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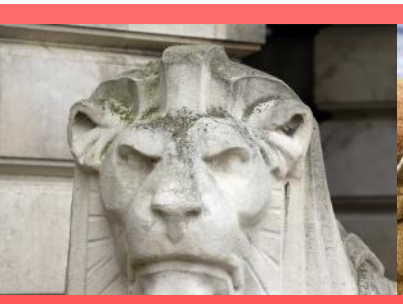


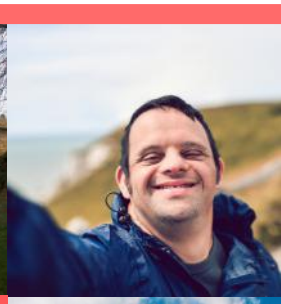

LeDeR
Learning from lives and deaths – People with a learning disability and autistic people

Midlands region






2021

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

Midlands



The Institute of Psychiatry, Psychology and Neuroscience (IoPPN)
King's College, London

16 De Crespigny Park
London
SE5 8AF
United Kingdom

Website: www.kcl.ac.uk/research/leder

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People with a learning disability and autistic people (LeDeR) report for 2021
(LeDeR 2021) - Midlands Region.

Autism and learning disability partnership,
University of Central Lancashire and King's College, London.

Contents

List of Abbreviations

DNACPR	Do Not Attempt Cardiopulmonary Resuscitation
GP	General Practitioner
ICB	Integrated Care Board
ICD-10	International Statistical Classification of Diseases and Related Health Problems - 10th Revision
IMD	Index of Multiple Deprivation
LeDeR	Learning from Lives and Deaths Review
MCCD	Medical Certificates of Cause of Death
NICE	National Institute for Health and Care Excellence
ONS	Office of National Statistics
OECD	Organisation for Economic Co-operation and Development
WHO	World Health Organisation

Background

This Regional Report has been produced in addition to the detailed national report about people who die in England with a learning disability. The introduction of regional reports allows for a more detailed look at some of the national report findings and can inform service priorities targeted by region. It is hoped that these regional reports will serve as a lens for enquiry and provide the regions with an opportunity to work with ICBs around opportunities for collective action to create opportunities for improvement.

In 2021 LeDeR was notified of 3,290 deaths of individuals with a learning disability and who also had a region identified*. Of these, 671 (20%) deaths were reported in the Midlands. Detailed analysis of these deaths is presented in this report.

This regional report is designed to supplement the LeDeR 2021 national report, found here. For the full data sets which accompany these reports, please see the national report appendix.

In the summer of 2021 there were some significant changes to the way in which LeDeR review data were collected. These have been highlighted in the national annual report, and further information can be found about these on the LeDeR website: at www.leder.nhs.uk/about

For this report, as in the national annual report, “older LeDeR” refers to the older collection questions from before June 2021 whilst “new LeDeR” refers to the questions from after June 2021. We have identified where it was not possible to completely merge the questions from the “old” and “new” data and have presented those data separately, but for the most part these have been merged and reported as a whole, where this was possible.

For more information about the LeDeR analysis for 2021, and to download a copy of the national report as well as easy read versions, presentations, and an easy read video, please see www.kcl.ac.uk/research/leder

*NB: The regional notification figures are slightly lower than the national report due to the exclusion of data with no region identified.

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Priorities

In this report we have identified priorities we would suggest would be beneficial for ICBs to focus on going forward. In terms of actionability, this may depend on internal policy and resources available at the time. However, these would be beneficial in ensuring better data collection and improving upon the quality of care offered.

- Deaths in minority ethnic populations may be under reported to the LeDeR programme. It is important to have accurate population data including ethnic group to ensure that all deaths of people from minority ethnic groups are reported to LeDeR and to help with the interpretation of findings with regard to ethnic disparities.

- Cardiovascular conditions were the most common long-term conditions in the Midlands, and diseases of the circulatory system were a common cause of death. It will likely be beneficial for the region to ensure appropriate care for people with a learning disability with these conditions.

- Compared to previous years there has been an increase in the amount of incorrectly applied and followed DNACPRs in the region during 2021. Action may be required to improve this.

- It may be helpful to review care pathways related to influenza and pneumonia, cerebrovascular disease, ischaemic heart disease and cancer care in the local region to reduce the proportion of avoidable deaths in people with a learning disability.

- COVID-19 was the most common cause of death in 2021, and efforts to reduce the impact of the pandemic should be maintained.

- It is important that as much data as possible are provided to LeDeR by the ICBs to enable the production of more detailed reports. For next year, LeDeR is aiming for at least 35% of reviews to be focused reviews. If this figure is met, the quality and detail of the data available will be strengthened.

Midlands Report 2021

Demographics

Midlands deaths in 2021 notified to LeDeR

There were 671 deaths of individuals with a learning disability which occurred in the Midlands in 2021 and which were notified to LeDeR. This constitutes 20% of the total number of deaths for 2021 (see Figure 1). Of the deaths occurring in 2021 in the Midlands and notified to LeDeR, 48 (7.1%) were of children aged 4-17 and 623 (92.8%) were of adults over 18.

There was a peak in deaths in January 2020 and 2021 which reflected the pattern of the COVID-19 pandemic. This trend can be seen in Figure 2, which shows notifications of deaths in the Midlands between 2018 and 2021. 1,862 deaths in the Midlands were notified to LeDeR for the period between 2018 and 2020.

Fig 1: Number of people who were notified and had an initial review or a focused review, to LeDeR in 2021 by region.

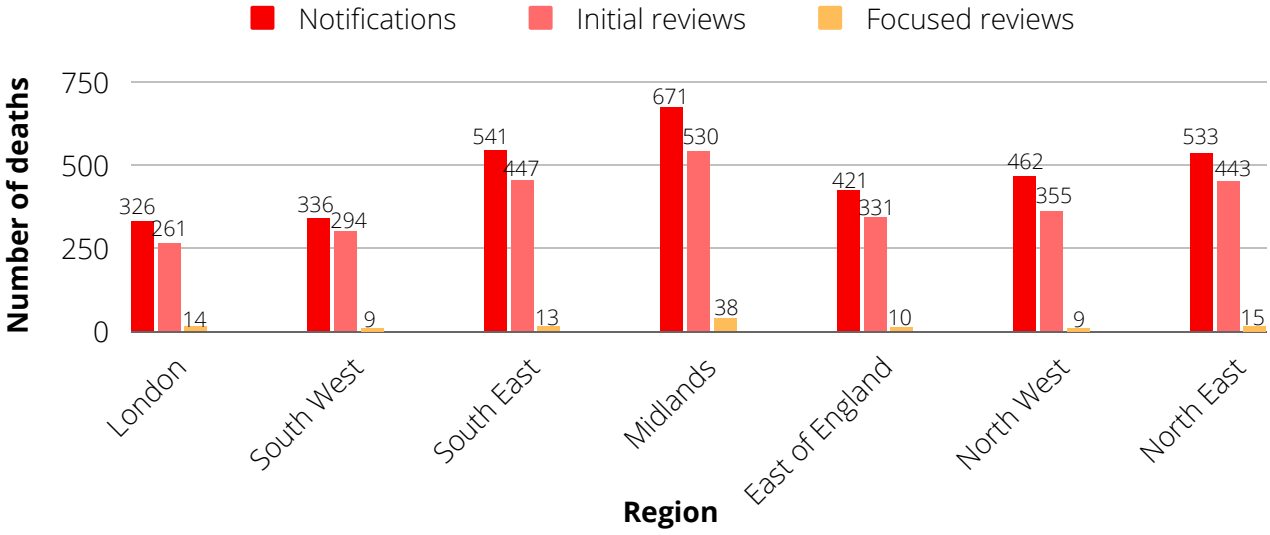
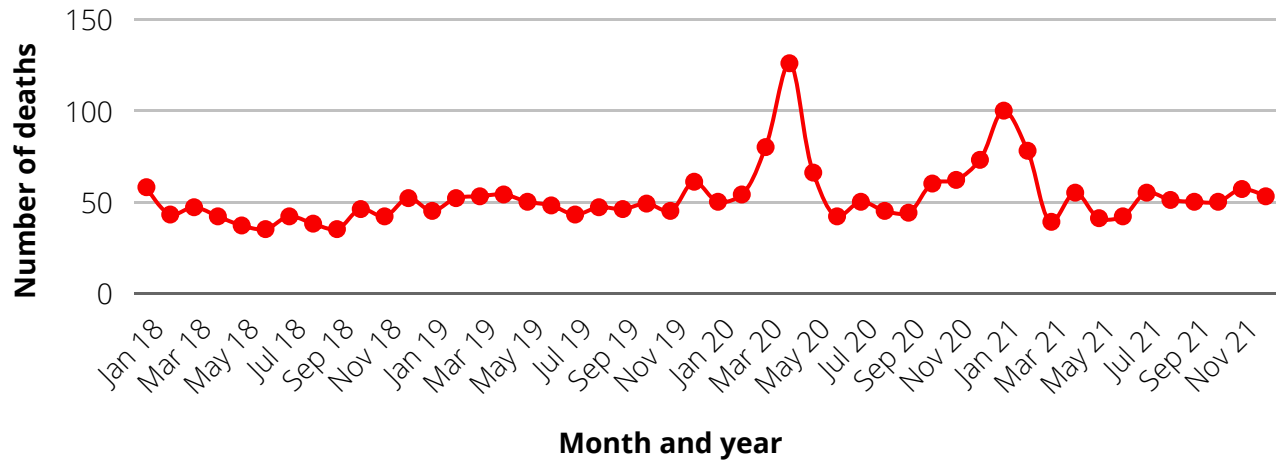


Fig 2: Number of notified deaths in the Midlands, January 2018 to December 2021.



Sex

Sex was reported for all 671 people from the Midlands whose deaths were notified to LeDeR in 2021. 384 (57%) people who died in 2021 were recorded as male and 287 (43%) were recorded as female. These proportions are similar to the figures across all regions.

Age at Death

The overall median age at death for the 671 notified deaths in 2021 in the Midlands was 59, slightly younger than the overall median age at death of 61 for people who died across all regions. For the 384 males, the median age at death was 59, and for the 287 females the median age at death was 59.

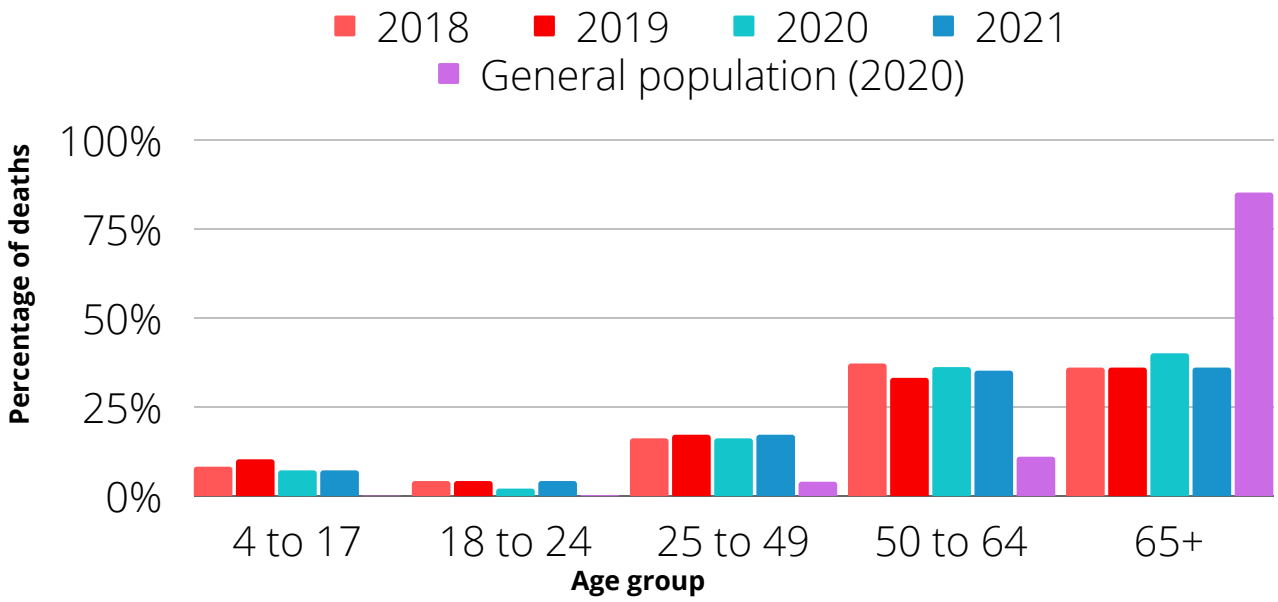
Looking at the 48 deaths of children (aged under 18 and over 4 years old), the median age at death was 12. Of the 623 deaths of adults, the median age at death was 60.

Figure 3 (overleaf) shows the age group at death for people with a learning disability who died in the Midlands in 2018, 2019, 2020 and 2021 compared to the age group at death in the general population in 2020[1]. General population data have been used to outline how the age at death of people with a learning disability compares to the population as a whole. The data are not directly comparable as the deaths included in LeDeR are only of people from the age of 4 years, whereas general population data includes information about children 0-3 years.

The COVID-19 global pandemic means data from 2020 and 2021 look different to data from 2018 and 2019. However, comparing trends from these years is useful to look at how the pandemic impacted age at death for people with a learning disability.

[1]https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables

Fig 3: Age group at death for people with a learning disability who died in the Midlands 2018-2021 compared to the general population (2020) .



In 2020, 85% of people in the general population died at age 65 or over. The percentage of people who died at age 65 or over with a learning disability in the Midlands was 36% in 2021; in other words, fewer than 2 of every 10 people that die in the general population will be younger than 65, while 6 in 10 of people with a learning disability that die in the Midlands are under the age of 65. These figures are similar across all regions.

Since 2020, the percentage of people with a learning disability who died aged 65 and over has decreased by 4% in the Midlands.

Ethnicity

Information about ethnicity was available for 633 people who died in the Midlands in 2021 and were notified to LeDeR. The majority of people who died in 2021 from the Midlands were White (90%) compared to 85% of the general population, 4% were Asian or Asian British compared to 8% of the general population, 3% were of a Mixed Ethnic Group compared to 1.8% of the general population and 2% were Black, Black British, Caribbean or African compared to 3.5% of the general population. 1% was described as other. The average across LeDeR for all regions was 9% of people were from an ethnicity other than White, compared to 10% for the Midlands[2].

[2].https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/populationestimatesbyethnicgroupandreligionenglandandwales/2019

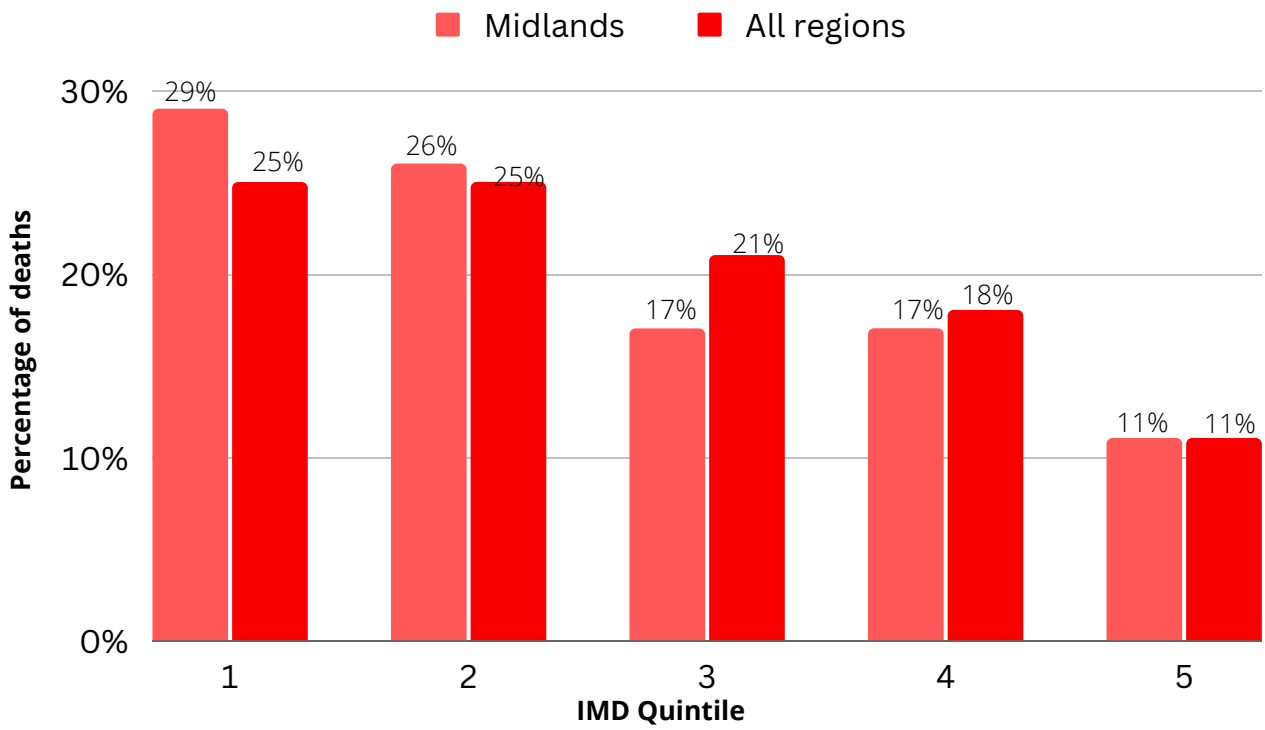
Deprivation

The Index of Multiple Deprivation (IMD) was used to look at the level of deprivation for the area of residence of the people who died. Deprivation is measured by looking at factors such as the average income, employment status, health statistics and crime rates in the area[3].

Residential postcodes are associated with an IMD score of 1 to 10. IMD scores are grouped into five quintiles from most to least deprived. Lower values indicate higher levels of deprivation.

Deprivation data were available for 534 people who died in the Midlands in 2021. Figure 4 shows the percentage of deaths of people with a learning disability who died in the Midlands and the average across all regions in 2021 by IMD quintile. 55% (n=292) of people in the Midlands died in areas rated as some of the most deprived (the two most deprived quintiles combined), which is slightly higher than the average of 50% across all regions.

Fig 4: Deaths of people with a learning disability who died in 2021 by IMD quintile in the Midlands and across all regions combined.



[3] https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019

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Long-Term Health Conditions

Long-Term conditions

When a death is reviewed by a LeDeR reviewer, information is collected about whether the person had any long-term conditions or health needs. These are referred to in this report as 'long-term health conditions'[4]. Some classifications included learning disability or autism as a long-term condition but for the purpose of this report we have not classed a learning disability or autism as long-term health conditions. Fourteen conditions are included in our definition of long-term health conditions[5].

Information about long-term health conditions is collected from initial reviews prior to the summer of 2021, focused reviews following summer 2021 and from the coded data, as in the national report. However, information about long-term health conditions is not always available as it is only present in the coded data where the reviewer has deemed it relevant to the review. Long-term health condition data were therefore available for 234 reviews of people who died in the Midlands in 2021 and had available initial review, focused and coded data. The percentages below reflect the percentage of the 234 people who were recorded as having that specific long-term health condition.

The five most frequently reported long-term health conditions identified by reviewers, for people who died in the Midlands in 2021 were:

·Cardiovascular conditions (36%, n=83)
·Epilepsy (33%, n=78)
·Mental health conditions (31%, n=73)
·Dysphagia (27%, n=64)
·Sensory impairment (25%, n=58)

Compared to the overall LeDeR sample across regions, the top 5 conditions are the same but the rank order of conditions is slightly different in the Midlands. In the overall LeDeR sample, epilepsy is the most common long-term condition, whereas this was replaced by cardiovascular conditions in the Midlands.

[4] Long-term health conditions are acquired conditions that cannot be cured but can be controlled with ongoing management (using medication and/or other therapies) over a period of years.

[5] Cancer, cardiovascular conditions, degenerative conditions, dementia, diabetes, deep vein thrombosis (DVT), epilepsy, hypertension, kidney problems, mental health conditions, osteoporosis, respiratory conditions, sensory impairment and dysphagia.

Multimorbidity

Multimorbidity is defined as the presence of two or more long-term health conditions occurring at the same time. Information about multimorbidity was available for 234 people who died in the Midlands in 2021 and received an initial review prior to the implementation of the new system.

The mean average number of long-term health conditions of people in the Midlands who died in 2021 was 2.63 (standard deviation = 1.50). This is similar to the average for all deaths in 2021 across regions reviewed by LeDeR, where the average number of long-term health conditions per person was 2.45 (standard deviation = 1.56). Note: due to methodology changes in the data collection, this figure is not directly comparable to previous years reports. Please see the national report for further details on the calculation of long-term health conditions.

9% (n=21) of people were reported to have no long-term health conditions at the time of their death.

Midlands Report 2021

Circumstances and Causes of Death

Circumstances of Death

This section reports the circumstances of death of people with a learning disability. We have drawn on data from LeDeR initial reviews and medical certificates of cause of death (MCCDs) for people who died across regions with initial reviews completed between 2018 and 2021.

Analysing the contextual information collected during initial reviews allows us to describe the circumstances in which people died. We report; where people died, whether their death was reported to a coroner, whether a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) recommendation was made prior to death, and whether the DNACPR recommendation was followed correctly.

Place of Death

Information about place of death was available for 521 people who died in the Midlands in 2021. The results were similar to the averages across all regions; 62% (n=325) of deaths in the Midlands occurred in hospital, 34% (n=178) died in their usual place of residence and 3% (n=18) died elsewhere.

Deaths with DNACPR

Information about DNACPR was available for 530 people that died in 2021 in the Midlands and had an initial review, 64% (n=340) had a DNACPR recommendation in place at the time of death (see table 1). This is the same as the overall figure of people who died in 2021 across regions.

Table 1: Percentage of adults with a DNACPR recommendation that died in the Midlands in 2018, 2019, 2020 and 2021.

DNACPR recommendation in place at the time of death	2018	2019	2020	2021
Yes	62.3%	64.3%	66.5%	64.2%
No	26.8%	24.9%	22.8%	24.2%
Not recorded	10.9%	11.0%	10.7%	11.7%
Total No.	440	420	522	530

Information about whether the reviewer thought the DNACPR recommendation had been made correctly was available for 339 of the deaths that occurred in 2021 in the Midlands. Compared to pre-2020 figures, there was a decrease in the proportion of deaths with a DNACPR recommendation that were deemed to be correctly completed and/or followed (see Table 2).

Table 2: Percentage of adults in the Midlands who died with a DNACPR recommendation at the time of their death, for whom documentation was completed and/or followed, by year.

DNACPR recommendation correctly completed and followed	2018	2019	2020	2021
Yes	72.6%	68.1%	70.9%	54.0%
No*	4.5%	3.1%	5.2%	7.1%
Not known by reviewer	22.9%	29.0%	23.8%	38.9%
Total No.	314	360	453	339

*includes deaths where a DNACPR recommendation was judged to have been correctly completed and not followed and neither correctly completed nor followed.

Deaths reported to a coroner

Deaths are legally required to be reported to a coroner in certain circumstances. These include (but are not limited to) suspicious deaths, deaths with an unknown cause, or deaths which have occurred whilst the person was detained by the state. Thus, whether a death is reported to a coroner is not a judgement of the quality of care a person received.

In 2020 and 2021 a lower proportion of deaths in the Midlands were reported to a coroner than in previous years (see Table 3). A similar reduction was seen in the overall figure for all regions. Some of this may be explained by an increase in the number of deaths due to COVID-19, deemed a natural cause of death that is unlikely to have resulted in a referral to a coroner.

Table 3: Percentage of deaths in the Midlands between 2018 and 2021 that were reported to a coroner.

Deaths reported to a coroner	2018	2019	2020	2021
Adults and children	25.7%	22.3%	15.8%	18.9%
Children (aged 4-17)	48.7%	63.5%	35.7%	33.3%
Adults (aged 18+)	23.7%	18.1%	15.0%	18.5%

Causes of Death

This section reports the common causes of death of people with a learning disability. We have drawn on data from LeDeR initial reviews and MCCD's for people who died with initial reviews completed between 2018 and 2021.

Determination of underlying cause

When someone dies, a doctor who was involved in the person's care completes an MCCD. This indicates the sequence of conditions which lead to death, including the underlying cause. The World Health Organization (WHO) defines the **underlying cause of death** as the disease or injury that initiated the train of events directly leading to death or the circumstances of the accident or violence that produced the fatal injury. The underlying cause of death was extracted from the lowest available line in part one of the MCCD and assigned one of approximately 14,200 codes according to the International Statistical Classification of Diseases and Related Health Problems – 10th reviion (ICD-10).

Grouping of ICD-10 codes

Grouping ICD-10 codes can enable more practical interpretations and provide service leads and policy makers with an appropriate level of detail in order to develop and generate appropriate health interventions. Two of the methods which summaries the causes of death in the national LeDeR report were used in this regional report. First, we group underlying cause of death codes by ICD-10 chapter. These chapters are split according to general types of injury or disease (e.g. Diseases of the Respiratory system). Grouping causes of death according to ICD-10 chapter allows for comparisons with the annual reports preceding this year's.

The second way in which the ICD-10 codes were grouped was by leading cause of death. This involved using an internationally recognised list developed by the WHO which splits certain prevalent conditions into subtypes, thereby providing a more epidemiologically meaningful picture of what causes death than the ICD-10 chapter alone [6][7]. It also enables comparisons with publications from the Office for National Statistics (ONS) which present the most common causes of death in the general population. It is important to note that not every condition is assigned to a leading cause of death group. A notable example is aspiration pneumonia, which is a prominent cause of death in people with a learning disability. We have included deaths due to COVID-19 as a leading cause using the following ICD-10 codes U.071, U.072 and U10.9.

6] Leading causes of death in England and Wales (revised 2016)
https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/methodologies/userguidetomortalitystatistics/leadingcausesofdeathinenglandandwalesrevised2016

[7] Leading causes of death, UK: 2001 to 2018
https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/articles/leadingcausesofdeathuk/2001to2018

When interpreting findings in the following analyses, it is important to note that no consideration has been made to other contributory conditions or causes mentioned on the death certificates. This means that, if an MCCD listed multiple causes of death, only that which was deemed the underlying cause of death on the MCCD has been used.

Most common cause of death by ICD-10 chapter

Table 4 provides the most common ICD-10 chapter causes of death for people who died in the Midlands from 2018 to 2021 and had an initial review completed by LeDeR before 31st Dec 2021.

The five most commonly reported underlying causes of death in 2021 in the Midlands were related to the following chapters: Codes for special purposes (COVID-19), diseases of the circulatory system, congenital malformations, deformations and chromosomal abnormalities, diseases of the respiratory system and neoplasms (cancer).

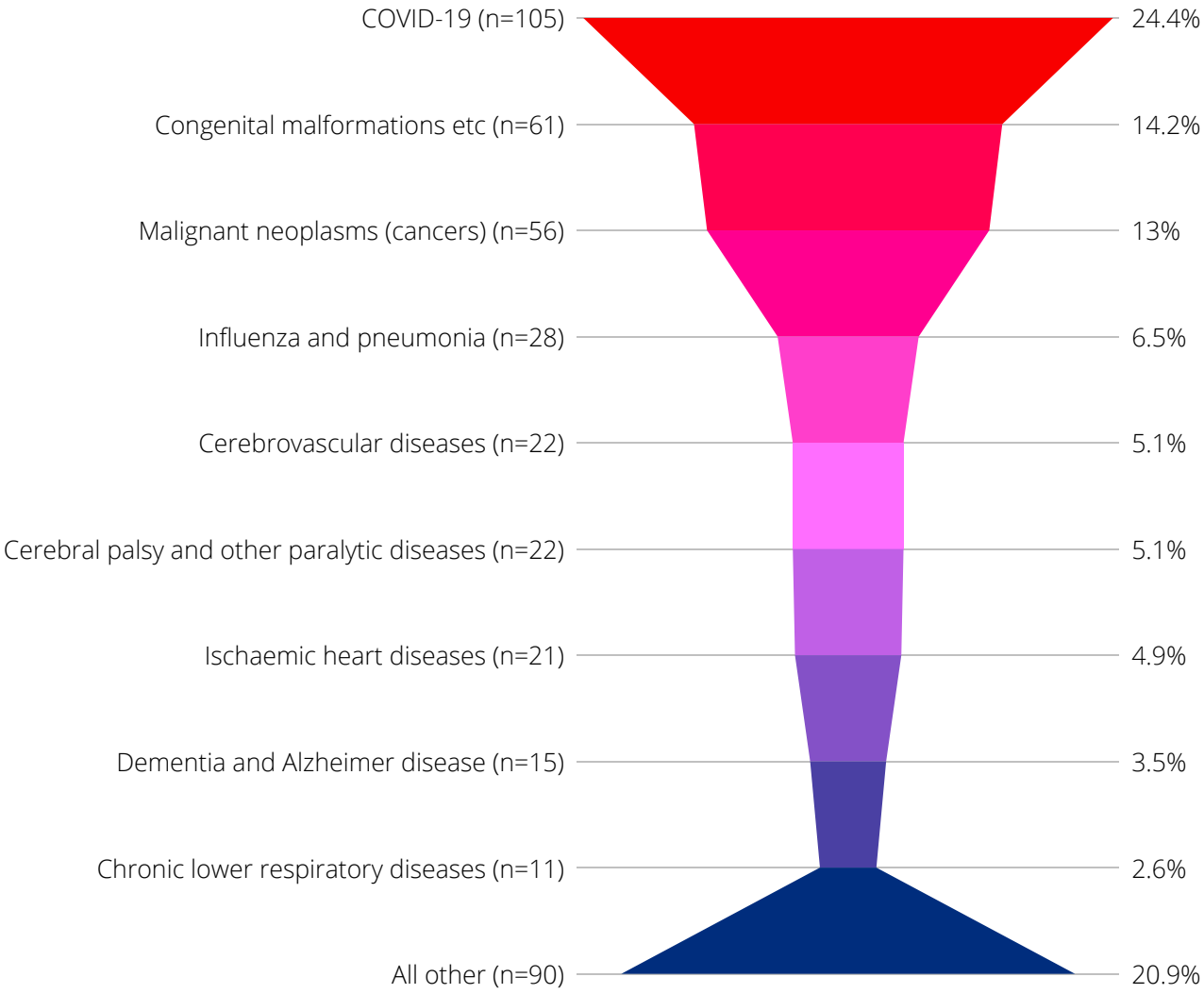
Table 4: The most frequently recorded ICD-10 chapter causes of death for 2018 to 2021 for people who died in the Midlands.

	2018	2019	2020	2021
ICD-10 chapter	No. (%)	No. (%)	No. (%)	No. (%)
Codes for special purposes (COVID-19)	-	-	132 (20.9	105 (21.7)
Diseases of the circulatory system	60 (12.5)	72 (13.4)	85 (13.4)	70 (14.4)
Diseases of the respiratory system	90 (18.8)	97 (18.0)	82 (13.0)	57 (11.8)
Neoplasms (Cancers)	61 (12.7)	83 (15.4)	80 (12.6)	56 (11.6)
Diseases of the nervous system	56 (11.7)	70 (13.0)	78 (12.3)	43 (8.9)
Congenital malformation, deformations and chromosomal abnormalities	66 (13.8)	81 (15.1)	60 (9.5)	61 (12.6)
Diseases of the digestive system	44 (9.2)	38 (7.1)	31 (4.9)	29 (6.0)
Mental and behavioural disorders	27 (5.6)	29 (5.4)	31 (4.9)	18 (3.7)

The overall leading cause of death

Figure 3 shows the available data for the leading causes of death for 431 people who died in 2021 in the Midlands and had an initial review completed by LeDeR before 31st Dec 2021. The overall leading cause of death was COVID-19, causing 24.4% of deaths (n=105). The second leading cause of death was congenital malformations, deformations and chromosomal abnormalities and the third leading cause of death was malignant neoplasms (cancer), causing 14.2% (n=61) and 13% (n=56) of deaths, respectively. Subtypes of causes of death, such as cancer, have not been analysed in this report as there is not sufficient data to draw accurate conclusions.

Fig 5: The leading overall cause of death in the Midlands in 2021.



Midlands Report 2021

Avoidable Deaths and Quality of Care

Avoidable deaths

Data regarding whether a death was classed as avoidable was available for 471 deaths in the Midlands in 2021. Of these, 53% (n=252) were classed as avoidable deaths. This figure is similar across regions.

Avoidable deaths are defined by applying the Organisation for Economic Cooperation and Development (OECD)/ Eurostat list of preventable and treatable causes of death using the underlying cause of death recorded on death certificates, for people who died at younger than 75 years old. This is the same definition as used by the ONS.

Table 5 presents the percentage of avoidable deaths in the Midlands in 2021 for each leading cause of death, however, it is important to consider that these figures are only based on available recorded data. Whilst the actual numbers are relatively low, the cause of death with the highest proportion of avoidable deaths in the Midlands in 2021 was chronic lower respiratory diseases (100%, 11) followed by COVID-19 (82%, n=86), cerebrovascular diseases (77%, n=17) and ischaemic heart disease (76%, n=16).

Table 5: The proportion of avoidable deaths for each leading cause of death in the Midlands n 2021.

Cause of Death	Total Number	Number (and %) of deaths rated as avoidable within cause of death grouping
COVID-19	105	86 (82%)
Cancer	56	29 (52%)
Congenital malformations, deformations and chromosomal abnormalities	61	8 (13%)
Influenza and pneumonia	28	20 (71%)
Cerebral palsy and other paralytic syndromes	22	0 (0%)
Cerebrovascular diseases	22	17 (77%)
Ischaemic heart disease	21	16 (76%)
Dementia and Alzheimer disease	15	0 (0%)
Chronic lower respiratory diseases	11	11 (100%)

Quality of Care

This section reports areas of good practice and areas for improvement across the health and social care pathway, as well as at around the time of death. It draws on data generated from several questions in the LeDeR review process that report on the quality of care that a person had received prior to their death.

The LeDeR review process changed in Summer 2021 and the older LeDeR initial review (conducted prior to June 2021) contained several questions that are not included in the new LeDeR initial review, but are included in the new LeDeR focused review (see national report for further details). Because of these differences in the way that quality of care indicators are collected in each version, the findings are reported separately. When interpreting the findings in this section, it is important to remember that they are based on relatively small numbers.

The older LeDeR reviews contain complete data from 412 adults aged over 18 who died across all regions in 2021, 88 of which are from the Midlands.

The new LeDeR focused review contains data for 108 people who died across all regions in 2021, including 35 people who died in the Midlands.

Quality of care analysis is therefore based on 123 deaths in the Midlands.

Grading of Quality of Care

Towards the end of each LeDeR review, the reviewer is asked to grade the overall quality of care provided to the person. Quality of overall care is rated on a six-point scale:

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 on the person's wellbeing but did not contribute to the cause of death
4=Satisfactory care
5=Good care
6=Excellent care

As the system was updated in the summer of 2021, so too were the questions asked on the rating scales. Although these differences are very slight, we are presenting the old version separately to the new below for reference. Going forward, all reviews will be completed on the new system.

For the pre summer 2021 data, the majority of people 46.6%, (n=41) who died in the Midlands in 2021, and who were reviewed under the old LeDeR process, received a reviewer rating of 'good' or 'excellent' care for overall quality of care. Table 6 shows the quality of care grades for the 88 people who died in the Midlands in the old reviews. The findings concerning quality of care grades are similar to the averages across all regions.

Table 7 below shows the quality of care grades for the 35 people who died in the Midlands in 2021 that were reviewed under the new, post summer 2021 LeDeR process. The majority of people (44.7%, n=17) who died received 'good' care.

Table 6: The proportion of quality of care for adults who died in the Midlands in 2021 (n=88, older pre summer 2021 LeDeR reviews).

Quality of Care Grade	Total Number
1	0
2	<5 (XX%)
3	18 (20.5%)
4	24 (27.3%)
5	41 (46.6%)
6	<5 (XX%)

Table 7: The proportion of quality of care for adults who died in the Midlands in 2021 (n= 35, new post summer 2021 LeDeR reviews).

Quality of Care Grade	Total Number
1	<5 (XX%)
2	<5 (XX%)
3	6 (15.8%)
4	6 (15.8%)
5	17 (44.7%)
6	<5 (XX%)

Identification of good practice

Similar to the national average, 65.9% (n=58) of people who died in 2021 in the Midlands, reviewed under the older LeDeR review process, were identified to have received good practice.

Under the new LeDeR focused reviews of people who died in the Midlands 81.6% (n=31) were identified to have received good practice.

Concerns with care

Where concerns had been expressed about the death we had data on 88 of these. Concerns had been expressed about the death of 10.2% (n=9) of people who died in the Midlands in 2021 using the older LeDeR review system, which is slightly higher than the national average of 7.3% (n=30).

Review of care package

Similarly to the average across all regions, the care package was deemed to meet the needs of the individual in 88.6% (n=78) of deaths in the Midlands in 2021 which were reviewed using the older LeDeR review system.

Furthermore, the care package was deemed to meet the needs of 76.3% (n=29) of the 38 people reviewed from the Midlands under the new LeDeR review.

Specific areas of problems with general care

In addition to general questions about quality of care, the LeDeR review asks about specific areas that may impinge on the quality of care that a person received. These are; delays in care or treatment, problems with organisational systems and processes and gaps in service provision. The new LeDeR focused review also includes an additional question about recommended diagnostic and treatment guidelines being met. The data from all regions reviewed by LeDeR has been combined to explore these areas; this way, certain examples regarding gaps in care can be highlighted.

Table 8 shows the proportion of older LeDeR 2021 reviews across all regions with evidence of service gaps; approximately 12% of people experienced delays in care or treatment and/or problems with organisational systems. A smaller proportion of people experienced gaps in care (7%).

Table 8: The proportion of problems with different aspects of care for adults who died across all regions reviewed by LeDeR in 2021 (n = 412, older pre summer 2021 LeDeR reviews).

Problems with different aspects of care	Total Number
Delays in care or treatment	52 (12.6%)
Problems with organisational systems	50 (12.1%)
Gaps in care	27 (6.6%)

Table 9 shows the proportion of new LeDeR 2021 focused reviews across all regions with evidence of gaps in care. The results from the new LeDeR focused reviews show a higher proportion of problems compared to the older LeDeR initial review; for example, 35% (n=38) of reviews reported problems with organisational systems. As mentioned above, the higher proportion of problems with care in the new LeDeR reviews may be explained by the fact that certain criteria result in a focused review being undertaken and thus, not everybody who receives an initial review will receive a focused review. Moreover, these results are based on a small number of reviews.

Table 9: The proportion of problems with different aspects of care for adults who died across all regions reviewed by LeDeR in 2021 (n = 108, new post summer 2021 LeDeR reviews).

Problems with different aspects of care	Total Number
Delays in care or treatment	31 (28.7)
Problems with organisational systems	38 (35.2%)
Gaps in care	29 (26.9%)
Guidelines not met	24 (22.2%)

Qualitative data from the new LeDeR focused reviews were reviewed to highlight examples of delays in care or treatment. Examples of these include delays in COVID-19 vaccination, dental-treatment, appropriate investigations and treatment, and information sharing.

To give an example of the sort of comments provided for quality of care, and to give context to the general themes running through the data, we have presented the following extracts, taken from the new 2021 focused reviews for the entire country:

Patient 1 - “There was a delay in reporting the lump in X's armpit to the General Practitioner (GP); there was a delay in diagnosis of breast cancer because the GP failed to note red flag symptoms of breast cancer and did not refer under the 2 week rule (as stipulated by the National Institute For Health and Care Excellence (NICE) guidelines) for suspected cancer. There was a further delay in identifying issues with discharge back to X's home resulting in their having to stay in hospital where they sadly died without the support of their sibling or familiar carers.”

Patient 2 - “There were issues whilst X was an inpatient regarding the prescribing of steroids which were required as part of the anti-rejection regime for the renal transplant. There was concern raised that X may have suffered an Addisonian crisis due to the steroids being missed.”

Patient 3- “The GP did not examine or see X face to face for any consultations. This resulted in X not receiving the appropriate care they required and X's parent did not receive the appropriate support that they needed by the GP.”

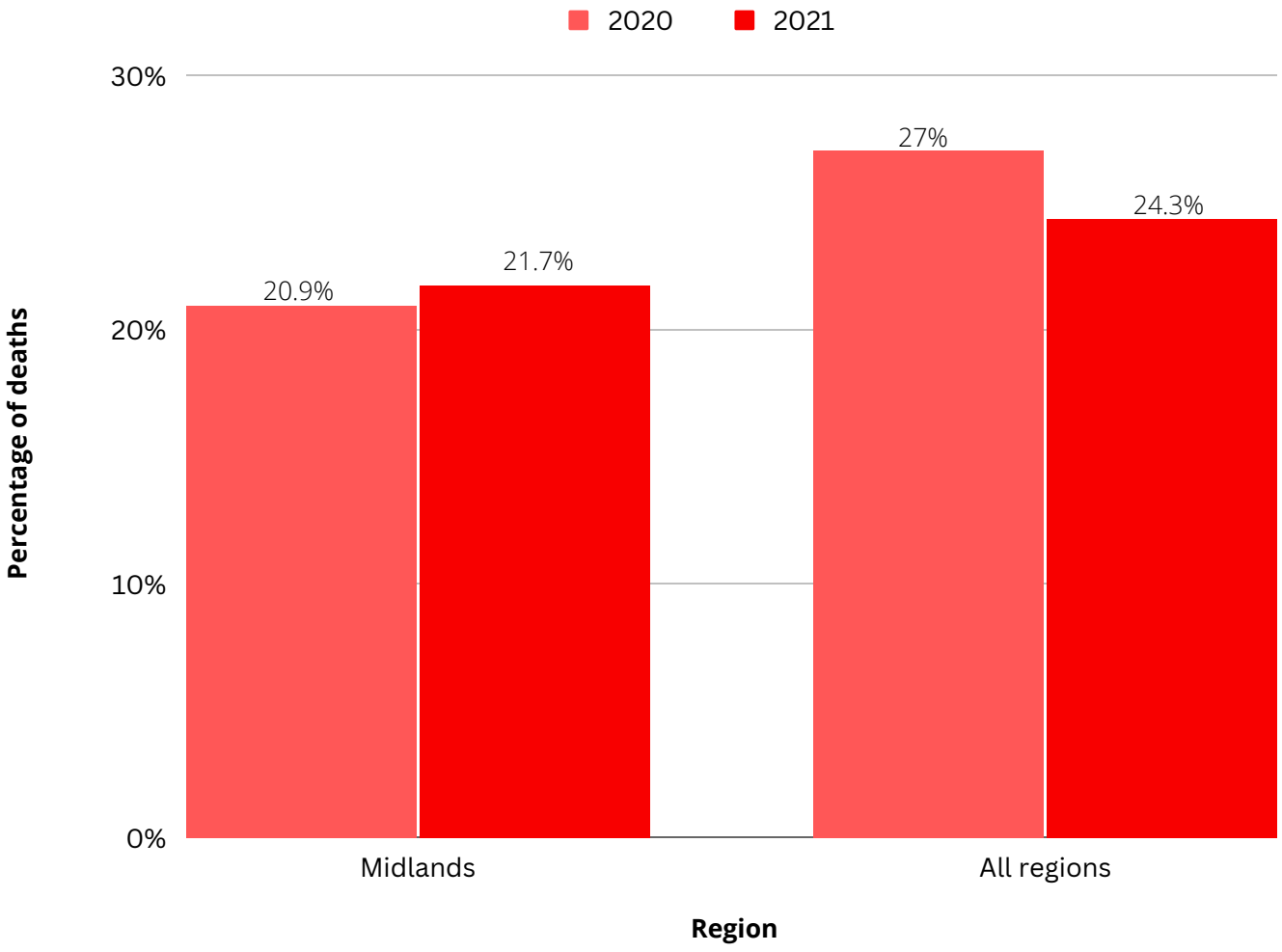
Midlands Report 2021

COVID-19

COVID-19

In the Midlands in 2020, COVID-19 replaced cancers as the primary leading cause of death, accounting for 20.9% (n=132) of all deaths. Although COVID-19 remained the leading cause of death in the Midlands in 2021, figure 7 shows that the proportion of deaths due to COVID-19 increased by 0.8% in comparison to 2020. Specifically, COVID-19 accounted for 21.7% (n=105) of deaths in the Midlands in 2021.

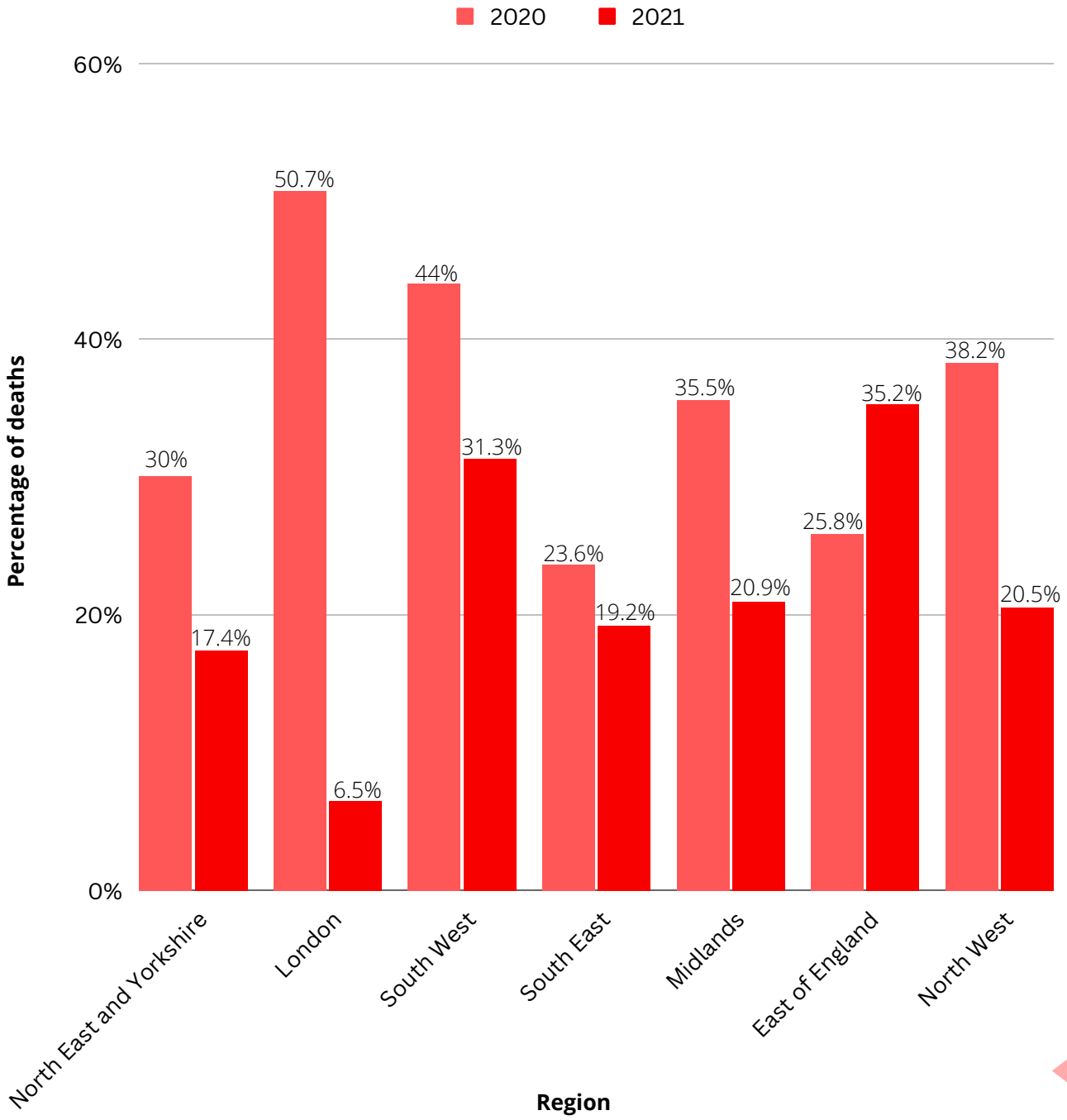
Fig 7: The percentage of deaths due to COVID-19 in the Midlands across all regions in 2020 and 2021.



There was considerable variation in excess deaths due to COVID-19 by region, and by year (2020 compared to 2021), as plotted in figure 8. Excess deaths were calculated by taking the average number of notified deaths in each region in 2018 and 2019 and assessing what percentage of deaths exceeded this figure in 2020 and 2021.

During 2020, the Midlands had an excess death rate of 35.5%, which reduced to 20.9% in 2021. Several factors such as demographic structure, vaccination roll-out and the spread of the virus through different regions at different times may account for some variation between regions.

Fig 8: The percentage of excess deaths by region and year (deaths occurring in 2020 and 2021).



End