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The causes and impact of CVD and circulatory disease in people with a learning disability in the 2022 LeDeR cohort

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A LeDeR Deep Dive report

Learning from Lives and Deaths -
People with a learning disability and autistic people
(LeDeR) report for 2024
(LeDeR 2022)

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The causes and impact of cardio-vascular disease in adults with a learning disability

Background

Cardio-vascular conditions impact the heart and circulatory system. Common cardio-vascular conditions include stroke, heart failure, deep vein thrombosis (DVT), and coronary artery disease (National Health Service [NHS], 2022). In 2022, diseases of the heart and circulatory system were the most common cause of death in people with a learning disability whose deaths had been reviewed by the LeDeR programme, accounting for 17% of all deaths reviewed (White et al., 2023). Risk factors for cardio-vascular disease are common in people with a learning disability, for example, people with a learning disability have high rates of diabetes (MacRae et al., 2015), physical inactivity (Melville et al., 2018; Dairo et al., 2016), obesity (Harris et al., 2018), and are more likely to have a poor diet (Humphries et al., 2009). Moreover, some genetic causes of learning disability, such as Down syndrome, are associated with increased risk of some types of cardio-vascular disease (Hermon et al., 2001). However, in comparison to the general population, people with a learning disability overall are less likely to drink alcohol or smoke, although rates are comparable to the general population in those with a mild learning disability (Emerson & Hatton, 2013). This deep dive has four objectives:

- To identify the most common cardio-vascular causes of death in adults with a learning disability and compare them with the general population.
- To identify the conditions associated with death from a cardio-vascular condition.
- To understand the demographics of the adults with a learning disability who had a focused LeDeR review who died from a cardio-vascular condition.
- To explore the management of common cardiovascular conditions in adults with a learning disability who have died from cardio-vascular diseases.

Following a robust analysis of the LeDeR and death certificate data[1], we will provide guidance to better target services and subsequent research to improve the management of cardio-vascular conditions for people with a learning disability[2].

Method

Sample selection

Two main samples of adults who died from cardio-vascular conditions were obtained for this deep dive; all adults who died of a cardio-vascular condition who had an initial or focused LeDeR review, and adults who died from a cardio-vascular condition who had a *focused* LeDeR review. Both samples were compared with a group of adults who had a LeDeR review and whose deaths were not due to a cardio-vascular condition. A description of the LeDeR review process, including the differences between initial and focused LeDeR reviews, can be found in the 2022 annual report.

[1] Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) is an English national service improvement programme established in 2017 which examines the lives and deaths of people with a learning disability, and autistic people. For more information see www.leder.nhs.uk/about

[2] Please note that whilst LeDeR does collect information about autistic people who have died in England, in this deep dive we are only examining the data of those who had a learning disability.

A person's cause of death was established with reference to their Medical Certificate of Cause of Death (MCCD). Deaths due to cardio-vascular causes were identified as any cause of death coded in the diseases of the circulatory system chapter of the International Classification of Diseases 10th revision (ICD-10), codes I00 to I99. Cardio-vascular deaths were defined as the presence of a relevant code in part one of the person's MCCD (see below for a description of death certificate data). People who had an ICD-10 code for COVID-19 (U07.1) anywhere on their death certificate were excluded.

Sample 1 – Adults with a LeDeR review who died from a cardio-vascular condition: Consists of all reviews (i.e. initial and focused) conducted by LeDeR for adults with a learning disability who died between 1st January 2018 and 31st December2022 from a cardio-vascular condition. Sample 1 was compared with a group of adults with a learning disability that had a LeDeR review whose deaths were not impacted by a cardio-vascular condition (i.e. they did not have a cardio-vascular condition listed anywhere on their death certificate).

Sample 2 – Adults with a focused LeDeR review who died from a cardio-vascular condition: Contains all focused (i.e. more detailed) reviews conducted by LeDeR for adults with a learning disability who died from a cardio-vascular condition. Sample 2 was compared with a group of adults with a learning disability that had a focused LeDeR review whose deaths were not impacted by a cardio-vascular condition (i.e. they did not have a cardio-vascular condition listed anywhere on their death certificate).

Data collection and analysis

Conditions which caused and contributed to death

Data collection

The following data were collected from medical certificates of cause of death (MCCD): the immediate cause of death, the sequence of conditions that lead directly to death, conditions which contributed but did not cause death (see Appendix 1 for a description of how these were extracted). The death certificate data was grouped in accordance with the Office for National Statistic's leading causes of death list to enable comparisons with the general population and in accordance with ICD-10 blocks to ensure that all circulatory diseases were included in this analysis (see Appendix 2 for more information on the cause of death groupings).
Avoidable mortality was determined with reference to the Organisation for Economic Co-operation and Development (OECD) / Eurostat definition (see Appendix 3).

Data analysis

The main sample consisted of all adults who died from a cardio-vascular condition between the 1st January 2018 and 31st December 2022 and received a review by LeDeR (sample 1). This analysis presented here determined: the percentage of deaths caused by specific cardio-vascular conditions, the percentage of deaths where a specific cardio-vascular condition was a contributory factor, the percentage of deaths caused by cardio-vascular conditions in each year, the percentage of cardio-vascular deaths in males and females and adults who died at

different ages, the most common cardio-vascular conditions mentioned in the sequence of events or conditions which led to death, the most common non-cardio-vascular conditions which were mentioned in the sequence of events or conditions which led to death, the most common conditions that contributed, but did not cause death and the leading causes of cardio- vascular death in adults with a learning disability. The leading cardio-vascular causes of death in adults with a learning disability were then compared to the leading causes of death in adults in the general population.

Demographics, long-term conditions, and management of cardio-vascular conditions

Data collection

Introduced in June 2021, focused reviews are the most comprehensive reviews conducted by LeDeR. Focused reviews are conducted in the following circumstances: if the person was from a British Minority Ethnic background, if the reviewer believed that there would be significant learning gained by conducting the focused review, if the person's family requested a focused review, if the review fell within a local priority (e.g. some health services conduct focused reviews if the person died from pneumonia), if the person had been under mental health or criminal justice restrictions at the time of death or 5 years previously. The information collected in focused reviews includes long-term health conditions, medical history, care arrangements and quality of care,

Data analysis

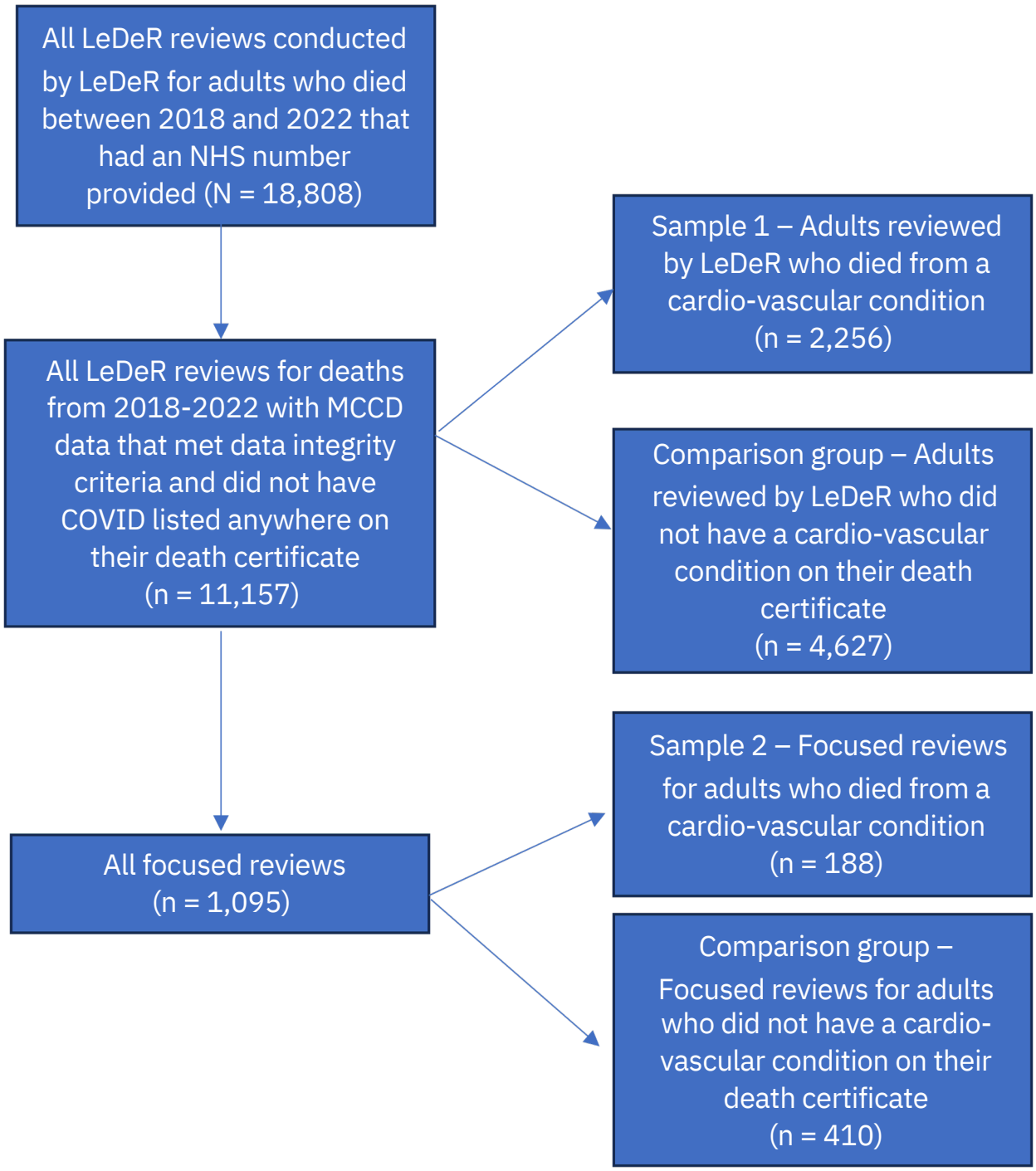
The demographics, long-term conditions and management of cardio-vascular conditions were summarised for all adults who died from a cardio-vascular condition and received a focused LeDeR review (sample 2). Where possible, the results were compared against a sample of adults whose deaths were not impacted by cardio-vascular conditions. The socio-demographic variables that were analysed include: the median age at death, sex, ethnicity, level of learning disability, living situation, region, and place of death. The management of cardio-vascular conditions was evaluated by looking at all focused reviews for adults who died of a cardio-vascular condition where the reviewer indicated that the person had a cardio-vascular condition before they died.

Results

Sample selection

The sample selection process is shown overleaf in Figure 1.

Figure 1: Sample selection



Conditions which caused and contributed to death

This section presents the proportion of deaths in each year caused by cardio-vascular conditions, the proportions of deaths in males, females and adults who died at different ages, the most common conditions which caused death and the most common conditions which contributed to death (see Appendix 4 for more information).

Year of death

Excluding those who had COVID-19 listed on their death certificate, 2,256 adults with a learning disability died between 2018 and 2022, had a review completed by LeDeR and had a cardio-vascular condition listed in part one of their death certificate. 19% of all the deaths in 2018 and 2019 that were reviewed by the LeDeR programme had a cardio-vascular condition listed in part one of the death certificate. In 2020, 2021 and 2022, 21% of all deaths reviewed by LeDeR had a cardio-vascular condition listed in part one of the death certificate.

	Adults with a cardio-vascular condition listed in part one of their death certificate	Total number of deaths (excluding COVID)
Year of death	**n (% of all deaths for that year)**	**n (% of all deaths for that year)**
2018	417 (19%)	2,242 (100%)
2019	449 (19%)	2,372 (100%)
2020	480 (21%)	2,274 (100%)
2021	507 (21%)	2,381 (100%)
2022	403 (21%)	1,888 (100%)
Total	2,256 (20%)	11,157 (100%)

Sex: Cardio-vascular deaths in males and females

59% of the sample of adults with a cardio-vascular condition listed in part one of their death certificate were male. The distribution of males and females in adults with a cardio-vascular condition listed on their death certificate was similar to the distribution of males and females in adults who did not have a cardio-vascular condition listed anywhere on their death certificate.

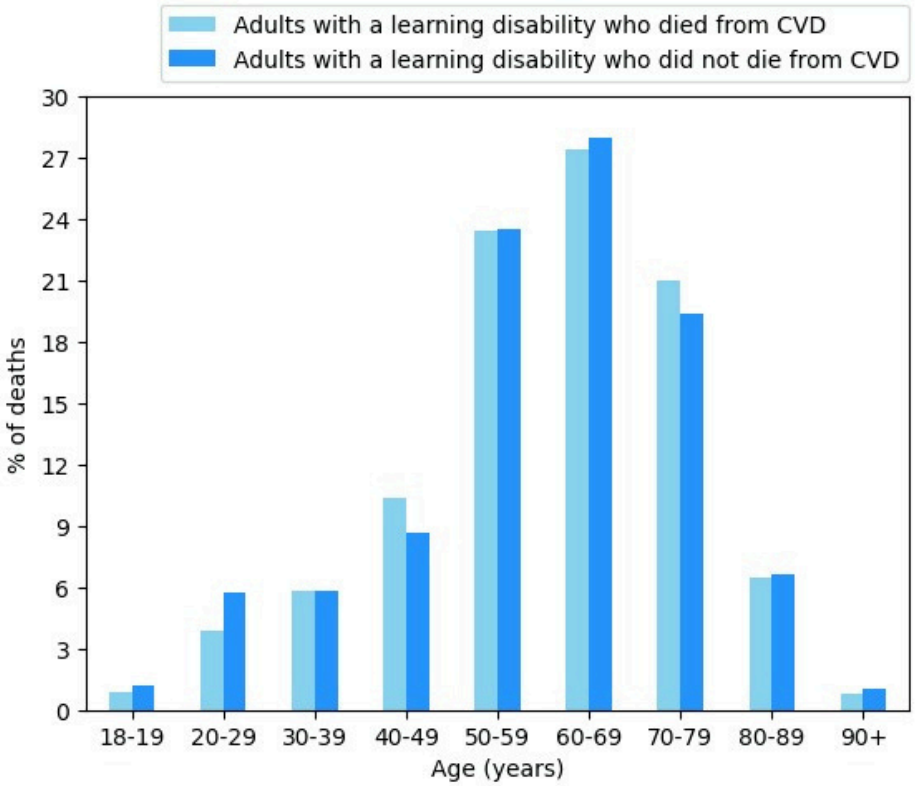
Table 2: Number of deaths in males and females

	Adults with a cardio-vascular condition listed in part one of their death certificate	Adults who did not have a cardio-vascular condition listed anywhere on their death certificate
Sex	**n (%)**	**n (%)**
Males	1,324 (59%)	2,528 (55%)
Females	932 (41%)	2,099 (45%)
Total	2,256	4,627

Age at death: Cardio-vascular deaths in different age groups

The percentage of deaths that occurred at different ages was similar for adults with a cardio-vascular condition listed in part one of their death certificate and adults who did not have a cardio-vascular condition listed anywhere on their death certificate. The leading causes of death for adults with a learning disability who died at different ages are presented alongside the most common causes of death for adults from the general population in Appendix 4.

Figure 2 Percentage of deaths in adults with a learning disability who died at different ages.



Cardio-vascular conditions that lead to death

The sequence of conditions which led directly to death are written in order with the most immediate causes of death being provided in part one line a) and the less immediate causes of death being provided in lines b) and c) (see Appendix 1).

Of the 2,256 adults who died between 2018 and 2022 and had at least one code for a cardio-vascular condition listed somewhere in part one of their death certificate. 77% had a cardio-vascular condition listed in the first line of part one, as the immediate cause of death.

Most common conditions that lead to death

The nine most common cardiovascular causes of death are provided in Table 3. This includes all codes from the diseases of the circulatory system chapter of the ICD-10. The most common cause of death was ischaemic heart disease, which was included 934 times in the sequence of events or conditions which led to death. 278 adults had a code for myocardial infarction in part one of their death certificate (ICD-10 code: acute myocardial infarction: I21). Chronic ischaemic heart disease was recorded 630 times. The second most common cause of death was cerebrovascular diseases, followed by heart failure. Pulmonary heart disease and diseases of pulmonary circulation, cardiac arrest and diseases of the veins, lymphatic vessels, and lymph nodes, which includes DVT, were other relatively common causes of death.

Table 3: The nine most common conditions found in part one of the death certificates of adults with a learning disability who died from a cardio-vascular condition.

	Adults with a cardio-vascular condition listed in part one of their death certificate (n = 2,256)	
ICD-10 blocks	ICD-10 codes	Number of mentions
Other forms of heart disease:	I30-I52	1,148
Heart failure	I50	470
Cardiac arrest	I46	225
Complications and ill-defined descriptions of heart disease	I51	144
Ischaemic heart diseases	I20-I25	934
Chronic ischaemic heart diseases	I25	630
Myocardial infarction	I21-I23	278
Cerebrovascular diseases	I60-I69	498
Pulmonary heart disease and diseases of pulmonary circulation (e.g. pulmonary embolism)	I26-I28	347
Diseases of veins, lymphatic vessels, and lymph nodes, not elsewhere classified (e.g., Phlebitis and thrombophlebitis)	I80-I89	159
Hypertensive diseases	I10-I15	134
Diseases of arteries, arterioles, and capillaries	I70-I79	85
Chronic rheumatic heart diseases	I05-I09	71
Other unspecified disorders of the circulatory system	I95-I99	*

Non-cardio-vascular conditions which lead to death

The ten most common non-cardio-vascular conditions that were provided in the sequence of events or conditions which directly caused death, in part one of the death of the death certificate, are summarised in Table 4. This provides the most common conditions that occur alongside the cardio-vascular causes of death. All codes other than those found in the diseases of the circulatory system ICD-10 chapter are included. The three most common non-cardiovascular causes of death included alongside a cardio-vascular condition in the sequence of events or conditions which led to death were: influenza and pneumonia, aspiration pneumonia, general symptoms, and signs.

Table 4: The ten most common non-cardio-vascular conditions found in part one of the death certificates of adults who died from a cardio-vascular condition.

	Adults with a cardio-vascular condition listed in part one of their death certificate (n = 2,256)	
Cause of death	**ICD-10 codes**	**Number of mentions**
Influenza and pneumonia	J09-J18	169
Lung diseases due to external agents (e.g., aspiration pneumonia)	J60-J70	143
General symptoms and signs (e.g., abiotrophy, asphyxia, convulsions)	R50-R69	129
Other disorders of the nervous system (e.g., disorders of the autonomic nervous system, hydrocephalus)	G90-G99	119
Congenital malformations of the circulatory system	Q20-Q28	82
Complications of medical or surgical care	Y40-Y84	62
Episodic and paroxysmal disorders	G40-G47	61
Renal failure	N17-N19	54
Other diseases of the intestines (e.g., paralytic ileus and intestinal obstruction without hernia, other functional intestinal disorders)	K55-K63	53
Other bacterial diseases	A30-A49	46
Other diseases of the respiratory system	J95-J99	44

The most common conditions that contributed to death

Part two of the death certificate includes conditions which were judged to have contributed to death but did not cause death (see Appendix 1). 20% of adults with a cardio-vascular condition listed in part one of their death certificate had a cardio-vascular condition in part two of their death certificate.

Table 5: The ten most common conditions found in part two of the death certificates of adults with a cardio-vascular condition listed in part one of their death certificate.

	Adults with a cardio-vascular condition listed in part one of their death certificate (n = 2,256)	
ICD-10 block	**ICD-10 codes**	**Number of mentions**
Diabetes mellitus	E10-E14	320
Other forms of heart disease Atrial fibrillation and flutter Heart failure	I30-I52 I48 I50	207 61 44
Episodic and paroxysmal disorders (e.g., epilepsy)	G40-G47	182
Chromosomal abnormalities, not elsewhere classified (e.g., Down syndrome)	Q90-Q99	173
Disorders of psychological development (e.g., specific developmental disorders of scholastic skills)	F80-F89	171
Renal failure	N17-N19	141
General symptoms and signs	R50-R69	112
Hypertensive diseases	I10-I15	105
Chronic lower respiratory diseases	J40-J47	97
Ischaemic heart diseases	I20-I25	84
Disorders of psychological development (e.g., specific developmental disorders of scholastic skills)	F80-F89	171
Renal failure	N17-N19	141
General symptoms and signs	R50-R69	112
Hypertensive diseases	I10-I15	105
Chronic lower respiratory diseases	J40-J47	97
Ischaemic heart diseases	I20-I25	84

Underlying causes of death

Leading cardio-vascular causes of death

75% of the adults with a cardio-vascular condition listed in part one of their death certificate had a cardio-vascular condition belonging to the ICD-10 diseases of the circulatory system chapter recorded as the underlying cause of death. The three most common leading cardio-vascular conditions that were provided as underlying causes of death were ischaemic heart diseases, cerebrovascular diseases, and heart failure. The percentage of cardio-vascular deaths caused by ischaemic heart diseases was 37% in adults with a learning disability. Ischaemic heart diseases caused 42% of cardio-vascular deaths in the general population. Pulmonary heart disease and diseases of pulmonary circulation caused 7% of cardio-vascular deaths in adults with a learning disability. Pulmonary heart disease and diseases of pulmonary circulation caused 2% of cardio-vascular deaths in the general population. Higher percentages of cardio-vascular deaths were caused by cardiac arrhythmias and aortic aneurysm and dissection in adults from the general population in comparison to in adults with a learning disability (cardiac arrhythmias: 2% of cardiovascular deaths in adults with a learning disability vs 6% of cardio-vascular deaths in adults from the general population; aortic aneurysm and dissection: 1% of cardiovascular deaths in adults with a learning disability vs 4% of cardio-vascular deaths in adults from the general population).

Table 6: Top ten leading causes of death for adults with a cardio-vascular condition listed in part one of their death certificate.

	Adults with a learning disability who had a cardio-vascular condition listed as their underlying cause of death	**General population death (Age 20+, 2018-2022)**
Leading cardio-vascular cause of death	**n (% of cardio-vascular conditions)**	**% of cardio-vascular deaths**
Ischaemic heart diseases	623 (37%)	42%
Cerebrovascular diseases	403 (24%)	22%
Heart failure and complications and ill-defined heart disease	127 (7%)	7%
Pulmonary heart disease and diseases of pulmonary circulation	111 (7%)	2%
Hypertensive diseases	78 (5%)	6%
Nonrheumatic valve disorders and endocarditis	74 (4%)	4%
Cardiac arrhythmias	41 (2%)	6%
Cardiomyopathy	41 (2%)	1%
Aortic aneurysm and dissection	24 (1%)	4%
Chronic rheumatic heart diseases	15 (1%)	1%
Total number of adults with a cardio-vascular condition as an underlying cause of death	1,694	

Avoidable deaths

According to the OECD's definition of avoidable mortality, 54% of the deaths for adults with a cardio-vascular condition listed in part one of the death certificate were from a cause of death that is classified as avoidable (see Appendix 3). 65% of these causes of death were classified as equally preventable and treatable. 28% were from a treatable cause of death and 7% of deaths were from a preventable cause of death.

Table 7: Avoidable mortality

	Adults with a cardio-vascular condition listed in part one of their death certificate (n = 2,256)	**Adults who did not have a cardio-vascular condition listed anywhere on their death certificate (n = 4,627)**
OECD classification	**n (%)**	**n (%)**
Preventable	47 (2%)	392 (8%)
Treatable	358 (16%)	975 (21%)
Equally preventable and treatable	814 (36%)	31 (0.7%)
Total avoidable deaths	**1,219 (54%)**	**1,398 (30%)**

Demographics, long-term conditions, and management of cardio-vascular condition

Demographics

There was little difference in the median age at death for the adults who did / did not die from a cardio-vascular condition. 57% of adults with a cardio-vascular condition listed in part 1 of their death certificate (sample 2) were male. This compared to 52% of adults who did not have a cardio-vascular condition listed anywhere on their death certificate. The percentage of adults from different ethnic backgrounds and adults living in different regions was similar between the two groups. There was a higher percentage of adults who had a mild learning disability in the sample of adults with a cardio-vascular condition listed in part one of their death certificate compared to the sample of adults who did not have a cardio-vascular condition listed (35% of adults who died from a cardio-vascular condition vs 20% of adults who did not die from a cardio-vascular condition). The percentage of adults with a severe or a profound learning disability was lower in the sample of adults with a cardio-vascular condition listed in part one of their death certificate in comparison to the sample of adults who did not have a cardio-vascular condition listed (severe learning disability: 27% of adults with a cardio-vascular condition listed in part one of their death certificate vs 35% of adults who did not have a cardio-vascular condition listed anywhere on their death certificate). A greater percentage of adults who had a cardio-vascular condition listed in part one of their death certificate died in their usual place of residence in comparison to adults who did not have a cardio-vascular condition (39% of adults who died from a cardio-vascular condition vs 26% of adults who did not die from a cardio- vascular condition).

Table 8: Socio-demographics of the adults who did / did not die from a cardio-vascular condition

	Adults with a cardio-vascular condition listed in part one of their death certificate	Adults who did not have a cardio-vascular condition listed anywhere on their death certificate
Age at death		
Median age at death (IQR)	55.8 years (17.9 years)	56.2 years (24.8 years)
Sex	n (%)	n (%)
Male	107 (57%)	212 (52%)
Female	81 (43%)	198 (48%)
Ethnicity		
White	129 (73%)	304 (76%)
Black, black British, Caribbean, or African	23 (13%)	50 (13%)
Asian or Asian British	15 (8%)	22 (6%)
Mixed or Other	10 (6%)	31(8%)
Region		
Midlands	48 (26%)	118 (29%)
North East and Yorkshire	36 (19%)	54 (13%)
South East	32 (17%)	41 (10%)
East of England	25 (13%)	76 (19%)
London	24 (13%)	57 (14%)
North West	14 (7%)	37 (9%)
South West	9 (5%)	37 (9%)
Level of learning disability		
Mild	44 (35%)	63 (20%)
Moderate	40 (32%)	87 (28%)
Severe	33 (27%)	109 (35%)
Profound/multiple	* (<4%)	40 (13%)
Not known	* (<4%)	15 (5%)
Living situation		
Residential/nursing home	75 (40%)	166 (40%)
Family home	49 (26%)	114 (28%)
Supported living	34 (18%)	101 (25%)
Other	30 (16%)	29 (7%)
Place of death		
Hospital	108 (58%)	293 (71%)
Usual place of residence	73 (39%)	106 (26%)
Other	6 (3%)	10 (2%)
Total number of adults	188	410

Long-term health conditions

The percentage of adults with a long-term health condition is shown in Table 9 for those who did/did not die from cardio-vascular conditions. These data were extracted from the LeDeR focused review forms. The list of conditions described here are similar to the conditions described in the annual reports for the LeDeR programme.

Unsurprisingly, there was a higher percentage of adults in the sample with a cardiovascular condition listed in part one of their death certificate that were recorded as having cardiovascular conditions and hypertension in comparison to the sample of adults who did not have a cardio-vascular condition listed anywhere on their death certificate. In comparison to the sample of adults who did not have a cardio-vascular condition listed anywhere on their death certificate, there was a higher percentage of the sample who had a cardio-vascular condition listed in part one of their death certificate that were obese and a higher percentage that had a mental health condition. There was a lower percentage of adults that were recorded as having swallowing difficulties and epilepsy in the sample who had a cardiovascular condition listed in part one of their death certificate in comparison to the sample of adults who did not have a cardio-vascular condition list anywhere on their death certificate.

Table 9: The percentage of adults who had a focused review with a long-term health condition.

	Adults with a cardio-vascular condition listed in part one of their death certificate	**Adults who did not have a cardio-vascular condition listed anywhere on their death certificate**
	n (%)	**n (%)**
Cancer	6 (3%)	52 (13%)
Cardiovascular conditions (other than hypertension)	108 (57%)	82 (20%)
Cerebral palsy	13 (7%)	49 (12%)
Dementia	20 (11%)	68 (17%)
Diabetes	44 (23%)	69 (17%)
Down syndrome	17 (9%)	60 (15%)
Epilepsy	62 (33%)	194 (47%)
Hypertension	54 (29%)	41 (10%)
Any mental health condition	48 (26%)	77 (19%)
Musculoskeletal conditions	51 (27%)	119 (29%)
Obesity	54 (29%)	47 (11%)
Parkinson's	* (<3%)	13 (3%)
Renal (kidney) conditions	28 (15%)	58 (14%)
Respiratory conditions	52 (28%)	140 (34%)
Sensory impairment	53 (28%)	132 (32%)
Swallowing difficulties	51 (27%)	204 (50%)
Median number of long-term health conditions (IQR)	3 (3)	3 (2)
Total number of focused reviews	188	410

Summary of information provided on LeDeR cardio-vascular recording forms

102 of the 188 (54%) adults who had a cardio-vascular condition listed in part one of their death certificate had a cardio-vascular condition reported on their focused review form.

Cardio-vascular history

Of the 102 adults who had a cardio-vascular condition listed in part one of their death certificate and recorded on their LeDeR focused review form, 27% were reported to have been admitted to hospital for a heart condition in the 12 months prior to death. 9% were reported to have a history of strokes or Transient Ischaemic Attacks (TIAs). Abdominal aortic aneurysm (AAA) screening Abdominal aortic aneurysm screening is routinely offered to males aged over 65 years. Of the 102 adults who had a cardio-vascular condition listed in part one of their death certificate and recorded on the LeDeR focused review form, 19% were reported to have received abdominal aortic aneurysm screening.

Management of cardio-vascular conditions

Of the adults with a cardio-vascular condition listed in part one of their death certificate, who had a cardio-vascular condition reported on their LeDeR focused review form, 57% were reported to have treatment and management which followed NICE, professional bodies or good practice guidelines. 4% were reported to have treatment and management which did not follow NICE, professional bodies or good practice guidelines. 56% of the adults with a cardio-vascular condition listed in part one of their death certificate, who had a cardio-vascular condition reported on their LeDeR focused review form, had treatment and management which was in accordance with local care pathways. Reviewers reported that less than 5% of adults had treatment and management which was not in accordance with local care pathways. 40% of the adults with a cardio-vascular condition listed in part one of their death certificate, who had a cardio-vascular condition reported on their LeDeR focused review form were assessed for prophylactic statins. 30% were not assessed for prophylactic statins; however, it is not recorded in focused review forms whether people had a history of hyperlipidaemia and cardiovascular risk assessment and therefore were eligible for statin prescriptions. 36% were reported to have seen a cardiologist in the 12 months prior to death. 58% of adults were reported not to have seen a cardiologist in the 12 months prior to death. 8% of adults were reported to have shown poor adherence to medications. 65% did not have poor adherence to medications.10% were reported to have shared care arrangements in place. 47% did not have shared care arrangements in place.

Discussion

Year of death

Between 2018 and 2022, 2,256 adults with a learning disability that had a LeDeR review had a cardio-vascular condition listed in the sequence of events or conditions that led directly to death. In 2018 and 2019, 19% of all deaths were caused by cardio-vascular conditions, whereas in 2020, 2021 and 2022, 21% of all deaths were caused by cardio-vascular conditions. The increased proportion of cardio-vascular deaths in 2020, 2021 and 2022 may have been

influenced by COVID-19 and context of the pandemic, which reduced people's activity and strained healthcare services.

Cardio-vascular deaths in males, females and in different age groups

Of the 2,256 adults with a learning disability who died from a cardio-vascular condition between 2018 and 2022, the majority (59%) were male. 55% of adults who deaths were not impacted by a cardio-vascular condition were male. The percentage of deaths occurring at different ages was similar for people with a learning disability who died from a cardio-vascular cause of death and for adults with a learning disability whose death was not impacted by a cardio-vascular condition.

The most common cardio-vascular conditions which caused death

The five most common cardio-vascular causes of death in adults with a learning disability are: ischaemic heart diseases, cerebrovascular diseases, heart failure, pulmonary heart disease and diseases of pulmonary circulation and cardiac arrest.

The most common conditions associated with cardio-vascular death

Influenza and pneumonia and aspiration pneumonia were the most common non-cardiovascular conditions that were in the sequence of events and conditions that led to death. The three most common conditions that were recorded as having contributed to but did not cause death from cardio-vascular conditions were: diabetes, other forms of heart disease (including atrial fibrillation and flutter) and epilepsy.

Cardio-vascular deaths in adults with a learning disability compared to the general population

A higher percentage of deaths in adults with a learning disability were caused by pulmonary heart disease and diseases of pulmonary circulation in comparison to adults from the general population (7% of cardio-vascular deaths in adults with a learning disability vs 2% of cardio-vascular deaths in adults from the general population. Adults with a learning disability are more likely to be obese (Harris et al., 2018), live sedentary lifestyles (Melville et al., 2018; Dairo et al., 2016), have reduced mobility (Melville et al., 2018), have co-occurring conditions that increase the risk of pulmonary embolism (e.g. Down syndrome) (Hermon et al., 2001) and have co-occurring conditions that are treated with medications that increase the risk of pulmonary embolism (e.g. anti-epileptic medications) than the general population (Robertson et al., 2015; Lee-Lane et al., 2021). A lower percentage of deaths in adults with a learning disability were caused by ischaemic heart diseases, cardiac arrhythmias, aortic aneurysm, and dissection in comparison to the general population, which may be the result of a lack of detection.

Demographic characteristics and long-term conditions common in adults who died from cardio-vascular causes of death

A higher percentage of adults who died from a cardio-vascular condition and had a focused review into their death had a mild learning disability (35%) in comparison to adults whose death was not impacted by a cardio-vascular condition (20%). Obesity, diabetes, mental health conditions and hypertension were present in a larger percentage of adults who died from a cardio-vascular condition in comparison to those whose deaths were not impacted by a cardio-vascular condition.

Cardio-vascular history
27% of adults who had a cardio-vascular condition listed in the sequence of conditions that lead directly to death had been admitted to hospital for a heart condition in the 12 months prior to death. 9% were reported to have a history of strokes or Transient Ischaemic Attacks (TIAs), which result from a low rate of detection.

Abdominal aortic aneurysm (AAA) screening
19% of adults who had a cardio-vascular condition listed in part one of their death certificate and recorded on the LeDeR focused review form were reported to have received abdominal aortic aneurysm screening.

Management of cardio-vascular conditions
Of the adults who died from a cardio-vascular condition and had a cardio-vascular condition identified on their LeDeR focused review form, 62% were recorded by reviewers as having had treatment and management which followed NICE, professional bodies or good practice guidelines. 5% were reported to have treatment and management which did not follow NICE, professional bodies or good practice guidelines. For 39% of adults, it was not recorded. 30% of the adults who died from a cardio-vascular condition and had a cardio-vascular condition identified on their LeDeR focused review form were not assessed for prophylactic statins. 36% were reported to have seen a cardiologist in the year before death. 58% were reported to have not seen a cardiologist in the year before death.

Strengths and limitations

This deep dive investigated the cardio-vascular causes of death in people with a learning disability. A large sample of adults with a learning disability who died from a cardio-vascular condition were analysed. This increases the likelihood that the cardio-vascular causes of death and conditions associated with death from a cardio-vascular condition are accurate. Detailed information regarding the management of cardio-vascular conditions is also presented. The insights presented here may help improve the care of people with a learning disability who have cardio-vascular conditions.

There are some limitations. LeDeR is an England wide national database of reported deaths of people with a learning disability and autistic adults. LeDeR only collects information about people who have died so none of the analyses included people who had a cardio-vascular condition who did not die. It is not mandatory to report to LeDeR, and the number of deaths may therefore be under-reported. However, LeDeR is largely representative of the causes of deaths of people with a learning disability, although certain groups including people from ethnic minority groups may be underreported to LeDeR. Please see the 2023 Race and Health Observatory report (Umpleby et al., 2023) for further discussion on the limitations of ethnicity data in LeDeR. Although adults with COVID-19 included on their death certificate were excluded from all analyses, two of the five years that the adults died in were strongly influenced by the impact of COVID-19, this may have altered the rates and treatment of cardio-vascular conditions for adults with a learning disability. The analyses of the demographics, long-term conditions, and management of cardio-vascular conditions used information provided by focused LeDeR review forms. Focused review forms are only completed in certain circumstances, which vary from: the reviewer believed there to have been significant learning to be gained by conducted the focused review, to the adult was

from an ethnic minority group or a local or national priority was set to conduct reviews into certain deaths. This reduces the likelihood that the findings from focused reviews generalise to other groups of adults with a learning disability, although focused reviews represent the most detailed information collected by the LeDeR programme and are conducted by trained professionals. 54% of the adults who died from cardio-vascular conditions had a history of a cardio-vascular condition identified on their focused LeDeR review form. This limited the information about the treatment and management of cardio-vascular conditions that was available. Only four of the 38 questions on the cardio-vascular forms are mandatory, which may have limited the availability of data further.

Summary

There were four objectives for this deep dive:

1. To identify the most common cardio-vascular causes of death in adults with a learning disability and compare them with the general population.

2. To identify the conditions associated with death from a cardio-vascular condition.

3. To understand the demographics of the adults with a learning disability who had a focused review who died from a cardio-vascular condition.

4. To explore the management of common cardiovascular conditions in adults with a learning disability who have died from cardio-vascular diseases.

The most common cardio-vascular causes of death in adults with a learning disability are ischaemic heart diseases, cerebrovascular diseases, and heart failure. Other conditions identified in people with a learning disability who had a cardio-vascular condition listed in part one of their death certificate were: aspiration pneumonia, influenza and pneumonia, diabetes, obesity, epilepsy, hypertension, and Down syndrome. The findings indicated that adults with a mild learning disability may be at particular risk of dying from a cardio-vascular condition. A small percentage of people were recorded by LeDeR reviewers as not having received care that was in line with NICE guidance or local care pathways.

Increased awareness of the risk factors and causes of death from cardio-vascular conditions among health providers and carers could help improve the health of adults with a learning disability and ensure that appropriate time and resources are allocated to prevention and treatment interventions.

Recommendations

The following recommendations can be drawn:

Recommendations for practice:

Adults with a learning disability should be supported to adopt a healthy lifestyle which includes a healthy diet and regular physical activity so that rates of obesity, diabetes and hypertension are reduced. Responsibilities to safeguard adults who lack capacity under the mental capacity act to make decisions about healthy lifestyles should be met by those who they depend on for health and care. Those with mild learning disability may be particularly vulnerable and may require additional support reduce the risk of developing cardiovascular conditions.

Proactive management and monitoring of risk factors associated with cardiovascular conditions may help to reduce avoidable deaths due to cardiovascular conditions. This may include promoting regular health checks, vaccinations (e.g flu, pneumonia) and medication monitoring and reviews.

Recommendations for research:

Cardio-vascular deaths in adults with a learning disability should continue to be closely monitored by researchers following the pandemic. Research comparing the management of cardio-vascular conditions in the general population could be conducted with a matched comparison sample. Additional work is needed to see how focused reviews can be used to collect more information on the and management of cardio-vascular conditions, as well as on factors such as hyperlipidaemia and cardio-vascular risk assessments. Additional work is needed to understand the role and how to better manage common risk factors for CVD in people with a learning disability, such as obesity, hypertension, and diabetes. Further research into pulmonary heart diseases and diseases of pulmonary circulation is required as this may help reduce cardio-vascular deaths in adults with a learning disability.

Other methodologies could be used including methods which monitor a cohort of people with a learning disability over a course of time to understand the progression of CVD and interventions in people with a learning disability.

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Appendix 1: Death certificate data

Part one of the medical certificate of cause of death certificate (MCCD) includes the sequence of events and conditions which directly caused death. There are three lines within part one. Each line may contain several conditions. Part one line a) contains the immediate (proximal) cause of death, which is the cause that led directly to death. Lines b) and c) contain the remaining conditions in the sequence of events and conditions which lead directly to death going backwards from the immediate cause of death.

Part two of the death certificate contains co-occurring conditions that had an indirect contribution to death (i.e. they were not considered to be in the sequence of events or conditions which led to death). The underlying cause of death is defined by the World Health Organisation (WHO) as the disease or condition that initiated the train of events leading to death. This is sometimes selected from the lowest available line in part one of the death certificate but can be selected from anywhere on the death certificate.

Appendix 2: Cause of death groupings

The first grouping was in accordance with the Office for National Statistic's leading causes of death list. The leading cause of death list was used for comparisons between adults with a learning disability and adults from the general population.

The second cause of death grouping was in accordance with ICD-10 blocks. ICD-10 blocks are a subdivision of the ICD-10. They contain groups of codes that share a common characteristic or are for the same condition. It was important to group conditions according to ICD-10 block as some common causes of death in adults with a learning disability are not included in the leading cause of death list. One condition that is not in the leading cause of death list is DVT, which is contained within the phlebitis and thrombophlebitis ICD-10 block.

Appendix 3: Definition of avoidable mortality

Avoidable mortality was determined with reference to the Organisation for Economic Co- operation and Development (OECD) / Eurostat definition (see Appendix X). The OECD definition categorises deaths that occur in people aged under 75 based on the underlying cause of death. Other factors such as the quality of care the individual received and co-morbidities are not considered in the classification. A death is avoidable if it was caused by a preventable or treatable cause. Preventable deaths are from causes that can mainly be avoided through public health and primary prevention measures. Treatable deaths are from causes that can mainly be avoided through timely and effective health care interventions. The OECD definition of avoidable mortality contains the following sub-classifications: preventable, treatable, equally preventable, and treatable.

Appendix 4: The leading causes of death for adults with a learning disability who died at different ages and adults from the general population

	Adults with a cardio-vascular condition listed in part one of their death certificate	General population (aged 20+)
Age at death	**Top three leading causes of death**	**Top three leading causes of death**
18-39	1. Congenital malformations, deformations, and chromosomal abnormalities 2. Cerebrovascular diseases 3. Pulmonary heart disease and diseases of pulmonary circulation	1. Ischaemic heart diseases 2. Cerebrovascular diseases 3. Cardiomyopathy
40-49	1. Ischaemic heart diseases 2. Congenital malformations, deformations, and chromosomal abnormalities 3. Cerebrovascular diseases	1. Ischaemic heart diseases 2. Cerebrovascular diseases 3. Cardiomyopathy
50-59	1. Ischaemic heart diseases 2. Cerebrovascular diseases 3. Pulmonary heart disease and diseases of pulmonary circulation	1. Ischaemic heart diseases 2. Cerebrovascular diseases 3. Hypertensive diseases
60-69	1. Ischaemic heart diseases 2. Cerebrovascular diseases 3. Heart failure and complications and ill-defined heart disease	1. Ischaemic heart diseases 2. Cerebrovascular diseases 3. Hypertensive diseases
70-79	1. Ischaemic heart diseases 2. Cerebrovascular diseases 3. Heart failure and complications and ill-defined heart disease	1. Ischaemic heart diseases 2. Cerebrovascular diseases 3. Aortic aneurysm and dissection
80+	1. Ischaemic heart diseases 2. Cerebrovascular diseases 3. Heart failure and complications and ill-defined heart disease	1. Ischaemic heart diseases 2. Cerebrovascular diseases 3. Cardiac arrhythmias