Appendicies

LeDeR

Annual Report 2021

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

Contents

Appendices and supplementary material is available here as a separate document from the main report.
(note, there are no appendix for chapter 3).

Appendix 0.1 - Foreword

LeDeR process and data

In the LeDeR report we use pseudonymised data which reflect different stages of the LeDeR review process.

LeDeR data quality checks
The web notification system contains measures to prevent the submission of deaths falling outside of the scope of LeDeR.

Additional data quality checks have been performed by the LeDeR research team before any analyses were run. These included the exclusion of data containing obvious errors, such as repeated values or error messages, any duplicate records, and notifications without key basic information (date of death, date of birth or sex). Demographic information was extracted from the notification dataset because it contains information from a larger subset of people reported to LeDeR than the initial review and focused review datasets.

More detail on changes in the review process for 2021

New notification forms were introduced in May 2021 alongside the new LeDeR online platform with new initial and focused review forms being introduced in summer 2021.

Before summer 2021 all people reported to LeDeR received a review consisting of between 59 and 65 questions. The most recent version of the questionnaire used prior to June 2021, referred to as the IR-10, contained 65 questions. The questionnaire was reduced during 2021 to 43 questions. Some of the questions were no longer included in the initial review form and moved to the focused review form, for example: the person's weight, long-term health conditions, medication history, the quality of care they received, reasonable adjustments and whether any evidence of best practise was identified.

Whilst like-for-like comparison between previous LeDeR review forms and the updated review forms was therefore not entirely possible, it was possible to collect information about some of these topics by analysing the textual inputs of the LeDeR reviews, for example from the pen portrait, which is a written summary that aims to provide insight into the person, their health and care needs, and the extent to which their needs were met.

Certain questions have been added to the initial review form, which may enable different forms of analysis in the future. These include questions about the deceased person's religion, whether the deceased person had children, or was pregnant. The version introduced in the summer of 2021 also contains more detail about Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) documentation.

Significant changes have also been made to the more in-depth LeDeR reviews. Prior to the summer of 2021, reviewers were responsible for conducting multi-agency review meetings between the person's family, loved ones and representatives from any agencies that have been involved in supporting the individual. These were conducted for approximately 3.5% of the LeDeR cohort if there were concerns about the individual's care or it was felt that additional learning could result from a review, and later, for a limited number of specific indications, such as being aged 18 to 24.

From summer 2021 a new process for conducting more in-depth reviews was introduced, now known as 'focused reviews'. To complete a focused review, a reviewer or senior reviewer follows a web-based form accessed on the LeDeR system in the following circumstances: when there are concerns about the quality of care, opportunities for additional learning or if the person was from a minority ethnic group.

From February 2022, focused reviews will also be conducted if the individual has been subject to detention under the Mental Health Act or had been in prison in the previous 5 years.
The form follows a 'skip logic model' whereby the availability of certain questions is triggered by answers to others. For example, if the person has a history of aspiration pneumonia, a further set of questions about this condition will appear. The aim of the form is to increase the efficiency of conducting more in-depth reviews and make sure that only the most relevant topics are reviewed in detail.

Child death reviews

Child deaths are reviewed as part of a separate, mandatory process overseen by Child Death Overview Panels (CDOP), meaning some data that are routinely collected as part of the LeDeR process are unavailable for child deaths (e.g. quality of care data). CDOP data from children with a learning disability aged 4 years and older who died are included in the LeDeR dataset.

Medical certificate of cause of death (MCCD)

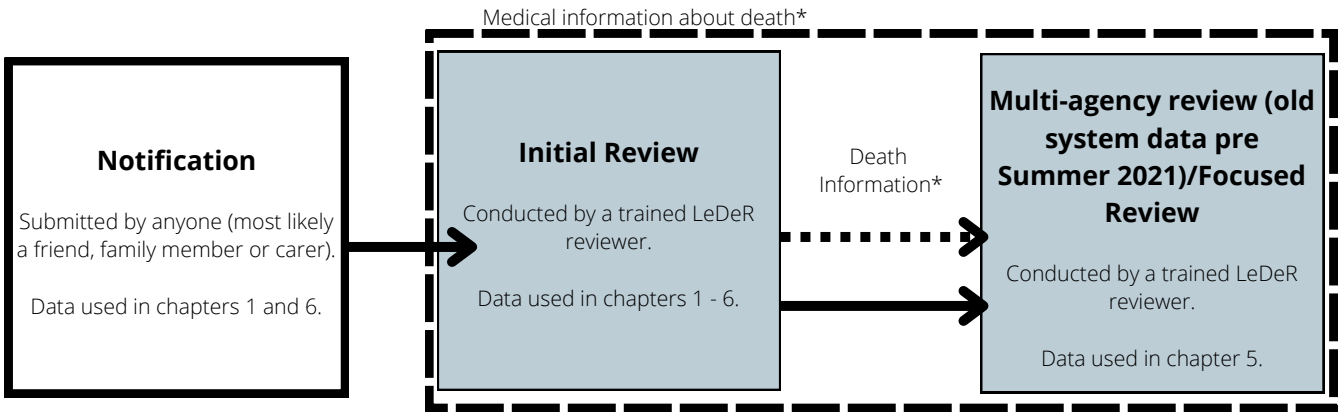
Once someone has died, a doctor involved in their care completes an MCCD which consists of two parts. Part one contains the sequence of events or conditions that led directly to the death. The underlying cause of death is defined as the disease or injury which initiated the chain of events leading directly to death. Other conditions which may have contributed to a death are provided in part two of the death certificate.

Once the MCCD has been completed, it is forwarded to the registry office to register the death. MCCD's are provided to LeDeR by the Office of National Statistics (ONS) using NHS numbers as identifiers. MCCD data are not always available from the ONS before an initial review is conducted. Some deaths are referred to a coroner which may delay the acquisition of information about a person's death. Referrals to a coroner happen in several different situations which include: if a doctor was not able to complete an MCCD, deaths with an unknown cause, suspicious deaths, or deaths which have occurred under state detention. See Appendix 2.2 for a full list of circumstances where a coroner's inquest should take place.

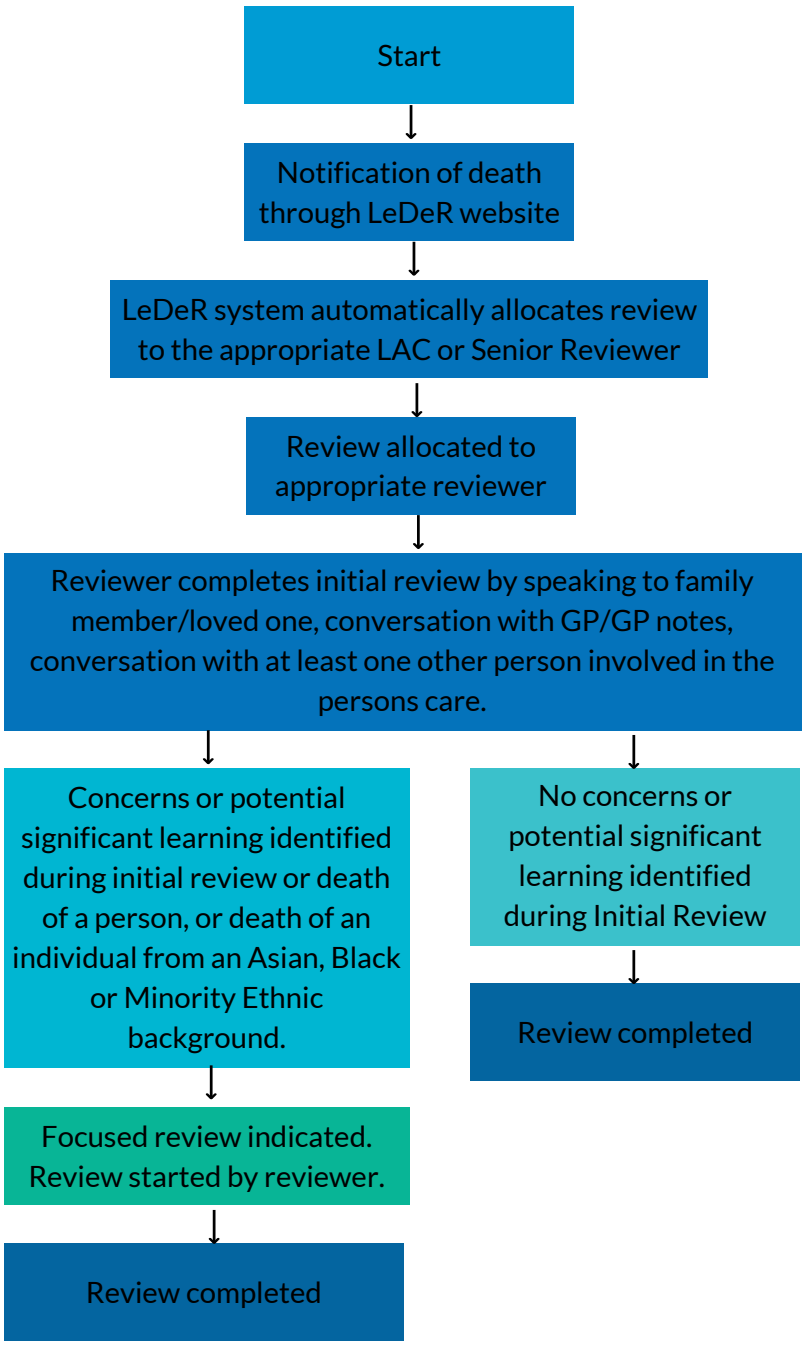
Data availability

The time it takes to process a notification, assign a reviewer, conduct an initial review and, where appropriate, a focused review means that some data are not available prior to the data extraction for inclusion in the annual report. Some deaths which occurred in 2021 may therefore not have been included in the analyses using the initial and focused review data. This may affect the numbers of deaths included in the latter part of the year. Data from 109 CDOP reviews and 1 focused review were available for children (aged 4-17) who died in 2021. On 31st December 2021, when the data used in this report were extracted, a lower proportion of reviews for children who died in 2021 were available in comparison to adults who died in 2021. MCCD data were also less available for the reviews that had been conducted for children in comparison to adults.

Appendix 0.2: Flow chart depicting how LeDeR data are used in the annual report.



Appendix 0.3: Flow chart depicting the LeDeR review process in 2021.



Appendix 0.4: Flow chart comapring the LeDeR review process in pre June 2021 and from June 2021.

Stage in process	Pre June 2021	From June 2021 onwards
Notification	Made by anyone via web form embedded in UoB website or telephone.	Made by anyone via the www.leder.nhs.u k website. Phone support available for people unable to complete online.
	Notification included basic demographic information, circumstances of the death, contact details of the notifier.	Notification includes basic demographic information, circumstances of the death, contact details of the notifier.
		Notification processed through DSCRO to validate information.
	Notification allocated via web-based platform to the CCG (via the LAC).	Notification allocated via web-based platform to a senior reviewer for the ICS (or LAC if no senior reviewer in place).
	LAC allocates case to a reviewer	Senior reviewer allocates case to a reviewer
Initial review	Generic web form generated for each review.	Web form containing series of specific questions using skip logic generated for each review.
	Reviewer contacts someone who knew the person well to request involvement in review (family / friends).	Reviewer contacts someone who knew the person well to request involvement in review (family/friends).
	Information gathered from GP.	Information gathered from GP either by speaking to the GP or be looking at the clinical record.
	Initial review form completed including pen portrait, and timeline.	Initial review form completed including pen portrait.
	Information gathered on medical history, treatment, quality of care and recommendations for all deaths.	Questions in form dependent on the complexity of the person who died and uses skip logic; therefore, some information not available on all deaths
	Decision with LAC about whether a multi-agency review (MAR) is required.	Reviewer (with input from senior reviewer if needed) determine whether focused review is needed.
	A multi-agency review was conducted for all deaths where concerns had been identified.	A focused review will be conducted for all deaths which meet any of the following criteria: • From a minority ethnic community. • Detained by the Criminal Justice system or under Mental Health Act restriction in last 5 years. • All autistic people aged 18 and above. • Local priorities for focused reviews. • Learning from life or death of individual to inform service improvements. • Request by a family member supported by the reviewer.
In depth review	Multi agency review (MAR)	Focused review
	Form downloaded.	Web form section opens for completion using skip logic.
		More detailed review of medical history, care, and treatment with specific lines of questioning for specific morbidities such as cancer, bowel health, epilepsy etc. Questions asked to depend on complexity of person who has died.
	A multi-agency meeting was convened to explore care in more detail and agree whether on balance, the death could have been potentially avoided. Action plan developed.	Areas of concern and areas of learning are identified by reviewer and shared with governance group. Governance group determine SMART actions to impact service improvement for the ICS.

Appendix 1 - Chapter 1

Appendix 1.1: Percentage of notifications by sex for 2018 - 2021, compared to ONS data from the general population[1].

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

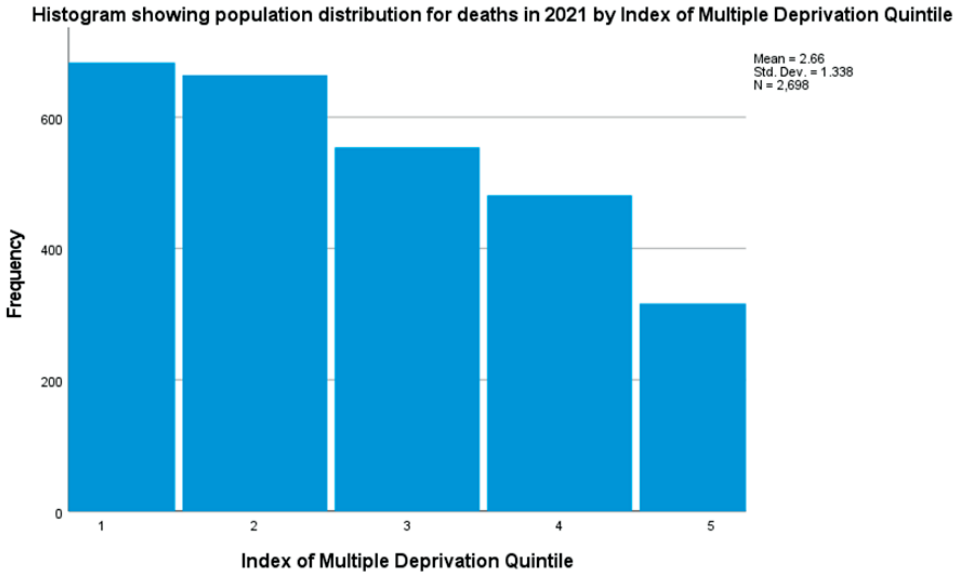
Appendix 1.2: Percentage of notifications by ethnicity for 2018 - 2021, compared to ONS data from the general population[2]

Children and adults	2018	2019	2020	2021	Average 2018-2021	General Population (2017-2019)
Asian or Asian British	2%	1%	1%	3%	2%	2%
Black, Black British, Caribbean or African	2%	2%	2%	2%	2%	1%
Mixed ethnic group	3%	4%	5%	3%	4%	<1%
White	92%	91%	90%	91%	91%	96%
Other	1%	2%	2%	1%	1%	<1%
Total No.	2,528	2,745	3,522	3,104	11,899	2,884,015
Adults (18+)						
Asian or Asian British	2%	2%	2%	2%	2%	
Black, Black British, Caribbean or African	2%	2%	2%	2%	2%	
Mixed ethnic group	2%	3%	4%	2%	3%	
White	94%	94%	92%	93%	93%	
Other	1%	1%	2%	1%	1%	
Total No.	2,361	2,535	3,325	2,917	11,138	
Children (4-17)						
Asian or Asian British	4%	5%	6%	15%	7%	
Black, Black British, Caribbean or African	7%	7%	7%	7%	7%	
Mixed ethnic group	24%	19%	23%	9%	19%	
White	60%	60%	61%	67%	62%	
Other	5%	9%	4%	2%	5%	
Total No.	167	210	197	187	761	

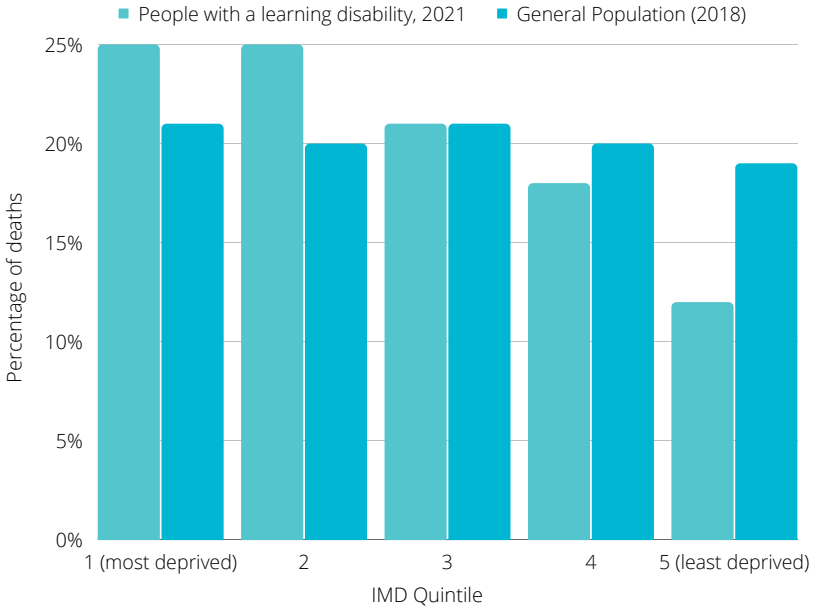
1. https://www.ons.gov.uk/releases/deathsregisteredinenglandandwales2020

2. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/mortalityfromleadingcausesofdeathbyethnicgroupenglandandwales
General population data is for adults 10 years and above who died between 2017 and 2019

Appendix 1.3: Population distribution by Index of Multiple Deprivation quintile for deaths that had initial review data in 2021.



Appendix 1.4: Percentage of deaths by IMD quintile for people with a learning disability (2021) and the general population (2018)[3].



3.https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthinequalities/datasets/changingtrendsinmortalitybynationalindicesofdeprivationenglandandwales

Appendix 1.5: Detail about how long-term health conditions are defined.

The following were defined as long term health conditions:

- **Cancer**
- **Cardiovascular conditions**
- **Degenerative conditions**
- **Dementia**
- **Diabetes**
- **Deep vein thrombosis (DVT)**
- **Epilepsy**
- **Hypertension**
- **Kidney problems**
- **Mental health conditions**
- **Osteoporosis**
- **Respiratory conditions**
- **Sensory impairment**
- **Dysphagia**

Some of these 'conditions' represent broader categories which are used to group a number of specific conditions. When completing initial reviews, reviewers could provide detail about the condition in a free text box. The following are selected examples from reviews of the specific conditions included within the categories:

- **Cancer**: *breast cancer*, *bowel cancer*, *melanoma*, *leukeumia*, *prostate cancer*, *lung cancer*
- **Cardiovascular conditions**: *Atrial fibrillation*, *congestive cardiac disease*, *TIAs*, *myocardial ischaemia*, *heart failure*, *AV canal failure*, *cardiac arrest*, *arrhythmia*
- **Degenerative conditions**: *motor neurone disease*, *myotonic dystrophy*, *Parkinson's*, *'degenerative disease'*, *macular degeneration*, *Sanfilippo syndrome*, *Huntington's disease*, *Becker's muscular dystrophy*, *Duchenne muscular dystrophy*
- **Kidney problems**: *kidney disease*, *tumors affecting kidney function*, *kidney infection*, *absent kidney*, *kidney injury*, *kidney failure*, *obstructed kidney*, *kidney stones*, *'kidney issues'*
- **Mental health conditions**: *anxiety*, *bipolar*, *psychosis*, *depression*
- **Respiratory conditions**: *asthma*, *COPD*
- **Sensory impairment**: *vision problems*, *hearing problems*
- **Diabetes**: *type 1 diabetes*, *type 2 diabetes*

Appendix 2 - Chapter 2

Appendix 2.1: Place of death for children and adults who died in 2018, 2019, 2020 and 2021, and comparison data from the general population. [3]

					General Population
Place of death	2018	2019	2020	2021	2019
Children and adults (aged 4 years and older)					
Hospital	60.4%	56.5%	59.0%	61.3%	46%
Usual place of residence	30.5%	33.2%	32.6%	33.3%	45%
Other	6.2%	6.2%	5.2%	4.1%	9%
Not recorded	3.0%	4.0%	3.2%	1.3%	
Total No.	2,537	2,724	3,444	2,662	517,909
Children (aged 4 – 17 years)					
Hospital	63.1%	64.4%	57.0%	51.4%	64%
Usual place of residence	22.4%	19.4%	27.9%	32.1%	23%
Other	12.9%	12.5%	11.7%	12.8%	4%
Not recorded	1.7%	3.7%	3.4%	3.7%	
Total No.	179	216	179	109	560
Adults (aged 18+)					
Hospital	60.1%	55.9%	59.1%	62.9%	46%
Usual place of residence	31.1%	34.4%	32.9%	30.8%	46%
Other	5.7%	5.7%	4.8%	4.8%	9%
Not recorded	3.1%	4.1%	3.2%	1.4%	
Total No.	2,358	2,583	3,364	2,553	517,349

Appendix 2.2: Circumstances in which a death should be 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.
- The registered medical practitioner suspects that the death has taken place while in custody or state detention (excluding those who died with a deprivation of liberty order in place).
- 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

3. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2020

Appendix 2.3.1: The most frequently reported ICD-10 chapter causes of death, by year of death, all ages.

	2018		2019		2020		2021	
ICD-10 chapter	M	F	M	F	M	F	M	F
Codes for special purposes (COVID-19)	0.07%	0.00%	0.00%	0.08%	23.13%	19.96%	22.12%	20.24%
Diseases of the circulatory system	16.34%	12.86%	13.66%	15.09%	12.02%	12.11%	15.25%	12.98%
Diseases of the respiratory system	20.57%	20.32%	17.91%	20.03%	12.32%	13.63%	11.67%	12.43%
Cancers	11.96%	14.82%	13.79%	13.50%	8.55%	11.01%	10.95%	12.07%
Diseases of the nervous system	12.17%	12.02%	13.14%	11.99%	10.71%	8.60%	11.67%	10.25%
Congenital malformations, deformations and chromosomal abnormalities	13.53%	12.95%	14.05%	13.75%	9.00%	10.32%	9.66%	10.53%
Diseases of the digestive system	7.52%	6.34%	7.25%	5.28%	5.43%	4.75%	6.16%	5.72%
Mental and behavioral disorders	3.90%	5.22%	3.99%	4.95%	3.02%	5.02%	3.15%	4.63%
Endocrine, nutritional and metabolic diseases	2.53%	2.89%	1.96%	2.35%	1.86%	1.86%	1.93%	3.45%
Diseases of the genitourinary system	1.98%	2.52%	2.16%	1.84%	2.31%	2.34%	2.22%	2.09%
Certain infectious and parasitic diseases	1.30%	2.33%	1.90%	1.76%	0.96%	0.89%	2.00%	1.45%
Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	0.68%	0.84%	0.85%	1.26%	0.60%	0.89%	0.86%	0.91%
External causes of morbidity and mortality	3.49%	2.33%	2.94%	2.18%	0.75%	0.89%	0.86%	0.73%
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	0.48%	0.75%	0.65%	0.75%	0.35%	0.62%	0.36%	1.09%
Diseases of the musculoskeletal system and connective tissue	0.62%	0.75%	0.52%	0.75%	0.40%	0.41%	0.50%	0.82%
Injury, poisoning and certain other consequences of external causes							0.36%	0.09%
Diseases of the skin and subcutaneous tissue	0.34%	0.65%	0.39%	0.25%	0.30%	0.48%	0.21%	0.36%
Certain conditions originating in the perinatal period	0.07%	0.00%	0.13%	0.17%	0.20%	0.21%	0.07%	0.18%
Diseases of the eye and adnexa	0.07%	0.00%	0.00%	0.00%	0.00%	0.00%		

Appendix 2.3.2: The most frequently reported ICD-10 chapter causes of death, by year of death, 4-17-year-olds.

	2018		2019		2020		2021	
ICD-10 chapter	M	F	M	F	M	F	M	F
Codes for special purposes (COVID-19)	1.01%	0.00%	0.00%	0.00%	1.80%	7.35%	12.82%	4.35%
Diseases of the circulatory system	5.05%	7.50%	4.10%	3.19%	5.41%	4.41%	5.13%	6.52%
Diseases of the respiratory system	11.11%	15.00%	13.11%	19.15%	5.41%	11.76%	7.69%	0.00%
Cancers	8.08%	6.25%	4.92%	5.32%	1.80%	7.35%	12.82%	4.35%
Diseases of the nervous system	29.29%	23.75%	27.05%	21.28%	24.32%	19.12%	33.33%	21.74%
Congenital malformations, deformations and chromosomal abnormalities	8.08%	12.50%	9.84%	13.83%	10.81%	19.12%	10.26%	23.91%
Diseases of the digestive system	5.05%	1.25%	5.74%	4.26%	6.31%	2.94%	2.56%	6.52%
Mental and behavioral disorders	0.00%	3.75%	0.00%	2.13%	0.90%	1.47%		
Endocrine, nutritional and metabolic diseases	10.10%	6.25%	7.38%	7.45%	11.71%	4.41%	7.69%	19.57%
Diseases of the genitourinary system	0.00%	3.75%	0.00%	0.00%	0.90%	1.47%	0.00%	4.35%
Certain infectious and parasitic diseases	6.06%	7.50%	4.92%	4.26%	2.70%	1.47%	2.56%	2.17%
Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	0.00%	0.00%	1.64%	0.00%	0.00%	0.00%	2.56%	0.00%
External causes of morbidity and mortality	4.04%	3.75%	2.46%	2.13%	0.90%	1.47%	2.56%	0.00%
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	2.02%	0.00%	1.64%	0.00%	1.80%	0.00%	0.00%	2.17%
Diseases of the musculoskeletal system and connective tissue	2.02%	0.00%	0.82%	0.00%	1.80%	1.47%		
Injury, poisoning and certain other consequences of external causes								
Diseases of the skin and subcutaneous tissue								
Certain conditions originating in the perinatal period	0.00%	0.00%	1.64%	2.13%	1.80%	2.94%	0.00%	4.35%
Diseases of the eye and adnexa	1.01%	0.00%	0.00%	0.00%	0.00%	0.00%		

Appendix 2.3.3: The most frequently reported ICD-10 chapter causes of death, by year of death, 18-64-year-olds.

	2018		2019		2020		2021	
ICD-10 chapter	M	F	M	F	M	F	M	F
Codes for special purposes (COVID-19)	0.00%	0.00%	0.00%	0.00%	20.84%	20.91%	20.52%	20.00%
Diseases of the circulatory system	15.13%	9.57%	12.53%	12.23%	12.92%	9.76%	14.58%	11.45%
Diseases of the respiratory system	16.54%	18.32%	14.20%	17.58%	8.61%	11.03%	9.81%	10.81%
Cancers	11.67%	16.50%	13.84%	14.98%	7.83%	10.90%	10.84%	12.74%
Diseases of the nervous system	14.36%	14.69%	16.71%	13.30%	13.31%	10.90%	14.06%	12.26%
Congenital malformations, deformations and chromosomal abnormalities	17.82%	17.99%	18.14%	19.11%	12.52%	14.32%	14.19%	14.52%
Diseases of the digestive system	8.33%	5.94%	6.09%	5.05%	6.56%	5.83%	6.58%	5.65%
Mental and behavioral disorders	1.92%	3.14%	2.98%	2.29%	1.86%	2.53%	1.29%	2.10%
Endocrine, nutritional and metabolic diseases	2.56%	2.48%	1.79%	2.45%	1.17%	1.77%	1.94%	3.55%
Diseases of the genitourinary system	1.67%	2.48%	1.79%	1.38%	1.76%	1.65%	1.68%	1.45%
Certain infectious and parasitic diseases	1.15%	1.49%	1.67%	1.53%	0.68%	0.51%	1.81%	1.45%
Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	0.77%	0.99%	0.72%	1.68%	0.59%	1.14%	0.65%	1.45%
External causes of morbidity and mortality	4.36%	2.31%	3.46%	2.60%	0.78%	0.76%	0.90%	0.97%
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	0.00%	0.00%	0.36%	0.31%	0.10%	0.00%	0.39%	0.32%
Diseases of the musculoskeletal system and connective tissue	0.26%	0.66%	0.60%	0.76%	0.49%	0.51%	0.52%	0.97%
Injury, poisoning and certain other consequences of external causes	0.51%	0.66%	0.36%	0.15%	0.20%	0.38%	0.13%	0.16%
Diseases of the skin and subcutaneous tissue	0.13%	0.00%	0.00%	0.00%	0.20%	0.13%	0.00%	0.16%
Certain conditions originating in the perinatal period	0.00%	0.00%	0.00%	0.00%	20.84%	20.91%	0.13%	0.00%

Appendix 2.3.4: The most frequently reported ICD-10 chapter causes of death, by year of death, people aged 65+.

	2018		2019			2020		2021	
ICD-10 chapter	M	F	M	F		M	F	M	F
Codes for special purposes (COVID-19)	0.00%	0.00%	0.00%	0.22%		28.62%	20.13%	24.87%	22.25%
Diseases of the circulatory system	19.86%	19.12%	17.37%	21.80%		11.80%	16.11%	16.81%	15.83%
Diseases of the respiratory system	27.57%	24.55%	24.39%	23.82%		17.64%	17.28%	14.41%	16.06%
Cancers	13.01%	13.95%	15.61%	13.03%		10.28%	11.58%	10.98%	11.93%
Diseases of the nervous system	6.34%	5.43%	4.91%	8.09%		5.84%	4.36%	7.03%	6.19%
Congenital malformations, deformations and chromosomal abnormalities	8.73%	5.17%	8.95%	5.84%		4.56%	4.03%	3.60%	3.44%
Diseases of the digestive system	6.85%	8.01%	9.30%	5.84%		3.97%	3.52%	5.83%	5.73%
Mental and behavioral disorders	7.19%	8.79%	6.32%	9.44%		4.67%	8.72%	5.83%	8.72%
Endocrine, nutritional and metabolic diseases	1.20%	2.84%	1.05%	1.12%		1.40%	1.68%	1.54%	1.61%
Diseases of the genitourinary system	2.74%	2.33%	3.16%	2.92%		3.15%	3.36%	3.09%	2.75%
Certain infectious and parasitic diseases	0.68%	2.58%	1.58%	1.57%		1.05%	1.34%	2.23%	1.38%
Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	0.68%	0.78%	0.88%	0.90%		0.70%	0.67%	1.03%	0.23%
External causes of morbidity and mortality	2.23%	2.07%	2.28%	1.57%		0.70%	1.01%	0.69%	0.46%
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	0.86%	2.07%	0.88%	1.57%		0.47%	1.51%	0.34%	2.06%
Diseases of the musculoskeletal system and connective tissue	0.86%	1.03%	0.35%	0.90%		0.12%	0.17%	0.51%	0.69%
Injury, poisoning and certain other consequences of external causes	0.17%	0.78%	0.53%	0.45%		0.47%	0.67%	0.69%	0.00%
Diseases of the skin and subcutaneous tissue	0.00%	0.00%	0.00%	0.22%		28.62%	20.13%	0.51%	0.69%
Certain conditions originating in the perinatal period									
Diseases of the eye and adnexa									

Appendix 2.4: The most frequently reported respiratory causes of death for 2018 to 2021.

2018			2019			2020			2021		
Cause of death	No.	% of resp deaths	Cause of death	No.	% of resp deaths	Cause of death	No.	% of resp deaths	Cause of death	No.	% of resp deaths
Pneumonia, organism unspecified	271	52.1	Pneumonia, organism unspecified	256	49.8	COVID	750	62.9	COVID-19	532	63.9
Pneumonitis due to solids and liquids	88	16.9	Pneumonitis due to solids and liquids	76	14.8	Pneumonia, Organism unspecified	211	17.7	Pneumonia, organism unspecified	176	21.2
Unspecified acute lower respiratory infection	39	7.5	Other chronic obstructive pulmonary disease	39	7.6	Pneumonitis due to solids and liquids	75	6.3	Other chronic obstructive pulmonary disease	29	3.5
Other chronic obstructive pulmonary disease	38	7.3	Unspecified acute lower respiratory infection	26	5.1	Unspecified acute lower respiratory infection	40	3.4	Pneumonitis due to solids and liquids	26	3.1
Asthma	20	3.8	Asthma	25	4.9	Other chronic obstructive pulmonary disease	35	2.9	Unspecified acute lower respiratory infection	24	2.9
						Asthma	22	1.8	Bronchiectasis	12	1.4
									Asthma	12	1.4

Appendix 2.5: The most frequently reported cancerous causes of death for 2018 to 2021.

2018			2019			2020			2021			General population (2016-2018)
Type of Cancers	No.	% of cancer deaths	Type of Cancers	No.	% of cancer deaths	Type of Cancers	No.	% of cancer deaths	Type of Cancers	No.	% of cancer deaths	% of cancer deaths
Digestive organs	**134**	**40.1**	**Digestive organs**	**126**	**33.8**	**Digestive organs**	**119**	**36.1**	**Digestive organs**	**99**	**34.6**	-
Most common sub-cancers:			*Most common sub-cancers:*			*Most common sub-cancers:*			*Most common sub-cancers:*			
Colon and rectum	*47*	14.1	*Colon and rectum*	*55*	14.7	*Colon and rectum*	*36*	10.9	*Colon and rectum*	*39*	13.6	10
Oesophagus	*26*	7.8	*Oesophagus*	*24*	6.4	*Oesophagus*	*29*	8.8	*Oesophagus*	*19*	6.6	5
Pancreas	*25*	7.5	*Pancreas*	*17*	4.6	*Pancreas*	*15*	4.5	*Pancreas*	*15*	5.2	6
Lymphoid, haematopoietic and related tissue	**38**	**11.4**	**Lymphoid, haematopoietic and related tissue**	**44**	**11.8**	**Lymphoid, haematopoietic and related tissue**	**31**	**9.4**	**Lymphoid, haematopoietic and related tissue**	**32**	**11.2**	-
Breast	**26**	**7.8**	**Ill-defined, secondary and unspecified sites**	**43**	**11.5**	**Ill-defined, secondary and unspecified sites**	**31**	**9.4**	**Respiratory and intrathoracic organs**	**24**	**8.4**	-
			Most common sub--category,cancers:			*Most common sub-cancers:*			*Most common sub-cancers:*			
			Other and unspecified types of non-Hodgkin lymphoma	*14*	3.8	*Other and unspecified types of non-Hodgkin lymphoma*	*9*	2.7	*Bronchus and lung*	*22*	7.7	21
Respiratory and intrathoracic organs	**24**	**7.2**	**Respiratory and intrathoracic organs**	**31**	**8.3**	**Breast**	**30**	**9.1**	**Breast**	**24**	**8.4**	**7**
Most common sub-cancers:			*Most common sub-cancers:*									
Bronchus and lung	*24*	7.2	*Bronchus and lung*	*25*	6.7							
Female genital organs	**22**	**6.6**	**Breast**	**27**	**7.2**	**Respiratory and intrathoracic organs**	**27**	**8.2**	**Female genital organs**	**23**	**8.0**	-
Most common sub-cancers:						*Most common sub-cancers:*			*Most common sub-cancers:*			
Cervix and uterus	*13*	3.9				*Bronchus and lung*	*27*	8.2	*Cervix and uterus*	*13*	4.5	4
Ovary	*8*	2.4							*Ovary*	*7*	2.4	5
Ill-defined, secondary and unspecified sites	**20**	**6.0**	**Urinary tract**	**25**	**6.7**	**Female genital organs**	**25**	**7.6**	**Urinary tract**	**22**	**7.7**	-
Most common sub-cancers:						*Most common sub-cancers:*						
Other and unspecified types of non-Hodgkin lymphoma	*11*	3.3				*Cervix and uterus*	*11*	3.3				
						Ovary	*10*	3.0				

Appendix 2.5: The most frequently reported cancerous causes of death for 2018 to 2021. (continued)

2018			2019			2020			2021			General population (2016-2018)
Type of Cancers	No.	% of cancer deaths	Type of Cancers	No.	% of cancer deaths	Type of Cancers	No.	% of cancer deaths	Type of Cancers	No.	% of cancer deaths	% of cancer deaths
Eye, brain and other parts of central nervous system	**19**	**5.7**	**Female genital organs** *Most common sub-cancers:* *Cervix and uterus* *Ovary*	**25** *14* *9*	**6.7** 3.8 2.4	**Urinary tract**	**21**	**6.4**	**Ill-defined, secondary and unspecified sites** *Most common sub-cancers:* *Other and unspecified types of non-Hodgkin lymphoma*	**21** *7*	**7.3** 2.4	- -
Urinary tract	**18**	**5.4**	**Male genital organs** *Most common sub-cancers:* *Prostate*	**17** *13*	**4.6** 3.5	**Male genital organs** *Most common sub-cancers:* *Prostate*	**14** *13*	**4.2** 3.9	**Eye, brain and other parts of central nervous system**	**16**	**5.6**	-
Male genital organs *Most common sub-cancers:* *Prostate*	**15** *13*	**4.5** 3.9	**Eye, brain and other parts of central nervous system**	**13**	**3.5**	**Eye, brain and other parts of central nervous system**	**13**	**3.9**	**Male genital organs** *Most common sub-cancers:* *Prostate*	**15** *11*	**5.2** 3.8	- 13

Appendix 2.6: Information about leading causes of death.

Which leading causes of death were presented in this report?

Adults

The top 8 leading causes of death for adults reported to LeDeR are presented for 2018 and 2019. The top 9 leading causes of death are presented for 2020 and 2021. The conditions are the same across all four years with the addition of COVID-19 in 2020 and 2021. These 8 or 9 leading causes are then examined in further detail across different age groups and sexes. Where other, more prominent leading causes have been found in different age groups and sexes, they are presented, providing that they surpassed the 2.30% threshold set by Epilepsy and status epilepticus, the 9th most common cause of death in 2021. This selection process meant that the percentage of deaths reported on for each year exceeded 55% on all analyses.

Children (aged 4 to 17)

A different approach was required for the analyses of the leading causes of death in children aged 4 to 17. This was because of lower rates of mortality within this age group and delays in data acquisition. In the analysis of children, data for a leading cause was presented if it accounted for more than 5 deaths each year.

Appendix 2.7.1: The most frequently reported leading causes of death, by year of death, all ages.

2018			2019			2020			2021		
Leading cause of death	No.	%	Leading cause of death	No.	%	Leading cause of death	No.	%	Leading cause of death	No.	%
Children and adults (aged 4+)											
Congenital malformations, deformations and chromosomal abnormalities	337	13.28	Congenital malformations, deformations and chromosomal abnormalities	378	13.88	COVID-19	750	21.78%	COVID-19	532	19.98%
Cancers	332	13.09	**Cancers**	373	13.69	**Cancers**	329	9.55	**Cancers**	286	10.74%
Influenza and pneumonia	290	11.43	Influenza and pneumonia	279	10.24	Congenital malformations, deformations and chromosomal abnormalities	328	9.52	Congenital malformations, deformations and chromosomal abnormalities	251	9.43%
Ischaemic heart diseases	129	5.08	Cerebrovascular diseases	130	4.77	Influenza and pneumonia	223	6.48	Influenza and pneumonia	176	6.61%
Cerebral palsy and other paralytic syndromes	126	4.97	Cerebral palsy and other paralytic syndromes	125	4.59	Cerebral palsy and other paralytic syndromes	143	4.15	Cerebral palsy and other paralytic syndromes	119	4.47%
Cerebrovascular diseases	109	4.30	Ischaemic heart diseases	122	4.48	Ischaemic heart diseases	130	3.77	Ischaemic heart diseases	119	4.47%
Dementia and Alzheimer disease	101	3.98	Epilepsy and status epilepticus	121	4.44	Cerebrovascular diseases	122	3.54	Cerebrovascular diseases	108	4.06%
Epilepsy and status epilepticus	84	3.31	Dementia and Alzheimer disease	106	3.89	Dementia and Alzheimer disease	116	3.37	Dementia and Alzheimer disease	86	3.23%
						Epilepsy and status epilepticus	83	2.41	Epilepsy and status epilepticus	62	2.33%

Appendix 2.7.2: The most frequently reported leading causes of death, by year of death (4- to 17-year-olds).

2018			2019			2020			2021		
Leading cause of death	No.	%	Leading cause of death	No.	%	Leading cause of death	No.	%	Leading cause of death	No.	%
Children (aged 4-17)											
Congenital malformations, deformations and chromosomal abnormalities	18	10.06	Congenital malformations, deformations and chromosomal abnormalities	25	11.57	Congenital malformations, deformations and chromosomal abnormalities	24	13.41	Congenital malformations, deformations and chromosomal abnormalities	15	13.76%
Cerebral palsy and other paralytic syndromes	16	8.94	Cerebral palsy and other paralytic syndromes	23	10.65	Cerebral palsy and other paralytic syndromes	16	8.94	Cerebral palsy and other paralytic syndromes	13	11.93%
Influenza and pneumonia	15	8.38	Influenza and pneumonia	21	9.72	Epilepsy and status epilepticus	10	5.59	**Cancers**	7	6.42%
Cancers	13	7.26	Epilepsy and status epilepticus	16	7.41	**Cancers**	7	3.91	COVID-19	7	6.42%
Epilepsy and status epilepticus	13	7.26	**Cancers**	11	5.09	COVID-19	7	3.91			
Acute respiratory infections other than influenza and pneumonia	6	3.35	Septicaemia	7	3.24	Influenza and pneumonia	6	3.35			
Septicaemia	6	3.35	Acute respiratory infections other than influenza and pneumonia	5	2.31						
Cerebrovascular diseases	5	2.79									

Appendix 2.7.3: The most frequently reported leading causes of death, by year of death (18- to 64-year-olds).

2018			2019			2020			2021		
Leading cause of death	No.	%	Leading cause of death	No.	%	Leading cause of death	No.	%	Leading cause of death	No.	%
Adults (aged 18-64)											
Congenital malformations, deformations and chromosomal abnormalities	248	17.88	Congenital malformations, deformations and chromosomal abnormalities	276	18.49	COVID-19	378	20.85	COVID-19	283	18.93%
Cancers	189	13.63	**Cancers**	215	14.40	Congenital malformations, deformations and chromosomal abnormalities	241	13.29	Congenital malformations, deformations and chromosomal abnormalities	200	13.38%
Influenza and pneumonia	146	10.53	Influenza and pneumonia	126	8.44	**Cancers**	165	9.10	**Cancers**	163	10.90%
Cerebral palsy and other paralytic syndromes	92	6.63	Epilepsy and status epilepticus	90	6.03	Cerebral palsy and other paralytic syndromes	104	5.74	Cerebral palsy and other paralytic syndromes	83	5.55%
Epilepsy and status epilepticus	57	4.11	Cerebral palsy and other paralytic syndromes	82	5.49	Influenza and pneumonia	99	5.46	Influenza and pneumonia	80	5.35%
Ischaemic heart diseases	55	3.97	Ischaemic heart diseases	56	3.75	Epilepsy and status epilepticus	61	3.36	Ischaemic heart diseases	62	4.15%
Cerebrovascular diseases	43	3.10	Cerebrovascular diseases	54	3.62	Ischaemic heart diseases	59	3.25	Epilepsy and status epilepticus	49	3.28%
Dementia and Alzheimer disease	33	2.38	Chronic lower respiratory diseases	37	2.48	Cerebrovascular diseases	54	2.98	Cerebrovascular diseases	47	3.14%
			Dementia and Alzheimer disease	29	1.94	Appendicitis, hernia and intestinal obstruction	42	2.32	Appendicitis, hernia and intestinal obstruction	33	2.21%
						Dementia and Alzheimer disease	36	1.99	Dementia and Alzheimer disease	22	1.47%

Appendix 2.7.4: The most frequently reported leading causes of death, by year of death (people aged 65+).

2018			2019			2020			2021		
Leading cause of death	No.	%	Leading cause of death	No.	%	Leading cause of death	No.	%	Leading cause of death	No.	%
Older adults (aged 65+)											
Cancers	130	13.39	**Cancers**	147	14.48	COVID-19	365	25.14	COVID-19	242	22.87%
Influenza and pneumonia	129	13.29	Influenza and pneumonia	132	13.00	**Cancers**	157	10.81	**Cancers**	116	10.96%
Ischaemic heart diseases	74	7.62	Dementia and Alzheimer disease	77	7.59	Influenza and pneumonia	118	8.13	Influenza and pneumonia	94	8.88%
Congenital malformations, deformations and chromosomal abnormalities	71	7.31	Congenital malformations, deformations and chromosomal abnormalities	77	7.59	Dementia and Alzheimer disease	80	5.51	Dementia and Alzheimer disease	64	6.05%
Dementia and Alzheimer disease	68	7.00	Cerebrovascular diseases	72	7.09	Ischaemic heart diseases	71	4.89	Cerebrovascular diseases	60	5.67%
Cerebrovascular diseases	61	6.28	Ischaemic heart diseases	66	6.50	Cerebrovascular diseases	66	4.55	Ischaemic heart diseases	57	5.39%
Chronic lower respiratory diseases	39	4.02	Chronic lower respiratory diseases	46	4.53	Congenital malformations, deformations and chromosomal abnormalities	63	4.34	Congenital malformations, deformations and chromosomal abnormalities	36	3.40%
Diseases of the urinary system	25	2.57	Diseases of the urinary system	30	2.96	Diseases of the urinary system	46	3.17	Chronic lower respiratory diseases	31	2.93%
Epilepsy and status epilepticus	14	1.44	Epilepsy and status epilepticus	15	1.48	Chronic lower respiratory diseases	44	3.03	Diseases of the urinary system	30	2.84%
						Epilepsy and status epilepticus	12	0.83	Epilepsy and status epilepticus	10	0.95%

Appendix 2.8.1: Most common leading causes of death in males

Males												
2018			2019			2020			2021			General population
Leading cause of death	No.	%	Leading cause of death	No.	%	Leading cause of death	No.	%	Leading cause of death	No.	%	2018
Adults and children (age 4 years and over)												
Congenital malformations, deformations and chromosomal abnormalities	198	13.5	Congenital malformations, deformations and chromosomal abnormalities	215	14.1	COVID-19	460	23.1	COVID-19	309	20.70%	
Cancers	174	11.9	**Cancers**	211	13.8	Congenital malformations, deformations and chromosomal abnormalities	178	9.0	**Cancers**	153	10.25%	
Influenza and pneumonia	162	11.1	Influenza and pneumonia	138	9.0	**Cancers**	170	8.6	Congenital malformations, deformations and chromosomal abnormalities	135	9.04%	
Ischaemic heart diseases	92	6.3	Ischaemic heart diseases	79	5.2	Influenza and pneumonia	132	6.6	Influenza and pneumonia	96	6.43%	5%
Cerebral palsy and other paralytic syndromes	73	5.0	Cerebral palsy and other paralytic syndromes	75	4.9	Cerebral palsy and other paralytic syndromes	95	4.8	Ischaemic heart diseases	81	5.43%	13.2%
Cerebrovascular diseases	66	4.5	Epilepsy and status epilepticus	72	4.7	Ischaemic heart diseases	88	4.4	Cerebral palsy and other paralytic syndromes	66	4.42%	
Dementia and Alzheimer disease	52	3.6	Cerebrovascular diseases	63	4.1	Cerebrovascular diseases	62	3.1	Cerebrovascular diseases	56	3.75%	
Epilepsy and status epilepticus	50	3.4	Dementia and Alzheimer disease	54	3.5	Dementia and Alzheimer disease	55	2.8	Dementia and Alzheimer disease	44	2.95%	8.9%
Chronic lower respiratory diseases	46	3.1	Chronic lower respiratory diseases	52	3.4	Chronic lower respiratory diseases	46	2.3	Appendicitis, hernia and intestinal	37	2.48%	
			Appendicitis, hernia and intestinal	36	2.4				Chronic lower respiratory diseases	34	2.28%	6%
Children (age 4-17 years)												
Epilepsy and status epilepticus	10	10.1	Cerebral palsy and other paralytic syndromes	15	12.3	Cerebral palsy and other paralytic syndromes	11	9.9	Cerebral palsy and other paralytic syndromes	6	12.00%	
Cerebral palsy and other paralytic syndromes	9	9.1	Congenital malformations, deformations and chromosomal abnormalities	12	9.8	Congenital malformations, deformations and chromosomal abnormalities	11	9.9	COVID-19	5	10.00%	
Cancers	8	8.1	Epilepsy and status epilepticus	11	9.0	Epilepsy and status epilepticus	6	5.4	**Cancers**	5	10.00%	
Influenza and pneumonia	8	8.1	Influenza and pneumonia	10	8.2							
Congenital malformations, deformations and chromosomal abnormalities	8	8.1	**Cancers**	6	4.9							

Appendix 2.8.2: Most common leading causes of death in females

Females												General population
2018			2019			2020			2021			2018
Leading cause of death	No.	%	Leading cause of death	No.	%	Leading cause of death	No.	%	Leading cause of death	No.	%	%
Adults and children (age 4 and over)												
Cancers	158	14.7	Congenital malformations, deformations and chromosomal abnormalities	163	13.7	COVID-19	290	20.0	COVID-19	223	19.1	-
Congenital malformations, deformations and chromosomal abnormalities	139	13.0	**Cancers**	161	13.5	**Cancers**	159	10.9	**Cancers**	133	11.4	-
Influenza and pneumonia	128	11.9	Influenza and pneumonia	141	11.8	Congenital malformations, deformations and chromosomal abnormalities	150	10.3	Congenital malformations, deformations and chromosomal abnormalities	116	9.9	-
Cerebral palsy and other paralytic syndromes	53	4.9	Cerebrovascular diseases	67	5.6	Influenza and pneumonia	91	6.3	Influenza and pneumonia	80	6.8	5.9%
Dementia and Alzheimer disease	49	4.6	Dementia and Alzheimer disease	52	4.4	Dementia and Alzheimer disease	61	4.2	Cerebrovascular diseases	52	4.5	6.5%
Cerebrovascular diseases	43	4.0	Cerebral palsy and other paralytic syndromes	50	4.2	Cerebrovascular diseases	60	4.1	Cerebral palsy and other paralytic syndromes	51	4.4	-
Ischaemic heart diseases	36	3.4	Epilepsy and status epilepticus	49	4.1	Cerebral palsy and other paralytic syndromes	48	3.3	Dementia and Alzheimer disease	42	3.6	16.7%
Epilepsy and status epilepticus	34	3.2	Ischaemic heart diseases	43	3.6	Ischaemic heart diseases	42	2.9	Ischaemic heart diseases	38	3.3	7.5%
Diseases of the urinary system	27	2.5	Chronic lower respiratory diseases	31	2.6	Epilepsy and status epilepticus	39	2.7	Epilepsy and status epilepticus	28	2.4	-
Children (age 4-17)												
Congenital malformations, deformations and chromosomal abnormalities	10	12.5	Congenital malformations, deformations and chromosomal abnormalities	13	13.8	Congenital malformations, deformations and chromosomal abnormalities	13	19.1	Congenital malformations, deformations and chromosomal abnormalities	11	18.6	
Cerebral palsy and other paralytic syndromes	7	8.8	Influenza and pneumonia	11	11.7	**Cancers**	5	7.4	Cerebral palsy and other paralytic syndromes	7	11.9	
Influenza and pneumonia	7	8.8	Cerebral palsy and other paralytic syndromes	8	8.5	Cerebral palsy and other paralytic syndromes	5	7.4				
Cerebrovascular diseases	5	6.3	**Cancers**	5	5.3	COVID-19	5	7.4				
Cancers	5	6.3	Epilepsy and status epilepticus	5	5.3							
Adults (age 18-64)												
Congenital malformations, deformations and chromosomal abnormalities	109	18.0	Congenital malformations, deformations and chromosomal abnormalities	124	19.0	COVID-19	165	20.9	COVID-19	159	19.0	

Appendix 2.8.2: Most common leading causes of death in females (continued)

Cancers	99	16.3	**Cancers**	98	15.0	Congenital malformations, deformations and chromosomal abnormalities	113	14.3	Congenital malformations, deformations and chromosomal abnormalities	110	13.1
Influenza and pneumonia	72	11.9	Influenza and pneumonia	67	10.2	**Cancers**	85	10.8	**Cancers**	84	10.0
Cerebral palsy and other paralytic syndromes	41	6.8	Epilepsy and status epilepticus	34	5.2	Influenza and pneumonia	47	6.0	Cerebral palsy and other paralytic syndromes	47	5.6
Epilepsy and status epilepticus	24	4.0	Cerebral palsy and other paralytic syndromes	30	4.6	Cerebral palsy and other paralytic syndromes	36	4.6	Influenza and pneumonia	43	5.1
Cerebrovascular diseases	16	2.6	Cerebrovascular diseases	22	3.4	Epilepsy and status epilepticus	30	3.8	Ischaemic heart diseases	42	5.0
Dementia and Alzheimer disease	16	2.6	Ischaemic heart diseases	20	3.1	Cerebrovascular diseases	21	2.7	Cerebrovascular diseases	27	3.2
Diseases of the urinary system	15	2.5	Chronic lower respiratory diseases	16	2.5				Epilepsy and status epilepticus	26	3.1
Appendicitis, hernia and intestinal	14	2.3							Appendicitis, hernia and intestinal obstruction	22	2.6
Older adults (age 65 and over)											
Cancers	54	14.0	Influenza and pneumonia	63	14.2	COVID-19	120	20.1	COVID-19	97	21.5
Influenza and pneumonia	49	12.7	**Cancers**	58	13.0	**Cancers**	69	11.6	**Cancers**	52	11.5
Dementia and Alzheimer disease	33	8.5	Cerebrovascular diseases	43	9.7	Dementia and Alzheimer disease	44	7.4	Influenza and pneumonia	43	9.5
Ischaemic heart diseases	25	6.5	Dementia and Alzheimer disease	41	9.2	Influenza and pneumonia	40	6.7	Dementia and Alzheimer disease	31	6.9
Cerebrovascular diseases	22	5.7	Congenital malformations, deformations and chromosomal abnormalities	26	5.8	Cerebrovascular diseases	38	6.4	Cerebrovascular diseases	31	6.9
Congenital malformations, deformations and chromosomal abnormalities	20	5.7	Ischaemic heart diseases	23	5.2	Ischaemic heart diseases	26	4.4	Ischaemic heart diseases	18	4.0
Chronic lower respiratory diseases	12	3.1	Chronic lower respiratory diseases	15	3.4	Congenital malformations, deformations and chromosomal abnormalities	24	4.0	Congenital malformations, deformations and chromosomal abnormalities	15	3.3
Acute respiratory infections other than influenza and pneumonia	10	2.6	Cerebral palsy and other paralytic syndromes	12	2.7	Diseases of the urinary system	20	3.4	Chronic lower respiratory diseases	12	2.7
Appendicitis, hernia and intestinal	9	2.3				Acute respiratory infections other than influenza and pneumonia	17	2.9	Diseases of the urinary system	12	2.7
						Chronic lower respiratory diseases	15	2.5			

Appendix 4 - Chapter 4

Appendix 4.1. Summary of demographic, clinical, and social care variables for those whose age at death was age 18 and older.

Variable	Level	Total (n=2,584)
Sex (n, %)	Male	1,445 (56%)
	Female	1,111 (43%)
	Unrecorded	28 (1%)
Ethnicity (n, %)	Asian or Asian British	44 (2%)
	Black, Black British, Caribbean or African	47 (2%)
	Mixed ethnic group	61 (2%)
	White	2,158 (84%)
	Other	18 (1%)
	Unrecorded	256 (10%)
Region of England (n, %)	Midlands	513 (20%)
	South East	435 (17%)
	North East	428 (17%)
	North West	347 (13%)
	East of England	323 (12%)
	South West	288 (11%)
	London	249 (10%)
	Unrecorded	1 (0%)
Place of death (n; %)	Hospital	1,592 (62%)
	Usual residence	864 (33%)
	Other	94 (4%)
	Unrecorded	34 (1%)
Epilepsy (n, %)	No	727 (28%)
	Yes	355 (14%)
	Unrecorded	1,502 (58%)
Cardiovascular conditions (n, %)	No	729 (28%)
	Yes	353 (14%)
	Unrecorded	1,502 (58%)
Mental health conditions (n, %)	No	729 (28%)
	Yes	353 (14%)
	Unrecorded	1,502 (58%)
Sensory impairment (n, %)	No	815 (32%)
	Yes	267 (10%)
	Unrecorded	1,502 (58%)
Dysphagia (n, %)	No	834 (32%)
	Yes	248 (10%)
	Unrecorded	1,502 (58%)
Dementia (n, %)	No	852 (33%)
	Yes	230 (9%)
	Unrecorded	1,502 (58%)
Kidney problems (n, %)	No	890 (34%)
	Yes	192 (7%)
	Unrecorded	1,502 (58%)
Diabetes (n, %)	No	918 (36%)
	Yes	164 (6%)
	Unrecorded	1,502 (58%)
Respiratory conditions (n, %)	No	931 (36%)
	Yes	151 (6%)
	Unrecorded	1,502 (58%)

Appendix 4.1. Summary of demographic, clinical, and social care variables for those whose age at death was age 18 and older. (continued)

Hypertension (n, %)	No	947 (37%)
	Yes	135 (5%)
	Unrecorded	1,502 (58%)
Osteoporosis (n, %)	No	1,017 (39%)
	Yes	65 (3%)
	Unrecorded	1,502 (58%)
Cancer (n, %)	No	1,020 (39%)
	Yes	62 (2%)
	Unrecorded	1,502 (58%)
Degenerative conditions (n, %)	No	1,036 (40%)
	Yes	46 (2%)
	Unrecorded	1,502 (58%)
DVT (n, %)	No	1,044 (40%)
	Yes	38 (1%)
	Unrecorded	1,502 (58%)
Annual health check (in past 12 months; n, %) *	No	182 (7%)
	Yes	537 (21%)
	Unrecorded	1,865 (72%)
Care package met needs (n, %)	No	102 (4%)
	Yes	656 (25%)
	Unrecorded	1,826 (71%)
Deprivation of liberty safeguards (n, %)	No	581 (22%)
	Applied for	32 (1%)
	Approved	89 (3%)
	Unrecorded	1,882 (73%)
Out of area placement (n, %)	No	413 (16%)
	Yes	27 (1%)
	Unrecorded	2,144 (83%)
Quality of care rating* (n, %)	1	10 (0%)
	2	50 (2%)
	3	148 (6%)
	4	198 (8%)
	5	311 (12%)
	6	34 (1%)
	Unrecorded	1,833 (71%)

*annual health checks are currently only targeted at those aged 14+

*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).

Appendix 4.2.1 Results of Cox proportional hazards model investigating the effects of predictor variables on time to 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	0.87, 1.02	0.03	0.96	0.88, 1.04	0.33
Ethnicity	Asian or Asian British	1.85	1.37, 2.49	<0.001	1.88	1.39, 2.55	<0.001
	Black, Black British, Caribbean or African	3.26	2.43, 4.36		3.37	2.49, 4.57	
	Mixed ethnic group	2.64	2.04, 3.41		2.61	2.01, 3.40	
	White	1	-		1	-	
	Other	0.86	0.53, 1.38		0.79	0.48, 1.32	
Region of England	London	1	-	-	1	-	-
	South West	0.88	0.74, 1.04	0.07	1.03	0.86, 1.24	0.25
	South East	0.94	0.80, 1.10		1.11	0.93, 1.31	
	Midlands	1.01	0.87, 1.18		1.13	0.96, 1.33	
	East of England	0.85	0.72, 1.01		0.99	0.82, 1.18	
	North West	0.90	0.76, 1.05		1.05	0.88, 1.25	
	North East	1.02	0.87, 1.19		1.17	0.99, 1.39	
Place of death	Hospital	1	-	-	1	-	-
	Usual residence	0.86	0.80, 0.94	<0.001	0.83	0.76, 0.91	<0.001
	Other	1.47	1.19, 1.81		1.36	1.08, 1.71	
Cancer	No	1	-	-	1	-	-
	Yes	0.84	0.65, 1.09	0.18	0.80	0.61, 1.05	0.11
Cardiovascular conditions	No	1	-	-	1	-	-
	Yes	0.71	0.62, 0.81	<0.001	0.73	0.63, 0.84	<0.001
Degenerative conditions	No	1	-	-	1	-	-
	Yes	1.03	0.76, 1.38	0.86	1.10	0.81, 1.50	0.54
Dementia	No	1	-	-	1	-	-
	Yes	0.83	0.72, 0.96	0.01	0.88	0.75, 1.03	0.11
Diabetes	No	1	-	-	1	-	-
	Yes	0.81	0.68, 0.95	0.01	0.96	0.80, 1.15	0.63
DVT	No	1	-	-	1	-	-
	Yes	1.30	0.94, 1.79	0.12	1.37	0.98, 1.91	0.07
Dysphagia	No	1	-	-	1	-	-
	Yes	0.87	0.75, 1.00	0.05	0.87	0.75, 1.01	0.06
Epilepsy	No	1	-	-	1	-	-
	Yes	1.45	1.28, 1.65	<0.001	1.47	1.28, 1.69	<0.001
Hypertension	No	1	-	-	1	-	-
	Yes	0.66	0.55, 0.79	<0.001	0.68	0.56, 0.83	<0.001
Kidney problems	No	1	-	-	1	-	-
	Yes	0.74	0.63, 0.86	<0.001	0.83	0.70, 0.98	0.03

Appendix 4.2.1 Results of Cox proportional hazards model investigating the effects of predictor variables on time to death. (continued)

Mental health conditions	No	1	-	-	1	-	-
	Yes	0.81	0.71, 0.92	<0.01	0.85	0.74, 0.97	0.01
Osteoporosis	No	1	-	-	1	-	-
	Yes	0.81	0.63, 1.04	0.09	0.82	0.63, 1.07	0.15
Respiratory conditions	No	1	-	-	1	-	-
	Yes	0.93	0.78, 1.10	0.39	0.97	0.81, 1.17	0.76
Sensory impairment	No	1	-	-	1	-	-
	Yes	0.91	0.80, 1.05	0.21	0.91	0.78, 1.05	0.19
Annual health check (in past 12 months)	No	1	-	-	1	-	-
	Yes	0.97	0.82, 1.15	0.75	0.93	0.77, 1.13	0.48
Care package met needs	No	1	-	-	1	-	-
	Yes	0.94	0.77, 1.16	0.59	1.00	0.77, 1.30	>0.99
Deprivation of liberty safeguards	No	1	-	-	1	-	-
	Applied for	1.05	0.74, 1.51	0.72	1.34	0.87, 2.04	0.35
	Approved	0.92	0.74, 1.15		0.94	0.72, 1.23	
Out of area placement	No	1	-	-	1	-	-
	Yes	0.90	0.61, 1.33	0.60	0.94	0.59, 1.48	0.34
Quality of care rating	6	1	-	-	1	-	-
	5	0.85	0.60, 1.22	0.47	0.76	0.50, 1.16	0.29
	4	0.83	0.57, 1.19		0.74	0.48, 1.14	
	3	0.92	0.63, 1.33		0.86	0.55, 1.36	
	2	1.10	0.71, 1.70		0.99	0.59, 1.67	
	1	0.73	0.36, 1.45		0.56	0.25, 1.22	

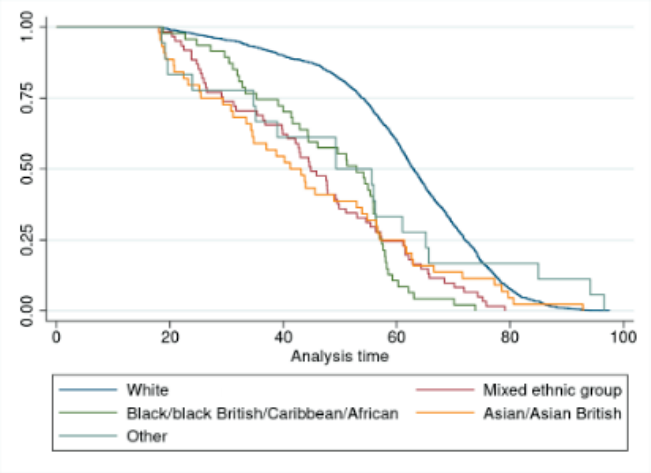
Appendix 4.2.2 Results of Cox proportional hazards model investigating the effects of predictor variables on time to death. (continued)

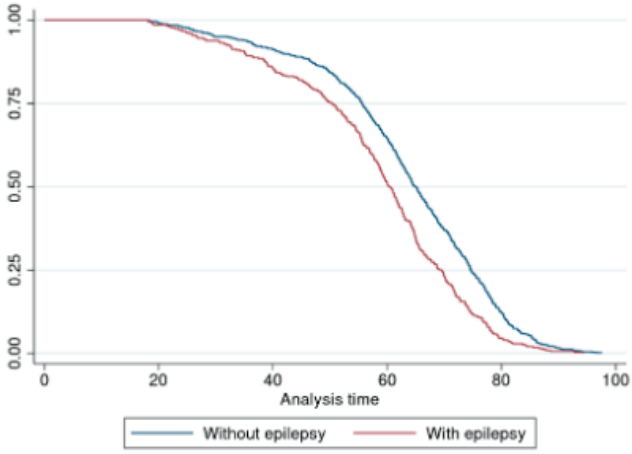
The estimated effects of the predictor variables were broadly similar between the unadjusted and adjusted analyses (see Appendix 2.2.1). The modelling provided no evidence that the hazard of death was lower for females than males (adjusted hazard ratio 0.96; 95% CI 0.88, 1.04). It suggested that the hazard of death was much greater for people of Black, Black British, Caribbean or African (hazard ratio 3.37; 95% CI 2.49, 4.57) and mixed ethnic group (hazard ratio 2.61; 95% CI 2.01, 3.40) compared to white ethnicity. Kaplan-Meier survival curves by levels of ethnicity are shown in Appendix 4.2.3.

There was evidence that hazard of time to death was greater for people with epilepsy compared to those without (hazard ratio 1.47; 95% CI 1.28, 1.69; see Appendix 2.2.1). Kaplan-Meier survival curves for those with and without epilepsy are shown in Appendix 4.2.3. There was weak evidence that hazard of time to death was greater for those with deep vein thrombosis compared to those without (hazard ratio 1.37; 95% CI 0.98, 1.91). Some conditions such as cancer, cardiovascular conditions, dementia, hypertension, kidney problems, mental health conditions, osteoporosis and dysphagia were associated with lower hazard of time to death.

However, it should be noted that the seeming reduction in hazard of death associated with these conditions may be related to the fact that the prevalence of many of these increases with age. There was no evidence that social and care variables were associated with time to death.

Appendix 4.2.3 Kaplan-Meier plots by ethnicity (left panel) and epilepsy status (right panel).





Appendix 5 - Chapter 5

Appendix 5.1: Summary of demographic, clinical, and social care variables by whether the death was classified as avoidable or not.

Variable	Level	Causes of death was not avoidable (n=1,222)	Cause of death was avoidable (n=1,170)	Total (n=2,392)
Sex (n, %)	Male	655 (54%)	675 (58%)	1,330 (56%)
	Female	555 (45%)	485 (41%)	1,040 (43%)
	Unrecorded	12 (1%)	10 (1%)	22 (1%)
Age at death (mean; SD)		61.2 (20.1)	57.0 (14.4)	59.1 (17.7)
Age group (n; %)	4-17 years old	59 (5%)	23 (2%)	82 (3%)
	18-24 years old	48 (4%)	29 (2%)	77 (3%)
	25-49 years old	179 (15%)	218 (19%)	397 (17%)
	50-64 years old	343 (28%)	510 (44%)	853 (36%)
	65+ years old	590 (48%)	390 (33%)	980 (41%)
	Unrecorded	3 (0%)	0 (0%)	3 (0%)
Ethnicity (n, %)	White	1,020 (83%)	960 (82%)	1,980 (83%)
	Mixed ethnic group	22 (2%)	45 (4%)	67 (3%)
	Black, Black British, African, Caribbean	18 (1%)	27 (2%)	45 (2%)
	Asian or Asian British	20 (2%)	20 (2%)	40 (2%)
	Other	6 (0%)	11 (1%)	17 (1%)
	Unrecorded	136 (11%)	107 (9%)	243 (10%)
Region of England (n, %)	London	118 (10%)	109 (9%)	227 (9%)
	South West	153 (13%)	110 (9%)	263 (11%)
	South East	215 (18%)	199 (17%)	414 (17%)
	Midlands	220 (18%)	251 (21%)	471 (20%)
	East of England	153 (13%)	144 (12%)	297 (12%)
	North West	148 (12%)	167 (14%)	315 (13%)
	North East	214 (18%)	190 (16%)	404 (17%)
	Unrecorded	1 (0%)	0 (0%)	1 (0%)
Place of death (n; %)	Hospital	708 (58%)	766 (65%)	1,474 (62%)
	Usual residence	449 (37%)	348 (30%)	797 (33%)
	Other	45 (4%)	43 (4%)	88 (4%)
	Unrecorded	20 (2%)	13 (1%)	33 (1%)
Cancer (n, %)	No	517 (42%)	451 (39%)	968 (40%)
	Yes	22 (2%)	39 (3%)	61 (3%)
	Unrecorded	683 (56%)	680 (58%)	1,363 (57%)
Cardiovascular conditions (n, %)	No	362 (30%)	336 (29%)	698 (29%)
	Yes	177 (14%)	154 (13%)	331 (14%)
	Unrecorded	683 (56%)	680 (58%)	1,363 (57%)
Degenerative conditions (n, %)	No	510 (42%)	477 (41%)	987 (41%)
	Yes	29 (2%)	13 (1%)	42 (2%)
	Unrecorded	683 (56%)	680 (58%)	1,363 (57%)
Dementia (n, %)	No	397 (32%)	411 (35%)	808 (34%)
	Yes	142 (12%)	79 (7%)	221 (9%)
	Unrecorded	683 (56%)	680 (58%)	1,363 (57%)
Diabetes (n, %)	No	465 (38%)	407 (35%)	872 (36%)
	Yes	74 (6%)	83 (7%)	157 (7%)
	Unrecorded	683 (56%)	680 (58%)	1,363 (57%)

Appendix 5.1: Summary of demographic, clinical, and social care variables by whether the death was classified as avoidable or not. (continued)

DVT (n, %)	No	520 (43%)	471 (40%)	991 (41%)
	Yes	19 (2%)	19 (2%)	38 (2%)
	Unrecorded	683 (56%)	680 (58%)	1,363 (57%)
Epilepsy (n, %)	No	354 (29%)	330 (28%)	684 (29%)
	Yes	185 (15%)	160 (14%)	345 (14%)
	Unrecorded	683 (56%)	680 (58%)	1,363 (57%)
Hypertension (n, %)	No	480 (39%)	421 (36%)	901 (38%)
	Yes	59 (5%)	69 (6%)	128 (5%)
	Unrecorded	683 (56%)	680 (58%)	1,363 (57%)
Kidney problems (n, %)	No	432 (35%)	413 (35%)	845 (35%)
	Yes	107 (9%)	77 (7%)	184 (8%)
	Unrecorded	683 (56%)	680 (58%)	1,363 (57%)
Mental health conditions (n, %)	No	369 (30%)	329 (28%)	698 (29%)
	Yes	170 (14%)	161 (14%)	331 (14%)
	Unrecorded	683 (56%)	680 (58%)	1,363 (57%)
Osteoporosis (n, %)	No	499 (41%)	468 (40%)	967 (40%)
	Yes	40 (3%)	22 (2%)	62 (3%)
	Unrecorded	683 (56%)	680 (58%)	1,363 (57%)
Respiratory conditions (n, %)	No	472 (39%)	409 (35%)	881 (37%)
	Yes	67 (5%)	81 (7%)	148 (6%)
	Unrecorded	683 (56%)	680 (58%)	1,363 (57%)
Sensory impairment (n, %)	No	401 (33%)	378 (32%)	779 (33%)
	Yes	138 (11%)	112 (10%)	250 (10%)
	Unrecorded	683 (56%)	680 (58%)	1,363 (57%)
Dysphagia (n, %)	No	378 (31%)	410 (35%)	788 (33%)
	Yes	161 (13%)	80 (7%)	241 (10%)
	Unrecorded	683 (56%)	680 (58%)	1,363 (57%)
Annual health check (in past 12 months; n, %)	No	73 (6%)	89 (8%)	162 (7%)
	Yes	186 (15%)	296 (25%)	482 (20%)
	Unrecorded	963 (79%)	785 (67%)	1,748 (73%)
Care package met needs (n, %)	No	39 (3%)	44 (4%)	83 (3%)
	Yes	247 (20%)	358 (31%)	605 (25%)
	Unrecorded	936 (77%)	768 (66%)	1,704 (71%)
Deprivation of liberty safeguards (n, %)	No	209 (17%)	318 (27%)	517 (22%)
	Applied for	14 (1%)	14 (1%)	28 (1%)
	Approved	39 (3%)	41 (4%)	80 (3%)
	Unrecorded	960 (79%)	797 (68%)	1,757 (73%)
Out of area placement (n, %)	No	132 (11%)	252 (22%)	384 (16%)
	Yes	11 (1%)	14 (1%)	25 (1%)
	Unrecorded	1079 (88%)	904 (77%)	1,983 (83%)

Appendix 5.1: Summary of demographic, clinical, and social care variables by whether the death was classified as avoidable or not. (continued)

Quality of care rating* (n, %)	1	4 (0%)	1 (0%)	5 (0%)
	2	18 (1%)	22 (2%)	40 (2%)
	3	62 (5%)	73 (6%)	135 (6%)
	4	66 (5%)	113 (10%)	179 (7%)
	5	119 (10%)	168 (14%)	287 (12%)
	6	13 (1%)	20 (2%)	33 (1%)
	Unrecorded	940 (77%)	773 (66%)	1,713 (72%)

*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).

Appendix 5.2: Results of logistic regression analyses of predictor variables on avoidable causes of death.

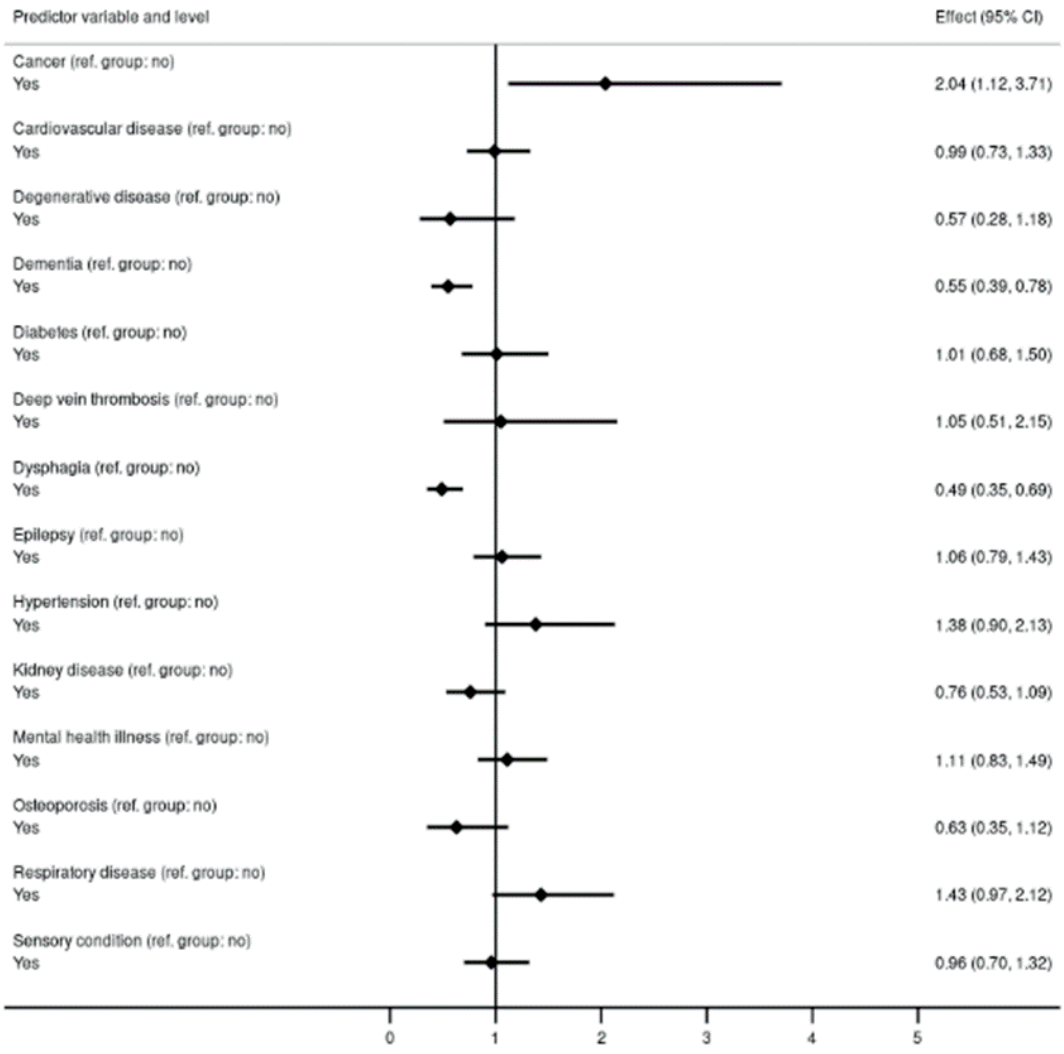
		Unadjusted			Adjusted		
Predictor variable	**Level**	**Odds ratio**	**95% confidence interval**	**p-value**	**Odds ratio**	**95% confidence interval**	**p-value**
Sex	Male	1	-	-	1	-	-
	Female	0.85	0.72, 1.00	0.05	0.86	0.72, 1.03	0.09
Age at death group	4-17 years old	1	-	-	1	-	-
	18-24 years old	1.55	0.80, 3.02	<0.001	1.27	0.57, 2.83	<0.001
	25-49 years old	3.12	1.86, 5.26		3.45	1.80, 6.60	
	50-64 years old	3.81	2.31, 6.29		4.54	2.40, 8.59	
	65+ years old	1.70	1.03, 2.79		2.06	1.09, 3.89	
Ethnicity	White	1	-	-	1	-	-
	Mixed ethnic group	2.17	1.30, 3.65	0.02	2.55	1.45, 4.51	0.01
	Black, Black British, Caribbean or African	1.59	0.87, 2.91		1.66	0.86, 3.22	
	Asian or Asian British	1.06	0.57, 1.99		1.15	0.59, 2.23	
	Other	1.95	0.72, 5.29		2.51	0.84, 7.48	
Region of England	London	1	-	-	1	-	-
	South West	0.78	0.54, 1.11	0.07	0.95	0.63, 1.42	0.09
	South East	1.00	0.72, 1.39		1.22	0.85, 1.76	
	Midlands	1.24	0.90, 1.70		1.47	1.03, 2.10	
	East of England	1.02	0.72, 1.44		1.35	0.92, 2.00	
	North West	1.22	0.87, 1.72		1.45	0.99, 2.13	
	North East	0.96	0.69, 1.33		1.16	0.81, 1.68	
Place of death	Hospital	1	-	-	1	-	-
	Usual residence	0.72	0.60, 0.85	<0.001	0.76	0.63, 0.92	0.02
	Other	0.88	0.57, 1.36		0.87	0.54, 1.42	
Cancer	No	1	-	-	1	-	-
	Yes	2.03	1.19, 3.48	0.01	2.04	1.12, 3.71	0.02

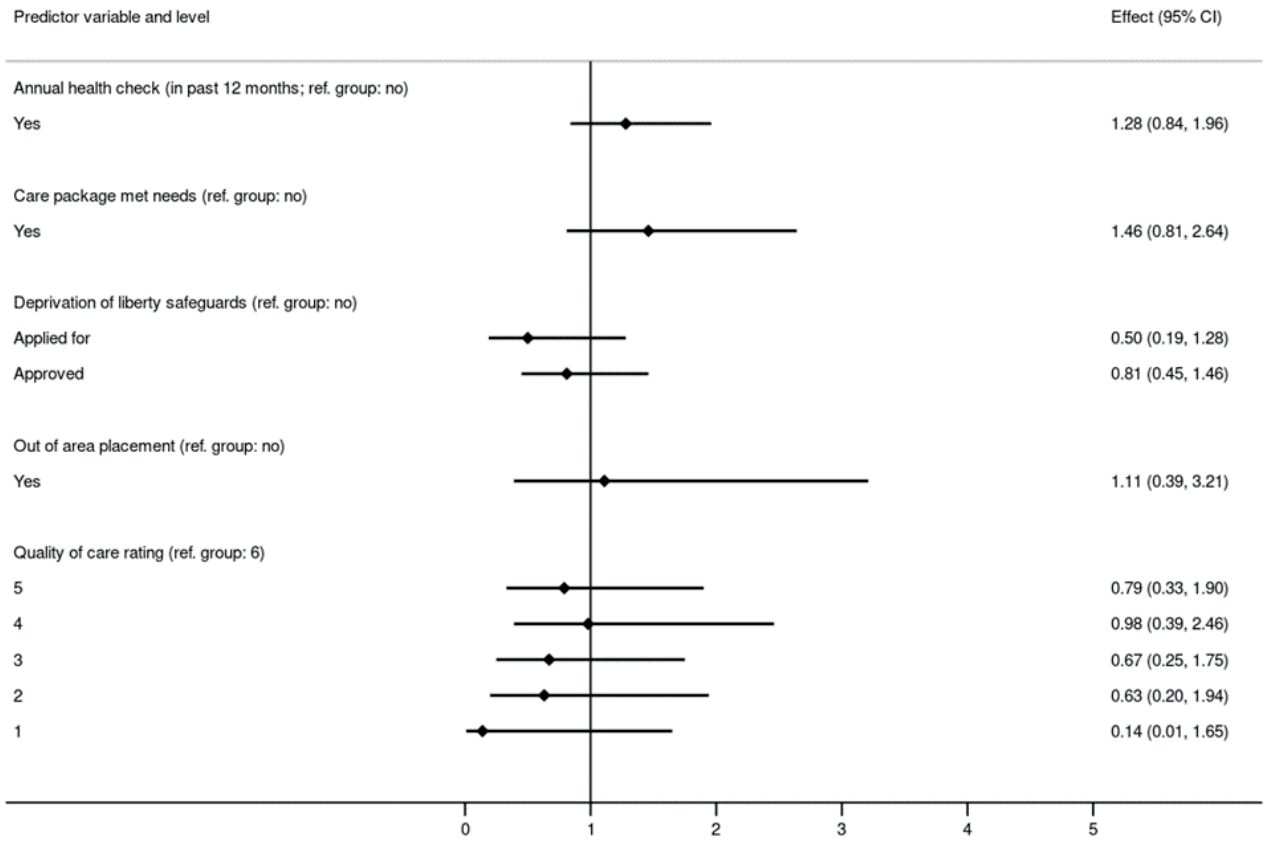
Appendix 5.2.1: Results of logistic regression analyses of predictor variables on avoidable causes of death. (continued)

Cardiovascular conditions	No	1	-	-	1	-	-
	Yes	0.94	0.72, 1.22	0.63	0.99	0.73, 1.33	0.94
Degenerative conditions	No	1	-	-	1	-	-
	Yes	0.48	0.25, 0.93	0.03	0.57	0.28, 1.18	0.13
Dementia	No	1	-	-	1	-	-
	Yes	0.54	0.40, 0.73	<0.001	0.55	0.39, 0.78	<0.01
Diabetes	No	1	-	-	1	-	-
	Yes	1.28	0.91, 1.80	0.15	1.01	0.68, 1.50	0.96
DVT	No	1	-	-	1	-	-
	Yes	1.10	0.58, 2.11	0.77	1.05	0.51, 2.15	0.90
Epilepsy	No	1	-	-	1	-	-
	Yes	0.93	0.72, 1.20	0.57	1.06	0.79, 1.43	0.69
Hypertension	No	1	-	-	1	-	-
	Yes	1.33	0.92, 1.93	0.13	1.38	0.90, 2.13	0.14
Kidney problems	No	1	-	-	1	-	-
	Yes	0.75	0.55, 1.04	0.08	0.76	0.53, 1.09	0.14
Mental health conditions	No	1	-	-	1	-	-
	Yes	1.06	0.82, 1.38	0.65	1.11	0.83, 1.49	0.47
Osteoporosis	No	1	-	-	1	-	-
	Yes	0.59	0.34, 1.00	0.05	0.63	0.35, 1.12	0.12
Respiratory conditions	No	1	-	-	1	-	-
	Yes	1.40	0.98, 1.98	0.06	1.43	0.97, 2.12	0.07
Sensory impairment	No	1	-	-	1	-	-
	Yes	0.86	0.65, 1.15	0.31	0.96	0.70, 1.32	0.80
Dysphagia	No	1	-	-	1	-	-
	Yes	0.46	0.34, 0.62	<0.001	0.49	0.35, 0.69	<0.001
Annual health check (in past 12 months)	No	1	-	-	1	-	-
	Yes	1.31	0.91, 1.87	0.15	1.28	0.84, 1.96	0.25
Care package met needs	No	1	-	-	1	-	-
	Yes	1.28	0.81, 2.04	0.29	1.46	0.81, 2.64	0.21
Deprivation of liberty safeguards	No	1	-	-	1	-	-
	Applied for	0.66	0.31, 1.41	0.20	0.50	0.19, 1.28	0.30
	Approved	0.69	0.43, 1.11		0.81	0.45, 1.46	
Out of area placement	No	1	-	-	1	-	-
	Yes	0.67	0.29, 1.51	0.33	1.11	0.39, 3.21	0.84
Quality of care rating*	6	1	-	-	1	-	-
	5	0.92	0.44, 1.92	0.38	0.79	0.33, 1.90	0.47
	4	1.11	0.52, 2.38		0.98	0.39, 2.46	
	3	0.77	0.35, 1.66		0.67	0.25, 1.75	
	2	0.79	0.31, 2.03		0.63	0.20, 1.94	
	1	0.16	0.02, 1.62		0.14	0.01, 1.65	

*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).

Appendix 5.2.2: Results of logistic regression analyses of predictor variables on avoidable causes of death - Forest plots





Appendix 6 - Chapter 6

Appendix 6.0: Methodological considerations for Chapter 6

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 people 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 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 people 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.

COVID-19 deaths during 2021 (based on underlying cause of death - MCCD)

1. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/impactofregistrationdelaysonmortalitystatisticsinenglandandwales/2020

Table 6.1: Comparison of deaths due to COVID-19 and non-COVID 19 causes of death

	Non-COVID-19 (n; %) 1997 (78.9)	COVID-19 (n; %) 534 (21.1)
Age* in years - mean (SD)	58.49 (18.12)	60.98 (15.85)
Sex		
Male	1093 (77.8)	311 (22.2)
Female	883 (79.8)	224 (20.2)
Region*		
East of England	216 (68.6)	99 (31.4)
London	177 (72.5)	67 (27.5)
North-East	360 (85.1)	63 (14.9)
Midlands	390 (78.6)	106 (21.4)
North-West	278 (81.5)	63 (18.5)
Season*		
Spring	576 (94.6)	33 (5.4)
Summer	527 (95.6)	24 (4.4)
Autumn	414 (91.4)	39 (8.6)
Winter#	481 (52.2)	440 (47.8)
Ethnicity*		
white	1649 (78.7)	446 (21.3)
mixed ethnicity	36 (52.2)	33 (47.8)
black/ Caribbean/ black British	38 (74.5)	13 (25.5)
asian/ asian British	38 (82.6)	8 (17.4)
Other ethnicity	12 (60.0)	8 (40.0)
Place of Death*		
Hospital	1146 (73.0)	423 (27.0)
Usual residence	740 (88.2)	99 (11.8)
Other (e.g. friend's home)	85 (91.4)	8 (8.6)
Long-term conditions+		
Cancer	56 (6.8)	7 (2.8)
Cardiovascular disease*	289 (35.1)	55 (22.4)
Degenerative disease	42 (5.1)	<5 (1.6)
Dementia	165 (20.0)	60 (24.4)
Diabetes	124 (15.1)	37 (15.0)
DVT	30 (3.6)	9 (3.7)
Dysphagia	199 (24.2)	47 (19.1)
Epilepsy	279 (33.9)	79 (32.1)
Hypertension	102 (12.4)	30 (12.2)
Kidney disease	141 (17.1)	47 (19.1)
Mental health conditions	255 (31.0)	89 (36.2)
Osteoporosis	50 (6.1)	15 (6.1)
Respiratory	111 (13.5)	38 (15.4)
Sensory conditions	194 (23.6)	70 (28.5)

+ total number with data on long-term conditions = 1069, of whom 246 had COVID-19 as underlying cause of death

* $p < 0.01$

Adjusted analysis

Table 6.2: Binary logistic regression of having COVID-19 as underlying cause of death on death certificate

	B	S.E.	Wald	df	Sig.	OR	95% CI for OR (lowest)	95% CI for OR (highest)
Region (reference is South-West)			**12.052**	**6**	**.061**			
East of England	1.098	.468	5.494	1	.019	2.998	1.197	7.507
London	.481	.479	1.008	1	.315	1.618	.632	4.141
North-East	.020	.445	.002	1	.965	1.020	.426	2.440
Midlands	.286	.428	.447	1	.504	1.331	.575	3.080
North-West	-.006	.451	.000	1	.989	.994	.410	2.408
South-East	.491	.431	1.301	1	.254	1.634	.703	3.801
Place of death (reference – Usual residence)			**32.267**	**2**	**<.001**			
Hospital	1.271	.226	31.551	1	<.001	3.566	2.288	5.557
Other	.371	.729	.259	1	.611	1.449	.347	6.055
Age at death (in years)	.024	.007	12.634	1	**<.001**	1.024	1.011	1.038
Sex (reference is male)	.184	.198	.864	1	.353	1.202	.816	1.770
Ethnicity (reference is white/ white British)			**5.567**	**4**	**.234**			
mixed ethnicity	.444	.719	.382	1	.537	1.560	.381	6.386
black/ Caribbean/ black British	-.234	.703	.111	1	.739	.791	.200	3.137
asian or asian British	.592	.920	.414	1	.520	1.808	.298	10.979
other	1.828	.843	4.706	1	.030	6.223	1.193	32.465
Season (reference is Spring)			**187.116**	**3**	**<.001**			
Summer	-.164	.450	.133	1	.715	.849	.351	2.051
Autumn	.620	.528	1.377	1	.241	1.859	.660	5.236
Winter	3.231	.287	126.321	1	**<.001**	25.304	14.405	44.452
Long-term conditions (reference is not having the condition)								
Cancer	-1.325	.492	7.247	1	**.007**	.266	.101	.697
Cardiovascular conditions	-.998	.235	18.020	1	**<.000**	.369	.232	.584
Degenerative diseases	-1.238	.657	3.552	1	.059	.290	.080	1.051
Dementia	.578	.246	5.499	1	**.019**	1.782	1.099	2.888
Diabetes	-.291	.293	.989	1	.320	.748	.421	1.326
DVT	.455	.550	.684	1	.408	1.576	.536	4.630
Epilepsy	.111	.214	.270	1	.604	1.118	.735	1.700
Hypertension	-.142	.319	.199	1	.655	.867	.464	1.620
Kidney disease	.259	.264	.964	1	.326	1.296	.772	2.174
Mental health conditions	.126	.211	.358	1	.550	1.135	.750	1.717
Osteoporosis	-.061	.395	.024	1	.876	.940	.434	2.038
Respiratory	-.013	.278	.002	1	.962	.987	.573	1.701
Sensory impairments	.124	.223	.307	1	.579	1.132	.731	1.753
Dysphagia	-.086	.249	.119	1	.730	.918	.563	1.496
Constant	-5.566	.648	73.720	1	<.001	.004		

End