumonia	90	6.0%	Influenza and pneumonia	30	5.8%
Epilepsy and status epilepticus	58	4.9%	Cerebral palsy and other paralytic syndromes	83	5.5%	COVID-19	29	5.6%
Cerebrovascular diseases	37	3.1%	Epilepsy and status epilepticus	67	4.5%	Epilepsy and status epilepticus	24	4.6%
Ischaemic heart diseases	29	2.4%	Cerebrovascular diseases	48	3.2%	Ischaemic heart diseases	22	4.3%
Dementia and Alzheimer's disease	26	2.2%	Ischaemic heart diseases	40	2.7%	Diseases of the urinary system	16	3.1%

2018 and 2019			2020 and 2021			2022		
Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%
Diseases of the urinary system	24	2.0%	Appendicitis, hernia and intestinal obstruction	33	2.2%	Cerebrovascular diseases	14	2.7%
Appendicitis, hernia and intestinal obstruction	20	1.7%	Dementia and Alzheimer's disease	28	1.9%	Dementia and Alzheimer's disease	10	1.9%
			Diseases of the urinary system	19	1.3%	Appendicitis, hernia and intestinal obstruction	9	1.7%
Total number of deaths	1,188	100%	Total number of deaths	1,496	100%	Total number of deaths	517	100%
Females aged 65+								
Influenza and pneumonia	109	13.6%	COVID-19	227	20.1%	Malignant neoplasms	44	10.6%
Malignant neoplasms	88	11.0%	Malignant neoplasms	103	9.1%	Dementia and Alzheimer disease	32	7.7%
Dementia and Alzheimer disease	73	9.1%	Dementia and Alzheimer disease	90	8.0%	Influenza and pneumonia	30	7.2%
Cerebrovascular diseases	66	8.2%	Influenza and pneumonia	80	7.1%	Congenital malformations, deformations and chromosomal abnormalities	28	6.7%
Congenital malformations, deformations and chromosomal abnormalities	46	5.7%	Cerebrovascular diseases	69	6.1%	Cerebrovascular diseases	27	6.5%
Ischaemic heart diseases	46	5.7%	Ischaemic heart diseases	49	4.3%	Ischaemic heart diseases	27	6.5%

2018 and 2019			2020 and 2021			2022		
Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%	Leading cause of death	Number of adults	%
Chronic lower respiratory diseases	26	3.2%	Diseases of the urinary system	43	3.8%	COVID-19	21	5.0%
Diseases of the urinary system	20	2.5%	Congenital malformations, deformations and chromosomal abnormalities	40	3.5%	Chronic lower respiratory diseases	19	4.6%
Appendicitis, hernia and intestinal obstruction	19	2.4%	Chronic lower respiratory diseases	34	3.0%	Appendicitis, hernia and intestinal obstruction	11	2.6%
Acute respiratory infections other than influenza and pneumonia	13	1.6%	Acute respiratory infections other than influenza and pneumonia	26	2.3%	Diseases of the urinary system	10	2.4%
			Appendicitis, hernia and intestinal obstruction	17	1.5%	Acute respiratory infections other than influenza and pneumonia	9	2.2%
Total number of deaths	803	100%	Total number of deaths	1,128	100%	Total number of deaths	417	100%

Chapter 3 – Factors associated with age at death

A3.1 - Supplementary Table 1. Results of Cox proportional hazards models investigating the effects of predictor variables on age at death.

		Unadjusted			Adjusted		
Predictor variable	**Level**	**Hazard ratio**	**95% confidence interval**	**p-value**	**Hazard ratio**	**95% confidence interval**	**p-value**
Sex	Male	1	-	-	1	-	-
	Female	0.94	0.86, 1.02	0.15	0.97	0.88, 1.06	0.44
Ethnicity	White	1	-	-	1	-	-
	Mixed	1.77	1.06, 2.94	<0.001	1.81	1.06, 3.08	<0.001
	Black	2.49	1.80, 3.43		2.90	2.07, 4.06	
	Asian British	2.55	1.99, 3.26		2.50	1.94, 3.23	
	Other	2.45	1.36, 4.44		2.68	1.47, 4.88	
Region of England	London	1	-	-	1	-	-
	South West	1.00	0.83, 1.20	0.23	1.12	0.93, 1.37	0.04
	South East	0.98	0.83, 1.15		1.06	0.89, 1.26	
	North Midlands	1.10	0.94, 1.29		1.16	0.98, 1.38	
	East of England	1.16	0.96, 1.40		1.31	1.08, 1.60	
	North West	1.00	0.84, 1.19		1.08	0.90, 1.30	
	North East	1.12	0.94, 1.32		1.26	1.06, 1.51	
IMD quintile	High deprivation	1	-	-	1	-	-
	Moderate-high deprivation	1.04	0.92, 1.18	0.77	1.05	0.92, 1.19	0.68
	Moderate deprivation	0.96	0.84, 1.09		0.97	0.85, 1.10	
	Low-moderate deprivation	1.02	0.89, 1.16		1.02	0.89, 1.17	
	Low deprivation	0.97	0.84, 1.14		0.95	0.81, 1.11	
Place of death	Hospital	1	-	-	1	-	-
	Usual residence	0.83	0.76, 0.91	<0.001	0.83	0.76, 0.91	<0.001

	Other	1.66	1.32, 2.10		1.73	1.36, 2.20	
		Unadjusted			**Adjusted**		
Predictor variable	**Level**	**Hazard ratio**	**95% confidence interval**	**p-value**	**Hazard ratio**	**95% confidence interval**	**p-value**
Learning disability level	Mild	1	-	-	1	-	-
	Moderate	1.11	0.92, 1.33	<0.001	1.08	0.89, 1.31	<0.001
	Severe	1.30	1.08, 1.57		1.32	1.08, 1.62	
	Profound/ multiple	2.27	1.61, 3.20		2.37	1.66, 3.39	
Living arrangements	Own or family home	1	-	-	1	-	-
	Supported living	0.47	0.36, 0.60	<0.001	0.49	0.37, 0.64	<0.001
	Residential/nursing home	0.36	0.29, 0.45		0.39	0.31, 0.49	
	Other	0.48	0.30, 0.78		0.60	0.35, 1.01	
Cancer	No	1	-	-	1	-	-
	Yes	0.80	0.69, 0.92	<0.01	0.86	0.73, 1.00	0.06
Cardiovascular disease	No	1	-	-	1	-	-
	Yes	0.95	0.87, 1.04	0.30	1.05	0.95, 1.17	0.35
Degenerative disease	No	1	-	-	1	-	-
	Yes	1.21	0.94, 1.57	0.14	1.34	1.00, 1.79	0.05
Dementia	No	1	-	-	1	-	-
	Yes	0.82	0.74, 0.93	<0.01	0.84	0.74, 0.95	<0.01
Diabetes	No	1	-	-	1	-	-
	Yes	0.85	0.75, 0.96	<0.01	0.95	0.83, 1.09	0.50
DVT	No	1	-	-	1	-	-
	Yes	1.26	0.99, 1.61	0.06	1.32	1.01, 1.73	0.04
Dysphagia	No	1	-	-	1	-	-

		Unadjusted			Adjusted		
Predictor variable	**Level**	**Hazard ratio**	**95% confidence interval**	**p-value**	**Hazard ratio**	**95% confidence interval**	**p-value**
	Yes	0.93	0.84, 1.02	0.13	0.90	0.80, 1.00	0.05
Epilepsy	No	1	-	-	1	-	-
	Yes	1.52	1.38, 1.67	<0.001	1.56	1.40, 1.74	<0.001
High blood pressure	No	1	-	-	1	-	-
	Yes	0.66	0.59, 0.74	<0.001	0.63	0.55, 0.71	<0.001
Kidney disease	No	1	-	-	1	-	-
	Yes	0.85	0.77, 0.95	<0.01	0.93	0.83, 1.05	0.27
Mental health	No	1	-	-	1	-	-
	Yes	0.99	0.91, 1.09	0.86	1.08	0.97, 1.20	0.16
Osteoporosis	No	1	-	-	1	-	-
	Yes	0.89	0.75, 1.05	0.17	0.89	0.74, 1.08	0.24
Respiratory	No	1	-	-	1	-	-
	Yes	0.83	0.73, 0.94	<0.01	0.87	0.76, 1.01	0.07
Sensory disorder	No	1	-	-	1	-	-
	Yes	0.91	0.83, 1.00	0.05	0.94	0.85, 1.05	0.28
COVID19	No	1	-	-	1	-	-
	Yes	0.87	0.73, 1.03	0.10	0.84	0.70, 1.02	0.08
Number of prescribed medications		1.00	0.98, 1.01	0.64	1.00	0.97, 1.02	0.86
Antipsychotic prescription	No	1	-	-	1	-	-
	Yes	0.95	0.73, 1.24	0.73	0.83	0.54, 1.28	0.40
Antidepressant prescription	No	1	-	-	1	-	-
	Yes	0.94	0.72, 1.24	0.69	0.57	0.34, 0.94	0.03

		Unadjusted			Adjusted		
Predictor variable	**Level**	**Hazard ratio**	**95% confidence interval**	**p-value**	**Hazard ratio**	**95% confidence interval**	**p-value**
COVID19 vaccination	No	1	-	-	1	-	-
	Yes	0.68	0.52, 0.89	<0.01	0.67	0.46, 0.98	0.04
Pneumococcal vaccination	No	1	-	-	1	-	-
	Yes	0.60	0.48, 0.75	<0.001	0.62	0.46, 0.84	<0.01
Annual health check (in past 12 months)	No	1	-	-	1	-	-
	Yes	0.83	0.65, 1.06	0.14	0.86	0.60, 1.24	0.43
Care package met needs	No	1	-	-	1	-	-
	Yes	0.83	0.66, 1.05	0.12	0.65	0.45, 0.93	0.02
Deprivation of liberty safeguards	No	1	-	-	1	-	-
	Applied for	0.90	0.64, 1.26	0.01	0.53	0.34, 0.84	<0.01
	Approved	0.73	0.59, 0.90		0.68	0.50, 0.91	
Out of area placement	No	1	-	-	1	-	-
	Yes	0.91	0.68, 1.22	0.53	1.16	0.74, 1.83	0.51
Quality of care rating*	6	1	-	-	1	-	-
	5	1.51	0.97, 2.36	0.35	1.56	0.81, 2.98	0.35
	4	1.33	0.85, 2.09		1.29	0.67, 2.51	
	3	1.28	0.81, 2.03		1.17	0.58, 2.36	
	2	1.53	0.94, 2.49		1.56	0.75, 3.23	
	1	1.08	0.48, 2.42		0.71	0.20, 2.48	

*1=Care fell short of expected good practice and this contributed to the cause of death; 2=Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death; 3=Care fell short of expected good practice and this did impact of the person's wellbeing but did not contribute to the cause of death; 4=Satisfactory care (it fell short of expected good practice in some areas but this did not significantly impact on the person's wellbeing); 5=Good care (it met expected good practice); 6=Excellent care (it exceeded good practice).

Chapter 4 – Avoidable Mortality

Table A4.1. Summary of demographic, clinical, and social care variables by whether the death was classified as avoidable or not (see chapter 3 for avoidable death definition).

Note: To interpret this table, the Causes of Death was not avoidable column should be read as, for example, "there were 1,201 people whose cause of death was rated as not avoidable, of those, 53% were male and 47% were female. 375 (31%) were 50-64 years old, 308 (26%) had high levels of deprivation, etc". Likewise, where cause of death was avoidable, there were 853 people. "Of those 853, 367 (43%) were female, 768 (90%) were white, etc..."

Variable	**Level**	**Causes of death was not avoidable (n=1,201)**	**Cause of death was avoidable (n=853)**	**Total (n=2,054)**
Sex (n, %)	Male	634 (53%)	486 (57%)	1,120 (55%)
	Female	567 (47%)	367 (43%)	934 (45%)
Age at death (mean; SD)		64.11 (17.01)	57.75 (12.89)	61.47 (15.75)
Age group (n; %)	18-24 years old	47 (4%)	19 (2%)	66 (3%)
	25-49 years old	157 (13%)	163 (19%)	320 (16%)
	50-64 years old	375 (31%)	389 (46%)	764 (37%)
	65+ years old	622 (52%)	282 (33%)	904 (44%)
Ethnicity (n, %)	White	1,086 (90%)	768 (90%)	1,854 (90%)
	Mixed ethnic group	7 (1%)	8 (1%)	15 (1%)
Variable	**Level**	**Causes of death was not avoidable (n=1,201)**	**Cause of death was avoidable (n=853)**	**Total (n=2,054)**
	Black, African, Caribbean or Black British	18 (1%)	20 (2%)	38 (2%)
	Asian or Asian British	42 (3%)	23 (3%)	65 (3%)
	Other	8 (1%)	<5 (<1%)	10 (0%)
	Unknown	40 (3%)	32 (4%)	72 (4%)
Region of England (n, %)	London	123 (10%)	97 (11%)	220 (11%)
	South West	129 (11%)	91 (11%)	220 (11%)

	South East	206 (17%)	145 (17%)	351 (17%)
	Midlands	276 (23%)	174 (20%)	450 (22%)
	East of England	129 (11%)	91 (11%)	220 (11%)
	North West	145 (12%)	118 (14%)	263 (13%)
	North East & Yorkshire	193 (16%)	137 (16%)	330 (16%)
Deprivation	High	308 (26%)	216 (25%)	524 (26%)
	Moderately high	286 (24%)	193 (23%)	479 (23%)
	Moderate	244 (20%)	185 (22%)	429 (21%)
Variable	**Level**	**Causes of death was not avoidable (n=1,201)**	**Cause of death was avoidable (n=853)**	**Total (n=2,054)**
	Moderately low	230 (19%)	155 (18%)	385 (19%)
	Low	128 (11%)	100 (12%)	228 (11%)
	Unknown	5 (0%)	<5 (<1%)	9 (0%)
Level of learning disability	Mild	119 (10%)	115 (13%)	234 (11%)
	Moderate	128 (11%)	96 (11%)	224 (11%)
	Severe	128 (11%)	77 (9%)	205 (10%)
	Profound / multiple	28 (2%)	9 (1%)	37 (2%)
	Unknown	798 (66%)	556 (65%)	1,354 (66%)
Place of death (n; %)	Hospital	692 (58%)	484 (57%)	1,176 (57%)
	Usual residence	477 (40%)	327 (38%)	804 (39%)
	Other	31 (3%)	40 (5%)	71 (3%)
	Unknown	<5 (<1%)	<5 (<1%)	<5 (<1%)
Cancer (n, %)	No	967 (81%)	676 (79%)	1,643 (80%)
	Yes	129 (11%)	95 (11%)	224 (11%)
	Unknown	105 (9%)	82 (10%)	187 (9%)
Variable	**Level**	**Causes of death was not avoidable**	**Cause of death was avoidable (n=853)**	**Total (n=2,054)**

		(n=1,201)		
Cardiovascular condition (n, %)	No	663 (55%)	417 (49%)	1,080 (53%)
	Yes	433 (36%)	354 (42%)	787 (38%)
	Unknown	105 (9%)	82 (10%)	187 (9%)
Degenerative condition (n, %)	No	1,049 (87%)	758 (89%)	1,807 (88%)
	Yes	47 (4%)	13 (2%)	60 (3%)
	Unknown	105 (9%)	82 (10%)	187 (9%)
Dementia (n, %)	No	802 (67%)	687 (81%)	1,489 (72%)
	Yes	294 (24%)	84 (10%)	378 (18%)
	Unknown	105 (9%)	82 (10%)	187 (9%)
Diabetes (n, %)	No	924 (77%)	622 (73%)	1,546 (75%)
	Yes	172 (14%)	149 (17%)	321 (16%)
	Unknown	105 (9%)	82 (10%)	187 (9%)
Deep vein thrombosis (n, %)	No	1,062 (88%)	737 (86%)	1,799 (88%)
	Yes	34 (3%)	34 (4%)	68 (3%)
	Unknown	105 (9%)	82 (10%)	187 (9%)
Variable	**Level**	**Causes of death was not avoidable (n=1,201)**	**Cause of death was avoidable (n=853)**	**Total (n=2,054)**
Dysphagia (n, %)	No	685 (57%)	573 (67%)	1,258 (61%)
	Yes	411 (34%)	198 (23%)	609 (30%)
	Unknown	105 (9%)	82 (10%)	187 (9%)
Epilepsy (n, %)	No	646 (54%)	453 (53%)	1,099 (54%)
	Yes	450 (37%)	318 (37%)	768 (37%)
	Unknown	105 (9%)	82 (10%)	187 (9%)
Hypertension (n, %)	No	862 (72%)	598 (70%)	1,460 (71%)
	Yes	234 (19%)	173 (20%)	407 (20%)
	Unknown	105 (9%)	82 (10%)	187 (9%)

Kidney disease (n, %)	No	826 (69%)	605 (71%)	1,431 (70%)
	Yes	270 (22%)	166 (19%)	436 (21%)
	Unknown	105 (9%)	82 (10%)	187 (9%)
Mental health condition (n, %)	No	636 (53%)	424 (50%)	1,060 (52%)
	Yes	460 (38%)	347 (41%)	807 (39%)
	Unknown	105 (9%)	82 (10%)	187 (9%)
Variable	**Level**	**Causes of death was not avoidable (n=1,201)**	**Cause of death was avoidable (n=853)**	**Total (n=2,054)**
Osteoporosis (n, %)	No	1,022 (85%)	701 (82%)	1,723 (84%)
	Yes	74 (6%)	70 (8%)	144 (7%)
	Unknown	105 (9%)	82 (10%)	187 (9%)
Respiratory illness (n, %)	No	953 (79%)	638 (75%)	1,591 (77%)
	Yes	143 (12%)	133 (16%)	276 (13%)
	Unknown	105 (9%)	82 (10%)	187 (9%)
Sensory condition (n, %)	No	656 (55%)	489 (57%)	1,145 (56%)
	Yes	440 (37%)	282 (33%)	722 (35%)
	Unknown	105 (9%)	82 (10%)	187 (9%)
COVID-19	No	982 (82%)	645 (76%)	1627 (79%)
	Yes	53 (4%)	88 (10%)	141 (7%)
	Unknown	166 (14%)	120 (14%)	286 (14%)
Annual health check* (in past 12 months; n, %)	No	43 (17%)	44 (18%)	87 (18%)
	Yes	108 (44%)	120 (49%)	228 (47%)
Variable	**Level**	**Causes of death was not avoidable (n=1,201)**	**Cause of death was avoidable (n=853)**	**Total (n=2,054)**

	Unknown	95 (39%)	79 (33%)	174 (36%)
Care package met needs* (n, %)	No	39 (16%)	49 (20%)	88 (18%)
	Yes	207 (84%)	194 (80%)	401 (82%)
Deprivation of liberty safeguards* (n, %)	No	141 (57%)	151 (62%)	292 (60%)
	Applied for	25 (10%)	10 (4%)	35 (7%)
	Approved	61 (25%)	63 (26%)	124 (25%)
	Unknown	19 (8%)	19 (8%)	38 (8%)
Out of area placement* (n, %)	No	221 (90%)	213 (88%)	434 (89%)
	Yes	23 (9%)	24 (10%)	47 (10%)
	Unknown	<5 (<1%)	6 (2%)	8 (2%)
Quality of care rating*,** (n, %)	1	<5 (<2%)	<5 (<1%)	6 (1%)
	2	28 (11%)	37 (15%)	65 (13%)
Variable	**Level**	**Causes of death was not avoidable (n=1,201)**	**Cause of death was avoidable (n=853)**	**Total (n=2,054)**
	3	41 (17%)	59 (24%)	100 (20%)
	4	73 (30%)	61 (25%)	134 (27%)
	5	88 (36%)	74 (30%)	162 (33%)
	6	12 (5%)	10 (4%)	22 (4%)

*Recorded as part of a focused review (489 people had focused reviews and had information about whether their death was avoidable or not); all other information recorded as part of an initial review.

**1=Care fell short of expected good practice and this contributed to the cause of death; 2=Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death; 3=Care fell short of expected good practice and this did impact of the person's wellbeing but did not contribute to the cause of death; 4=Satisfactory care (it fell short of expected good practice in some areas but this did not significantly impact on the person's wellbeing); 5=Good care (it met expected good practice); 6=Excellent care (it exceeded good practice).

Table A4.2. Results of logistic regression analyses of predictor variables on avoidable causes of death.

		Unadjusted			Adjusted		
Predictor variable	**Level**	**Odds ratio**	**95% confidence interval**	**p-value**	**Odds ratio**	**95% confidence interval**	**p-value**
Sex	Male	1	-	-	1	-	-
	Female	0.84	0.71, 1.01	0.061	0.82	0.68, 0.99	0.036
Age at death group	18-24 years old	1	-	-	1	-	-
	25-49 years old	2.57	1.44, 4.57	<0.001	3.19	1.70, 5.99	<0.001
	50-64 years old	2.57	1.48, 4.45		2.98	1.62, 5.48	
	65+ years old	1.12	0.65, 1.95		1.30	0.71, 2.40	
Level of learning disability	Mild	1	-	-	1	-	-
	Moderate	0.78	0.54, 1.22	0.012	0.73	0.49, 1.10	<0.001
	Severe	0.62	0.43, 0.91		0.48	0.31, 0.74	
	Profound /multiple	0.33	0.15, 0.74		0.25	0.10, 0.60	
Deprivation	High	1	-	-	1	-	-
	Moderately high	0.96	0.75, 1.24	0.820	0.95	0.73, 1.23	0.823
	Moderate	1.08	0.83, 1.40		1.11	0.84, 1.45	
	Moderately low	0.96	0.74, 1.26		0.99	0.75, 1.31	
	Low	1.11	0.81, 1.53		1.08	0.78, 1.51	
Ethnicity	White	1	-	-	1	-	-

		Unadjusted			Adjusted			
Predictor variable	**Level**	**Odds ratio**	**95% confidence interval**	**p-value**	**Odds ratio**		**95% confidence interval**	**p-value**
	Mixed ethnic group	1.62	0.58, 4.48		1.57		0.52, 4.70	
	Black, African, Caribbean or Black British	1.57	0.83, 2.99	0.240	1.27		0.64, 2.52	0.291
	Asian or Asian British	0.77	0.46, 1.30		0.70		0.40, 1.22	
	Other	0.35	0.07, 1.67		0.30		0.06, 1.48	
Region of England	London	1	-	-	1	-	-	
	South West	0.89	0.61, 1.31		0.81	0.54, 1.22		
	South East	0.89	0.63, 1.25		0.85	0.59, 1.22		
	Midlands	0.80	0.58, 1.11		0.72	0.51, 1.02		
	East of England	0.89	0.61, 1.31		0.84	0.55, 1.26		
	North West	1.03	0.72, 1.48	0.767	1.04	0.71, 1.53	0.376	
	North East & Yorkshire	0.90	0.64, 1.27		0.83	0.57, 1.21		

		Unadjusted				Adjusted	
Predictor variable	**Level**	**Odds ratio**	**95% confidence interval**	**p-value**	**Odds ratio**	**95% confidence interval**	**p-value**
Place of death	Hospital	1	-	-	1	-	-
	Usual Residence	0.98	0.82, 1.18	0.038	1.02	0.84, 1.24	0.087
	Other	1.84	1.14, 2.99		1.79	1.07, 3.01	
Cancer	No	1	-	-	1	-	-
	Yes	1.05	0.79, 1.40	0.718	1.15	0.82, 1.61	0.416
Cardiovascular condition	No	1	-	-	1	-	-
	Yes	1.30	1.08, 1.57	0.006	1.37	1.08, 1.73	0.009
Degenerative condition	No	1	-	-	1	-	-
	Yes	0.38	0.21, 0.71	0.002	0.42	0.19, 0.90	0.026
Dementia	No	1	-	-	1	-	-
	Yes	0.33	0.26, 0.43	<0.001	0.32	0.23, 0.44	<0.001
Diabetes	No	1	-	-	1	-	-
	Yes	1.29	1.01, 1.64	0.041	1.24	0.92, 1.68	0.162
Deep vein thrombosis	No	1	-	-	1	-	-
	Yes	1.44	0.89, 2.34	0.139	1.31	0.74, 2.31	0.352
Dysphagia	No	1	-	-	1	-	-
	Yes	0.58	0.47, 0.71	<0.001	0.66	0.52, 0.84	0.001
Epilepsy	No	1	-	-	1	-	-
	Yes	1.01	0.84, 1.22	0.936	1.01	0.80, 1.28	0.937
Hypertension	No	1	-	-	1	-	-
	Yes	1.07	0.85, 1.33	0.575	0.92	0.69, 1.22	0.545
Kidney disease	No	1	-	-	1	-	-
	Yes	0.84	0.67, 1.05	0.119	0.81	0.62, 1.05	0.115

		Unadjusted			Adjusted		
Predictor variable	**Level**	**Odds ratio**	**95% confidence interval**	**p-value**	**Odds ratio**	**95% confidence interval**	**p-value**
Mental health condition	No	1	-	-	1	-	-
	Yes	1.13	0.94, 1.36	0.192	1.20	0.95, 1.50	0.124
Osteoporosis	No	1	-	-	1	-	-
	Yes	1.38	0.98, 1.94	0.064	1.92	1.27, 2.90	0.002
Respiratory illness	No	1	-	-	1	-	-
	Yes	1.39	1.07, 1.80	0.012	1.26	0.93, 1.72	0.138
Sensory condition	No	1	-	-	1	-	-
	Yes	0.86	0.71, 1.04	0.119	0.98	0.78, 1.24	0.894
Annual health check (in past 12 months)	No	1	-	-	1	-	-
	Yes	1.09	0.66, 1.78	0.744	0.71	0.32, 1.57	0.401
Care package met needs	No	1	-	-	1	-	-
	Yes	0.75	0.47, 1.19	0.216	0.85	0.39, 1.85	0.684
Deprivation of liberty safeguards	No	1	-	-	1	-	-
	Applied for	0.37	0.17, 0.81	0.041	0.39	0.13, 1.16	0.235
	Approved	0.96	0.63, 1.47		0.84	0.44, 1.60	
Out of area placement	No	1	-	-	1	-	-
	Yes	1.08	0.59, 1.98	0.796	2.01	0.72, 5.62	0.182

		Unadjusted			Adjusted			
Predictor variable	**Level**	**Odds ratio**	**95% confidence interval**	**p-value**	**Odds ratio**	**95% confidence interval**	**p-value**	
Quality of care rating*	6	1	-	-	1	-	-	
	5	1.01	0.41, 2.47		0.77	0.18, 3.26		
	4	1.00	0.41, 2.48		0.70	0.17, 2.99	0.492	
	3	1.73	0.68, 4.37	0.185	1.45	0.31, 6.72		
	2	1.59	0.60, 4.19		0.81	0.17, 3.93		
	1	0.60	0.09, 3.99		-		-	

*1=Care fell short of expected good practice and this contributed to the cause of death; 2=Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death; 3=Care fell short of expected good practice and this did impact of the person's wellbeing but did not contribute to the cause of death; 4=Satisfactory care (it fell short of expected good practice in some areas but this did not significantly impact on the person's wellbeing); 5=Good care (it met expected good practice); 6=Excellent care (it exceeded good practice).

A4.3: ONS Definitions of avoidable death for treatable and preventable conditions.

Avoidable mortality definition				
Causes of death (classified using the International Classification of Diseases, tenth revision (ICD-10)) considered to be avoidable				
Condition group and cause	**ICD-10 codes**	**Age**	**Treatable**	**Preventable**
Infectious diseases				
Intestinal diseases	A00-A09	0-74		•
Diphtheria, Tetanus, Poliomyelitis	A35, A36, A80	0-74		•
Whooping cough	A37	0-74		•
Meningococcal infection	A39	0-74		•
Sepsis due to streptococcus pneumonia and sepsis due to haemophilus influenzae	A40.3, A41.3	0-74		•
Haemophilus influenza infections	A49.2	0-74		•
Sexually transmitted infections (except HIV/AIDS)	A50-A60, A63, A64	0-74		•
Varicella	B01	0-74		•
Measles	B05	0-74		•
Rubella	B06	0-74		•
Viral Hepatitis	B15-B19	0-74		•
HIV/AIDS	B20-B24	0-74		•
Malaria	B50-B54	0-74		•
Haemophilus and pneumococcal meningitis	G00.0, G00.1	0-74		•
Tuberculosis	A15-A19, B90, J65	0-74	• (50%)	• (50%)
Scarlet fever	A38	0-74	•	
Sepsis	A40 (excl. A40.3), A41 (excl. A41.3)	0-74	•	
Cellulitis	A46, L03	0-74	•	
Legionnaires disease	A48.1	0-74	•	
Streptococcal and enterococci infection	A49.1	0-74	•	
Other meningitis	G00.2, G00.3, G00.8, G00.9	0-74	•	
Meningitis due to other and unspecified causes	G03	0-74	•	
Avoidable mortality definition				
Causes of death (classified using the International Classification of Diseases, tenth revision (ICD-10)) considered to be avoidable				
Condition group and cause	**ICD-10 codes**	**Age**	**Treatable**	**Preventable**
Neoplasms				
Lip, oral cavity and pharynx cancer	C00-C14	0-74		•
Oesophageal cancer	C15	0-74		•
Stomach cancer	C16	0-74		•
Liver cancer	C22	0-74		•
Lung cancer	C33-C34	0-74		•
Mesothelioma	C45	0-74		•
Skin (melanoma) cancer	C43	0-74		•
Bladder cancer	C67	0-74		•
Cervical cancer	C53	0-74	• (50%)	• (50%)
Colorectal cancer	C18-C21	0-74	•	
Breast cancer (female only)	C50	0-74	•	

Uterus cancer	C54, C55	0-74	•	
Testicular cancer	C62	0-74	•	
Thyroid cancer	C73	0-74	•	
Hodgkin's disease	C81	0-74	•	
Lymphoid leukaemia	C91.0, C91.1	0-74	•	
Benign neoplasm	D10-D36	0-74	•	
Endocrine and metabolic diseases				
Nutritional deficiency anaemia	D50-D53	0-74		•
Diabetes mellitus	E10-E14	0-74	• (50%)	• (50%)
Thyroid disorders	E00-E07	0-74	•	
Adrenal disorders	E24-E25 (excl. E24.4), E27	0-74	•	
Diseases of the nervous system				
Epilepsy	G40, G41	0-74	•	
Avoidable mortality definition				
Causes of death (classified using the International Classification of Diseases, tenth revision (ICD-10)) considered to be avoidable				
Condition group and cause	**ICD-10 codes**	**Age**	**Treatable**	**Preventable**
Diseases of the circulatory system				
Aortic aneurysm	I71	0-74	• (50%)	• (50%)
Hypertensive diseases	I10-I13, I15	0-74	• (50%)	• (50%)
Ischaemic heart diseases	I20-I25	0-74	• (50%)	• (50%)
Cerebrovascular diseases	I60-I69	0-74	• (50%)	• (50%)
Other atherosclerosis	I70, I73.9	0-74	• (50%)	• (50%)
Rheumatic and other heart diseases	I00-I09	0-74	•	
Venous thromboembolism	I26, I80, I82.9	0-74	•	
Diseases of the respiratory system				
Influenza	J09-J11	0-74		•
Pneumonia due to streptococcus pneumonia or haemophilus influenza	J13-J14	0-74		•
Chronic lower respiratory diseases	J40-J44	0-74		•
Lung diseases due to external agents	J60-J64, J66-J70, J82, J92	0-74		•
Upper respiratory infections	J00-J06, J30-J39	0-74	•	
Pneumonia, not elsewhere classified or organism unspecified	J12, J15, J16-J18	0-74	•	
Acute lower respiratory infections	J20-J22	0-74	•	
Asthma and bronchiectasis	J45-J47	0-74	•	
Adult respiratory distress syndrome	J80	0-74	•	
Pulmonary oedema	J81	0-74	•	
Abscess of lung and mediastinum pyothorax	J85, J86	0-74	•	
Other pleural disorders	J90, J93, J94	0-74	•	
Diseases of the digestive system				
Gastric and duodenal ulcer	K25-K28	0-74	•	
Avoidable mortality definition				

Causes of death (classified using the International Classification of Diseases, tenth revision (ICD-10)) considered to be avoidable				
Condition group and cause	**ICD-10 codes**	**Age**	**Treatable**	**Preventable**
Appendicitis	K35-K38	0-74	•	
Abdominal hernia	K40-K46	0-74	•	
Cholelithiasis and cholecystitis	K80-K81	0-74	•	
Other diseases of gallbladder or biliary tract	K82-K83	0-74	•	
Acute pancreatitis	K85.0, K85.1, K85.3, K85.8, K85.9	0-74	•	
Other diseases of pancreas	K86.1, K86.2, K86.3, K86.8, K86.9	0-74	•	
Diseases of the genitourinary system				
Nephritis and nephrosis	N00-N07	0-74	•	
Obstructive uropathy	N13, N20-N21, N35	0-74	•	
Renal failure	N17-N19	0-74	•	
Renal colic	N23	0-74	•	
Disorders resulting from renal tubular dysfunction	N25	0-74	•	
Unspecified contracted kidney, small kidney of unknown cause	N26-N27	0-74	•	
Inflammatory diseases of genitourinary system	N34.1, N70-N73, N75.0, N75.1, N76.4, N76.6	0-74	•	
Prostatic hyperplasia	N40	0-74	•	
Pregnancy, childbirth and the perinatal period				
Tetanus neonatorum	A33	0-74		•
Obstetrical tetanus	A34	0-74		•
Pregnancy, childbirth and the puerperium	O00-O99	0-74	•	
Certain conditions originating in the perinatal period	P00-P96	0-74	•	
Avoidable mortality definition				

Causes of death (classified using the International Classification of Diseases, tenth revision (ICD-10)) considered to be avoidable				
Condition group and cause	**ICD-10 codes**	**Age**	**Treatable**	**Preventable**
Congenital malformations				
Certain congenital malformations (neural tube defects)	Q00, Q01, Q05	0-74		•
Congenital malformations of the circulatory system (heart defects)	Q20-Q28	0-74	•	
Adverse effects of medical and surgical care				
Drugs, medicaments and biological substances causing adverse effects in therapeutic use	Y40-Y59	0-74	•	
Misadventures to patients during surgical and medical care	Y60-Y69, Y83-Y84	0-74	•	

Medical devices associated with adverse incidents in diagnostic and therapeutic use	Y70–Y82	0-74	•	
Injuries				
Transport Accidents	V01-V99	0-74		•
Accidental Injuries	W00-X39, X46-X59	0-74		•
Intentional self-harm	X66-X84	0-74		•
Event of undetermined intent	Y16-Y34	0-74		•
Assault	X86-Y09, U50.9	0-74		•
Alcohol-related and drug-related deaths				
Alcohol-specific disorders and poisonings	E24.4, F10, G31.2, G62.1, G72.1, I42.6, K29.2, K70, K85.2, K86.0, Q86.0, R78.0, X45, X65, Y15	0-74		•
Other alcohol-related disorders	K73, K74.0-K74.2, K74.6	0-74		•
Drug disorders and poisonings	F11-F16, F18-F19, X40-X44, X85, Y10-Y14	0-74		•
Intentional self-poisoning by drugs	X60-X64	0-74		•
Provisional assignment of new diseases				
COVID-19	U07.1-U07.2	0-74		•

Chapter 5 – Quality of Care

Table A5.1 Overall quality of care ratings for deaths occurring in 2021 and 2022.

Overall quality of care rating	Deaths occurring in 2021, number of adults (valid %)	Deaths occurring in 2022, number of adults (valid %)
1 (fell far short)	21 (3.8%)	8 (1.6%)
2	89 (15.9%)	66 (13.1%)
3	157 (28.1%)	103 (20.4%)
4	143 (25.6%)	137 (27.2%)
5	133 (23.8%)	166 (32.9%)
6 (excellent)	16 (2.9%)	24 (4.8%)
Missing	4	0
Total	563 (559)	504 (504)

Table A5.2 Availability and effectiveness of care ratings for deaths occurring in 2021 and 2022.

Acceptability and effectiveness of care	Deaths occurring in 2021, number of adults (valid %)	Deaths occurring in 2022, number of adults (valid %)
1 (fell far short)	18 (3.2%)	10 (2.0%)
2	69 (12.3%)	59 (11.7%)
3	161 (28.8%)	103 (20.4%)
4	128 (22.9%)	132 (26.2%)
5	171 (30.6%)	179 (35.5%)
6 (excellent)	12 (2.1%)	21 (4.2%)
Missing	4	0
Total (valid)	563 (559)	504 (504)

Table A5.3 Reviewer responses to care issue questions for deaths occurring in 2021 and 2022.

	Delays in care and treatment		Problems with organisational processes and systems		Gaps in service provision		Recommended diagnostic and treatment guidelines met*	
	Deaths occurring in 2021	Deaths occurring in 2022	Deaths occurring in 2021	Deaths occurring in 2022	Deaths occurring in 2021	Deaths occurring in 2022	Deaths occurring in 2021	Deaths occurring in 2022
Yes	230 (40.9%)	175 (34.7%)	267 (47.5%)	182 (36.1%)	162 (28.8%)	97 (19.2%)	417 (74.2%)	386 (76.6%)
No	332 (59.1%)	329 (65.3%)	295 (52.5%)	322 (63.9%)	400 (71.1%)	407 (80.8%)	145 (25.8%)	118 (23.4%)
Missing	1	0	1	0	1	0	1	0
Total (valid)	563 (562)	504 (504)	563 (562)	504 (504)	563 (562)	504 (504)	563 (562)	504 (504)

*Please note that this question asks whether recommended diagnostic and treatment guidelines were met; a "yes" response therefore indicates good care in contrast to "yes" responses in the other domains.

Table A5.4 Reviewer assessment of reasonable adjustments to care for deaths occurring in 2021 and 2022.

Reasonable adjustments should have been provided but were not	Deaths occurring in 2021, number of adults (valid %)	Deaths occurring in 2022, number of adults (valid %)
Yes	193 (34.3%)	126 (25.0%)
No	370 (65.7%)	378 (75.0%)
Missing	0	0
Total (valid)	563 (563)	504 (504)

Table A5.5 Reviewer assessment of need for a mental capacity assessment for deaths occurring in 2021 and 2022.

Need for mental capacity assessment	Deaths occurring in 2021, number of adults (valid %)	Deaths occurring in 2022, number of adults (valid %)
Yes	439 (78.5%)	382 (75.8%)
No	120 (21.5%)	122 (24.2%)
Missing	4	0
Total (valid)	563 (559)	504 (504)

Table A5.6 Reviewer assessment of whether the Mental Capacity Act was followed in cases where a mental capacity assessment was needed for deaths occurring in 2021 and 2022.

Was the Mental Capacity Act followed	Deaths occurring in 2021, number of adults (valid %)	Deaths occurring in 2022, number of adults (valid %)
Yes	237 (70.7%)	283 (74.9%)
No	66 (19.7%)	61 (16.1%)
Don't know	32 (9.6%)	34 (9.0%)
Missing	104	4
Total (valid)	439 (335)	382 (378)

Chapter 6 – Covid, Weather, Flu

A6.1. As this is a continuation of the excess COVID-19 deaths calculation from the 2021 report, below is the explanation given in that report.

Methodological considerations

We have used several related datasets in this analysis. To show the changes due to deaths with COVID-19 over time, and to calculate the proportion of excess deaths for comparison with the general population, we used deaths notified to NHSE, which contained data on deaths since 2018. In this dataset, COVID-19 diagnosis was recorded by the notifier. Using notified rather than reviewed deaths helped to overcome several issues – firstly, it addressed the delays in reporting associated with reviewing deaths, and secondly, it allowed us to use data from 2018 – 2021 with no bias due to a change in the way that deaths were reviewed during 2021. There are however some limitations to using notified deaths. We have ensured that all duplications were removed, and that only adults with a confirmed learning disability have been included. However, a diagnosis of COVID-19 reported by notifiers may be inaccurate in some cases; to overcome this limitation, we defined the COVID-19 group as deaths in which COVID-19 was reported as a "certain" diagnosis, rather than as a "possible" or "unknown" diagnosis. To consider the factors associated with deaths due to COVID-19, we used data on deaths that occurred during 2021 and had initial review data as well as data from death certificates. COVID-19 deaths in this analysis were defined as those that had this diagnosis designated as underlying cause of death on the death certificate. However, it does not include cases where COVID-19 may have contributed to the death of the person but was not deemed to be the main cause of death, and furthermore, it does not include deaths that did not have death certificate data, or that did not have initial review data. This means that this analysis may underestimate the full impact of COVID-19 particularly during the last few months of 2021; however, in adjusted analyses, this is very unlikely to change the findings. Both the datasets that were used had a limited number of variables available for analysis. Specifically, the notification dataset did not include data on co-morbid diagnoses (also called long-term health conditions) or medication. Furthermore, the switch during 2021 to the new way of recording data meant that co-morbid diagnoses were not recorded for all the deaths included in the initial reviews, and unrecorded data varied during the year (see earlier chapters for more details). We therefore had to use data on a limited number of long-term health conditions that was extracted by coders from free text (see Appendix 1.5). This may have underestimated the conditions people may have had during life.

Estimating excess deaths and comparison with general population data

We followed the methodology used by the ONS to calculate the numbers of excess deaths for 2020 and 2021. This is based on calculating an expected number of deaths for 2020 and 2021. This is based on calculating an expected number of deaths by month, based on data from preceding years. ONS based their calculation on the average number of deaths by month using 5 years of observations before the pandemic (2015 – 2019), while we were only able to use data for adults with learning disability for the 2 years preceding the pandemic (2018 – 2019). However, the overall difference between these years were relatively small, with 7.8% more deaths notified to LeDeR during 2019 compared to 2018. Another difference is that ONS reports death by date of registration, while we used date of death. Although there may be delays in deaths being reported to ONS, deaths registered within one week of death in 2020 was 75.2%, and deaths registered within two weeks was 89.1%. Furthermore, deaths due to COVID-19 were typically reported quickly – in 2020, 86.5% of deaths due to coronavirus (COVID-19) were registered within one week (seven days or fewer)[1]. Since we compared deaths by month rather than by week, the impact of the difference in reporting date methodology is likely to be small.

Excess deaths are expressed as a %, calculated as the number of excess deaths over the number of expected deaths for the relevant group or period in 2018/2019. We calculated binomial 95% confidence intervals for the % excess deaths. Factors associated with COVID-19 as underlying cause of death: We first compared factors that may be associated with COVID-19 as underlying cause of death using univariable statistical tests (Chi-Square Test, Student-T test, and Mann-Whitney, as appropriate). We then undertook a logistic regression to compare factors associated with

having COVID-19 recorded as underlying cause of death or not, and included age, sex, region, season, ethnicity, place of death and long-term conditions as predictors in an “enter” procedure.

A6.2 ONS Monthly Death Totals for England (overall population)

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
2015	57,034	43,727	44,809	42,286	36,713	39,289	37,916	33,823	38,876	39,458	38,883	42,495
2016	44,387	43,033	45,308	43,755	38,716	39,378	36,484	38,006	37,742	37,835	43,523	42,624
2017	53,675	44,815	45,594	36,422	41,383	39,447	35,940	38,341	37,535	40,745	42,690	42,295
2018	60,075	45,918	47,726	43,478	39,951	37,213	38,059	37,610	34,682	41,466	40,971	38,710
2019	50,385	42,847	41,117	41,167	41,504	36,180	39,614	36,271	37,462	43,257	42,280	44,286
2022	49,807	43,081	46,202	42,944	45,526	41,441	42,034	44,381	42,614	45,353	47,611	49,339

A6.3 Met Office Central England Temperature (centigrade) Data for 2022

Note: For dates that do not exist, e.g. Feb 30th, -99.9 are presented. This is the table as presented by the Met Office.

Avg	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
min	1.6	3.7	3.3	2.2	1.9	1.3	3.1	4	1.2	2.5	2.5	-0.5
max	8	10.3	12.4	14.1	17.5	19.8	23.4	24.1	18.7	16.5	11.9	6.6
1	14.5	12.9	8.4	8.2	12.9	16.9	19.1	24.4	22.7	17.8	14.3	5.9
2	11.3	11.4	7.3	9.4	15.2	19.4	19	24.4	21.9	16.9	13.5	5.9
3	10	10.6	9.9	9.9	14.7	20	19.3	24.1	22.1	17	12.2	7.3
4	4.5	7.5	8.6	13.2	15.6	16.5	19.2	20.8	23.3	17.4	12	5.8
5	5.8	9.3	8	12.5	18.3	12.8	20	20.3	23	16.6	12.7	7.2
6	6.4	9.3	8.2	12.1	17.9	16.2	21.5	21.5	21	17.7	12.2	6
7	6.7	10.9	7.5	10.6	18	20.4	21.4	23.7	21.5	16.7	14.2	4.5
8	9.3	11.8	11.2	10.7	18.1	19.1	23.8	25.7	19	15.5	13.9	3
9	7.8	10.8	12.6	11	19.4	18.3	23.2	27.4	20.1	16.9	13.7	3.5
10	9.2	7.7	14.5	12.4	18.2	20.9	26.4	28.9	20.1	14.5	15	3.2
11	9.4	8.1	12.2	15.6	15.6	19.9	29	30.9	21.8	14.8	15.9	0.7
12	7.9	9.2	12.4	15	16.3	18.3	26.4	31.4	22.1	14.9	15.2	0.1
13	7.7	9.8	12.3	16.2	17.9	18.2	23.1	31.4	18.7	16.2	14.5	-0.4
14	4.9	8.4	12.8	16.7	20.7	21	21.2	31.7	19	14.9	13.4	0.4
15	5.6	12.2	14.1	19.9	19.2	23.5	22.4	25.9	17	15.1	12.2	0.5
16	8.6	15	10.7	19.5	20.4	25.7	25	22.8	15.7	15.6	11.1	2.8
17	8.5	10.4	13.1	18.8	22.8	28.2	30	20.9	16.2	17.2	10.4	4
18	7	8.2	15.4	14.9	20.4	16.6	34.8	22.9	17.3	16.5	11	13
19	8.9	10.7	14.6	14.3	18.8	17.6	37.3	21.8	17	15.2	10.6	13.5
20	5.2	12.2	11.1	17	17.4	19.7	22.4	23.1	18.4	15	10.8	9.8
21	5.5	10.8	14.2	17.4	18.3	23.2	20.9	22.2	18.9	16.9	8.2	9.4
22	6.9	12	18.1	15.9	20.7	24	20.9	21.7	18.5	16.7	9.7	9
23	5.2	10.1	18.7	15.8	16.6	24.2	22.9	23.8	18	17.2	11.1	10.2
24	4.4	6.6	18.3	16.2	16.1	20.3	25.4	23.2	17.5	15.7	11.4	9.9
25	5.1	10.5	17.7	13.8	17.4	19.7	20.7	19.3	15.1	16.7	11.5	10.6
26	9.2	10.4	18.1	14.5	17.9	19.5	19.9	21.9	14.5	17.7	12.1	7.4
27	11.6	10.9	14.7	10.9	16.9	17.7	21.9	23.5	14.4	18.3	11.4	9.9
28	11	11	15.5	11.3	17	18.6	20.5	23	14.2	17	10.6	11.1
29	12.9	-99.9	10.1	12.8	14.5	19.4	23.9	20.6	16.7	19.5	5.1	8.8
30	8.4	-99.9	8	16.1	13.8	18.9	21.5	21.4	14.8	16.2	6.8	11.8
31	9.5	-99.9	-6.9	99.9	14.6	-99.9	23.7	22.4	-99.9	15.8	-99.9	11.3

Chapter 7 – Deaths of Autistic Adults in LeDeR 2022

A7.1 **National Statistics Definition of Suicide in the ICD-10**

The ONS defines suicide deaths as those which include an underlying cause of intentional self-harm (ages 10 years and over), and deaths with an underlying cause of death of undetermined event (aged 15 years and over).

The National Statistics definition of suicide based on codes from the International Classification of Diseases (ICD), England and Wales are:

ICD codes	Description	Notes
ICD 10 (deaths registered 2001 onwards)		
X60-X84	Intentional self-harm	Persons aged 10 years and above
Y10-Y34	Injury/poisoning of undetermined intent	Persons aged 15 years and above; excludes Y33.9 where the coroner's verdict was pending for the years 2001-2006

Source: Office for National Statistics,