The Learning Disabilities Mortality Review (LeDeR) Programme

University of BRISTOL

Annual Report 2020

University of Bristol Norah Fry Centre for Disability Studies

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Acknowledgements and credits

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Foreword

The University of Bristol comes to a planned end to its current involvement with the English Learning Disabilities Mortality Review (LeDeR) programme on 31st May 2021. The programme will continue, albeit with some changes[1]. The LeDeR programme was established in 2015; since then, it has been introduced across England, deaths of people with learning disabilities[2] have been notified and reviewed, and the findings from completed reviews have been collated, analysed, and presented in the programme's annual reports.

This year's report focuses on findings from completed reviews of the deaths of people with learning disabilities that occurred in the calendar years 2018, 2019 and 2020, identifying any trends that have occurred over time. Because of the incremental roll out of the LeDeR programme in England during 2016 and 2017, 2018 is the first year in which the programme has relatively complete data. Our analysis is supplemented by cause of death data received from NHS Digital.

It must be noted that the baseline used in this year's annual report (year of death) is different from that of previous annual reports which focused on deaths reviewed in a particular year, irrespective of when the death occurred. By shifting our focus to year of death we can more accurately track any improvements in health and care over time. As such, data in this annual report is not directly comparable with data contained in previous annual reports.

When reading the findings of this report it should be kept in mind that the LeDeR programme is not mandatory so does not have complete coverage of all deaths of people with learning disabilities, that some data is missing, particularly data relating to children, and that numbers in some sub-categories are small so must be interpreted with caution. In particular, in Chapter 7 we have merged year of death to accommodate small numbers, but findings must be considered indicative rather than conclusive. To avoid the possibility of identification of individuals, all numbers below 10, and all percentages referring to numbers below 10, have been suppressed throughout this report.

2020 was the year in which the global coronavirus pandemic hit, which has affected the lives and deaths of the entire population, including people with learning disabilities. In many ways, 2020 has been an 'unusual' year. For this reason, comparisons of 2020 data with those of previous years should be interpreted with this caution in mind.

Throughout 2020 LeDeR reviewers have worked hard to complete all reviews within six months of a person's death wherever possible. It is testament to them that 94% of reviews of deaths of adults with learning disabilities were completed within the six-month timeframe by the end of December 2020. This results in more timely local learning from the review of the person's death; descriptions of some of this learning are included in NHS England Action from Learning reports.

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[1] https://www.england.nhs.uk/publication/learning-from-lives-and-deaths-people-with-a-learning-disability-and-autistic-people-leder-policy-2021/

[2] The terms 'learning disabilities' and 'learning disability' are used interchangeably in this report.

Glossary of abbreviations used

A&E	Accident and Emergency department
ACE	Adverse Childhood Experiences
ADASS	Association of Directors of Adult Social Services
ADCS	Association of Directors of Children's Services
BAME	Black, Asian and Minority Ethnic group
BNF	British National Formulary
CCG	Clinical Commissioning Group
CIPOLD	Confidential Inquiry into Premature Deaths of People with Learning Disabilities
DoLS	Deprivation of Liberty Safeguards
DNACPR	Do Not Attempt Cardio-Pulmonary Resuscitation
DVT	Deep Vein Thrombosis
EOL	End of Life
HEE	Health Education England
ICD-10	International Classification of Diseases version 10
ICS	Integrated Care System
IMD	Index of Multiple Deprivation
ITU	Intensive Therapy Unit
JSNA	Joint Strategic Needs Assessment
LeDeR	Learning Disabilities Mortality Review programme
LD	Learning disabilities[3]
MCA	Mental Capacity Act
MCCD	Medical Certificate of Cause of Death
NECS	North East Commissioning Support Unit
NEWS	National Early Warning Score
NICE	National Institute for Health and Care Excellence
No.	Number
ONS	Office for National Statistics
PE	Pulmonary embolism
PEG	Percutaneous Endoscopic Gastrostomy
SCIE	Social Care Institute for Excellence
SCW CSU	South Central and West Commissioning Support Unit
SD	Standard Deviation
SJR	Structured Judgement Review
STAMP	Supporting treatment and appropriate medication in paediatrics
STOMP	Stopping the over-medication of children and young people with a learning disability, autism or both

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[3] We prefer not to use the abbreviation 'LD' as we feel that this is depersonalising. We have, however, used it where necessary in tables to shorten their length.

Contents

Some of the people who have died

As with previous annual reports, we want to start this report with brief glimpses of some of the people who have died in 2018-2020. We have added further brief stories throughout the following chapters to keep our focus on the people with learning disabilities at the heart of the report.

The people are not just numbers as presented in the report; they were people with strengths and talents and hopes for their futures. Some had their lives shortened by the coronavirus (COVID-19) or other causes; others lived long and happy lives.

All details have been anonymised[4], but the stories are those as told by families or paid carers to reviewers. We would like to thank the many families who have given us permission to use their stories.

Angela, died aged 56 from bronchopneumonia.

Angela was funny and had a good sense of humour. She could say a few words and knew a little Makaton. Angela used to enjoy lots of activities including swimming, climbing, bowling and walking but she was less active as she got older. She liked to visit garden centres and listen to classical music.

John, died aged 69 from COVID-19.

John was a 'happy go lucky' person. He had a good sense of humour and liked jokes. John needed to have routines, such as his walk to the shop each day to buy a paper. John liked to have a chat with people at the local pub where he was well known. He loved to watch Westerns, particularly ones with John Wayne in. His favourite meal was fish and chips.

Madhu P (Ms P), died aged 72 from pulmonary thromboembolus.

Ms P enjoyed cooking and eating meals with her family. Ms P had 2 sons. She had lived with her parents most of her life until they died a few years ago. After this she continued to live with one of her sons. She would often go out with her brother.

Linda, died aged 51 from rectal cancer.

Linda loved being pampered. She liked to have her hair and nails done. Her dad said she had a ‘sparkle’! Linda preferred being outside rather than indoors. She like to ‘people watch’. Linda had a lovely gentle character. If she did not like something that was happening, she had a ‘look’ that she would give.

Christopher, died aged 65 from aspiration pneumonia.

Christopher enjoyed watching sports, listening to music, using sensory toys and going bowling. He was a season ticket holder at his local football team. His favourite music was from the 1960s. He had a routine of walking around the garden each day.

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[4] Please note that all names throughout this report have been changed to protect confidentiality.

Executive summary

The University of Bristol ends its current involvement with the English Learning Disabilities Mortality Review (LeDeR) programme on 31st May 2021, five years since the inception of the programme. In this our final annual report, we look back at the most recent three years, comparing data based on year of death for people with learning disabilities aged four years and over whose deaths have been notified to the LeDeR programme.

2020 was the year in which the global coronavirus pandemic hit, which has affected the lives and deaths of the entire population. It has not been a 'normal' year. For this reason, caution is required in drawing comparisons between 2020 data and that of previous years.

When reading the findings of this report it should be kept in mind that the LeDeR programme is not mandatory so does not have complete coverage of all deaths of people with learning disabilities, that some data is missing, particularly data relating to children, and that numbers in some sub-categories are small so must be interpreted with caution. Findings must be considered indicative rather than conclusive.

Deaths occurring in 2018, 2019 and 2020

A total of 9,110 deaths of people with learning disabilities (622 deaths of children; 8,488 deaths of adults) occurring between 1st Jan 2018 and 31st December 2020 were notified to the LeDeR programme. Between 2018–2020 the number of deaths fluctuated between 200-300 each month with a larger number of deaths reported during winter months. There was a significant increase in the number of deaths at the peak of the COVID-19 pandemic from March – May 2020.

By 31st December 2020, 93% of deaths (75% of children; 94% of adults) notified to the programme between 1st January 2018 and 30th June 2020 had been reviewed[5].

Most deaths received an initial review only. The proportion receiving a full multi-agency review has fallen from 4% in 2018, to 3% in 2019 and 2% in 2020.

Demographic information about people who died 2018-2020

Overall, males accounted for 57% of deaths. Among adults, there was little variation in this across the three years. For children, the proportion of males ranged from 54% in 2018 to 61% in 2020.

A large majority of adults with learning disabilities were of white British ethnicity (91% of those who died in 2018; 90% in 2019; 89% in 2020) but this was the case for a smaller proportion of children (59% of those who died in 2018; 59% in 2019; 54% in 2020).

The number of deaths of people from different minority ethnic groups is too small for analysis by individual ethnicities and data is therefore less robust. Fewer than 5% of adults who died were of Asian/Asian British ethnicity (3% of those who died in 2018; 3% in 2019; 4% in 2020), but this was the case for a quarter of children (26% of those who died in 2018; 22% in 2019; 25% in 2020).

A much smaller proportion of adults with learning disabilities had profound and multiple learning disabilities (9% of those who died in 2018; 8% in 2019; 7% in 2020) than

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[5] Overall, 94% of adult deaths notified between the start of the programme (2016) and June 2020 had been reviewed by December 2020.

children with learning disabilities (47% of those who died from 2018-2020 combined), although there is a substantial amount of missing data for children in this respect.

The median age at death has increased by one year for deaths occurring between 2018 and 2020.

In 2019, the majority (85%) of people in the UK population died aged 65 and over. The corresponding proportion of people with learning disabilities from 2018-2019 was 38%.

The lowest median age at death of adults, at 33 years, was for males from minority ethnic groups and with severe, profound and multiple learning disabilities. Their median age at death had increased from 30 years in 2018 to 32 years in 2019 and 42 years in 2020.

Potential influences on age at death

Almost half (46%) of adults had 7 to 10 long-term health conditions when they died.

A person's usual place of residence varied by age, ethnicity and level of learning disability. Those in the youngest age groups, people with profound and multiple learning disabilities, and people from minority ethnic groups were more likely than others to live in their own or their family home.

A person's usual place of residence influenced from whom they were most likely to receive their main support. Young adults aged 18-24 years, people with profound and multiple learning disabilities, or people from minority ethnic groups were more likely than others to receive their main support from a family member or an informal carer.

Almost a quarter of adults (24%) were usually prescribed an antipsychotic medication. There was an increased likelihood of being prescribed antipsychotic medication if a person:

- Had been subject to mental health or criminal justice restrictions in the five years prior to death (the likelihood was 6.9 times greater than someone not under such restrictions).
- Was already prescribed antidepressant medication (2.7 times greater than someone not).
- Was aged 65 or over (2.6 times greater than someone aged 18-24 years).
- Was aged 50 to 64 (2.1 times greater than someone aged 18-24 years).
- Was in an out-of-area placement (1.9 times greater than someone who was not).
- Was from a Black/African/Caribbean/ Black British ethnic group (1.9 times greater than someone of white British ethnicity).

28% of adults (n=1,855) were usually prescribed an antidepressant medication. There was an increased likelihood of being prescribed antidepressant medication if a person was:

- Aged 50 to 64 (the likelihood was 3.5 times greater than someone aged 18-24 years).
- Aged 65 or over (3.3 times greater than someone aged 18-24 years)
- Aged 25-49 years (3 times greater than someone aged 18-24 years).
- Already prescribed antipsychotic medication (2.7 times greater than someone not).
- Female (1.3 times greater than males).

People aged 18-24 years, or those with mild learning disabilities were less likely to have received an annual health check in the year prior to their death.

Several variables were significantly associated with the likelihood of dying aged 18-49 years:

- Being of Asian/Asian British ethnicity (the likelihood was 9.2 times greater than a white British person).
- Having profound and multiple learning disabilities (6.4 times greater than someone with mild learning disabilities).
- Had been subject to mental health or criminal justice restrictions in the five years prior to death (4.3 times greater than someone not under such restrictions).
- Being of mixed/multiple ethnicities (3.9 times greater than someone of white British ethnicity).
- Being of Black/African/Caribbean/Black British ethnicity (3.6 times greater than someone of white British ethnicity).
- Having severe learning disabilities (2 times greater than someone with mild learning disabilities).
- Not having had an annual health check in the previous year (1.5 times greater).

Causes of death

The most frequently reported underlying causes of death[6] in 2018 and 2019 were in the ICD-10 chapter of disorders of the respiratory system. There was little reduction in the proportion of deaths from these causes between 2018-2019.

- Underlying causes of death related to the respiratory system were more frequent in those aged 65 and over, or in people with severe or profound or multiple learning disabilities.
- Underlying causes of death related to the circulatory system were more frequent in those aged 65 and over, or in people with mild or moderate learning disabilities.
- Underlying causes of death related to the nervous system were more frequent in the youngest age group (15 – 49 years), people from minority ethnic groups, or people with severe or profound and multiple learning disabilities.
- Underlying causes of death related to congenital and chromosomal conditions were most frequent in people aged 50 – 64 years, or white British people.
- Underlying conditions related to COVID-19 were more frequently reported in people from minority ethnic groups.
- Underlying causes of death related to neoplasms were more frequently reported in people with mild or moderate learning disabilities.

In 2018 and 2019, for both males and females, the leading condition-specific underlying causes of death were very different for people with learning disabilities compared to the general population. Cerebral palsy, epilepsy and bacterial pneumonia were the condition-specific leading causes of death in people with learning disabilities age ages 5-49 years. By contrast, in the general population, the condition-specific leading causes of deaths at these ages were related to suicide and injury or poisoning of undetermined intent; for females aged 35-49 it was malignant neoplasm of the breast.

In 2020, the condition-specific leading cause of death in people with learning disabilities from age 35 and over for males, and age 20 and over in females was COVID-19.

We considered those conditions that are mentioned anywhere in Part I of the Medical

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[6] The World Health Organisation defines the underlying cause of death as the disease or injury which initiated the train of events leading directly to death, or the circumstances of the accident or violence which produced a fatal injury.

Certificate of Cause of Death (MCCD)[7]. In 2018 and 2019, the conditions most frequently cited in Part I of the MCCD were bacterial pneumonia (24% in 2018; 23% in 2019) and aspiration pneumonia (15% in 2018; 16% in 2019). In 2020, the condition most frequently cited in Part I of the MCCD was COVID-19 (23%). Bacterial pneumonia (19%) and aspiration pneumonia (11%) were in second and third place in 2020.

Following instruction in June 2019 from the Chief Medical Officer that a single condition associated with a person having learning disabilities should never be used to describe the only cause of death on Part I of the MCCD, there has been an improvement in this. Since June 2019, individual conditions associated with learning disabilities (e.g. Down's syndrome, cerebral palsy, Rett's syndrome) were the only condition cited on the MCCD of 11 people.

There is an encouraging picture of an overall reduction in the proportion of preventable, treatable and overall avoidable medical causes of death of adults and children with learning disabilities from 2018 to 2020. Overall avoidable medical causes of deaths in adults were 54% in 2018, 52% in 2019, and 50% in 2020. In children, the proportion was 36% across the three years.

Overall avoidable medical causes of death include those that are preventable through effective public health and primary prevention interventions, and treatable by timely and effective health care interventions.

Preventable medical causes of death in adults were 24% in 2018, 23% in 2019 and 24% in 2020. For children[8] the proportion was 10% across the three years.

Treatable medical causes of death in adults were 41% in 2018, 40% in 2019 and 39% in 2020. For children, the proportion overall proportion was 29%.

Compared to the general population, people with learning disabilities were more than 3 times as likely to die from an avoidable medical cause of death (671 per 100,000 compared to 221 per 100,000 in the general population). The majority of the excess was due to treatable medical causes of death.

Circumstances of deaths

The majority of children and adults with learning disabilities died in hospital in 2018, 2019 and 2020, the proportion remaining fairly stable at approximately 60% each year. In England in 2019, 46% of deaths of all ages from 5 years and over in the general population occurred in hospital[9]. The impact of the COVID-19 pandemic on the place of death in 2020 is addressed in Chapter 8.

Of those who died between 2018 and 2020[10], 26 had their liberty restricted by the criminal

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[7] MCCD are divided into two sections, Parts I and II. Part I contains the immediate cause of death, tracking the sequence of causes back to any underlying cause or causes. Part II is used to list other significant conditions, diseases or injuries that contributed to the death, but were not part of the direct sequence. Guidance for doctors completing MCCD in England and Wales is available at: https://www.gov.uk/government/ publications/guidance-notes-for-completing-a-medical-certificate-of-cause-of-death

[8] For comparison with data published by ONS, the category of 'children' includes those aged 4-19 years.

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

[10] The number of deaths of adults subject to restricted liberty by order of the courts or through mental health legislation is too small to analyse separately for each year (generally fewer than 10 deaths in each category each year), so we have merged those deaths into a total grouping for 2018-2020.

justice system at the time of their death[11]. A small number (fewer than 10) had had restrictions imposed during the five years prior to their death, but the restrictions were not in place at the time of death.

A small number (n=13) of people had had their liberty restricted by mental health legislation at the time of their death[12] or had had restrictions imposed during the five years prior to their death, but not at the time of death (fewer than 10).

The proportion of adults with a DNACPR decision at the time of their death was 71% in 2018, 70% in 2019 and 73% in 2020. Several variables were associated with an increased likelihood of a person having a DNACPR decision in place at the time of death in 2020: living in a nursing or residential home, being aged 65 years or over, having moderate, severe or profound or multiple learning disabilities, or having COVID-19 included as a cause of death on the MCCD.

Of those with a DNACPR decision, the proportion that were known by the reviewer to be correctly completed and followed decreased from 76% in 2018, to 73% in 2019 and 71% in 2020.

The proportion of deaths of adults and children with learning disabilities known to have been reported to a coroner was 33% in 2018 and 31% in 2019. This is a smaller proportion than adults and children in the general population (41% in 2018 and 40% in 2019).

Most deaths of children were reported (on the statutory Child Death Analysis Form) to have had one or more factors intrinsic to the child that contributed to vulnerability, ill-health, or death. A quarter, 24% had 'learning disabilities' mentioned on the form as a contributory cause for the death.

Potentially modifiable factors related to a child's death were identified in 11% of reviews.

Indicators of the quality of care provided

Overall, the proportion of reviewers providing examples of best practice increased from 54% in 2018, to 66% in 2019 and 71% in 2020.

The proportion of reviewers noting problematic aspects of care decreased slightly between 2018-2020. The most problematic aspects of care provision were in relation to organisational systems and processes that led to a poor standard of care for the person. Such problems were reported in 17% of completed reviews of deaths in 2018, 15% in 2019 and 14% in 2020.

Concerns about aspects of care provision or the death of the person were raised in 12% of completed reviews of deaths in 2018, 11% in 2019 and 10% in 2020. Families raised concerns in more than a third of the deaths (35% in 2018; 38% in 2019; 42% in 2020), underlining the importance of proactively providing families with the opportunity to raise any concerns.

At the end of their review, having considered all the evidence available to them, reviewers are requested to provide an overall assessment of the quality of care provided to the person. There has been a steady increase from 2018-2020 in the proportion of reviewers who felt that a person's care met or exceeded good practice. In 2018, the proportion of reviewers reporting this was

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[11] These people were in prison, forensic secure settings, on probation, or were subject to a section of the Mental Health Act imposed by the courts at the time of their death.

[12] These people were subject to a section of the Mental Health Act.

48%; it was 55% in 2019 and 58% in 2020. Although this is encouraging, it still means that in 2020, 42% of reviewers felt that the person's care had not met good practice standards.

Deaths of people from minority ethnic groups

The number of deaths in some minority ethnic groups is small, so these findings should be interpreted with caution.

Compared to English census data of 2011, there was a greater proportion of deaths of people with learning disabilities from a white British ethnic group (92%) reported to the LeDeR programme than are in the general population (85.4%). It is likely that this represents under-reporting of deaths of people from minority ethnic backgrounds rather than a greater proportion of deaths amongst people from white British ethnicity.

The disparity between deaths of males and females was greatest in people from Black/African/Caribbean/Black British ethnicity (60% males; 40% females).

There were greater proportions of adults with profound and multiple learning disabilities in Asian/Asian British (21%) and Black/African/ Caribbean/Black British ethnic groups (14%) than in the white British group (7%).

32% of deaths of people from mixed/multiple ethnicities were of 4–17-year-olds, compared to 31% from Asian/Asian British ethnicity; 22% of Black/African/Caribbean/Black British ethnicity; 19% of 'other' ethnic groups; and 4% of white British people.

42% of white British people died aged 65 and over, compared to 7% of people of Asian/Asian British ethnic groups and 5% of people of Black/African/Caribbean/Black British ethnicity.

Adults with the lowest median age at death were males of Asian/Asian British ethnicity and with profound and multiple learning disabilities (median age of 30 years) and males of Black African /Caribbean/Black British ethnicity and profound and multiple learning disabilities (median age of 33 years).

Males from mixed/multiple ethnicities had the lowest median age in children at 9 years.

The care provided was considered by reviewers to have met the needs of 90% or more of people from white British, Black/African/Caribbean/Black British and 'other' ethnic groups, 88% of Asian/Asian British people and 76% of people from mixed/multiple ethnicities.

Dementia and Alzheimer's disease was one of the six most frequently mentioned conditions in white British people only. Cardiac arrest (a mode of death, not a cause of death, which doctors are advised to avoid using in the MCCD[13]) was one of the six most frequently mentioned conditions in people of Black/African/ Caribbean/Black British ethnicity only. Ischaemic heart disease was one of the six most frequently mentioned conditions in people of 'other' ethnic groups only.

Adults and children from Black/African/ Caribbean/Black British ethnic groups, and mixed/multiple ethnicities had a higher proportion of treatable medical causes of death (44% and 43% respectively) than people from other ethnic groups.

The proportions of deaths where there were problematic aspects of care were higher in

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[13] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/877302/guidance-for-doctors-completing-medical-certificates-of-cause-of-death-covid-19.pdf

each of the minority ethnic groups than in the white British group. The biggest disparity was in relation to concerns about the death, which were raised about 24% of deaths of people from mixed/multiple ethnicities but 11% of deaths of white British people.

Overall, 53% of people were thought to have received care that met or exceeded good practice, but the proportion was less for Asian/Asian British people at 45%.

Just two of the recommendations made by multi-agency review panels made specific reference to ethnicity.

Deaths from COVID-19

The peak month for deaths from COVID-19 was April 2020, when 59% of all deaths were from COVID-19.

In each region, the proportion of deaths of people with learning disabilities from COVID-19 notified to the LeDeR programme was greater than the proportion of deaths from COVID-19 in the general population.

A greater proportion of males than females with learning disabilities died from COVID-19, more so than in the general population.

As is reflective of the younger age at death for people with learning disabilities, those people with learning disabilities who died from COVID-19 were largely in younger age groups than people in the general population: 4% of people with learning disabilities were aged 85 or over, compared to 42% in the general population.

In people with learning disabilities, a significantly larger proportion of people who died from COVID-19 had Down's syndrome (21%) than did those who died from other causes (16%).

Demographic variables significantly associated with a greater likelihood of dying from COVID-19 were: being of Asian/Asian British ethnicity, or living in a nursing home, supported living setting or a residential home.

Adults who died from COVID-19 were more likely to be obese compared to adults who died from other causes.

The most frequently reported symptoms of COVID-19 were a cough (52%), a fever (51%) or difficulty breathing (37%). None of those who died from COVID-19 were reported to have had a loss of sense of smell or taste, although this is a regularly reported symptom in people in the general population.

Reviewers reported that 69% of the DNACPR decisions made in relation to people who died from COVID-19 were correctly completed and followed. The proportion in people who died from other causes was 72%.

Of the adults with learning disabilities who died from COVID-19, 83% died in hospital. This is higher than that of adults (aged 20 years and over) in the general population who died from COVID-19 in hospital (68%).

Of the completed reviews of deaths of people who died from COVID-19, 17% noted problems that a person had in accessing timely and appropriate healthcare.

Care received by 3% of those who died from COVID-19 was reported to have fallen so far short of good practice it had a significant impact on the person's health or wellbeing or contributed to their death. Such poor-quality care was most frequently due to delays in the diagnosis and treatment of illness.

The numbers are small so must be interpreted with caution, but there appeared to be differences in the overall assessment of the quality of care for people from different ethnic groups who died from COVID-19. People from a white British background more frequently received care graded as meeting or exceeding good practice (54%), compared to people from minority ethnic groups (48%).

Summary and conclusions

There are some early indicators of improvements in the care of people with learning disabilities between 2018 and 2019, but there are also indications that such improvements are not felt across all aspects of service provision or groups of people with learning disabilities. Of particular concern are the significant inequalities in the experiences of people from minority ethnic groups. In addition, the COVID-19 pandemic has highlighted the impact of health inequalities and deficiencies in the provision of care of people with learning disabilities, with rates of their deaths being more than those of others'.

Recommendations

Recommendation 1: LeDeR reviews to be undertaken through the lens of greater racial awareness. (Audience: NHS England).

Recommendation 2: Local Authorities to ensure that Joint Strategic Needs Assessments (JSNA) collect and publish local data on the health needs of children and adults with learning disabilities, capturing any characteristics that relate to specific ethnic groups. Integrated Care Systems (ICS),[14]and their commissioned Primary Care Networks to take actions to reduce any disparities between people from different ethnic groups when planning local services for people with learning disabilities and their families. Accountability for this to be monitored at regional level, and by NHS England. (Audience: Local Authorities, NHS England and NHS Improvement, ICSs, NHS Race and Health Observatory).

Recommendation 3: A nationally endorsed standard resource is required, with local flexibility, that provides information for people with learning disabilities and their families about legal rights and entitlements, national services and how to access them, and local sources of support. Mechanisms must be in place for its effective distribution, particularly to people from minority ethnic groups. (Audience: NHS England).

Recommendation 4: Strategically planned, long-term, targeted, joint investment is needed to strengthen partnerships with local communities and provide support for peer-to-peer networks, to build on and future-proof existing contacts and structures within local communities and increase trusted word-of-mouth communication and information sharing. (Audience: Local Authorities, ICSs, Primary Care Networks).

Recommendation 5: Local systems, including commissioning, to be responsive and develop strategic plans that address the longstanding needs of people with learning disabilities and their families that the COVID-19 pandemic has illuminated, including the availability of specialist learning disability teams in acute, primary and community care. (Audience: ICSs).

Recommendation 6: From the outset of any future public health emergency, the needs and circumstances of people with learning disabilities must be considered and built into

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[14] The NHS Long Term Plan confirmed that all parts of England would be served by an integrated care system. NHS England and NHS Improvement has now asked the Government and Parliament to establish ICSs in law and legislative change is awaited. All recommendations naming ICSs as the audience should be the responsibility of NHS England in the interim.

national policy and guidance by the National Institute for Health Protection and the Department of Health and Social Care. A data collection tool should be established to capture emerging evidence relating to people with learning disabilities, which would trigger adjustments to policy, guidance, systems and processes as required. (Audience: National Institute for Health Protection, Department of Health and Social Care; NHS England).

Recommendation 7: Commissioning guidance for NHS111 services to include a requirement for the provision of specifically tailored training to NHS111 staff about how to respond appropriately to calls about people with a learning disability or from people with a learning disability and their families. (Audience: NHS England/NHS Improvement).

Recommendation 8: A LeDeR representative should routinely and as of right be involved with the child death review meeting/process for children with learning disabilities, in order to ensure that necessary information is collected and transferred into the wider LeDeR programme.
(Audience: NHS England).

Recommendation 9: NHS England to collect and collate evidence about the needs and circumstances of people who have been subject to mental health or criminal justice restrictions and use this to inform appropriate, personalised service provision for this group of people. While waiting for this evidence, robust after-care support (as required by S117 of the Mental Health Act) must be provided. (Audience: NHS England, Local Authorities).

Recommendation 10: Previous recommendations about minimising the risk of aspiration pneumonia in people with learning disabilities need to be addressed. (Audience: NICE, Department of Health and Social Care, NHS England).

Chapter 1

Deaths occurring in 2018, 2019 and 2020

Carol Chilcott, Houses on the hill

Deaths occurring in 2018, 2019 and 2020 and notified to the LeDeR programme

Deaths of people with learning disabilities[15] are notified to the LeDeR programme by a wide range of sources, including health and care professionals and family members. Although there is no mandatory requirement for deaths to be reported, the number of deaths notified has increased and stabilised since 2018. In 2020, Public Health England estimated that the LeDeR programme was being notified of approximately 65% of deaths of people with learning disabilities aged 4 years and over[16].

Figure 1.1 shows the number of deaths occurring each month from January 2018 to December 2020.

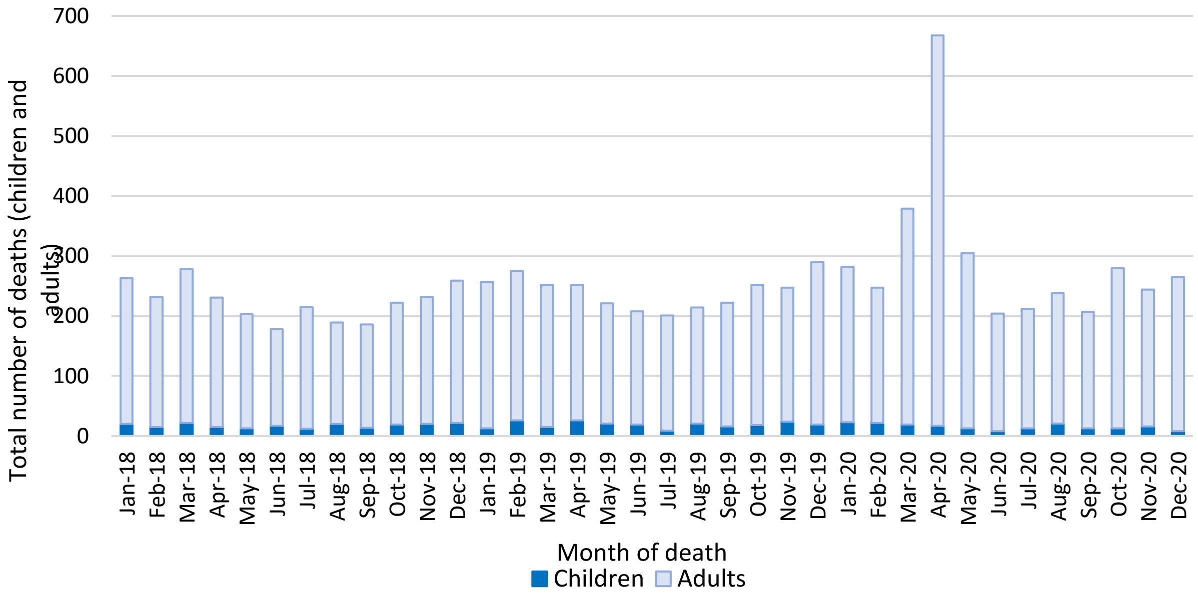
A total of 9,110 deaths of people with learning disabilities (622 deaths of children; 8,488 deaths of adults) occurring between 1st Jan 2018 and 31st December 2020 were notified to the LeDeR programme. These are the deaths that are the focus of this report.

Table A1, Appendix 1[17] details the number of deaths in 2018, 2019 and 2020 by NHS England region.

The number of deaths generally fluctuated between 200-300 each month with a larger number of deaths reported during winter months. There was a significant increase in the number of deaths at the peak of the COVID-19 pandemic from March – May 2020.

Chapter 8 focuses on deaths from COVID-19.

Figure 1.1 The number of deaths occurring each month from January 2018 to December 2020



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[15] The definition of 'learning disabilities' is that of Valuing People 2001. See: https://www.gov.uk/government/publications/valuing-people-a-new-strategy-for-learning-disability-for-the-21st-century

[16] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/933612/COVID-19__learning_disabilities_mortality_report.pdf

[17] For ease of reading, we have placed tables and figures in Appendix 1 if they do not add substantially to the main issues raised in the report. The tables should be read in conjunction with the text of the report, not as a stand-alone document.

Progress in completing reviews of deaths

All deaths notified to the LeDeR programme are reviewed locally by trained reviewers. The focus of each review is to identify good practice and what has worked well, as well as where improvements to the provision of care could be made.

In June 2019, NHS England requested that all deaths of adults with learning disabilities notified to the programme on or before 31st May 2020 should be reviewed by 31st December 2020. Thus, the intention was that reviews would be completed within the six-month period after the death was notified, whenever possible.

Figure A1 (Appendix 1) shows the number of completed reviews each quarter from 1st January 2018 to 31st December 2020.

By 31st December 2020, 92% of deaths (73% of children; 93% of adults) notified to the programme between 1st January 2018 and 30th June 2020 (irrespective of the year of death of the person) had been reviewed[18].

Initial reviews and multi-agency reviews

Deaths of children with learning disabilities are reviewed by the statutory Child Death Review programme. LeDeR reviewers may contribute to this process, but do not lead such reviews. Deaths of adults with learning disabilities receive a LeDeR initial review. The purpose of this is to provide sufficient information from a range of appropriate informants to be able to determine if there are any areas of concern in relation to the care of the person who has died.

If areas of significant concern have been raised, or if any further learning could be gained from a fuller review of the death that would contribute to improving practice, a LeDeR multi-agency review should be undertaken. In some local areas, these have been in conjunction with other safeguarding or serious incident investigations.
From June 2021 these will be known as 'focused reviews'.

The proportion of deaths of adults occurring each year that received a full multi-agency review has decreased between 2018-2020, although many deaths since June 2020 would not yet have been reviewed so 2020 data must be considered incomplete.

Of the deaths occurring in 2018, 4% (n=100) received a full multi-agency review. The corresponding proportions are 3% (n=72) of deaths occurring in 2019, and 2% (n=38) of deaths occurring in 2020.

Recommendations made by multi-agency reviews are included in Appendix 5.

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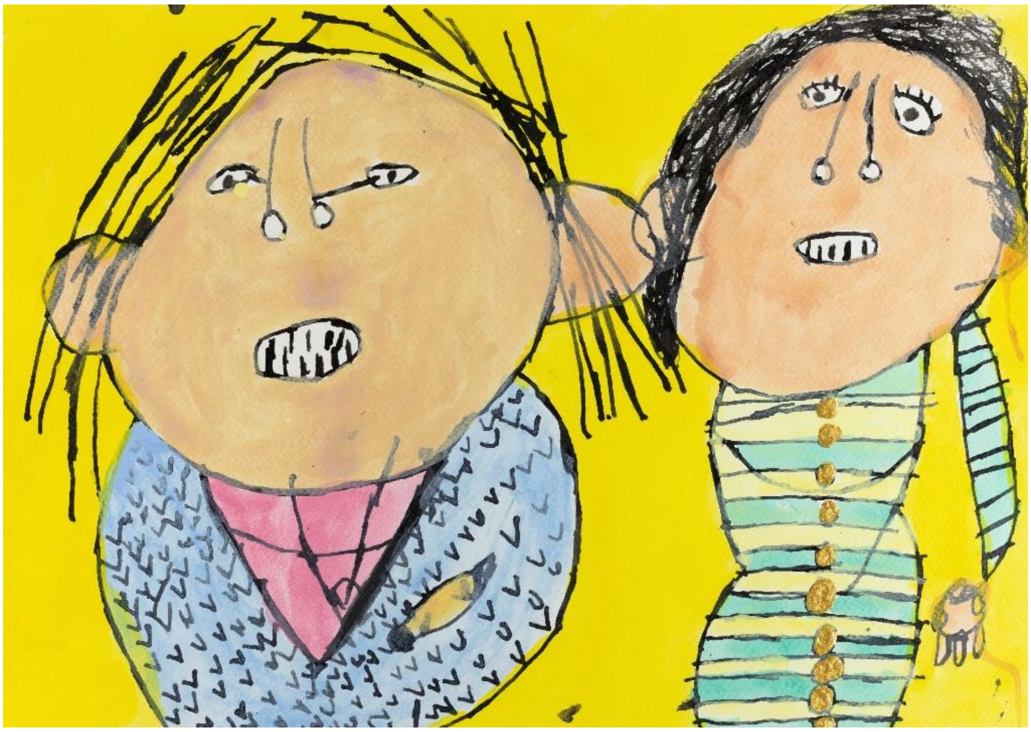
[18] Overall, 94% of adult deaths notified between the start of the programme (2016) and June 2020 had been reviewed by December 2020.

Chapter 2

Demographic information about people who died 2018-2020



Emily Boden, Friends

In this chapter we focus on the 622 children and 8,488 adults with learning disabilities who died between 1st January 2018 and 31st December 2020[19]. The focus of analyses is the gender, ethnicity, and level of learning disabilities of those who died, and their age at death. Data about age, gender and ethnicity is provided at the notification of a death; data about the level of learning disability is only available for completed reviews.

Gender

Gender was reported for 622 children and 8,487 adults who died between 2018 and 2020.

Overall, males accounted for 57% of deaths, females accounted for 43% and less than 1% (fewer than 10) deaths were identified as 'other'. Among adults, there was little variation in this across the three years. For children, the proportion of males ranged from 54% in 2018 to 61% in 2020 (Table A2, Appendix 1).

Ethnicity

The person's ethnicity was reported for 531 deaths of children and 8,054 of adults between 2018 and 2020[20].

Overall, the proportion of adults and children with learning disabilities whose ethnic group was described as 'white British' was higher than that recorded in the most recently available data for the general population of England and Wales in 2018[21]. It is likely that this represents underreporting of deaths of people from minority ethnic backgrounds rather than a greater proportion of deaths amongst people from white British ethnicity.

There was a substantial difference between adults and children, although the number of children in some groups is small so the data should be treated cautiously (Table A3, Appendix 1).

A large majority of adults with learning disabilities were of white British ethnicity (91% of those who died in 2018; 90% in 2019; 89% in 2020), but this was the case for a much smaller proportion of children (59% of those who died in 2018; 59% in 2019; 54% in 2020).

A quarter of children were of Asian/Asian British ethnicity but fewer than 5% of adults.

Chapter 7 focuses on people from minority ethnic groups, where a fuller analysis of the data is available.

Level of learning disabilities

The level of learning disabilities was reported for 76 deaths of children and 6,887 adults between 2018-2020, shown in Table 2.1. Thus, there is a large amount of missing data in relation to this[22].

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[19] At the point of notification of a death, some of the key demographic information may be missing; the reviewer completes any missing information during the review process. For deaths where the review process has not yet been completed, we have excluded the missing information from that presented here.

[20] Further information about people from different ethnic groups is included in Chapter 7.

[21] The number of deaths of people from different minority ethnic groups is too small for analysis by individual ethnicities. At places in this report, they have therefore been merged into different groupings, although we acknowledge that the experiences of people from different ethnic groups within these groupings may not be the same.

[22] There are several reasons for the large amount of missing data. From 2018, the question was no longer asked as part of the notification of the death; rather, reviewers were asked to include this information as part of their initial review of deaths of adults. For deaths that occurred after 1st June 2020 and for which the review of the death is not yet completed, this information is not available. Some reviewers may have been unsure as to the level of learning disability of a person. The large amount of missing data in

Overall, there has been little difference in the level of learning disabilities of adults who died between 2018 and 2020.

The very small number of children for whom this information is available (14% of all child deaths, n=76 for the three years combined) makes a meaningful comparison between 2018 – 2020 and comparison between children and adults difficult.

Table 2.1 Level of learning disabilities of adults and children, by year of death

Level of Learning Disability	Year of death 2018	2019	2020	Total No.
Adults and children				
Mild	30%	31%	33%	2,177
Moderate	33%	33%	35%	2,341
Severe	28%	27%	25%	1,860
Profound &multiple	9%	9%	7%	585
Total No.	*2,334*	*2,445*	*2,184*	*6,963*
Adults				
Mild	31%	31%	33%	2,171
Moderate	33%	33%	35%	2,327
Severe	28%	27%	25%	1,840
Profound &multiple	9%	8%	7%	549
Total No.	*2,299*	*2,419*	*2,169*	*6,887*
Children				
Mild	◆			◆
Moderate	18%			14
Severe	26%			20
Profound &multiple	47%			36
Total No.	*76*			*76*

[‡] Level of learning was not recorded for 2,147 people (1,601 adults and 546 children).

There is a greater proportion of deaths of children with profound and multiple learning disabilities than of adults.

Age at death

The person's age at death was reported for 622 children and 8,487 adults who died between 2018 and 2020. Table 2.2 shows the proportion in each age group, and the median age at death[23], by year of death.

The median age at death has increased by one year for deaths occurring between 2018 and 2020.

In 2018 and 2019 the median age was 60; in 2020 it was 61. The increase was for both males and females. For children, the median age at death was 10 years in 2018, 11 years in 2019 and 11 years in 2020.

Table 2.2 Age group at death, and median age at death, by year of death

Age in years	Year of death 2018	2019	2020	Total No.
4-17	8%	8%	5%	622
18-24	4%	4%	3%	302
25-49	16%	18%	16%	1,504
50-64	35%	33%	35%	3,127
65+	38%	37%	41%	3,554
Total[+]	*2,688*	*2,891*	*3,530*	*9,109*
Median age adults & children	60	60	61	60
Median age adults	61	61	62	62
Median age children	10	11	11	11

[+] The age of one person who died in 2020 was unknown

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relation to deaths of children is due to this information not being available from the information provided by the Child Death Review process.

[23] The median age at death is the age at which exactly half the deaths were deaths of people above that age and half were deaths below that age.

Comparisons with published data for the general population of England are indicative but not directly comparable: deaths of people with learning disabilities are notified to the LeDeR programme from the age of four years, while general population data also include information about children aged 0-3 years. In addition, the global pandemic in 2020 will have influenced data for that year, leading to potentially inaccurate interpretations of comparisons with previous years.

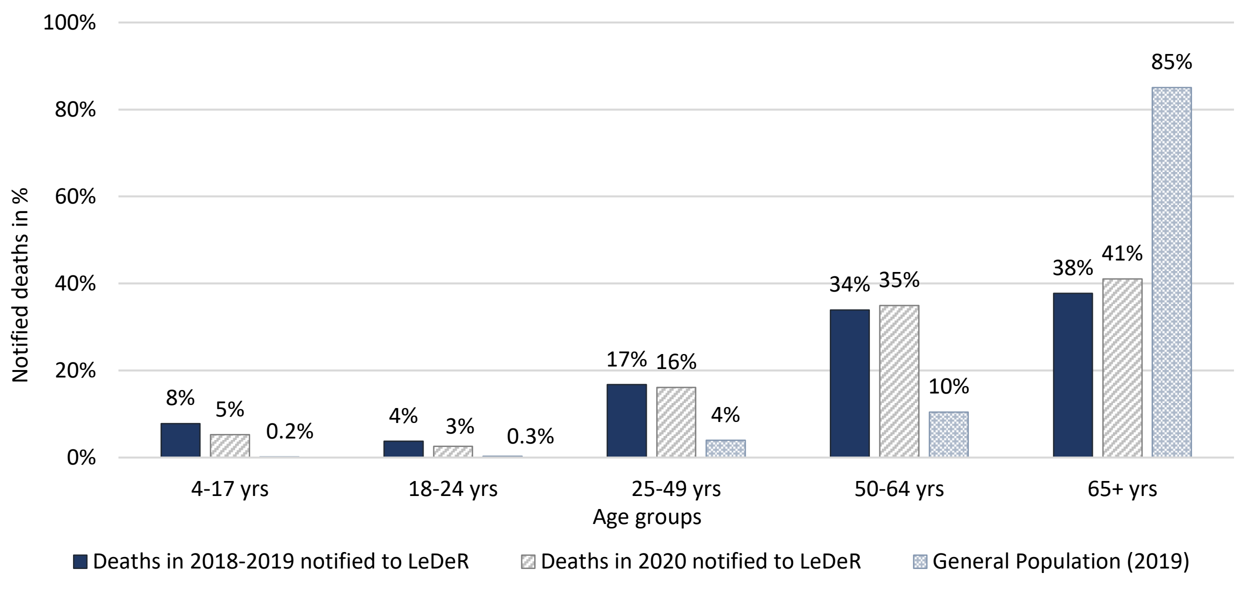
Bearing this in mind, Figure 2.1 shows the age group at death of people with learning disabilities who died between 2018-2019, and separately for 2020 to take account the impact of the pandemic, compared to general population data for the UK for 2019[24].

In 2019, the majority (85%) of people in the UK population died aged 65 and over. The corresponding proportion of adults and children with learning disabilities for 2018 and 2019, was 38%.

In the general population of England from 2016-2018, the median age at death (for people of all ages, including 0-4 years) was 83 years for males and 86 years for females. Our data suggest that in 2018-2019, the disparity between the median age at death for people with learning disabilities (age 4 years and over) and the general population (all ages) was 23 years for males and 27 years for females.

The median age at death for adults and children with learning disabilities varied little by geographical region. The increase in median age at death was apparent in all regions apart from the South West where it was 61 in 2018, 62 in 2019, and 59 in 2020.

Figure 2.1 Age group at death, people with learning disabilities and the general population



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[24] This is the most recent year for which general population data are available. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables

How personal characteristics interact

Previous analyses of LeDeR data, as reported in the 2019 annual report, confirmed that characteristics such as gender, ethnicity, level of learning disabilities and age at death, all interact. Here we consider how age at death is influenced by personal characteristics.

Table 2.3 shows the median age at death in 2018, 2019, and 2020 considering personal characteristics. We have separated children and adults because, as we have already highlighted, data about the level of learning disabilities is largely incomplete for children.

Median age at death was influenced by ethnicity and by level of learning disability. The highest median age at death in adults was for males and females of white British ethnicity and with mild or moderate learning disabilities. Their median age at death was 64 years. For females, the median age at death had increased from 64 in 2018 and 2019 to 66 years in 2020. For males, the median age at death was 65 in 2018, 64 in 2019 and 65 in 2020.

The lowest median age at death of adults, at 33 years, was for males from minority ethnic groups and with severe, profound and multiple learning disabilities. Their median age at death had increased from 30 years in 2018 to 32 years in 2019 and 42 years in 2020.

In children, the median age at death for both males and females of white British ethnicity was 11 years, compared to 10 years for males and females from minority ethnic groups.

Table 2.3 Median age at death in 2018, 2019, and 2020, taking into account different personal characteristics

Characteristics	**Median age at death**				**Total No.**
	Year of death				
	2018	**2019**	**2020**	**2018-2020**	
Adults					
Female, white British, mild/moderate LD[2]	64	64	66	64	1,722
Male, white British, mild/moderate LD	65	64	65	64	2,348
Male, white British, severe, profound & multiple LD	59	59	59	59	1,133
Female, white British, severe, profound & multiple LD	56	57	60	57	882
Male, minority ethnic group, mild/moderate LD	53	55	58	56	148
Female, minority ethnic group, mild/moderate LD	56	55	54	55	118
Female, minority ethnic group, severe, profound & multiple LD	41	48	49	45	118
Male, minority ethnic group, severe, profound & multiple LD	30	32	42	33	150
Total No.	*2,228*	*2,314*	*2,077*	*6,619*	*6,619*
Children					
Male, white British	11	12	12	11	171
Female, white British	10	11	11	11	133
Male, minority ethnic group	10	11	9	10	130
Female, minority ethnic group	8	11	12	10	97
Total No.	*172*	*194*	*165*	*531*	*531*

Chapter 3

Potential influences of age at death

Brenda Cook, Chubby cheeks

In this chapter we consider different aspects that may influence the age at death, including the presence of long-term health conditions, living arrangements, the type of support provided, whether the person had a learning disability annual health check in the year before they died, and the medications prescribed for them. Most of this data is derived from completed reviews of deaths occurring in 2018, 2019 and 2020. Because of the different review processes for adults and children with learning disabilities and the different data collected, much of the information is available for adults only.

Firstly, we present the distribution of the key variables which may influence the age at death. We then present an analysis which takes each of these key variables into account to assess the most significant influences on the likelihood of dying before the age of 50.

Long-term health conditions

Reviewers are asked to report if the person had any long-term medical conditions or additional health needs. We refer to these as 'long-term health conditions' in this report[25]. Information about long-term health conditions was reported for 6,775 adults who died in 2018, 2019 or 2020 and for whom the review of their death had been completed. Data was collected about 28 conditions[26], including one category for 'other'.

On average adults had eight long-term health conditions (ranging from 0 to 22 conditions; standard deviation[27] (SD) = 3.5) (Table A4, Appendix 1).

Almost half (46%) of adults had 7 to 10 long-term health conditions when they died. A small proportion of adults (3%) had three or fewer long-term health conditions.

In all years, the most frequently reported single conditions were mobility impairment, incontinence, and long-term respiratory conditions (Table A5, Appendix 1). More than 50% of adults in each of the three years were reported to have had one or more of these conditions.

Due to their high frequency as single conditions, the most frequently reported combinations of long-term health conditions also tended to be combinations of mobility impairment, incontinence, and respiratory conditions, as well as skin conditions, epilepsy, constipation, and sensory impairments (Table A6, Appendix 1). The pattern of these varied little each year.

Gillian had several long-term conditions when she died aged 65 from lower respiratory tract infection. Gillian was lively and friendly and enjoyed interacting with others – she was always ready to join in with activities. Gillian particularly enjoyed cooking. She was described as laughing, smiling, stubborn and outspoken.

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[25] Long-term health conditions are those that cannot be cured but can be controlled with ongoing management (using medication and/or other therapies) over a period of years. Multimorbidity is defined as the presence of two or more long-term health conditions. See https://www.nice.org.uk/guidance/ng56 We have also included additional long-term health needs here, such as incontinence.

[26] Allergies, cancer, cardiovascular problems, cerebral palsy, constipation, degenerative condition, dementia, dental problems, diabetes, deep vein thrombosis (DVT), epilepsy, falls, gastric reflux, genetic conditions, hand use impairment, hypertension, incontinence, kidney problems, mental health needs, mobility impairment, obesity, osteoporosis, prostate problems, respiratory conditions, sensory impairment, skin conditions, swallowing issues and dysphagia, and 'other' conditions.

[27] Standard Deviation Standard is a measure of spread or dispersion which tells us how far the results are from the mean. If the standard deviation is small, the results are close to the mean; if the standard deviation is large, then the results are more spread out.

Usual living arrangements

The person's usual living arrangements were reported for 6,077 adults who died between 2018-2020 and for whom the review of their death had been completed.

There was little difference in the proportion of people in different living arrangements from 2018 – 2020 (Table A7, Appendix 1). Approximately 30% had usually lived in a residential care home, 29% in a supported living setting, 25% in their own or their family home and 15% in a nursing home.
A person's usual living arrangements were significantly associated with their age, level of learning disability and ethnic group.

Those in the youngest age groups, people with profound and multiple learning disabilities, or those from minority ethnic groups were more likely to live in their own or their family home.

Out-of-area placements
We also considered whether the person had been in an 'out-of-area' placement[28] either in a residential/nursing placement or in a supported living tenancy. This information is available for 6,007 adults for whom a review of their death had been completed.

There was little difference from 2018-2020 in the proportion of people in an out-of-area placement when they died. Of those who died in 2018 and 2019, 7% of adults were in out-of-area placements; of those who died in 2020, it was 8%.

The proportion of out-of-area placements was highest in London and the South East (12%) and lowest Yorkshire and the North East, and the North West (4% in each region).

The main support received

Information about the type of support received was reported for 6,086 adults for whom a review of their death had been completed.

From 2018-2020, the majority of adults (83%) received their main form of support from a paid carer, 16% received their main support from a family member or informal carer and 2% were reported to have had no support (Table A8, Appendix 1). There was little variation in the proportions of the main source of support individuals received.

The type of main support received was significantly associated with a person's age, their level of learning disability and their ethnicity.

Those who received their main support from a family member or an informal carer, were more likely to be young adults aged 18-24 years, have profound and multiple learning disabilities, or to be from minority ethnic groups.

Prescribed medications

Information about medication was reported for a total of 6,691 deaths of adults for whom a review of their death had been completed.

The number of usual medications prescribed
Most people (98%) who died in 2018, 2019 or 2020 had had one or more usual[29] medications prescribed (Table A9, Appendix

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[28] An 'out-of-area' placement is when a person is supported in a placement outside the area of the local authority responsible for them.
[29] Usual medications exclude those to be given as and when necessary and end-of-life medications.

1). The mean (average) number of usual medications prescribed was 6.2 (SD = 3.6, range 0 – 20) for people who died in 2018; 6.5 (SD = 3.6, range 0 – 21) in 2019; and 6.6 (SD = 3.6, range 0 – 24) in 2020[30].

Most frequently prescribed categories of usual medications

The most frequently prescribed usual medications were from the British National Formulary (BNF)[31] Chapter 4, medications for the central nervous system (Table A10, Appendix 1). Of the adults who died in 2018 and 2019, 84% of people were prescribed one or more medications from this chapter; in 2020 the proportion was 82%.

The most frequently prescribed medications for the central nervous system were anti-epileptics prescribed to almost half of all people with learning disabilities.

The second most frequently prescribed usual medications were from BNF Chapter 1, medication for the gastro-intestinal system. Of those who died in 2018, 69% were prescribed one or more medications from this chapter; in 2019 the proportion was 71% and in 2020 it was 72%. The most frequently prescribed medications for the gastro-intestinal system were antisecretory drugs and mucosal protectants.

Names of the most frequently prescribed usual mediations

The names of the most frequently prescribed usual medications changed little by year of death (Table A11, Appendix 1). Valproate, Colecalciferol, Lansoprazole, and Levothyroxine (2018 and 2020 only) were all prescribed for more than 20% of adults with learning disabilities.

Antipsychotic medications

Antipsychotics are one type of psychotropic medication used to treat several conditions, including, bipolar disorder, schizophrenia and psychosis. Some are licensed as a short-term measure to treat severe anxiety. Sometimes they are prescribed to help manage behaviour.

There is a concern that people with learning disabilities are prescribed antipsychotic medication although they may not have the health conditions for which the medicines are prescribed[32]. Since 2015, NHS England has been supporting actions to tackle the over-prescribing of psychotropic drugs in general, including antipsychotics, for people with learning disabilities through the STOMP/STAMP programme[33].

Almost a quarter of adults (24%, n=1,588) were usually prescribed an antipsychotic medication.

The proportion was 24% (n=569) in 2018; 23% (n=567) in 2019; and 24% (n=452) in 2020.

Most of those prescribed antipsychotic medication were taking one type of antipsychotic medication. For 2018 – 2020 combined, 268 people (4% of those prescribed antipsychotics) were taking two or more (4%, n= 90 in 2018; 4%, n=94 in 2019; 4%, n=84 in 2020).

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[30] Comparable data for the general population is not available.

[31] https://openprescribing.net/bnf/

[32] https://webarchive.nationalarchives.gov.uk/20160704150153/http://www.improvinghealthandlives.org.uk/publications/1248/Prescribing_of_psychotropic_medication_for_people_with_learning_disabilities_and_autism

[33] https://www.england.nhs.uk/2015/07/urgent-pledge/

Between 2018 – 2020, the most frequently prescribed antipsychotics did not vary much, with Risperidone, Olanzapine, and Quetiapine the most frequently prescribed each year. Chlorpromazine, Haloperidol and Aripiprazole vary across years as the fourth and fifth most frequently prescribed (Table A12, Appendix1).

We modelled the likelihood of people being prescribed antipsychotic medication using logistic regression[34] (Table A13, Appendix 1). The variables we took account of in the model included gender, ethnicity, age group, level of learning disabilities, if the person was in an out-of-area placement, if needs were met, if they were prescribed antidepressant medication, if they had had an annual health check in last year, if they had been subject to mental health or criminal justice restrictions in the past five years, and index of multiple deprivation[35]. The data was available for 4,761 cases.

Several variables were associated with greater likelihood of being prescribed antipsychotic medication:

- Subject to mental health or criminal justice restrictions in the five years prior to death (the likelihood was 6.5 times greater than someone not).
- Prescribed antidepressant medication (2.8 times greater than not).
- Aged 65 or over (2.5 times greater than someone aged 18-24 years).
- Aged 50 to 64 (1.9 times greater than someone aged 18-24 years).
- Of Black/African/Caribbean/Black British ethnic group (2.2 times greater than white British ethnicity).
- In an out-of-area placement (1.9 times greater than not).
- Severe learning disability (1.3 times greater than mild)

Variables associated with reduced likelihood of being prescribed antipsychotic medication included:

- Having profound and multiple learning disabilities (the likelihood was 0.5 times less than someone with mild learning disabilities).
- Not having had a learning disability annual health check in the past year (0.8 times less than someone who had).

Jelani died aged 56 years. He had been prescribed both antipsychotic and antidepressant medication for mental health problems. Jelani had a very positive outlook on life and liked a laugh with people. He loved music, particularly R&B and soul music and had a collection of vinyl records.

Antidepressant medications

Antidepressants are a type of psychotropic medication, primarily used to treat depression. Sometimes they are prescribed to help manage anxiety, obsessive compulsive behaviour or panic disorders, or (unlicensed) to help manage pain.

28% of adults (n=1,855) were usually prescribed an antidepressant medication.

The proportion was 27% (n=625) in 2018, 28% (n=683) in 2019 and 29% (n=547) in 2020.

Most of those prescribed antidepressant medications were prescribed one type of such medication. For 2018-2020 combined, 173 people (3% of those prescribed

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[34] A logistic regression model exploits any association between the dependent and independent variables to predict category membership of the dependent variable. The measure of likelihood used is the ‘odds ratio’. For ease of reading this report we refer to the likelihood of an occurrence.

[35] Variables for individual and total number of long-term conditions, usual living arrangements, main type of support received, and the number of prescribed medications were excluded due to their correlation with age.

antidepressants) were prescribed two or more (2%, n=45 in 2018; 3%, n=68 in 2019; 3%, n=60 in 2020).

Between 2018 – 2020, the most frequently prescribed antidepressants remained similar, with Citalopram, Sertraline and Mirtazapine the most frequently prescribed in each year (Table A14, Appendix 1).

Again, we modelled the likelihood of people being prescribed antidepressant medication using logistic regression[34] (Table A15, Appendix 1). The variables we took account of in the model included gender, ethnicity, age group, level of learning disabilities, if the person was in an out-of-area placement, if they were prescribed antipsychotic medication, if needs were met, if they had had an annual health check in last year, if they had been subject to mental health or criminal justice restrictions in the past five years, and index of multiple deprivation. This data was available for 4,761 cases.

Several variables were associated with greater likelihood of being prescribed antidepressant medication:

- Aged 50 to 64 (the likelihood was 3 times greater than someone aged 18-24 years).
- Aged 65 or over (2.9 times greater than someone aged 18-24 years).
- Aged 25-49 years (2.8 times greater than someone aged 18-24 years).
- Prescribed antipsychotic medication (2.8 times greater than someone not).
- Female (1.3 times greater than males).

Variables associated with reduced likelihood of being prescribed antidepressant medication included:

- Having profound and multiple learning disabilities (the likelihood was 0.3 times less than someone with mild learning disabilities).
- Having severe learning disabilities (0.4 times less than someone with mild learning disabilities).
- Being of an Asian ethnic group (0.6 times less than someone of white British ethnicity).
- Having moderate learning disabilities (0.8 times less than someone with mild learning disabilities).

Learning disability annual health check

People aged 14 or over who are on their GP's learning disability register can have a free learning disability annual health check once a year. The health check, which should also include a medication review, provides an opportunity for the person to talk to a health professional about their health and for any previously undetected or unmanaged health conditions to be identified and treated[36,37].

Information about whether the person had received an annual health check was reported for 5,850 deaths of adults for whom a review of their death had been completed.

Overall, approximately three-quarters of adults had had a learning disability annual health check in the year before they died. There was little variation across the years (Table A16, Appendix 1).

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[36] https://www.gov.uk/government/publications/annual-health-checks-and-people-with-learning-disabilities/annual-health-checks-and-people-with-learning-disabilities

[37] https://webarchive.nationalarchives.gov.uk/20160704145757/http://www.improvinghealthandlives.org.uk/projects/annualhealthchecks

Whether a person had received an annual health check was significantly associated with their age and their level of learning disability.

Those who had not received an annual health check were more likely to be in the 18-24 years age group or to have mild learning disabilities.

If the person's needs were met

Reviewers are asked to report, from the evidence they had, if they thought that the care package provided met the needs of the person. Information was available for 6,086 adults for whom a review of their death had been completed.

Overall, most reviewers thought that the care package that had been provided had met the person's needs (90% in 2018; 91% in 2019; 91% in 2020) (Table A17, Appendix 1).

Whether or not the care package met a person's needs differed by gender, level of learning disabilities and usual living arrangements. Those for whom the care package had *not* met their needs were more likely to be:

- Male rather than female (male 11%; female 8%).
- Have mild learning disabilities rather than severe or profound and multiple learning disabilities (mild learning disabilities 13%; severe or profound and multiple learning disabilities 6%).
- Lived in their own or the family home rather than a residential care home (own or family home 13%; residential home 6%).

Whether or not the care package met a person's needs did not differ by ethnicity.

Area deprivation

Based on the postcode people usually lived at before they died, we calculated the Index of Multiple Deprivation for that geographical area[38]. Information was available for 8,391 adults and children.

Between 2018 and 2020 there was an increase in the proportion of children and adults with learning disabilities living in the most deprived quintile [39](25% in 2018; 27% in 2019; 27% in 2020). There was a corresponding decrease in the proportion of children and adults living in the least deprived quintile (14% in 2018; 13% in 2019; 12% in 2020) (Table A18, Appendix 1).

Living in a deprived area varied by age, ethnicity, and level of learning disabilities. Those living in the most deprived quintile were more likely to be:

- Children aged 4-17 years from minority ethnic groups compared to white British children (children from minority ethnic groups 41%; white British children 34%).
- Adults aged 18 and over from minority ethnic groups compared to white British adults (adults from minority ethnic groups 34%; white British adults 25%).
- Adults[40] with mild learning disabilities compared to those with profound and multiple learning disabilities (mild learning

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[38] Indices of multiple deprivation (IMD) classify the relative deprivation (essentially a measure of poverty) of small areas. Multiple components of deprivation (including income, employment, education, health, crime, housing and services and the living Environment) are compiled into a single score of deprivation. See: https://www.gov.uk/government/collections/english-indices-of-deprivation

[39] Quintiles divide the data into five equal sets. Here the quintiles range from most to least deprived: 1-20%,21-40%,41-60%,61-80% and 81-100%.

[40] This data is not comprehensively available for children.

disabilities 30%; profound and multiple learning disabilities 19%).

Faisal was described as kind-natured and with a lovely smile. He lived at home with his family and went to a day centre during the week. He enjoyed going to the local shops and to the park to feed the ducks. Faisal could become anxious in new situations which could lead to behaviours that challenged those supporting him. Faisal died at the age of 23 from a sudden illness.

Age at death and its influences

There are a number of factors that influence the health of people in the general population (see, for example, Dahlgren and Whitehead's 1991 'rainbow' model which sets out the relationship between an individual and the social and environmental factors that determine their health). Such factors include the individual and their own personal characteristics, as well as lifestyle factors, social and community networks, and the more general socio-economic, cultural and environmental conditions in which we live.

We modelled[33] the likelihood of adults with learning disabilities dying before the age of 50, using the information we had from LeDeR reviews, which included a person's gender, ethnicity, level of learning disabilities, if they had been in an out-of-area placement, if they were prescribed antipsychotic or antidepressant medication, if they had an annual health check in past year, if they had been subject to mental health or criminal justice restrictions in the previous five years, if their care package had met their needs, and index of multiple deprivation [34] (Table A19, Appendix 1). This data was available for 4,325 cases.

Several variables were significantly associated with greater likelihood of dying aged 18-49 years:

- Asian/Asian British ethnicity (the likelihood was 9.2 times greater than a white British person of dying aged 18-49 years).
- Profound and multiple learning disabilities (6.4 times greater than someone with mild learning disabilities).
- Subject to mental health or criminal justice restrictions in the five years prior to death (4.3 times greater than someone not under such restrictions).
- Of mixed/multiple ethnicities (3.9 times greater than someone of white British ethnicity).
- Of Black/African/Caribbean/ Black British ethnic group (3.6 times greater than someone of white British ethnicity).
- Severe learning disabilities (2 times greater than someone with mild learning disabilities).
- Not had an annual health check in the previous year (1.5 times greater).

Variables associated with reduced likelihood of dying aged 18-49 years:

- Prescribed antipsychotic medication (the likelihood was 0.7 times less than someone not).
- Prescribed an antidepressant medication (0.9 times less than someone not).

Chapter 4

Causes of death

Louise Morgan, After John Everett Millais ‘The bridesmaid’

In this chapter we focus on the causes of death of the 521 children (aged 4 – 17) and 7,969 adults (aged 18 and over)[41] who died between 1st January 2018 – 31st December 2020.

Underlying cause of death by ICD-10 chapter[42]

The World Health Organisation defines the underlying cause of death as the disease or injury which initiated the train of events leading directly to death, or the circumstances of the accident or violence which produced a fatal injury.

Here we present underlying cause of death data for the 8,461 people aged 5 and over (8,092 adults aged 15 years and over and 369 children aged 5-14 years) notified to the LeDeR programme from 2018-2020, for whom we have received the official Office for National Statistics (ONS) ICD-10 codes (via NHS Digital) for the causes of death[43].

The most frequently reported ICD-10 chapters for underlying causes of death have remained stable between 2018-2019. In 2020, the most frequently reported ICD-10 chapter was the emergency code for COVID-19.

In 2018 and 2019, the most frequently reported underlying causes of death were in the ICD-10 chapter of disorders of the respiratory system.

The proportion of deaths of people with learning disabilities included in the ICD-10 chapter of disorders of the respiratory system (2018: 21% males and 20% females; 2019: 19% males and 20% females) was greater than in the general population in 2019 (14% males and females) (Table A20, Appendix 1).

The second most frequently reported underlying causes of death in 2018 and 2019 were in the ICD-10 chapter of disorders of the circulatory system.

The proportion of deaths of people with learning disabilities included in the ICD-10 chapter of disorders of the circulatory system (2018: 17% males and 13% females; 2019: 14% males and 16% females) was lower than in the general population in 2019 (26% males and 23% females).

The third most frequently reported underlying causes of death in 2018 and 2019 were in the ICD-10 chapter of congenital and chromosomal disorders.

The proportion of deaths of people with learning disabilities included in the ICD-10 chapter of congenital and chromosomal disorders (2018: 13% males and 14% females; 2019: 15% males and 14% females) was greater than the proportion in the general population (<1% males and females).

Other differences between people with learning disabilities and the general population were in relation to neoplasms (fewer reported in people with learning disabilities) and disorders of the nervous system (more reported in people with learning disabilities).

The number of deaths of children is too small for robust comparison by ICD-10 chapter, but

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[41] This is the definition of adults and children used elsewhere in this report. In this chapter, however, comparisons with national datasets mean different age groupings are used. This is made explicit through the text and in the Tables.

[42] International Statistical Classification of Diseases and Related Health Problems 10th Revision.

[43] Data are not available for 616 people as insufficient information was available, e.g., NHS number, for notifications to be matched with ONS data.

the proportion of disorders of the nervous system in children with learning disabilities was greater than that of the general population.

Deaths from COVID-19 are covered in Chapter 8 of this report[44].

The ICD-10 chapter for the underlying cause of death varied by age group, ethnicity, and level of learning disabilities (Tables A21, A22, and A23 in Appendix 1).

- Underlying causes of death related to the respiratory system were more frequent in those aged 65 and over, or in people with severe or profound or multiple learning disabilities.
- Underlying causes of death related to the circulatory system were more frequent in those aged 65 and over, or in people with mild or moderate learning disabilities.
- Underlying causes of death related to the nervous system were more frequent in the youngest age group (15 – 49 years), people in minority ethnic groups, or people with severe or profound and multiple learning disabilities.
- Underlying causes of death related to congenital and chromosomal conditions were most frequent in people aged 50 – 64 years, or in white British people.
- Underlying conditions related to COVID-19 were more frequently reported in people from minority ethnic groups.
- Underlying causes of death related to neoplasms were more frequently reported in people with mild or moderate learning disabilities.

Condition-specific underlying causes of death

The most frequently reported condition-specific underlying causes of death varied by gender and age group (Table A24, Appendix 1).

In 2018 and 2019, for both males and females, the leading condition-specific underlying causes of death were very different for people with learning disabilities compared to the general population.

Cerebral palsy, epilepsy and bacterial pneumonia were the condition-specific leading causes of death in people with learning disabilities age ages 5-49 years. By contrast, in the general population, the condition-specific leading causes of deaths at these ages were related to suicide and injury or poisoning of undetermined intent, apart from females aged 35-49 for whom it was malignant neoplasm of the breast.

In the age 50-64 years age group, Down's syndrome was most frequently reported in people with learning disabilities; for many, this was associated with Alzheimer's disease. At or above age 65, it was bacterial pneumonia. In the general population, ischaemic heart disease and dementia and Alzheimer disease predominated at these ages, apart from females aged 65-79 for whom it was malignant neoplasm of trachea, bronchus and lung.

Of note, is that in 2020, the condition-specific leading cause of death in people with learning disabilities from age 35 and over for males, and age 20 and over in females was COVID-19.

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[44] Deaths from COVID-19 are included in a separate chapter of the ICD-10 - 'Codes for special purposes'.

Deaths from COVID-19 are considered in more detail in Chapter 8.

Table A25, Appendix 1, shows the leading causes of death by Clinical Commissioning Group (CCG).

Melissa died aged 35 from bacterial pneumonia. The initial sign that she was becoming unwell was that her breathing became noisier. Over the course of a week, she became increasingly chesty and breathless. She was started on antibiotics at home but admitted to hospital two days later where she died the following day.

Most frequently reported conditions causing death reported anywhere in Part I of MCCD

Although the underlying cause of death is most commonly used in national statistics, concerns have been repeatedly raised about potential inaccuracies in recording deaths of people with learning disabilities in this way[45,46].

It is instructive to therefore consider those conditions that are mentioned anywhere in Part I of the MCCD[7].

In 2018 and 2019, the conditions most frequently cited in Part I of the MCCD were bacterial pneumonia (24% in 2018; 23% in 2019) and aspiration pneumonia (15% in 2018; 16% in 2019) (Table A26, Appendix 1).

In 2020, the condition most frequently cited in Part I of the MCCD was COVID-19 (23%). Bacterial pneumonia (19%) and aspiration pneumonia (11%) were in second and third place.

Generally, there was little change in the proportion of the conditions most frequently cited in Part I of the MCCD by demographic characteristics.

For both males and females in 2018 and 2019, across all age groups, the condition most frequently cited anywhere in Part I of the MCCD was bacterial pneumonia.

The only exception to this was in females aged 50-64 years, for whom the most frequently recorded condition was Down's syndrome, likely to be associated with Alzheimer's disease (Table A27, Appendix 1).

In 2020, COVID-19 was the condition most frequently cited anywhere in Part I of the MCCD for males and females in each age group at 35 years and above.

In the younger age groups, cerebral palsy (for males and females aged 5-19 years) and bacterial pneumonia (for males and females aged 20-34 years) were the conditions most frequently reported.

In May 2019, Professor Stephen Powis, the National Medical Director at the time, sent a letter to Trusts and CCGs reminding them that the terms 'learning disability' and 'Down syndrome' should never be used to describe the underlying, or only, cause of death on Part I of the MCCD. Learning disabilities are not fatal conditions and should never be used as a cause of death. Since June 2019, individual conditions associated with learning disabilities (e.g., Down's syndrome, cerebral palsy, Rett's syndrome) were the *only* condition cited on the MCCD of 11 people.

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[45] https://onlinelibrary.wiley.com/doi/full/10.1111/jar.12448

[46] https://pubmed.ncbi.nlm.nih.gov/30804035/

We have not made a specific recommendation for this small number of deaths but suggest that MCCDs should not be accepted by coroner's officers and medical examiners if there is single cause of death related to 'learning disabilities'.

Deaths from potentially avoidable medical causes

In 2019, a harmonised definition of avoidable mortality and a list of causes of death considered to be avoidable was agreed for use across Europe. In February 2020, the Office for National Statistics published national data for England and Wales using the new definition. Note that the definitions relate to underlying medical causes of death, not an examination of the circumstances leading to death. Thus, these are 'avoidable causes of deaths' not 'avoidable deaths'[47].

Preventable mortality	Causes of death that can be mainly avoided through effective public health and primary prevention interventions (i.e., before the onset of diseases/ injuries, to reduce incidence).
Treatable mortality	Causes of death that can be mainly avoided through timely and effective health care interventions, including secondary prevention and treatment (i.e., after the onset of diseases, to reduce case-fatality).
Avoidable mortality	Avoidable causes of deaths are all those defined as preventable or treatable.

Figure 4.1 shows the proportion of preventable, treatable and avoidable medical causes of death for deaths occurring in 2018, 2019 and 2020 for which we have the ICD-10 codes for the cause of death. The analyses exclude deaths occurring after the age of 74[48] and deaths from COVID-19 which was identified after the harmonised list was finalised.

There is an encouraging picture of an overall reduction in the proportion of preventable, treatable and overall avoidable medical causes of death of people with learning disabilities from 2018 to 2020. Numbers for children are insufficient for annual data to be presented, so the figures have been aggregated. For a regional analysis of this data see Table A28 in Appendix 1.

Ken was a quiet man who knew his own mind. He died at the age of 72. Ken loved a beer, going to the pub, and having fry ups. He'd suffered from pneumonia about 3 years before he died, following which he'd been advised to give up smoking.

Preventable deaths

Underlying causes of deaths in adults aged 20-74 that could mainly have been prevented through effective public health and primary prevention interventions were 24% in 2018, 23% in 2019 and 24% in 2020. In children[49] the proportion was 10% across the three years.

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[47] To remind the reader about this we have used the term 'medical causes of death' in this section.

[48] https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/bulletins/avoidablemortalityinenglandandwales/2019

[49] For comparison with data published by ONS, the category of 'children' includes those aged 4-19 years.

Regionally, the proportion of preventable medical causes of deaths amongst adults was greatest in the North East and Yorkshire, and the North West in 2018 (26% in each region), and the North West in 2019 (28%) and 2020 (26%). In children, preventable medical causes of death were highest, at 11%, in both the North East and Yorkshire, and London.

Among adults, those more likely to die from preventable medical causes were:

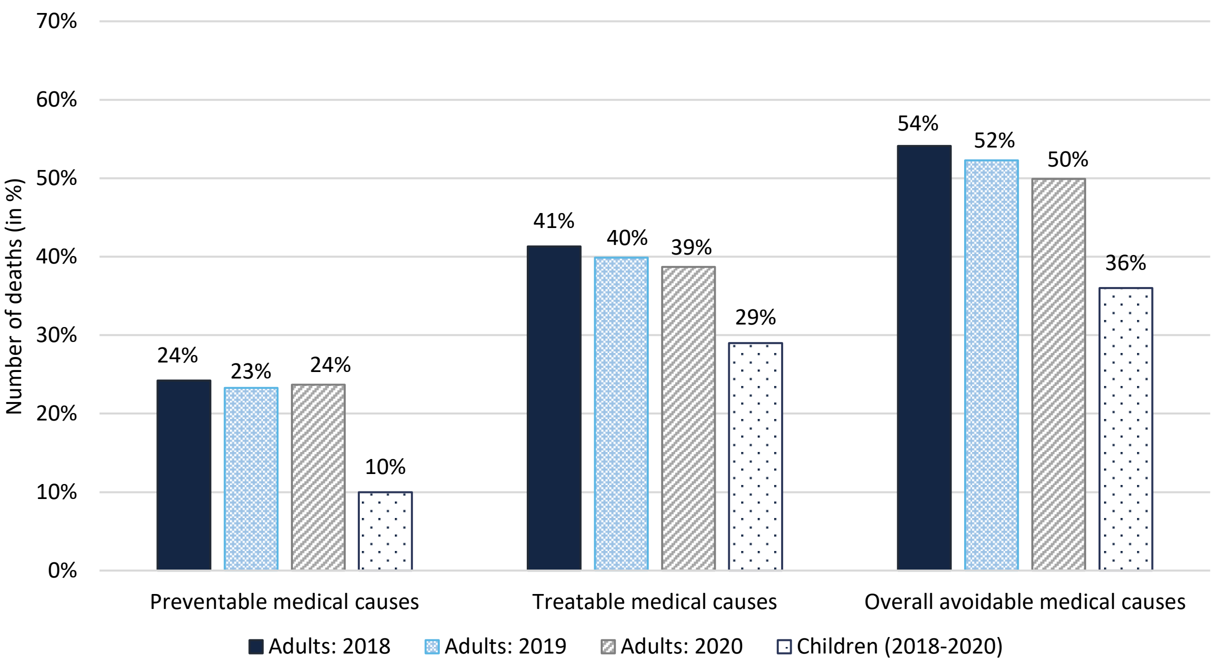
- Males compared to females (26% males; 20% females).
- People with mild or moderate learning disabilities compared to people with severe or profound and multiple learning disabilities (27% mild or moderate learning disabilities; 17% severe, profound or multiple learning disabilities).
- People aged 65 – 74 years compared to people aged 19-24 years (30% aged 65 – 74 years; 9% aged 19 – 24 years).

In children, there was no association between their demographic characteristics and the frequency with which they died from a preventable medical cause.

The most frequently recorded type of preventable medical causes of deaths in adults were ischaemic heart disease (22%, n=311), aspiration pneumonia (12%, n=168) and strokes (8%, n=107).

In children, influenza was the only preventable medical cause of death recorded for more than 10 deaths (35%, n=20).

Figure 4.1 The proportion of preventable, treatable and avoidable medical causes of death for deaths occurring in 2018, 2019 and 2020



Treatable medical causes of death

Underlying causes of deaths in adults aged 20–74 that could mainly have been treated with timely and effective health care interventions were 41% in 2018, 40% in 2019, and 39% in 2020.
In children, the proportion was 29% across all three years.

Regionally, the proportion of treatable medical causes of deaths among adults was greatest in London in 2018 (46%), and the Midlands in 2019 (45%) and 2020 (42%). Among children, the East of England had the highest proportion (37%).

Adults *more* likely to die from treatable medical causes were:

- Females compared to males (43% females; 38% males).

In children, there was no association between their demographic characteristics and the likelihood of dying from a treatable medical cause of death.

The most frequently recorded types of treatable medical causes of deaths among adults were bacterial pneumonia (24%, n=567), ischaemic heart disease (13%, n=311) and epilepsy (10%, n=237).

In children, epilepsy was the most frequently recorded treatable medical cause of death (27%, n=47), followed by bacterial pneumonia (18%, n=32) and acute lower respiratory infections (10%, n=17).

Overall avoidable medical causes of death

Overall avoidable medical causes of deaths in adults were 54% in 2018, 52% in 2019, and 50% in 2020.
In children, the proportion was 36% across the three years.

Regionally, the proportion of overall avoidable medical causes of deaths among adults was greatest in London and the North West in 2018 (57% in each region), the Midlands and the North West in 2019 (58% in each region), and London in 2020 (53%).
In children, the proportion of overall avoidable medical causes of deaths was greatest in the East of England (42%).

Adults *least* likely to die from overall avoidable medical causes were:

- People with severe or profound and multiple learning disabilities (49%) compared to those with mild or moderate learning disabilities (54%).
- People living in residential care homes or nursing homes compared to people living in other settings (48% in residential care or nursing homes; 56% in other settings).
- People in the lowest age group (aged 19-24) compared to older people (43% aged 19-24; 54% aged 25-49; 48% aged 50-64; 58% aged 65 – 74).

The most frequently recorded type of overall avoidable medical causes of deaths among adults were bacterial pneumonia (18%, n=570), ischaemic heart disease (10%, n=311) and epilepsy (8%, n=237).

In children, the most frequently recorded were epilepsy (22%, n=47), bacterial pneumonia (15%, n=32), and influenza (9%, n=20).

Comparison of avoidable medical causes of death between people with learning disabilities and the general population (excluding deaths from COVID-19)

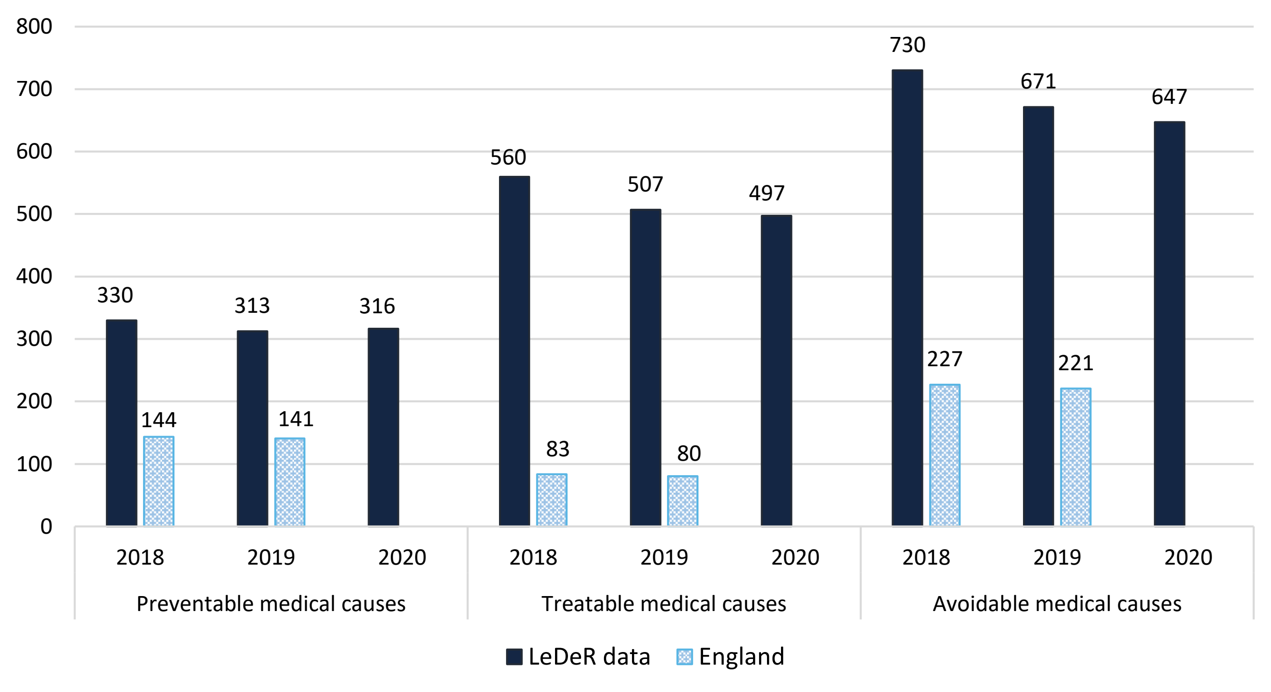
In order to take account of the different age profiles of people with learning disabilities and those in the general population, we have age standardised the data[50].

Figure 4.2 shows the age-standardised rates (per 100,000 population) for preventable, treatable and avoidable medical causes of death, for people with learning disabilities (2018, 2019 and 2020[51], and comparative data for the general population in England (2018 and 2019).

For preventable, treatable and overall avoidable medical causes of death, the standardised avoidable mortality rate for people with learning disabilities has fallen between 2018 and 2020 (Figure 4.2). Compared to the general population, people with learning disabilities are over three times as likely to die from an avoidable medical cause of death (671 per 100,000 compared to 221 for the general population in 2019).

The majority of this excess mortality is due to treatable, rather than preventable, causes. In 2019, treatable causes accounted for 507 per 100,000 deaths in people with learning disabilities, compared with 80 per 100,000 in the general population.

Figure 4.2 Age-standardised avoidable, treatable and preventable mortality rates (per 100,000), people with learning disabilities 2018, 2019 and 2020 (excluding deaths from COVID-19), and the general population in 2019



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[50] Age-standardisation allows populations to be compared when the age profiles of the populations are quite different. For more information on the methods used to age-standardise LeDeR data, please contact the University of Bristol.

[51] COVID-19 deaths are not included in the figures for 2020 as the definition of avoidable mortality was published before COVID-19 was identified. The 2020 figures should therefore be regarded as provisional until it is known whether future revisions will categorise COVID-19 as a medically avoidable cause of death.

Chapter 5

Circumstances of deaths

Brenda Cook, Steve's shirt

In this chapter we consider some specific circumstances of deaths, including the place of death, deaths of adults subject to restrictive legislation or in a restrictive setting, the use of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions, and whether the death was reported to a coroner. We also consider contributory and potentially avoidable factors in deaths of children.

Place of death

Information about the place of death was reported for a total of 433 children and 8,412 adults who died between 2018 and 2020.

The majority of children and adults with learning disabilities died in hospital in 2018, 2019 and 2020, the proportion remaining fairly stable at approximately 60% each year.

In the general population of England in 2019, 46% of deaths of all ages from 5 years and over occurred in hospital[52]. (Table A29, Appendix 1).

Deaths of adults subject to restrictive legislation or in a restrictive setting

We considered the proportion of adults subject to restricted liberty prior to their death, either through mental capacity legislation, by order of the courts or through mental health legislation.

Information about this was reported for a total of 6,218 adults for whom a review of the death had been completed (Tables A30 and A31, Appendix 1).

In each of the years 2018-2020, a quarter of those who died were subject to Deprivation of Liberty Safeguards (DoLS)[53] authorised by the local authority. A further 10% were awaiting approval for an application for DoLS. Those who were subject to DoLS tended to be of an older age and to have more severe learning disabilities.

Of those who died between 2018 and 2020[54], 26 had their liberty restricted by the criminal justice system at the time of their death[55]. A small number (fewer than 10) had had restrictions imposed during the five years prior to their death, but the restrictions were not in place at the time of death.

A small number (n=13) had had their liberty restricted by mental health legislation at the time of their death[56] or had had restrictions imposed during the five years prior to their death, but not at the time of death (fewer than 10).

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

[53] The Deprivation of Liberty Safeguards are an amendment to the Mental Capacity Act 2005 and allow restraint and restrictions that amount to a deprivation of liberty to be used in hospitals and care homes if they are in a person's best interests. To deprive a person of their liberty in this way, care homes and hospitals must request standard authorisation from a local authority.

[54] The number of deaths of adults subject to restricted liberty by order of the courts or through mental health legislation is too small to analyse separately for each year (generally fewer than 10 deaths in each category each year), so we have merged those deaths into a total grouping for 2018-2020.

[55] These people were in prison, forensic secure settings, on probation, or were subject to a section of the Mental Health Act imposed by the courts at the time of their death.

[56] These people were subject to a section of the Mental Health Act.

The use of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions[57] or decisions to allow a natural death

Previous annual reports from the LeDeR programme have raised concerns about some decisions not to attempt cardiopulmonary resuscitation (DNACPR) in some people with learning disabilities. DNACPR decisions should be based on an individualised medical decision, but evidence suggests poor involvement, poor record keeping, and a lack of oversight and scrutiny of the decisions being made.[58]

LeDeR reviewers are asked whether the person had a DNACPR decision in place at the time of their death, and if so, whether the documentation was correctly completed and followed.

Information about DNACPR decisions was reported for almost all (99%, n=6,716) adults for whom a review had been completed. Table A32, Appendix 1 shows the proportion of adults with a DNACPR decision at the time of their death.

The proportion of adults with a DNACPR decision at the time of their death was 71% in 2018, 70% in 2019 and 73% in 2020.

We modelled the likelihood of people having a DNACPR decision in place in 2020 (Table A33, Appendix 1). The variables we took account of in the model included age group, gender, ethnicity, the level of learning disabilities, usual living arrangements, index of multiple deprivation, if the person was in an out-of-area placement, and if the person had COVID-19 included anywhere on the MCCD. As with elsewhere in this report, caution must be taken in interpreting this data due to the small numbers in some groupings and the unequal sample sizes.

Several variables were associated with greater likelihood of having a DNACPR decision in place at the time of death in 2020:

- Usually lived in a nursing home (the likelihood was 3.7 greater than someone living in their own or the family home).
- Aged 65 and over (2.5 times greater than a person aged 18-24 years).
- Profound/multiple learning disabilities (2.5 times that of a person with mild learning disabilities).
- Usually lived in a residential home (2.3 times greater than someone living in their own or the family home).
- Moderate learning disabilities (1.5 times that of a person with mild learning disabilities).
- Severe learning disabilities (1.5 times that of a person with mild learning disabilities).
- Had COVID-19 included as a cause of death on MCCD (1.8 times that of a person who died from other causes).

Variables associated with reduced likelihood of having a DNACPR decision included:

- Living in an out-of-area placement (the likelihood was 0.6 times less than someone not in an out-of-area placement).

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[57] Cardio-pulmonary resuscitation is when a person receives chest compressions and artificial breaths to help pump blood around their body when their heart has stopped. A decision not to attempt cardio-pulmonary resuscitation is made and recorded in advance when it would not be in the best interests of the person because they are near the end of their life or the procedure would be unlikely to be successful.

[58] https://www.cqc.org.uk/sites/default/files/20210318_dnacpr_printer-version.pdf

Additionally, if someone had a DNACPR in place, we considered how this was carried out and documented. Table A34, Appendix 1 shows whether adults with a DNACPR decision at the time of their death had the documentation correctly completed and followed.

Of those with a DNACPR decision, the proportion that were known by the reviewer to be correctly completed and followed decreased from 76% in 2018, to 73% in 2019 and 71% in 2020.

A small proportion of reviewers (4% in 2018; 4% in 2019; 6% in 2020) confirmed that the DNACPR decision had not been correctly completed and followed. The numbers are small, so the proportions needed to be interpreted cautiously.

There were three main reasons given as to why reviewers thought that the DNACPR decision had not been made correctly (Table A35, Appendix 1).

1. There appeared to be no evidence of proper decision-making processes, in line with the Mental Capacity Act, being followed (29%, n=14 of the reasons in 2018; 40%, n=27 in 2019; 40%, n=25 in 2020).

'The record of the discussion of the decision was not documented' (reviewer of death in 2019).

'It was completed without any family involvement, although his sister had power of attorney for his health and welfare' (reviewer of death in 2020).

2. Problems with the documentation itself, such as illegible handwriting, missing sections of the DNACPR form, the form not being appropriately signed, or the form containing incorrect personal details (31%, n=15 of the reasons in 2018; 29%, n=20 in 2019; 26% n=16 in 2020).

'Form not fully completed by GP and no second signature obtained' (reviewer of death in 2020).

'It named the wrong person as next of kin' (reviewer of death in 2019).

3. The rationale for the decision was based on an inappropriate medical condition or impairment or circumstance of the individual e.g., the terms used were 'learning disabilities' or 'Down's syndrome' or 'care home resident' (27%, n=13 of the reasons in 2018; 18%, n=12 in 2019; 23%, n=14 in 2020).

[DNACPR form stated:] *'Although mobile, poor functional baseline given learning disabilities and care home needs'* (quoted by reviewer of death in 2020).

'One of the clinical reasons given not to resuscitate was 'learning disability'…[the] *other reason documented was epilepsy'* (reviewer of death in 2020).

For several people each year a DNACPR decision had not been correctly followed. All had cardiopulmonary resuscitation attempted even though a decision had been made not to do so, usually due to the appropriate documentation not being available, staff being unaware of the decision, or attending staff 'panicking' at finding a person in a collapsed state.

Deaths reported to a coroner

Previous annual reports from the LeDeR programme have raised concerns about the apparently low proportion of deaths of people with learning disabilities referred to a coroner[59], compared with all referrals. Here, we consider this by year of death to assess any change.

Information about whether the death was referred to a coroner or not was reported for a total of 8,488 adults and 622 children who died between 2018-2020. This information is collected at the notification of the death and checked and amended by a reviewer during the review.

The proportion of deaths of adults and children known to have been reported to a coroner was 33% in 2018 and 31% in 2019. In the general population of England and Wales, 41% of the deaths of adults and children were reported to a coroner in 2018 and 40% in 2019. (Table A36, Appendix 1).

The proportion of deaths of people with learning disabilities reported to a coroner decreased significantly in 2020 to 22%. This is likely to be due to very few deaths from COVID-19 reported to a coroner – it is estimated that 9% of all deaths from COVID-19 were referred to a coroner in 2020.

Those people with learning disabilities who had their death reported to a coroner were more likely to be male, younger than aged 50 years, to have mild or moderate learning disabilities or to be from Black/African/Caribbean/Black British or mixed/multiple ethnicities.

Of adults with learning disabilities whose deaths were reported to a coroner, approximately half had a post-mortem examination and a third had an inquest opened. These proportions are higher than the proportion of adults and children in the general population[60].
(Table A37, Appendix 1).

Contributory factors leading to deaths of children

The Child Death Review Analysis form includes mention of any relevant factors that may have contributed to the child's death. Four domains are included: factors intrinsic to the child; factors in the social environment including family and parenting capacity; factors in the physical environment; and factors in service provision[61]. For each of the four domains, the level of influence is scored. Here we report factors that are likely to have contributed to vulnerability, ill-health or death in the 638 reports of child deaths from 2018-2020 where this information is available.

Factors intrinsic to the child that contributed to vulnerability, ill-health or death

Most deaths of children were reported to have had one or more factors intrinsic to the child that contributed to vulnerability,

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[59] The following are the circumstances where a death would normally be reported to a coroner: i) There is no doctor who can issue a medical certificate of cause of death ii) The deceased was not seen by the doctor issuing the medical certificate after death nor within 14 days before death iii) The cause of death is unknown iv) The cause of death is believed to be unnatural or suspicious v) The death occurred during an operation or before recovery from an anaesthetic vi) The death was due to industrial disease or industrial poisoning.

[60] It must be acknowledged that we are not comparing like with like here. LeDeR data is pertaining to adults only; coroner's statistics include adults and children.

[61] Child Death Analysis Form. https://www.gov.uk/government/publications/child-death-reviews-forms-for-reporting-child-deaths

ill-health, or death. A quarter, 24% had 'learning disabilities' mentioned as a contributory cause for the death (Table A38, Appendix 1).

Smaller proportions mentioned a chronic long-term illness (23%), or a pre-existing medical condition (21%). 18% were reported to have had an acute sudden illness or the sudden onset of an event that contributed to their death – for almost all of these, the illness or event was the complete explanation for their death.

Other factors considered to contribute to vulnerability, ill-health or death

Smaller proportions of children were reported to have had contributory factors in the provision of care (14%, n=91), the physical environment (13%, n=84), or the social environment (8%, n=50).

The most frequently reported were:

- Issues relating to treatment or healthcare management plan (n=29).
- The child was already receiving palliative care (n=26).
- The child was already known to social services (n=20).
- Consanguinity (n=17).
- Problems with access to healthcare (n=17).

Potentially modifiable factors leading to the deaths of children

The Child Death Review Analysis form reports whether the review of the child's death has identified any factors which may have contributed to the death of the child and which might, by means of a locally or nationally achievable intervention, be modified to reduce the risk of future child deaths. These are called 'potentially modifiable factors'.

68 of the 638 reviews (11%) for which the information was available, identified one or more potentially modifiable factors related to a child's death.

The numbers are small, but the most frequently reported factors (Table A39, Appendix 1 were:

- Aspects of the direct provision of care e.g., lack of appropriate assessment.
- Preventative health measures e.g., parental smoking.
- The responsiveness of health services e.g., early warning signs not responded to appropriately.
- Consanguinity.
- Broader issues e.g., lack of evidence base of particular interventions.

Chapter 6

Indicators of the quality of care provided

Sarah McGreevy, This is me

LeDeR reviewers are asked about several different aspects of the quality of care provided, including any best practice, based on what they learn from the review of the death. The statutory child death review process does not assess the quality of care in the same way, so children aged 4-17 years have been excluded from the analysis.

As in previous reports, here we consider the following for deaths occurring in 2018, 2019 and 2020:

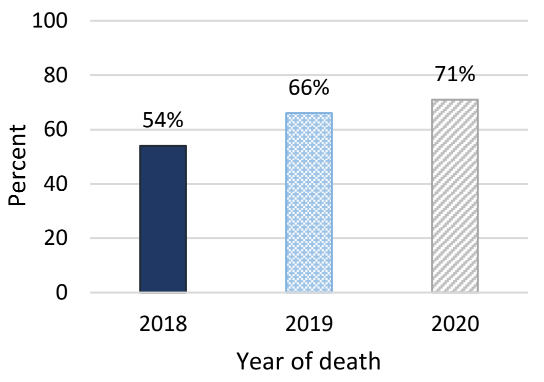
- Examples of best practice provided.
- If there were any concerns about the death.
- If there were any delays in the person's care or treatment that adversely affected their health.
- If there were any problems with organisational systems and processes that led to a poor standard of care.
- If there were any gaps in service provision that may have contributed to the person's death.

Overall, the proportion of reviewers providing examples of best practice increased from 2018 – 2020 and the proportion of completed reviews noting problematic aspects of care decreased.

Examples of best practice

Reviewers are asked, having reviewed the person's death, whether they have identified any best practice and if so, to describe this. Of the deaths that occurred in 2018, 54% (n=1,266) of reviewers gave one or more examples of what they perceived to be best practice. In 2019, this increased to 66% (n=1,640) and in 2020 it was 71% (n= 1,381) (Figure 6.1).

Figure 6.1 Proportion of reviewers providing examples of best practice, by year of death



Many of the descriptions of 'best' practice are what would routinely be expected for a person in receipt of care. One reviewer explained this as:

> *'There is lots of evidence of what I would describe as good practice. I am describing it as best practice as its rarely completed although expected'* (reviewer of death in 2018).

The boundary between what is 'best' practice and what would normally be expected and delivered within the context of relevant local policies and guidelines seems to be variable, and reviewers appeared to have different interpretations of what would be expected to be 'best' practice.

As such, we have not provided quantitative data as to the proportion of reviewers reporting specific aspects of such care. Generally, however, comments about well-coordinated care, person-centred care and being proactive rather than reactive were commonly made.

'The coordination of her health care, (specifically in the last year of her life) as this became more complex, was provided by the specialist community learning disability nurse. This provided clear responsibilities across the care community. This was supported with multiple multi-disciplinary health review meetings, involving many consultants and specialists. The coordination provided by the nurse ensured all elements of need had been considered and communicated across the health system' (reviewer of death in 2018).

'His environment was adapted to meet his changing needs rather than he had to move to have his needs accommodated' (reviewer of death in 2018).

'An autism profile completed by the provider agency specified in detail how to support Bill and ensure his needs as an individual with autism were central to his care and support. This included how to support his specific interests, how to minimise his extensive anxieties and both proactive and reactive strategies for behaviours of concern' (reviewer of death in 2020).

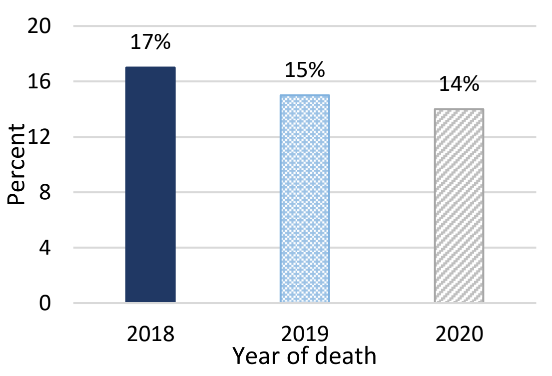
Appendix 4 presents a range of examples of best practice provided by reviewers.

Problematic aspects of care

Problems with organisational systems and processes that led to a poor standard of care

Based on the evidence they had, reviewers were asked if they thought that there were any problems with organisational systems and processes that led to a poor standard of care for the person. Such problems were reported in 17% (n=401) of completed reviews of deaths in 2018, 15% (n=374) in 2019 and 14% (n=279) in 2020 (Figure 6.2).

Figure 6.2 Proportion of reviewers reporting problems with organisational systems and processes that led to a poor standard of care, by year of death



The most frequently reported problems with organisational systems and processes are presented in Table A40, Appendix 1. They were:

1. The coordination of a person's care (20% in 2018; 18% in 2019; 20% in 2020). This was reported more frequently than any other type of problem with organisational systems and processes.
2. Deviation from recognised care pathways or organisational policy (8% in 2018; 9% in 2019; 10% in 2020).

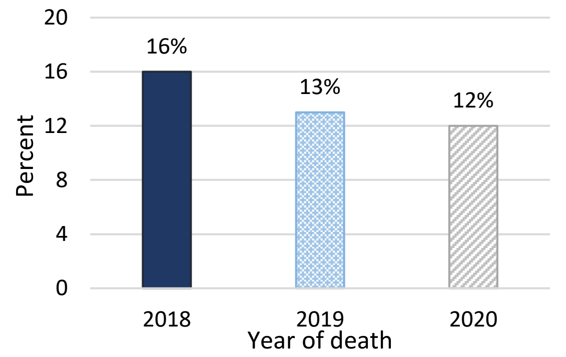
'Care co-ordination was lacking, there was very little co-ordination between acute and community providers and any interactions were based around episodic presentations and focussed on handovers of care. The frequency of admissions, increasing presentations of aspiration or suspected sepsis and issues in relation to capacity to consent to treatment should have triggered a multi-disciplinary approach' (reviewer of death in 2019).

'A referral should have been made in accordance with NICE (2018) guidance on chronic heart failure' (reviewer of death in 2020).

Delays in the person's care or treatment that adversely affected their health

Reviewers were asked if, from the evidence they had, they felt there were any delays in the person's care or treatment that had adversely affected their health. Over the three years from 2018 – 2020 the proportion of people for whom delays in their care or treatment had adversely affected their health reduced from 16% (n=377) in 2018, to 13% (n=329) in 2019 and 12% (n=238) in 2020 (Figure 6.3).

Figure 6.3 Proportion of reviewers reporting delays in the person's care or treatment that had adversely affected their health, by year of death



The most frequently reported causes of delays are presented in Table A41 Appendix 1. They were:

1. The investigation and diagnosis of signs and symptoms (26% of all delays in 2018; 19% in 2019; 19% in 2020).
2. Referral to specialist care (20% of all delays in 2018; 16% in 2019; 15% in 2020). Many of these referrals were for Speech and Language Therapy input or swallowing assessments (21% of delayed referrals in 2018; 11% in 2019; and 15% in 2020). Other delays were referrals to community learning disability teams, neurologists, psychology or psychiatric services, falls clinics, palliative care services, or secondary care clinical specialists.
3. Delays in instigating a treatment plan (16% of all delays in 2018; 12% in 2019; 12% in 2020). A wide variety of treatments were reported to have been delayed, including initiating antibiotics and other treatments.

'Breast lump found by carer in March, referred under 2-week rule, however needle biopsy not undertaken until July, a delay of almost 4 months' (reviewer of death in 2018).

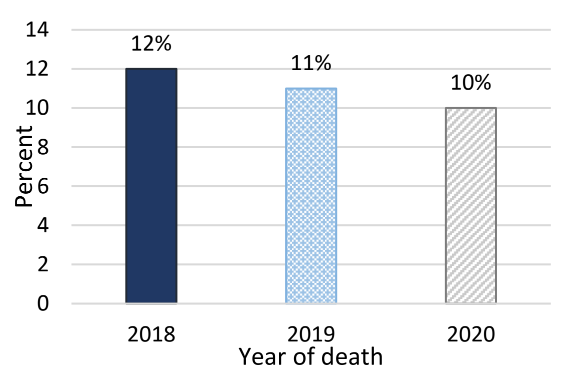
'Although there was a care plan in place to say that Andrew was at risk of choking and all food should be cut up into small pieces…there was no speech and language review of his swallow, or speech and language guidance in place' (reviewer of death in 2020).

'The severity of the acute kidney injury could have been avoided during his last admission if he had been catheterized and given more IV fluids in a timely manner' (reviewer of death in 2019).

Concerns raised about a death

Concerns about a person's death mentioned at the notification of the death or during the review process reduced between 2018-2020. Concerns were raised in 12% (n=275) of completed reviews of deaths in 2018, 11% (n=276) in 2019 and 10% (n=192) in 2020 (Figure 6.4).

Figure 6.4 Proportion of concerns raised about a death, by year of death



Families raised concerns in more than a third of the deaths for which this information was available (35% in 2018; 38% in 2019; 42% in 2020), underlining the importance of proactively providing families with the opportunity to raise any concerns. (Table A42, Appendix 1).

Many of the concerns were addressed as part of the review process, and some of those who had raised concerns felt that these had been addressed and allayed:

‘Care provider has shared with me her views…following discussions and my explanations of the facts….[she] informed me that she is now satisfied that everything possible was done for this patient. [Care provider] also informed me that she has had unanswered questions in her mind for the last two years and our discussions have allowed her to finally put her mind at rest and she thanked me for my contact’ (reviewer of death in 2018).

Other concerns prompted a referral to a coroner or to a Safeguarding[62] team when this might not otherwise have happened:

‘Her nephew and carer have concerns as to whether care at the nursing home immediately prior to her death may have contributed to her death and have questioned whether if Ms. Andrei had received better care she may have lived longer. A safeguarding enquiry fully investigated the concerns raised by family and carer [and] found partially substantiated safeguarding concerns but that this did not necessarily lead to her death’ (reviewer of death in 2018).

The most frequently reported concerns in each year were in relation to:

1. The perceived quality of care provided (40% of all concerns in 2018; 44% in 2019; 50% in 2020) (Table A43, Appendix 1). Although different aspects of the quality of care were mentioned, concerns about safe discharges from hospital were frequently raised each year.
2. Perceived late diagnosis and treatment of the person (17% of all concerns in 2018; 23% in 2019; 24% in 2020).

‘The family were dissatisfied with the [hospital] discharges which they perceived as premature when the person was clearly still very ill on returning home. In [his sister’s] words he was 'sent in - sent home' and 'sent in - sent home' which concerned the family’ (reviewer of death in 2020).

‘Abdul’s mother and brother said that no one was really listening to their concerns and they felt like a pendulum swinging back and forth between the GP, dietician and gastroenterology. They believe that if he had been seen by gastroenterology sooner he may not have developed aspiration pneumonia and may still be alive today’ (reviewer of death in 2018).

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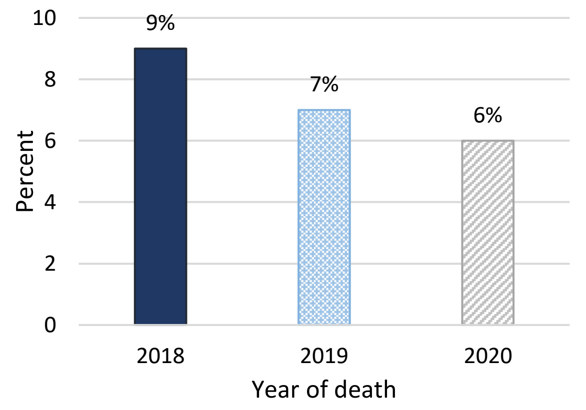
[62] Safeguarding reports must be made if it is thought that a person is being abused or neglected. See: https://www.england.nhs.uk/safeguarding/

Gaps in service provision that may have contributed to the person's death

Gaps in service provision that may have contributed to the person's death have reduced between 2018-2020. Such gaps in service provision were reported in 9% (n=208) of completed reviews of deaths in 2018, 7% (n=164) in 2019 and 6% (n=117) in 2020 (Figure 6.5).

Figure 6.5 Proportion of reviewers reporting gaps in service provision that may have contributed to the person's death, by year of death



Many of the gaps described by reviewers related to deficiencies in an individual's care that have been mentioned elsewhere, such as delays in the person's care and treatment. Here we only consider gaps in the availability or provision of a particular service which may have contributed to the person's death. The most frequently reported gaps in service provision are presented in Table A44, Appendix 1. They were:

1. Staff availability, skills or training other than in specialist learning disability services (10% in 2018; 7% in 2019; 12% in 2020).
2. The availability of specialist learning disability services (8% in 2018; 4% in 2019; 2% in 2020). Many of the gaps described were in relation to the inclusion or exclusion criteria of a particular services, or of their geographical boundaries.

'The provider had no commissioned requirement for epilepsy training, for an epilepsy risk assessment or a care plan. No staff had undergone any training to enable them to recognise the seriousness of this condition' (reviewer of death in 2019).

'There is a learning disabilities nurse at X hospital however they do not cover patients from Y area' (reviewer of death in 2018).

Overall assessment of the quality of care

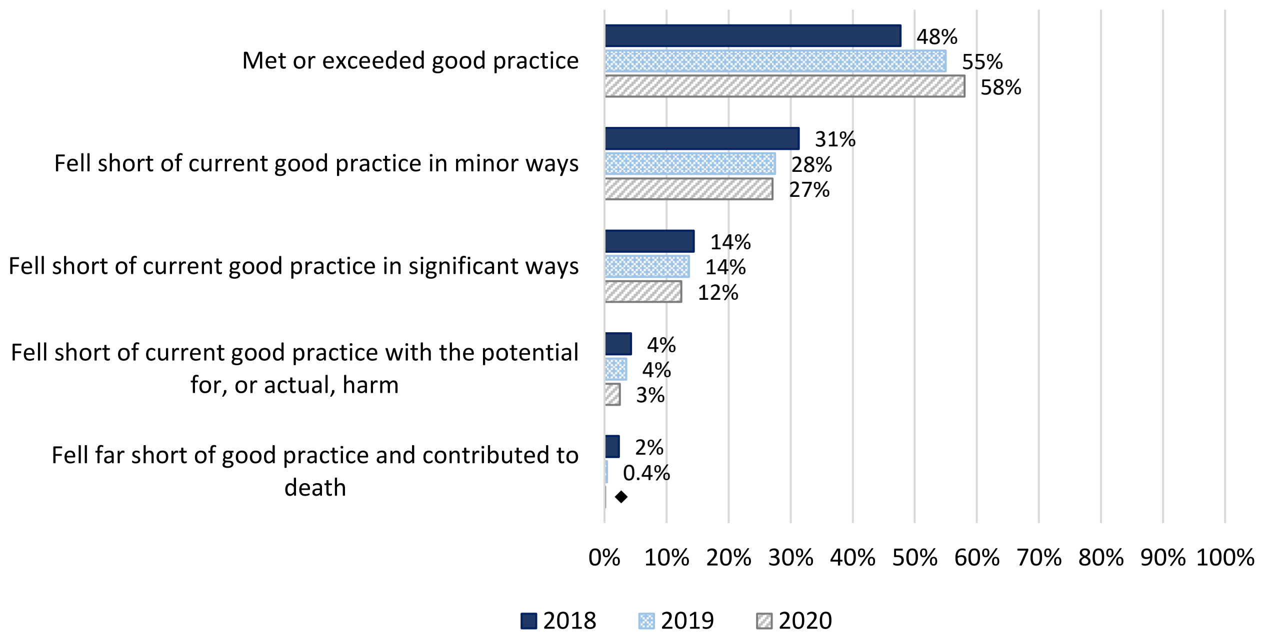
At the end of their review, having considered all the evidence available to them, reviewers are requested to provide an overall assessment of the quality of care provided to the person.

The grading is as follows:

1. Care met or exceeded good practice.
2. Care fell short of current good practice in one or more minor areas, but this did not significantly impact on the person's well-being.
3. Care fell short of expected good practice in one or more significant areas, but this did not significantly impact on the person's well-being.
4. Care fell short of expected good practice and this significantly impacted on the person's well-being and/or had the potential to contribute to the cause of death.
5. Care fell far short of expected good practice and this contributed to the cause of death.

Figure 6.6 presents the reviewer assessment of the quality of care provided to adults with learning disabilities whose deaths were reviewed in 2018, 2019 and 2020.

Figure 6.6 Reviewer assessment of the quality of care provided for deaths of adults occurring in 2018, 2019 and 2020



There has been a steady increase in the proportion of reviewers who felt that a person's care met or exceeded good practice from 2018 to 2020. In 2018, the proportion of reviewers reporting this was 48%; it had risen to 58% in 2020.

Although this is encouraging, it still means that in 2020, 42% of reviewers felt that the person's care had not met good practice standards.

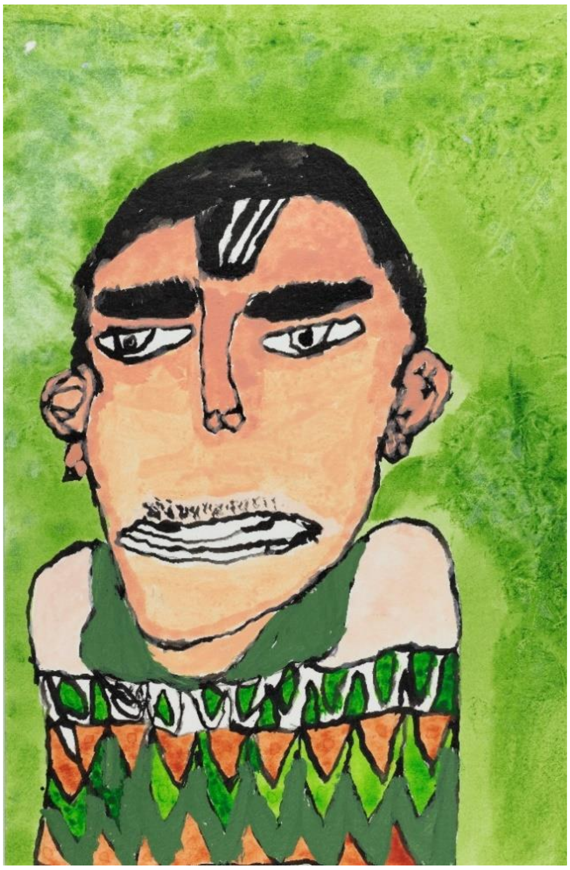
We modelled[33] the likelihood of which factors were associated with someone receiving the poorest quality of care (care that fell short of current good practice with the potential for, or actual harm, or where it contributed to the person's death). The variables we took account of in the model included age group, gender, ethnicity, level of learning disabilities, usual living arrangements, indices of multiple deprivation, if the person was in an out-of-area placement, and if the person had been subject to restrictive legislation (through mental health or criminal justice system involvement) in the 5 years before they died.

The model fit, however, was poor and only explained a very small amount of the variation. None of the variables considered in the model significantly increased the likelihood of receiving the poorest quality of care.

Being aged 50-64 years or 65 years and over or having moderate or profound/multiple learning disabilities were weakly associated with a lower likelihood of receiving the poorest quality of care.

Chapter 7

Deaths of people from minority ethnic groups



Nicholas Selway, A portrait of me

In our annual report for 2019 (published in 2020) we noted that the LeDeR programme did not yet have sufficiently good epidemiological evidence about the contributory factors leading to deaths of people from minority ethnic groups because of the small number of deaths in some groups.

We recommended that a continued focus on the deaths of all adults and children from minority ethnic groups was required, both in the LeDeR programme itself and in other mortality review programmes and service improvement initiatives.

In this chapter we consider the available information from the LeDeR programme for children and adults who died between 2018-2020 with a focus on ethnicity. We have merged the data for the years 2018, 2019 and 2020 to provide greater numbers in those groups where there are few deaths each year.

Despite merging three years of data, the number of adults and children in some ethnic groups is very small so, for the remainder of this chapter, we have focused on five aggregated ethnic group categories (White; Asian/Asian British; Black/African/Caribbean/ Black British; Mixed/multiple ethnicities; 'Other' ethnic groups). Specific ethnic groups are included only when they differ from the broad category by more than 5%.

Nevertheless, the number of people in minority ethnic groups is very small compared to the large number of people in the white British group. Comparison between these ethnic groups is not robust, so findings must be considered indicative rather than conclusive.

This chapter has several large tables of data which indicate the availability or otherwise of data. Those indicating key differences between people have been retained in the text below; others are in Appendix 1.

Number of deaths

We have already seen on p. 20 the person's ethnicity was reported for a total of 531 deaths of children and 8,054 of adults between 2018 and 2020.

Table 7.1 details the number of adults and children from different ethnic groups who died between 2018 and 2020 and are the focus of this chapter. Numbers fewer than 10 have been suppressed, as elsewhere in this report.

Compared to English census data of 2011, there was a greater proportion of deaths of people with learning disabilities from a white British ethnic group (92%) reported to the LeDeR programme than are in the general population (85.4%). It is likely that this represents under-reporting of deaths of people from minority ethnic backgrounds rather than a greater proportion of deaths amongst people from white British ethnicity.

The proportion of people with learning disabilities from all other ethnic groups was less than that in the general population, particularly so for Asian/Asian British people (4.7% of deaths of people with learning disabilities compared to 7.8% of people in the general population).

94% of deaths of adults were of white British ethnicity, compared to 63% of children. 4% of deaths of adults were of Asian/Asian British ethnicity, compared to 24% of children.

Table 7.1 Ethnicity of children and adults who died in 2018-2020 and whose deaths were notified to the LeDeR programme, with a comparison to general population data

Ethnic group	LeDeR data				England General Population (2011) %[63]
	Adults No. (%)	Children No. (%)	Total No.	Total %	
White	7,573 (94%)	335 (63%)	7,908	92%	85.4%
White British	7,426	304	7,730	90%	79.8%
White Irish	42	◆	45	0.5%	1.0%
White Gypsy or Irish Traveller	11	◆	14	0.2%	0.1%
Any other White Background	94	25	119	1.4%	4.6%
Asian/Asian British	280 (4%)	127 (24%)	407	4.7%	7.8%
Indian	85	21	106	1.2%	2.6%
Pakistani	115	71	186	2.2%	2.1%
Bangladeshi	29	11	40	0.5%	0.8%
Chinese	◆	◆	11	0.1%	0.7%
Any other Asian background	43	21	64	0.7%	1.5%
Black/African/Caribbean/ Black British	144 (2%)	41 (8%)	185	2.2%	3.5%
Black African	30	25	55	0.6%	1.8%
Black Caribbean	94	◆	103	1.2%	1.1%
Any other Black background	20	◆	27	0.3%	0.5%
Mixed/Multiple ethnicities	49 (1%)	23 (4%)	72	0.8%	2.3%
White and Black Caribbean	20	◆	24	0.3%	0.8%
White and Black African	◆	◆	◆	◆	0.3%
White and Asian	◆	◆	15	0.2%	0.6%
Any other mixed/multiple ethnicities	17	◆	26	0.3%	0.5%
Other ethnic groups	◆	◆	13	0.2%	1%
Arab	◆	◆	◆	◆	0.4%
Any other ethnic group	◆	◆	10	0.1%	0.6%
Column total No. †	*8,054*	*531*	*8,585*	*100%*	*100%*

†Ethnicity was not recorded for 525 people.

Nagina and her family moved to the UK from Kenya when Nagina was an adult. She would often say “when I go back to Nairobi…”. Nagina lived with her family until the last few years of her life when her support needs increased, and she moved to a care home.

Demographic characteristics

Gender

Table 7.2 shows the gender of children and adults who died from 2018-2020 by ethnicity.

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[63] https://www.nomisweb.co.uk/census/2011/DC2101EW/view/2092957699?rows=c_ethpuk11&cols=c_sex

Overall, across all ethnic groups, a greater proportion of males than females died. The disparity between deaths of males and females was greatest in people from Black/African/Caribbean/Black British ethnicity (60% males; 40% females).

Table 7.2 Gender of children and adults who died 2018-2020, by ethnicity

Ethnic group	**Adults & Children**				**Adults**				**Children**			
	Male	**Female**	**Other**	**Total No.**	**Male**	**Female**	**Other**	**Total No.**	**Male**	**Female**	**Other**	**Total No.**
White British	57%	43%	◆	7,730	57%	43%	◆	7,426	56%	44%	0%	304
Asian/Asian British	55%	45%	0%	407	55%	45%	0%	280	54%	46%	0%	127
Pakistani	59%	41%	0%	186	62%	38%	0%	115	54%	47%	0%	71
Bangladeshi	65%	35%	0%	40	66%	35%	0%	29	◆	◆	0%	11
Other Asian	45%	55%	0%	64	40%	61%	0%	43	57%	◆	0%	21
Black/ African/ Caribbean/ Black British	61%	40%	0%	185	60%	40%	0%	144	61%	39%	0%	41
Black African	66%	35%	0%	55	63%	37%	0%	30	68%	◆	0%	25
Mixed/Multiple ethnicities	54%	46%	0%	72	49%	51%	0%	49	65%	◆	0%	23
White and Black Caribbean	58%	42%	0%	24	55%	◆	0%	20	◆	◆	0%	◆
White and Asian	◆	73%	0%	15	0%	◆	0%	◆	◆	◆	0%	◆
Other ethnic groups	56%	45%	0%	191	55%	45%	0%	155	58%	42%	0%	36
Column total number†	*4,896*	*3,686*	◆	*8,585*	*4,595*	*3,456*	◆	*8,054*	*301*	*230*	0	531
Column total %	*57%*	*43%*	◆	*100%*	*57%*	*43%*	◆	*100%*	*57%*	*43%*	0%	*100%*

Level of learning disability

As has already been mentioned on pp.20-21, information about the level of learning disabilities was only available for a very small number of children (14% of all child deaths, n=76) for the three years combined, so a meaningful comparison between children and adults is difficult. We noted that based on this limited information, there appeared to be a greater proportion of deaths of children with profound and multiple learning disabilities than adults.

Because of the small number of children for whom the level of learning disabilities is known and the small numbers of children in different ethnic groups, we have excluded children from the analysis below. However, a clear recommendation for the LeDeR programme in the future is to ensure that data about the level of learning disabilities is collected and collated (retrospectively and prospectively) to be able to analyse with more accuracy, the proportion of children from different ethnic groups who have different levels of learning disabilities.

Table 7.3 shows the level of learning disability of adults who died from 2018-2020 by ethnicity, where numbers are sufficient not to be suppressed. Again, it should be noted that the numbers in some categories are small, so where this is the case findings should be treated cautiously.

The proportion of adults with severe or profound and multiple learning disabilities was highest for people from an Asian/Asian British ethnicity.

Table 7.3 Level of learning disability of adults, by ethnicity

Ethnic group	**Mild**	**Moderate**	**Severe**	**Profound/ multiple**	**Total No.**
White British	32%	35%	26%	7%	*6,088*
Asian/Asian British	18%	23%	39%	21%	*233*
Indian	20%	31%	41%	◆	*75*
Bangladeshi	◆	◆	41%	41%	*27*
Black/African/Caribbean/Black British	29%	30%	27%	14%	*123*
Mixed/Multiple ethnicities	26%	◆	40%	◆	*43*
Other ethnic groups	25%	33%	30%	11%	*135*
White Irish	◆	43%	28%	◆	*40*
Column total No.†	*2,092*	*2,247*	*1,756*	*527*	*6,622*
Column total %	*32%*	*34%*	*27%*	*8%*	*100%*

†Of those adults whose ethnicity is known; the level of learning disability was not recorded for 1,432 adults.

Age at death

Table 7.4 shows the age group at death of children and adults who died in 2018-2020 by ethnicity.

Table 7.4 Age at death of children and adults, by ethnicity

Ethnic group	**4-17 yrs**	**18-24 yrs**	**25-49 yrs**	**50-64 yrs**	**65 yrs and over**	**Total No.**
White British	4%	3%	15%	36%	42%	7,730
Asian/Asian British	31%	12%	32%	17%	7%	407
Indian	20%	◆	37%	21%	19%	106
Pakistani	38%	16%	30%	15%	◆	186
Bangladeshi	28%	30%	40%	◆	0%	40
Other Asian	33%	◆	27%	27%	◆	64
Black/African/Caribbean/Black British	22%	11%	27%	35%	5%	185
Black African	46%	20%	27%	◆	◆	55
Black Caribbean	◆	◆	27%	50%	◆	103
Mixed/Multiple ethnicities	32%	◆	24%	31%	◆	72
White and Black Caribbean	◆	◆	◆	46%	0%	24
Other ethnic groups	19%	6%	14%	25%	36%	191
White Irish	◆	0%	◆	33%	44%	45
Column total No.	*531*	*287*	*1,400*	*2,979*	*3,388*	*8,585*
Column total %	*6%*	*3%*	*16%*	*35%*	*40%*	100%

4% of deaths of white British people were of 4–17-year-olds, compared to 32% of people from mixed/multiple ethnicities; 31% of people from Asian/Asian British ethnicity; 22% of Black/African/Caribbean/ Black British ethnicity; and 19% of people of ‘other’ ethnic groups.

42% of white British people died aged 65 and over, compared to 7% of people of Asian/Asian British ethnic groups and 5% of people of Black/African/Caribbean/Black British ethnicity.

These differences for age at death are reflected in the median age at death of adults and children from different ethnic groups which are considered in relation to personal characteristics in the following section.

How personal characteristics interact

In Table 2.3 (p. 23) we showed the median age at death in 2018, 2019, and 2020 for people, taking into account their personal characteristics. In that table, because of small numbers for some groups, we grouped people from minority ethnic groups together, and compared them to people of white British ethnicity. In Table A45 Appendix 1, we provide more detail where possible, but please note that caution should be taken in interpreting this data because of the small numbers in some groupings, and the comparison with the larger number of people in the white British group. Due to the small number of children for whom information about level of learning disability is available, we have only considered gender and ethnicity for children.

Overall, as Table A45 shows, adults with the highest median age at death were males and females from ‘other’ ethnic groups (median age 68 for males and 66 for females). Males and females of white British ethnicity and with mild or moderate learning disabilities had a median age at death of 64 years.

Adults with the lowest median age at death were males of Asian/Asian British ethnicity and with profound and multiple learning disabilities (median age of 30 years) and males of Black African/Caribbean/Black British ethnicity and profound and multiple learning disabilities (median age of 33 years).

Male and female children of white British ethnicity had the highest median age at death in children at 11 years. Male children from mixed/multiple ethnicities had the lowest median age in children at 9 years.

Nirvaan died aged 25. He had a congenital disorder, several other health problems and was at high risk of catching infections. Nirvaan communicated using sounds rather than words, and particularly enjoyed sensory experiences, such as feeling different textures, smelling strong scents, looking at sparkly things and feeling the wind in his face. Nirvaan had a sister with the same congenital disorder who had died the previous year.

Age at death and its potential influences, by ethnicity

In this section we consider some different aspects of the lives of people with learning disabilities of different ethnic groups that may affect their age at death. Much of this data is only available for adults for whom a review of their death has been completed.

As we mentioned on p. 31 there are a number of factors that influence the health of people in the general population, including the individual and their own personal characteristics, lifestyle factors, social and community networks, and the more general socio-economic, cultural and environmental conditions in which we live. Not all of these are taken account of in this report. Here, we report on those influences for which we have information.

Long-term health conditions

Table A46, Appendix 1, shows the number of long-term health conditions and additional health needs[64] identified in adults by ethnicity and year of death, where this information was available in completed reviews.

The relatively small number of people from Black/African/Caribbean/Black British ethnicity had fewer long-term health conditions reported than people of other ethnic groups.

Living arrangements

Table A47, Appendix 1, shows the living arrangements for adults by ethnicity.

The proportion reported to be living in their own or the family home was 23% for white British people, 67% of people of Asian/Asian British ethnic groups (84% of Pakistani and Bangladeshi people); 44% of people of Black/African/Caribbean/Black British ethnicity; and 42% of people of mixed or multiple ethnicities.

The differences between people from different ethnic groups in supported living or residential care settings was also notable, with a larger proportion of people from white British ethnicity in these settings than people from other ethnic groups.

We also considered whether the person had been in an 'out-of-area' placement, either in a residential/nursing placement or in a supported living tenancy.

The small proportion of people in an 'out-of-area' placements was greatest for people from mixed or multiple ethnicities (18%). It was 13% for people of Black/African/Caribbean ethnicity; 12% for 'other' ethnic groups; 8% for Asian/Asian British ethnicity; and 7% for white British.

The main source of support

We considered the main source of support received by the person (Table A48, Appendix 1).

Almost half (49%) of people from Asian/ Asian British ethnic groups (rising to 64% of Pakistani people) received their main support from a family member or informal carer. The corresponding proportion for people of white British ethnicity was 14%.

The care provided

Overall, for 91% of deaths in the years 2018 to 2020 reviewers felt that the care package provided met the needs of the individual.

Reviewers considered that the care provided met the needs of 91% of those from white British ethnicity; 90% of people of Black/African/Caribbean/Black British ethnicity; 90% of people from 'other' ethnic groups; 88% of Asian/Asian British people; and 76% of people from mixed/multiple ethnicities.

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[64] Allergies, Cancer, Cardiovascular Problems, Cerebral Palsy, Constipation, Degenerative Condition, Dementia, Dental Problems, Diabetes, DVT, Epilepsy, Falls, Gastric Reflux, Genetic Conditions, Hand Use Impairment, Hypertension, Incontinence, Kidney Problems, Mental Health Needs, Mobility Impairment, Obesity, Osteoporosis, Other Conditions, Prostate Problems, Respiratory Conditions, Sensory Impairment, Skin Conditions, Swallowing Issues/Dysphagia

Prescribed medications

From 2018-2020 the average (mean) number of prescribed medications differed little by ethnic group. People of mixed/multiple ethnicities were prescribed an average (mean) of 6.8 medications (SD = 4.1); people from ‘other’ ethnicity 6.6 (SD = 3.8); white British 6.4 (SD = 3.6); Asian/Asian British ethnicity 6.3 (SD = 3.7); and Black/African/Caribbean/Black British ethnicity 6.2 (SD = 3.6).

There was little difference in the most frequently prescribed medications by ethnic group (Table A49, Appendix 1). Exceptions to this were that Lansoprazole was in the ten most frequently prescribed medications for all groups except people from Black/African/Caribbean/Black British ethnic groups; Levothyroxine was in the ten most frequently prescribed medications for all groups except people from Asian/Asian British ethnicity.

When considering the most frequently prescribed medications by BNF chapter and subchapter and ethnic group (Table A50, Appendix 1), findings suggest differences in prescriptions of specific drugs affecting the central nervous system.

We have already seen in Table A13, Appendix 1 that people from Black/African/Caribbean/Black British ethnic groups were 2.2 times more likely to be prescribed antipsychotic medication, whilst taking account of demographic and other variables. Table A15, Appendix 1 also showed that people from Asian ethnic groups were less likely to be prescribed antidepressants than white British people, once a range of demographic and other variables had been taken into account.

Learning disability annual health checks

Of 5,635 people for whom data was available, the proportion reported to have received an annual health check was 78% for people of Black/African/Caribbean/Black British ethnicity; 78% of those from mixed/multiple ethnicities; 74% of white British; 74% of Asian/Asian British; and 72% of ‘other’ ethnic groups.

Within these aggregated groupings, there was some variation: for example, within the Asian/Asian British grouping, 82% of Indian people had received a learning disability annual health check compared to 65% of Bangladeshi people.

Age at death and its influences

As we have already mentioned, we have only included here a small number of factors that might influence the health of a person.

We presented the findings of a logistic regression model[65] (Table A19, Appendix 1) in which we predicted which of these variables were associated with increased likelihood of dying aged 18-49 years.

Several variables were significantly associated with greater likelihood of dying aged 18-49 years including that:

- People of Asian/Asian British ethnicity had an 9.2 times greater likelihood than people of white British ethnicity.
- People of mixed/multiple ethnicities had 3.9 times greater likelihood than someone of white British ethnicity.
- People of Black/African/Caribbean/Black British ethnic group had 3.6 times greater

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[65] A logistic regression model exploits any association between the dependent and independent variables to predict category membership of the dependent variable. The measure of likelihood used is the ‘odds ratio’. For ease of reading this report we refer to the likelihood of an occurrence.

likelihood than someone of white British ethnicity.

Circumstances of death

Month of death

Figure 7.1 shows month of death by ethnicity. The numbers on the left axis are for people from white British ethnicity; those on the right are for people from minority ethnic groups.

It clearly shows an undulating pattern of the number of deaths; the greater variation in deaths of people from minority ethnic groups is due to the smaller numbers in each group and the different scale of the vertical axis.

The peak in deaths from March to May 2020 was due to deaths from COVID-19. As can be seen, most ethnic groups experienced a peak in deaths during these months, Asian/British Asian, white British, and those from 'other' ethnic groups proportionately more so.

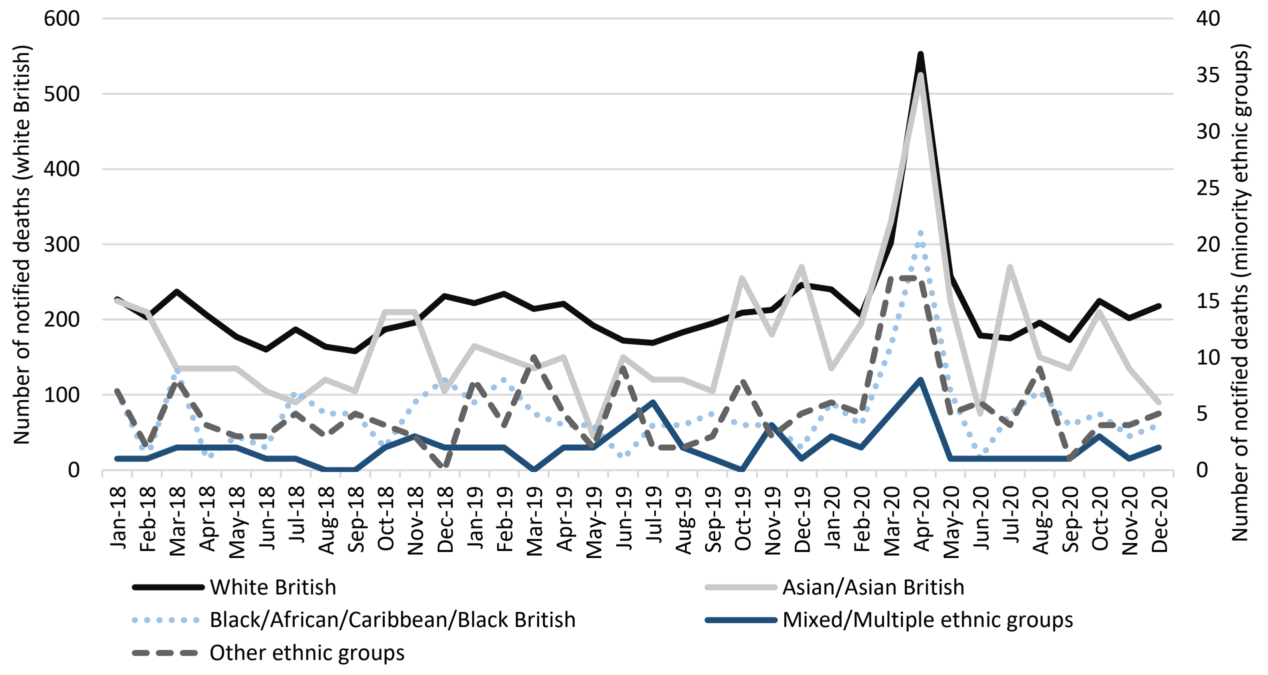
Place of death

For adults and children, there was some variation in place of death by ethnicity (Table A51, Appendix 1).

Those who most frequently died in hospital were people from Asian/Asian British ethnicity (68%), compared to people of Black/African/Caribbean/Black British ethnicity (61%), mixed/multiple ethnicities (59%), white British (58%), and 'other' ethnic groups (55%).

The pattern of adults and children is broadly similar, the most apparent difference being in people of mixed/multiple ethnicities where 74% of children died in hospital compared to 52% of adults.

Figure 7.1 Number of notified deaths by month of death for adults and children with learning disabilities 2018-2020, by ethnicity



Use of Do Not Attempt Cardiopulmonary Resuscitation decisions or decisions to allow a natural death

Almost three-quarters (73%) of people of white British and white 'other' ethnic groups had a DNACPR decision in place at the time of their death (Table 52, Appendix 1). This was more than for any other ethnic group, although is likely to be due to a number of confounding factors.

We saw in Table A33, Appendix 1 that variables associated with increased likelihood of having a DNACPR decision were place of residence, age, level of learning disability and whether the person died from COVID-19 or not in 2020. The ethnicity of a person was not a significant predictor.

Deaths reported to a coroner

The proportion of people whose death was reported to a coroner varied by ethnicity (Table A53, Appendix 1). The numbers in some categories are small, so again, this data must be interpreted cautiously.

Combining data for adults and children, people in minority ethnic groups had their deaths reported to a coroner more frequently than did white British people[66].

Of those from mixed/multiple ethnicities, 47% had their death reported to a coroner, compared to 40% of people from Black African/Caribbean/Black British groups; 35% of people from Asian/Asian British groups, and 'other' ethnic groups; and 27% of white British people.

Once a death had been reported to a coroner, there was little difference by ethnic group as to whether a post-mortem examination was undertaken, or an inquest was opened.

Cause of death

Table A54, Appendix 1 shows the ICD-10 chapter for the underlying cause of death for adults and children with learning disabilities, by ethnicity and year of death. Once again, the numbers in some groups are small so findings need to be treated cautiously. We have merged the data for adults and children for this reason.

Asian/Asian British people were less likely than others to die from disorders of the circulatory system and from neoplasms - but this is likely to be due to an effect of age – circulatory disorders and cancers are predominantly diseases of older age groups.

Asian/Asian British people more frequently died from diseases of the nervous system and endocrine nutritional and metabolic disorders than others.

Most frequently reported conditions causing death reported anywhere in Part I of MCCD

As we have already mentioned, although the underlying cause of death is most frequently used in national statistics, it is instructive to consider those conditions that are mentioned anywhere in Part I of the MCCD[7].

The six conditions most frequently cited in Part I of the MCCD from 2018-2020 for adults and children with learning disabilities for whom we have a verified ICD-10 code for the causes of death and for whom data about ethnicity is available are detailed in Table 7.5 below.

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[66] This is likely to be associated with age at death – comparatively fewer white British people died at young ages.

Table 7.5 The six conditions and ICD-10 codes most frequently cited in Part I of the MCCD 2018-2020, for adults and children, by ethnicity

White British	Asian/ Asian British	Black/African/ Caribbean/Black British	Mixed/multiple ethnicities	Other ethnic groups
Bacterial pneumonia	Bacterial pneumonia	Bacterial pneumonia	◆	Bacterial pneumonia
Aspiration pneumonia	COVID-19	COVID-19	◆	Aspiration pneumonia
Down's syndrome	Aspiration pneumonia	Other disorders of nervous system	◆	COVID-19
Dementia & Alzheimer's disease	Cerebral palsy	Epilepsy	◆	Ischaemic heart disease
COVID-19	Epilepsy	Aspiration pneumonia	◆	Down's syndrome
Sepsis	Acute lower respiratory infection	Cardiac arrest	◆	Epilepsy

◆ signifies that the number is less than 10 and the category name has therefore been suppressed

Table 7.5 indicates:

- Bacterial pneumonia was the cause of death most frequently reported in each of the aggregated ethnic groups.
- Aspiration pneumonia and COVID-19 were frequently reported causes of death for each ethnic group.
- Dementia and Alzheimer's disease was one of the six most frequently mentioned conditions only in white British people.
- Cardiac arrest (a mode of death, not a cause of death, terminology which doctors are advised to avoid using on the MCCD[67]) was one of the six most frequently mentioned conditions only in people of Black/African/ Caribbean/Black British ethnicity.
- Ischaemic heart disease was one of the six most frequently mentioned conditions only in people of 'other' ethnic groups.
- There were no conditions that were reported in 10 or more people of mixed/multiple ethnicities.

Deaths from potentially avoidable medical causes

We looked at the deaths of people from different ethnic groups using the harmonised definition of avoidable mortality and the list of causes of death considered to be avoidable (see p.36 for the definition). As a reminder, the definitions relate to underlying medical causes of death, not an examination of the circumstances leading to death. Thus, these are 'avoidable causes of deaths' not 'avoidable deaths' per se.

Table 7.6 shows the proportion of preventable, treatable and avoidable medical causes of death for deaths occurring from 2018-2020 for which we have the ICD-10 codes for the cause of death. The analysis excludes deaths from COVID-19 which was identified after the harmonised list was finalised. For comparability with data published by ONS, it also excludes people who died after the age of 74.

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[67] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/877302/guidance-for-doctors-completing-medical-certificates-of-cause-of-death-covid-19.pdf

Table 7.6 Preventable, treatable, and overall avoidable medical causes of death in adults and children (ages 4 – 74), by ethnicity

Ethnic group	Preventable		Treatable		Overall avoidable	
	No.	%	No.	%	No.	%
White British	1,274	23%	2,170	39%	2,839	51%
Asian/Asian British	50	16%	114	36%	139	43%
Black/ African/Caribbean/Black British	26	19%	60	44%	73	54%
Mixed/multiple ethnicities	10	20%	22	43%	26	51%
Other ethnic groups	28	21%	48	36%	63	47%
Total	*1,388*	*22%*	*2,414*	*39%*	*3,140*	*51%*

The proportion of deaths from preventable medical causes is broadly similar across the ethnic groups. There is, however, some difference when considering treatable medical causes of death, although the numbers in some groups are small.

Adults and children from Black/African/Caribbean/Black British ethnic groups, and mixed/multiple ethnicities had a higher proportion of treatable medical causes of death (44% and 43% respectively) than people from other ethnic groups.

Indicators of the quality of care received

LeDeR reviewers are asked about several different aspects of the quality of care provided, including any best practice, based on what they learn from the review of the death. See Chapter 6 for more information about this. We explored whether any aspects of the quality of care provided were specifically related to a person's ethnicity (Table A55, Appendix 1).

Examples of best practice were provided by reviewers in 70% of deaths of people of mixed/multiple ethnic groups; 64% of white British; 61% of Black/African/Caribbean/Black British; 61% of 'other' ethnic groups; and 59% of people of Asian/Asian British ethnicity.

The proportions of deaths where there were problematic aspects of care were higher in minority ethnic groups than in the white British group. The biggest disparity was in relation to concerns about the death, which were raised about 23% of the small number of deaths of people from mixed/multiple ethnicities and 10% of deaths of white British people.

Overall grading of care

At the end of their review, having considered all the evidence available to them, reviewers are requested to provide an overall assessment of the quality of care provided to the person. The grading scale used is described in Chapter 6.

Overall, 53% of people were thought to have received care that met or exceeded good practice, but the proportion was less for Asian/Asian British people at 45% (Table A56, Appendix 1).

Specific learning or recommendations regarding ethnicity

Only two of the recommendations made by multi-agency review panels made specific reference to ethnicity.

Chapter 8

Deaths of adults from COVID-19

Steven Canby, Different coloured head

In July 2020, the Learning Disabilities Mortality Review (LeDeR) programme published a short report describing key information relating to the first 50 completed LeDeR reviews of deaths of adults with learning disabilities whose deaths had been attributed to COVID-19[68]. This was followed by a report published in November 2020 of more detailed analysis (undertaken in September 2020) of the circumstances leading to death for a representative sample of 206 adults with learning disabilities who died from suspected or confirmed COVID-19[69].

In this chapter we update this work by considering adults[70] who died during 2020 and who had COVID-19 included as a cause of death on their Medical Certificate of Cause of Death (MCCD). This includes 718 adults whose deaths were notified in 2020 and for whom we have an ICD-10 code for COVID-19 on the MCCD; and a sub-sample of this group comprised of 476 people for whom a review of their death had been completed. We compare this data with that of adults who had died from other causes in 2020.

Some of the data in this chapter may therefore be slightly different to that in previous reports which were based on deaths from *suspected or confirmed* COVID-19.

The COVID-19 pandemic is still ongoing at the time of writing this report. The deaths reviewed as part of this report are those deaths for which the review was completed by December 2020 and thus deaths from early in the pandemic.

Number and proportion of deaths

During 2020, 3,035 deaths of adults were notified to the LeDeR programme. Of these, 718 (24%) were from COVID-19; 2,317 (76%) were from other causes.

By the end of 2020, LeDeR reviews had been completed for 476 of the 718 deaths (66%) from COVID-19.

The number of deaths occurring each month from January 2018 to December 2020 is shown in Figure 1.1 on p.17.

Figure 8.1 indicates the proportion of deaths of adults with learning disabilities each month from COVID-19[71]. The number of deaths each month is included in Table A57, Appendix 1.

The peak month for deaths from COVID-19 was April 2020, when 59% of all deaths were from COVID-19.

Following the peak in spring and early summer 2020, the proportion steadily rose again from 14% of all deaths in October, to 31% in November and 37% in December.

Ed, died aged 48 from COVID-19 and aspiration pneumonia. He had several long-term health conditions and lived in a residential home. Ed was fond of music - particularly Queen. He had a beautiful smile and a kind nature. Ed was admitted to hospital with COVID-19. It was hoped that he could return home to die but died in hospital before arrangements could be finalised.

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[68] http://www.bristol.ac.uk/sps/leder/news/2020/leder-covid-19-reviews.html

[69] http://www.bristol.ac.uk/media-library/sites/sps/leder/Deaths%20of%20people%20with%20learning%20disabilities%20from%20COVID-19.pdf

[70] Fewer than 10 children died from COVID-19 so their data would be suppressed. This chapter therefore only includes information about adults.

[71] Deaths for which we have an International Classification of Diseases version 10 (ICD-10) code, and COVID-19 was included as a cause of death on the Medical Certificate of Cause of Death (MCCD).

Figure 8.1 Proportion of deaths with COVID-19 included as a cause of death on the MCCD, and those who died from other causes, by month of death in 2020

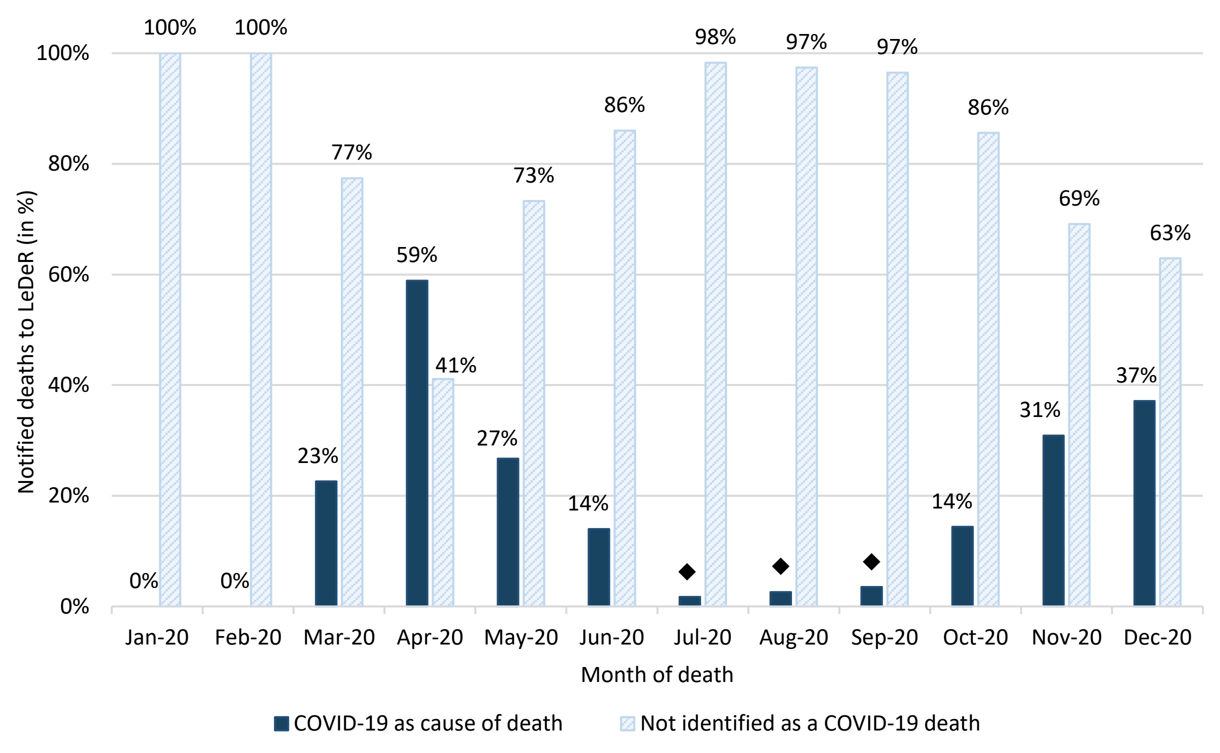

Table 8.1 presents the number and proportion of deaths from COVID-19 and from other causes by geographical region, and with a comparison to general population data.

Table 8.1 The number and proportion of deaths from COVID-19 and from other causes during 2020 by region and comparison with general population data

Region	**Deaths notified to the LeDeR programme**					**General population data (England)**[72]			
	COVID-19		**Other causes**		**Total**	**COVID-19**		**Other causes**	
	No.	%	No.	%	No.	No.	%	No.	%
East of England	81	24%	251	76%	332	7,076	11%	64,553	89%
London	148	38%	243	62%	391	10,820	18%	60,304	82%
Midlands	134	21%	503	79%	637	15,938	14%	118,027	86%
North East & Yorkshire	115	24%	368	76%	483	13,853	15%	93,538	85%
North West	106	25%	320	75%	426	13,596	16%	84,903	84%
South East	95	20%	372	80%	467	10,145	11%	92,295	89%
South West	39	13%	260	87%	299	4,354	7%	61,787	93%
Total	*718*	*24%*	*2,317*	*76%*	*3,035*	*75,782*	*13%*	*575,407*	*87%*

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[72] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/weeklyprovisionalfiguresondeathsregisteredinenglandandwales

In each region, the proportion of deaths of people with learning disabilities from COVID-19 notified to the LeDeR programme was greater than the proportion of deaths from COVID-19 in the general population.

Regional variation was more marked in people with learning disabilities than in the general population. The region with the largest proportion of deaths from COVID-19 in people with learning disabilities was London (38% of all deaths). The region with the smallest proportion was the South West (13% of all deaths).

Demographic information

Table A58, Appendix 1, shows demographic information about adults who died from COVID-19 and those who died from other causes, with comparison data from the general population where it is available.

A greater proportion of males than females with learning disabilities died from COVID-19, more so than in the general population.

As is reflective of the younger age at death for people with learning disabilities, those who died from COVID-19 were largely in younger age groups than people in the general population: 4% of people with learning disabilities who died from COVID-19 were aged 85 and over, compared to 42% in the general population.

Pre-existing health conditions

Autism

In people with learning disabilities, there was no significant difference in the proportion of autistic people who died from COVID-19 (11%, n=51) compared to autistic people who died from other causes (9%, n=131).

Down's syndrome

In people with learning disabilities, a larger proportion of people who died from COVID-19 had Down's syndrome (21%, n=102) than did those who died from other causes (16%, n=238).

Compared to all other people who died from COVID-19 in 2020, people with Down's syndrome who died from COVID-19 were less likely to have dementia, but more likely to be obese[73].

We modelled[33] the likelihood of adults with learning disabilities dying from COVID-19, taking into account a person's age group, gender, ethnicity, level of learning disabilities, usual place of residence, and index of multiple deprivation (Table A59, Appendix 1). This data was available for 1,468 cases (of which 428 were COVID-19 deaths).

Several demographic variables were significantly associated with greater likelihood of dying from COVID-19:

- Asian/Asian British ethnicity (the likelihood was 3 times greater than a white British person of dying from COVID-19).
- Living in a nursing home (2 times greater than someone living in their own or the family home).
- Living in a supported living setting (1.7 times greater than someone living in their own or the family home).

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[73] We do not have information in LeDeR data about under-weight, and thus it's potential as a risk factor for dying from COVID-19. For information about this see: https://pubmed.ncbi.nlm.nih.gov/33592042/

- Living in a residential care home (1.5 times greater than someone living in their own or the family home).

Variables associated with reduced likelihood of dying from COVID-19 included:

- Being female (the likelihood was 0.8 times less than a male).

Long-term health conditions

Almost all (99%, n=469) people with learning disabilities who died from COVID-19 and for whom a review of their death had been completed had three or more long-term health conditions, as did those who died from other causes in 2020 (98%, n=1,438).

Two significant differences were identified in the long-term health conditions of adults who died from COVID-19 compared to adults who died from other causes. Adults who died from COVID-19 were significantly more likely to be obese and less likely to have cancer compared to adults who died from other causes (Table A60, Appendix 1).

The prevention and characteristics of COVID-19 infection

Shielding

If people were identified as at high risk of complications from COVID-19 (the 'clinically extremely vulnerable') they received a letter from their GP, hospital or other health provider advising them to shield themselves from the virus from the beginning of April 2020. Their name was also held in a central list of 'shielded' patients. Those shielding were informed that they should stay at home at all times and avoid all face-to-face contact for a period of at least 12 weeks. Formal shielding measures were paused on 1 August 2020. However, the 'clinically extremely vulnerable' continued to be encouraged to follow strict preventative measures, such as avoiding busy areas and if they could, working from home was strongly advised.[74]

Information about shielding was reported in 63 (13%) completed reviews of deaths of people who had died from COVID-19; it was not provided in the completed review of 413 people (87%). It is therefore not clear from the completed reviews how many people who died from COVID-19 were included in the 'clinically extremely vulnerable' group and were advised to shield.

Where information was available, reviewers reported that 35 people had been placed on the central list of 'shielded patients'; 28 had not received a letter instructing them to shield, but had, nevertheless, been protected as if shielded.

The likely source of COVID-19 infections

Information about the most likely source of COVID-19 infection was provided for 28% (n = 132) of adults who died from COVID-19. Again, such a large amount of missing data makes interpretation of this difficult. Where information was available, reviewers reported that the likely source of infection for 53 people was other residents or staff in their home setting; for 26 people it was a recent hospital stay.

Symptoms of COVID-19

The key symptoms of COVID-19 are a high temperature, a new, continuous cough, difficulty breathing and/or a loss of, or change to, the sense of smell or taste. NHS England

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[74] Up to date guidance can be found at: https://www.gov.uk/coronavirus

reports that most people with COVID-19 have at least one of these symptoms.[75]

Information about the symptoms of illness was available for 64% (n=306) of completed reviews of deaths. Table A61, Appendix 1 shows the most frequently reported.

The most frequently reported symptoms of COVID-19 were a cough (52%), a fever (51%) or difficulty breathing (37%). 9% of those who died had all three symptoms; 32% had two of the symptoms; 47% had one of these symptoms.
None of those who died from COVID-19 were reported to have had a loss of sense of smell or taste, although this is a regularly reported symptom in people in the general population.

Lethargy or tiredness (15%), diarrhoea and vomiting (13%), and loss of appetite (12%), were the next most frequently reported symptoms.

Access to healthcare

Access to healthcare has come under scrutiny during the COVID-19 pandemic. The use of NHS111 online and NHS111's role in responding to calls about COVID-19 added an additional layer of potential complexity for people with learning disabilities. The *COVID-19 rapid guideline: critical care in adults* published by NICE in March 2020[76] recommended the use of a frailty index which disadvantaged people with learning disabilities from accessing critical care. The guideline was changed in April 2020 to clarify that the index ought not be used with people with learning disabilities. We were therefore interested if reviewers reported any problems with accessing healthcare for the people with learning disabilities.

Of the completed reviews of deaths of people who died from COVID-19, 17% (n=80) noted problems that a person had in accessing timely and appropriate healthcare.

Problems in accessing healthcare were varied. The most frequently cited problems were:

- Testing for COVID-19 – both the provision of testing in general, and testing when moving from one setting to another, mentioned in 66%, (n=53) of completed reviews.
- The lack of availability of support from specialist learning disability services (26%, n=21).
- Difficulties in using the NHS111 service, including difficulties getting through to the service, calls not being returned, and the appropriateness of assessments of people with learning disabilities (15%, n=12).

'No testing for COVID-19 was available in the community early in the outbreak of the virus. It would have been crucial for staff and residents to find out if they had the virus in order to take the prescribed action to reduce its spread' (reviewer).

'The learning disability liaison nurse …had limited involvement with Angela to support and advocate for her on her admission to hospital due to the pandemic. They only had telephone and email contact' (reviewer).

'An algorithm is used to prioritise calls to the NHS111 out-of-hours service. Often the subtle signs that are picked up by carers about a deterioration in health is not always identified within the algorithm so may not trigger an alert. COVID-19 has

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[75] https://www.nhs.uk/conditions/coronavirus-COVID-19/symptoms/

[76] https://www.nice.org.uk/guidance/ng159

caused a need to reassess what information is required from individuals contacting the NHS111 service' (reviewer).

The deaths of the people with learning disabilities from COVID-19

Recognition of deterioration prior to death

It is vital that indications that a person's health is deteriorating are detected and recognised promptly, and action is taken to escalate care. NEWS2 is endorsed by NHS England and NHS Improvement as the recognised early warning system for identifying acutely ill and deteriorating patients in hospitals in England. It is also, increasingly, being used in primary care and community settings.

23% (n=69) of people who died from COVID-19 were reported to have had one or more NEWS2 scores recorded. It appeared that some NEWS scores were a single recording to support decision-making and on other occasions, it was the change in a succession of NEWS2 scores that provided an indication of deterioration in a person's health.

Some concerns were raised about the absence of tools used to help recognise signs of deterioration, or the equipment needed for their use (e.g., oxygen saturation monitors or blood pressure machines).

In addition, there were some recommendations made about the need for clearer guidance for families and paid carers about identifying acute deterioration specifically in relation to COVID-19.

'A plan needs to be developed with local authorities to ensure the availability of oxygen saturation equipment and training of staff to use this' (reviewer).

'Develop clear protocols during pandemics for care providers and GPs concerning management of infections for people with learning disability who may be compromised due to co-morbidities and/or lower physiological baselines. This should include provision of monitoring equipment and development of deterioration and escalation tools' (reviewer).

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision[67]

Information about DNACPR decisions for all adults who died between 2018 and 2020 is reported in Chapter 5.

Of those who died from COVID-19, 81% (n=385) had a DNACPR decision. The corresponding proportion in people who died from other causes was 72% (n=982).

Reviewers reported that 69% (n=266) of the DNACPR decisions made in relation to people who died from COVID-19 were correctly completed and followed. The proportion in people who died from other causes was 72% (n=709).

The reasons given for DNACPR decisions not to be correctly completed and followed in people who died from COVID-19 were various, but several reviewers noted that frailty or 'learning disabilities' was given as a rationale[77]:

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[77] On 25 March 2020, NICE clarified that the Clinical Frailty Scale should not be used for younger people, people with stable long-term disabilities, learning disabilities or autism.

'Initial DNACPR completed incorrectly stating learning disabilities as reason for completion. "wheelchair bound, needs to be hoisted, care home resident, learning disability". [This was].. rewritten on the advice of learning disabilities liaison nurse' (reviewer).

Several reviewers also noted that the decision-making process for DNACPR decisions had not adhered to the Mental Capacity Act (MCA).

A community DNACPR…was completed by Jacobs's GP. His nursing care team raised a referral to an Independent Mental Capacity Advocate (IMCA) due to their concerns that the process was not followed using the legal framework for assessing capacity, appointing an Independent Mental Capacity Advocate (IMCA) and involving Jacob in the process' (reviewer).

Place of death

Information about the place of death is available for all deaths, not just those that had been reviewed.

Of the adults with learning disabilities who died from COVID-19, 85% (n=598) died in hospital. This is higher than the proportion of adults (aged 20 years and over) in the general population who died from COVID-19 in hospital (68%)[78]. It is also higher than the proportion of hospital deaths of adults with learning disabilities who died from other causes (52%, n=1,175).

Indicators of the quality of care provided

As already mentioned in Chapter 6, LeDeR reviewers consider several different aspects of the quality of care provided.

Information about the quality of care was available for 476 (66%) people who died from COVID-19 and 1,361 (59%) who died from other causes in 2020 (Table A62, Appendix 1).

The proportion of people receiving care that indicated best practice was similar for people who died from COVID-19 and people who died from other causes. Problematic aspects of service provision were more frequently reported for people who had died from COVID-19.

Examples of best practice

Almost three-quarters (72%) of reviews of people who died from COVID-19, and 71% of reviews of people who died from other causes, indicated examples of best practice at some time in the provision of care. As we mentioned in Chapter 6 many of these examples are what would be reasonably expected in the provision of good quality care.

The main areas in which more than 10% of reviewers reported examples of best practice for people who died from COVID-19 were:

- Taking a person-centred approach to care and support.
- 'Joined-up' working with good communication between those involved.
- The involvement of families.
- Responsiveness to a change in a person's health.

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[78] Deaths registered monthly in England and Wales - Office for National Statistics (ons.gov.uk) https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/monthlyfiguresondeathsregisteredbyareaofusualresidence

> *‘The staff team working with Karl was very consistent and this enabled them to get to know him and his chosen methods of communication very well’* (reviewer).

> *‘There was multi-agency working ongoing throughout Neil’s treatment and care. All agencies and teams would interlink with the other specialist agencies involved ensuring consistency in treatment and care whichever service or hospital was involved at that time. For example, one service contacted the community speech and language therapy team…ensuring the relevant guidelines were up to date following a change in care’* (reviewer).

> *‘[Her] parents were listened to and actively involved in decision-making’* (reviewer).

> *‘Good escalation of concerns when NEWS increased, resulting in prompt administration of IV antibiotics and IV fluids’* (reviewer).

Problems with organisational systems and processes that led to a poor standard of care

The most problematic aspect of care provision appeared to be with organisational systems and processes that led to a poor standard of care. This was the case for 18% of people who died from COVID-19 and 13% of people who died from other causes. The most frequently reported problems for people who died from COVID-19 were:

- The arrangements in hospitals for COVID-testing and protecting patients from transmission of the virus.
- Systems and processes that did not make reasonable adjustments for people with learning disabilities.
- Confusion about national guidance about protecting people from COVID-19.

> *‘When Rebecca was first admitted to hospital, she was told there were no side wards available. As Rebecca was displaying symptoms of COVID-19 she was placed on a ward with three other patients who were COVID positive. Rebecca was tested COVID-negative, and she was discharged…[but]…she had contracted COVID-19 whilst on a ward with others with COVID’* (reviewer).

> *‘Reasonable adjustments should have been considered in terms of allowing the family and/or carers to provide support during his admission to hospital, considering his diagnosis of learning disabilities and communication and behavioural support requirements’* (reviewer).

> *‘Although there was COVID-19 guidance available for supported living and care homes, the professionals in this case feel it was insufficient and left carers unsure what to do in some situations’* (reviewer).

Delays in the person’s care or treatment that adversely affected their health

The second most problematic aspect of care provision for people who died from COVID-19 was delays in the person’s care or treatment that had adversely affected their health. This was identified in relation to 16% of people who died from COVID-19 and 11% of people who died from other causes. The most frequently reported delays were in relation to:

- Diagnosing COVID-19.
- Following treatment plans.

> *‘There was information in the notes to escalate his treatment to ICU, but this was not done’* (reviewer).

'There was no physical examination of Jacqueline due to COVID-19… and it was accepted that she was getting a urine infection as she had had them previously' (reviewer).

Concerns about the death

For 11% of deaths from COVID-19 (9% of people who died from other causes), concerns had been raised about the person's care. These were largely in relation to:

- Concerns about aspects of clinical or nursing care.
- Concerns about hospital discharge arrangements.
- Concerns about COVID-19 transmission.
- Concerns that signs of deterioration were not noticed.

'His family are not sure whether everything was done in hospital to prevent or minimise the risk of Luke dying' (reviewer).

'Aidan was sent home after 4 days in hospital when he had been diagnosed with COVID-19 and was still unwell and very lethargic… When [the care home manager] contacted the hospital on the day of his discharge to express her concerns she was informed the hospital directive was to send all patients home if they were able to maintain own oxygen levels' (reviewer).

'His brother suspects that Alistair may have contracted COVID-19 in the hospital. They were informed by the learning disability nurse that Alistair was COVID-19 positive 19 days after his admission to hospital' (reviewer).

'His increased NEWS (National Early Warning Score) was not responded to on the evening prior to Ryan's death and action not taken at the ward round' (reviewer).

Gaps in service provision that may have contributed to the person's death

A small number of reviewers (7%) of deaths from COVID-19, (6% of people who died from other causes) indicated that there had been gaps in service provision that may have contributed to the person's death. Such gaps were largely in relation to:

- Aspects of clinical care.
- Professional knowledge and skill gaps.

'Due to the COVID-19 pandemic, Samuel was unable to have an x-ray at the hospital, which may have led to him not having early detection and treatment of his pneumonia' (reviewer).

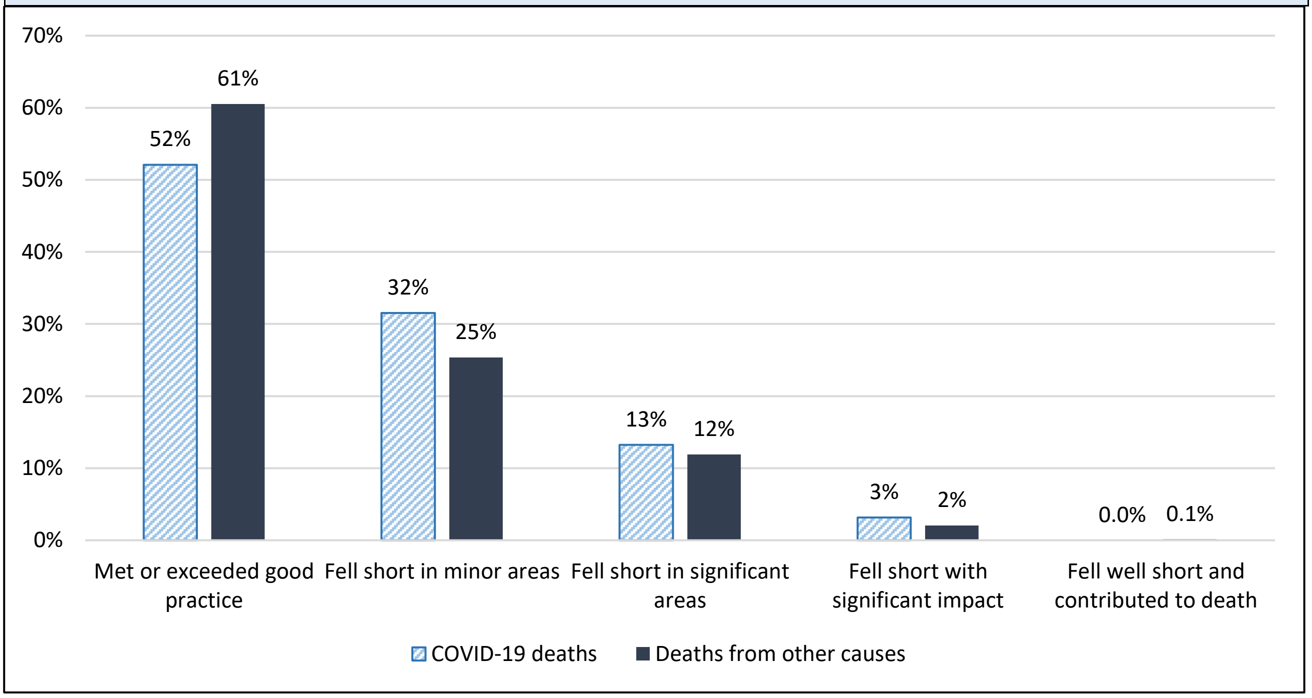
'Staff are not trained to recognise and report physical health-related symptoms' (reviewer).

Overall assessment of the quality of care

At the end of their review, having considered all the evidence available to them, reviewers are requested to provide an overall assessment of the quality of care provided to the person. The grading is as described in Chapter 6.

Figure 8.2 shows the reviewer assessment of the quality of care provided to adults with learning disabilities who died from COVID-19, and those who died from other causes.

Figure 8.2 Reviewer assessment of the quality of care provided for deaths of adults from COVID-19 and from other causes



Care received by 3% of those who died from COVID-19 (and 2% of those who died from other causes) was reported to have fallen so short of good practice it had a significant impact on the person's health or wellbeing or contributed to the cause of death.

For people who died from COVID-19, such poor-quality care was most frequently due to delays in the diagnosis and treatment of illness.

'The NHS 111 records do not evidence a follow-up contact on the evening of [date] at the time when the condition of Benjamin was deteriorating' (reviewer).

'There is no substantial evidence that the residential care staff provided care whilst waiting for the ambulance service' (reviewer).

'The Serious Incident investigation determined that 'diagnostic overshadowing due to COVID-19 led to an unsafe discharge on the scene' (reviewer).

There were differences in the overall assessment of the quality of care for people from different ethnic groups who died from COVID-19. People from a white British background more frequently received care graded as meeting or exceeding good practice (54%), compared to people from minority ethnic groups (48%).

Conversely, people from minority ethnic groups more frequently received care graded as falling short of good practice in minor (34%) or significant (15%) ways compared to white British adults (31% and 12% respectively).

Broader impacts of COVID-19 on the lives of people with learning disabilities

A range of broader impacts of the COVID-19 pandemic were mentioned in completed reviews. These were predominantly in relation to four key issues:

- Restrictions on face-to-face visits or contact.
- Delays in the provision of clinical care, particularly hospital admissions for both routine and emergency care, and the closure of social care facilities.
- An impact on the physical and mental health of people with learning disabilities.
- Poor quality bereavement experiences.

> *'Due to guidelines his mother was unable to visit Brian. Face-to-face discussion with professionals may have resolved any concerns from [his mother] and established her understanding of his condition and prognosis'*

> *From January, Ms Johnson experienced rectal bleeding; she was due to have an appointment to assess this at the hospital however this was cancelled due to COVID-19'* (reviewer).

> *'His constipation was reported to have become very problematic during COVID-19 lockdown which Ollie's GP had attributed as secondary to reduced movement…Ollie was unable to attend his day service… which provided movement and exercise which had a positive impact on his bowel movement'* (reviewer).

> *'Eddie's wife …said that when Eddie passed away, she didn't get a chance to say goodbye, and this was very hard for her… at that time there was a 'no visitors allowed' policy… News that Eddie was unlikely to survive was delivered over the phone to Eddie's wife and not face-to-face'* (reviewer).

Other broader impacts of the COVID-19 pandemic were in relation to the closure of day services, delays to existing plans, the isolation of people with learning disabilities, and an increase in clinical responsibilities for family and paid carers.

Recommendations from reviewers and suggestions for service improvement

A number of COVID-19-specific recommendations to improve service provision were made by reviewers. Table 8.2 shows a selection of them, loosely grouped together in themes.

The main themes of the recommendations made by reviewers were relating to:

- Clinical assessment and the provision of care.
- Preventative measures.
- The provision of reasonable adjustments.
- Strategic policy and planning.

Table 8.2 Selection of reviewers’ recommendations related to COVID-19

Clinical assessment and provision of care

'Develop a specific deterioration tool for use in care home settings when COVID-19 is suspected’.

'Often the subtle signs that are picked up by carers about a deterioration in health are not always identified within the algorithm [used to prioritise calls to NHS111] so may not trigger an alert’.

'Develop clear protocols during pandemics for care providers and GPs concerning management of infections in people with learning disabilities who may be compromised due to co-morbidities and/or lower physical baselines'.

'Explore if thresholds for referral into hospital for patients with learning disabilities with suspected COVID-19, need to be different from the general population taking into account differing physiological baselines’.

Preventative measures

‘In a pandemic involving an infectious disease, there should be clear guidelines for use of Personal Protective Equipment (PPE) and good infection control for vulnerable people, including those with a learning disability, in all care and supported living accommodation. Sufficient PPE should be available for all. Residents, relatives and staff must be confident of safety measures’.

‘In pandemic situations, professionals should actively consider the potential for a patient to have the virus, even if symptoms are atypical, and early preventative measures should be put in place’.

‘Process is needed to ensure that patients moving from a ‘hot’ COVID-19 area are no longer COVID-19 positive, to reduce risk of cross-contamination and risks to other patients and staff’.

‘All…providers should have access to an oximeter'.

'Request to be made…for earlier screening of staff…should similar circumstances recur'.

Provision of reasonable adjustments

‘There is a requirement for a range of considerations to ease interventions in patients with learning disabilities who during a pandemic such as COVID-19 are additionally distressed by an unfamiliar environment, away from the familiar and reassuring faces of family members or carers’.

'COVID wards to enable learning disability liaison [nurse] presence…to increase support to staff to provide a high quality of care'.

‘In the event of a potential second wave of COVID-19, hospitals should make reasonable adjustments for visitors to be with a relative’.

‘When using PPE recognise the need to adjust communication to counteract the inability to see facial expressions, accommodate changes in speech and take into account hearing or visual loss in patients with learning disabilities’.

Strategic policy and planning

‘A county wide strategy is needed for people with learning disabilities…which covers all aspects of managing a pandemic in community settings’.

‘An 'emergency allowance' [should be] built into care packages where foreseeable difficulties may arise'.

'Risk analysis to be in place to manage episodes of high levels of staff sickness with a strategy on where to recruit short term staff '.

'Providers should ensure they have appropriate contingency plans and additional sources of equipment in the event of equipment breaking or high demand'.

Chapter 9

Summary and recommendations

Peter Sutton, Flower

This year's report focuses on findings from completed reviews of the deaths of people with learning disabilities that occurred in the calendar years 2018, 2019 and 2020, identifying any trends that have occurred over time, and considering implications for service improvement. We acknowledge that 2020 was an 'unusual' year because of the COVID-19 pandemic and for this reason, comparisons of 2020 data with those of previous years should be interpreted with this caution in mind.

When reading the findings of this report it should be kept in mind that the LeDeR programme is not mandatory so does not have complete coverage of all deaths of people with learning disabilities, that some data is missing, particularly data relating to children, and that numbers in some sub-categories are small so must be interpreted with caution. Findings must be considered indicative rather than conclusive.

We discussed the key findings included in the report with a consultation group of people with learning disabilities (with whom we met twice), and family members. We also consulted with a range of other people with specific expertise or an interest in particular aspects of the findings. We would like to thank everyone who has helped in this way.

As we reported in our previous annual report, the key to providing good quality support appeared to be the provision of proactive and responsive, well-coordinated, person-centred care. We need to move more quickly to this being the reality for people with learning disabilities and their families, and to make sure that services embed this in their organisational systems and processes.

There are some early indicators of improvements in the care of people with learning disabilities between 2018 and 2019:

- The median age at death has increased by one year for deaths occurring between 2018 and 2020.
- There is an encouraging picture of an overall reduction in the proportion of preventable, treatable and overall avoidable medical causes of death of adults and children with learning disabilities between 2018 and 2020 (although it remains considerably greater than for people in the general population).
- The proportion of reviewers providing examples of best practice has increased between 2018 and 2020.
- The proportion of reviewers noting problematic aspects of care decreased slightly between 2018 and 2020.
- There has been a steady increase between 2018 and 2020 in the proportion of reviewers who felt that a person's care met or exceeded good practice.

However, there are also indications that such improvements are not felt across all aspects of service provision or groups of people with learning disabilities:

- There are indications of significant inequalities in the experiences of people from minority ethnic groups compared to white British people, although the small numbers in some groups mean that the data must be interpreted cautiously:
  - Fewer deaths of people from minority ethnic groups were reported to the LeDeR programme than would be expected.
  - 32% of deaths of people from mixed/multiple ethnicities were of 4–17-year-olds, compared to 31% of people

    from Asian/Asian British ethnicity; 22% of Black/African/Caribbean/Black British ethnicity; 19% of people of 'other' ethnic groups and 4% of white British.
  - Adults of Asian/Asian British ethnicity had an 8 times greater likelihood of dying in early adulthood (aged 18-49 years) than people of white British ethnicity. People from Black/African/Caribbean/Black British ethnic groups, and of mixed/multiple ethnicities, had a likelihood over 4 times greater.
  - Adults with the lowest median age at death were males of Asian/Asian British ethnicity and with profound and multiple learning disabilities (median age of 30 years) and males of Black African/Caribbean/Black British ethnicity and profound and multiple learning disabilities (median age of 33 years).
  - Male children from mixed/multiple ethnicities had the lowest median age at death in children at 9 years.
  - The care provided met the needs of 88% of Asian/Asian British people and 76% of those from mixed/multiple ethnicities. For other ethnic groups, it was 90% or more.
  - Cardiac arrest (a mode of death which doctors are advised to avoid using when reporting a cause of death on the MCCD) was one of the six most frequently mentioned conditions on the MCCD of people of Black/African/Caribbean/Black British ethnicity.
  - Adults and children from Black/African/Caribbean/Black British ethnic groups, and people from mixed/multiple ethnicities had a higher proportion of treatable medical causes of death than other ethnic groups.
  - The proportions of deaths where there were problematic aspects of care were higher in each of the minority ethnic groups than in the white British group. The biggest disparity was in relation to concerns about the death, which were raised about 24% of deaths of people from mixed/multiple ethnicities.
  - 45% of adults from Asian/Asian British ethnic groups were thought to have received care that met or exceeded good practice.
  - Only two of the recommendations made by multi-agency review panels made specific reference to ethnicity.
- The COVID-19 pandemic has highlighted the impact of health inequalities and deficiencies in the provision of care in relation to people with learning disabilities, with rates of deaths of people with learning disabilities more than those of the general population.
- There has been little reduction in the proportion of deaths from bacterial pneumonia or aspiration pneumonia between 2018 and 2019[79].
- A small number of MCCDs still report conditions associated with learning disabilities as the single and only cause of death.
- The proportion of adults with a DNACPR decision at the time of their death has risen slightly between 2018 and 2020. Of those with a DNACPR decision, the proportion that were known by the reviewer to be correctly completed and followed decreased from 2018 to 2020.
- The proportion of deaths of adults and children with learning disabilities known to have been reported to a coroner

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[79] The high proportion of deaths from COVID-19 in 2020 makes direct comparison between this and previous years difficult.

reduced between 2018 and 2019[80] and remains below the proportion in the general population.

- Families raised an increased proportion of concerns about deaths from 2018-2020.
- In 2020, reviewers of 42% of deaths felt that the person's care had not met good practice standards.
- Several variables were significantly associated with greater likelihood of dying aged 18-49 years: being of Asian/Asian British ethnicity, mixed/multiple ethnicities, or of Black/African/Caribbean/ Black British ethnicity; having severe or profound and multiple learning disabilities; being subject to mental health or criminal justice restrictions in the five years prior to death; and not having an annual health check in the year prior to death.

Recommendations to support service improvement

Table 1 in Appendix 5 notes the most frequently reported categories of recommended changes to local practices made by multi-agency panels and reviewers from 2018 – 2020. These incorporate recommendations in relation to care coordination, communication and information sharing, training and the development of staff, person centred planning, proactive care planning, the provision of reasonable adjustments and improvements to documentation and systems. Such recommended changes to local practices are important to remember and action.

Here, we draw out 10 specific recommendations based on the findings of this report.

Deaths of people from minority ethnic communities

Recommendation 1: LeDeR reviews to be undertaken through the lens of greater racial awareness.
(Audience: NHS England).
It is, perhaps, only in looking at the reports of many completed reviews together that we can see so clearly the disparities in deaths of people from different minority ethnic groups. Nevertheless, we have found it astounding that just two recommendations made by multi-agency review panels over the past three years have made specific reference to ethnicity.

Our first recommendation is therefore for LeDeR reviews themselves to be undertaken through the lens of greater racial awareness, at the level of the review of the death itself, by local or regional panels making recommendations for service improvement, and at national level in the Health Improvement Strategy for the Learning Disability and Autism team at NHS England.

We are aware that all deaths of adults from minority ethnic groups will receive a full multi-agency review from June 2021, and welcome this. However, these deaths should not be reviewed in isolation; there is an urgent need for findings and recommendations to be shared and acted upon in a timely way, so that others can learn from them and take appropriate action. Clear leadership for this should be provided at

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[80] The very low proportion of death from COVID-19 that were reported to the coroner makes comparison between this and previous years difficult.

national level, with the national team holding regional areas to account to support this delivery.

Recommendation 2: Local Authorities to ensure that Joint Strategic Needs Assessments (JSNA) collect and publish local data on the health needs of children and adults with learning disabilities, capturing any characteristics that relate to specific ethnic groups. Integrated Care Systems (ICS)[81], and their commissioned Primary Care Networks to take actions to reduce any disparities between people from different ethnic groups when planning local services for people with learning disabilities and their families. Accountability for this to be monitored at regional level, and by NHS England. (Audience: Local Authorities, NHS England and NHS Improvement, ICSs, NHS Race and Health Observatory).

Integrated care systems (ICSs) are new partnerships between the organisations that meet health and care needs across a geographical area. They are required to have a good understanding of data and other intelligence about the health and well-being of all people in their area so they can coordinate services and plan in a way that improves population health and reduces inequalities between different groups[82]. ICSs will agree system-wide objectives with relevant NHS England/NHS Improvement regional directors and be accountable for their performance against these objectives[83]. Our recommendation is therefore for ICSs to consider, and take actions to reduce, the existing disparities between people from different ethnic groups when planning local services for people with learning disabilities and their families, and for accountability to be embedded at regional and national levels.

Recommendation 3: A nationally endorsed standard resource is required, with local flexibility, that provides information for people with learning disabilities and their families about their legal rights and entitlements, national services available and how to access them, and local sources of support. Mechanisms must be in place for its effective distribution, particularly to people from minority ethnic groups.
(Audience: NHS England).

The consultation groups with whom we discussed the findings presented in this report were clear that there needs to be a nationally endorsed, standard resource, with local flexibility, that provides information for people with learning disabilities and their families, particularly people from minority ethnic groups for whom accessing such information may be problematic. The resource should summarise:

- Legal rights and entitlements, and policy guidance (e.g., the provision of ‘reasonable adjustments’; rights to be consulted in decisions made for a person in their ‘best interests’; rights in relation to DNACPR decisions; the role of Medical Examiners etc).
- Universal services available and how to access them (e.g., GP registers of people with learning disabilities; Summary Care

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[81] The NHS Long Term Plan confirmed that all parts of England would be served by an integrated care system. NHS England and NHS Improvement has now asked the Government and Parliament to establish ICSs in law and legislative change is awaited. All recommendations naming ICSs as the audience should be the responsibility of NHS England in the interim.

[82] https://www.england.nhs.uk/integratedcare/what-is-integrated-care/

[83] https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf

Records; learning disability annual health checks; flu vaccinations; genetic testing etc).
- Information about national and local sources of support (e.g., specialist community learning disability teams; hospital learning disability liaison nurses; hospital passports/profiles etc).

We found many examples in the completed reviews of deaths where families from all ethnic groups were not aware of the Equality Act 2010 and the duty for services to provide 'reasonable adjustments', nor of the Mental Capacity Act 2005 which is designed to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment. We saw examples of families appearing to be unaware of potential local sources of support available to them, finding out about services by chance, or not accessing services because they were not tailored to meet their needs.

Our consultation groups of people with learning disabilities and family members agreed that as a starting point, there is a need for a standard national resource that sets out, in clear terms, what people with learning disabilities and their families from any ethnic group could and should expect from services. Such a resource needs to be co-produced with people with learning disabilities and their families, including people from minority ethnic groups.

Mechanisms also need to be in place to ensure its effective distribution to self-advocates, families and carers of people with learning disabilities, particularly those from minority ethnic groups.

Recommendation 4: Strategically planned, long-term, targeted, joint investment is needed to strengthen partnerships with local communities and provide support for peer-to-peer networks, to build on and future-proof existing contacts and structures within local communities and increase trusted word-of-mouth communication and information sharing.
(Audience: Local Authorities, ICSs, Primary Care Networks).

Research suggests that culture and ethnicity play a key role in how learning disability services are perceived and accessed by potential users[84] and services need to do much more in this regard to ensure that they are appropriate for, and available and accessible to people from all ethnic groups. There has been a loss of community link workers due to austerity measures, and a perceived diminishing of investment into local communities, particularly communities of people from minority ethnic groups. The people with learning disabilities and families that we spoke to reflected on the value of having accurate information from a trusted source, and of sharing their experiences with peers who could often provide informal advice about sources of support they were not aware of. Opportunities for peer networks to share information with commissioners so that more responsive services could be provided was also valued.

To address some of the health inequities that are identified faced by people from minority ethnic communities, Local Authorities must provide strategically planned, long-term, targeted, joint investment to build stronger, sustainable and trusted relationships with

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[84] https://www.birmingham.ac.uk/Documents/college-social-sciences/government-society/inlogov/briefing-papers/2012/learning-disabilities-bme-communities.pdf

people with learning disabilities, their families and communities and to champion peer-to-peer supports to help people to access appropriately tailored services that meet their needs.

Deaths of people from COVID-19

Recommendation 5: Local systems, including commissioning, to be responsive and develop strategic plans that address the longstanding needs of people with learning disabilities and their families that the COVID-19 pandemic has illuminated, including the availability of specialist learning disability teams in acute, primary and community care.
(Audience: ICSs).

The COVID-19 pandemic has shone a light on the impact of inequalities and deficiencies in the provision of care on public health outcomes for people with learning disabilities and many long-standing difficulties in relation to the care of people with learning disabilities have been brought to the fore:

- The disproportionate impact of health inequalities on people from minority ethnic groups.
- Problematic or unsafe hospital discharges.
- Diagnostic over-shadowing when diagnosing illness and considering options for the escalation of care.
- Problems with accessing timely and appropriate healthcare, including NHS111, primary and secondary care, and in reliance on digital access to healthcare.
- The importance of communication within and between different care providers and the coordination of a person's care.
- Lack of consideration of the need for 'reasonable adjustments' to existing policies and processes for people with learning disabilities.
- Incomplete learning disability registers held by GPs.
- Learning disability registers held by GPs not always able to differentiate people with different levels of learning disability.
- The importance of Summary Care Records and 'hospital passports' for sharing key information.
- Lack of application of the Mental Capacity Act.
- The vital importance of specialist learning disability liaison nurses in hospitals, yet the patchy availability of this provision.
- The limited availability in some places of Speech and Language Therapists.
- Families not feeling listened to or their concerns acted upon.
- The importance of respite provision for family carers.
- The high rate of use of antipsychotic medication in people with learning disabilities.

We have commented upon many of these aspects of service provision in previous LeDeR programme annual reports and made recommendations about some (see Appendix 6). All of these recommendations still stand.

We were unable to clearly model the factors associated with someone receiving the poorest quality of care, suggesting that variation in local service provision plays a significant role in this. Our recommendation is for place-based systems to address, at strategic level, the long-standing difficulties in the care of people with learning disabilities and their families that the COVID-19 pandemic has illuminated.

Recommendation 6: From the outset of any future public health emergency, the needs and circumstances of people with learning disabilities must be considered and built into national policy and guidance by the National Institute for Health Protection and the Department of Health and Social Care. A data collection tool should be established to capture emerging evidence relating to people with learning disabilities, which would trigger adjustments to policy, guidance, systems and processes as required.
(Audience: National Institute for Health Protection, Department of Health and Social Care, NHS England).

It is clear that the response to the COVID-19 pandemic has not always included or addressed the needs of people with learning disabilities appropriately; they were 'under the radar' of some of the public health measures and messaging until this was challenged. This must not be allowed to happen again. As we have seen, people with learning disabilities were at high risk of death, and specific consideration of their needs was essential.

Our recommendation is that from the outset of any future public health emergency, the needs and circumstances of people with learning disabilities must be considered and built into national policy and guidance by the new National Institute for Health Protection (the successor to Public Health England) and the Department of Health and Social Care. A data collection tool should be established to capture emerging evidence relating to people with learning disabilities, which would trigger adjustments to policy, guidance, systems and processes as required.

Recommendation 7: Commissioning guidance for NHS111 services to include a requirement for the provision of specifically tailored training to NHS111 staff about how to respond appropriately to calls about people with a learning disability or from people with a learning disability and their families.
(Audience: NHS England/NHS Improvement).

We are aware that the Valuing People Alliance (comprised of Learning Disability England, BILD and the National Development Team for Inclusion) is currently conducting a survey to find out how NHS111 is working for people with learning disabilities and their families. We hope that this will provide helpful information about the ways in which NHS111 could build on what currently works well and improve any gaps in provision for people with learning disabilities and their families. The lack of responsiveness at times by NHS111 call handlers to the needs of people with learning disabilities during the COVID-19 pandemic was a cause of extreme concern for us.

The consultation groups of people with learning disabilities and family members with whom we discussed this were clear that improvements need to be instigated now, rather than waiting for the findings of the survey, in case there is a further spike in the COVID-19 pandemic. Our recommendation is that the forthcoming commissioning guidance for NHS111 services must include a specific requirement for the provision of training to NHS111 staff about how to respond appropriately to calls about people with a learning disability or from people with a learning disability and their families. We recommend that such training is designed and delivered in conjunction with people with learning disabilities and their families.

Deaths of children

**Recommendation 8: A LeDeR representative should routinely and as of right be involved with the child death review meeting/process for children with learning disabilities, in order to ensure that necessary information is collected and transferred into the wider LeDeR programme.
(Audience: NHS England).**

The LeDeR programme receives the 'Analysis' form (formerly the 'Form C') from the Child Death Review programme for deaths of children with learning disabilities. This does not routinely include some key demographic information, including the level of learning disabilities of a child[85]. Thus, although there are indications that children from minority ethnic groups have more severe learning disabilities than white British children, we have been unable to quantify this.

We have also been unable to compare the experiences of children with those of adults with learning disabilities in relation to many aspects of the quality of care provided, e.g., if the child was on a GP register of people with learning disabilities; if those aged 14 and over had received an annual health check; if there had been any problematic aspects of care or best practice that could be shared. Our recommendation is for these gaps in the available information to be filled by a LeDeR representative routinely attending the local child death review meetings for all children with learning disabilities.

The current child death review process (revised in 2018) makes a local death review meeting compulsory - involving all professionals involved in the care of the child in life and those involved in investigating the death. Guidance should be issued to Child Death Review Panels nationally for a LeDeR representative to be routinely involved with the local death review meeting for children with learning disabilities in order to ensure that necessary information is collected and transferred into the wider LeDeR programme.

Other aspects of service provision

Recommendation 9: NHS England to collect and collate evidence about the needs and circumstances of people who have been subject to mental health or criminal justice restrictions and use this to inform appropriate, personalised service provision for this group of people. While waiting for this evidence, robust after-care support (as required by S117 of the Mental Health Act) must be provided. (Audience: NHS England, Local Authorities).

A person's ethnicity and level of learning disabilities were significantly associated with a greater likelihood of dying in early adulthood, but so too was having been subject to mental health or criminal justice restrictions in the five years prior to death. Here, the likelihood of dying aged 18-49 years was more than four times greater than for someone who had not been under such restrictions. Several of the deaths concerned were related to suicide in the year or two after such restrictions had been lifted.

The numbers are small but indicate a clear need for consideration about the longer-term needs of people who had been subject to such restrictions and how their needs are

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[85] There has been a supplementary form available to capture specific information about deaths of children with learning disabilities, but this has not been widely used.

met. Further information is required, through research, systematic reviews of existing evidence, and full focused LeDeR reviews of deaths of people who had been subject to restrictive legislation in the five years prior to their death to inform effective service provision for this group of people. However, action is also required now, whilst such information is being collected, to ensure that robust after-care support (as required by S117 of the Mental Health Act) is provided.

Recommendation 10: Progress on actions in response to previous recommendations about minimising the risk of aspiration pneumonia in people with learning disabilities needs to be published. (Audience: NICE, Department of Health and Social Care, NHS England).

The proportion of deaths of people with learning disabilities from aspiration pneumonia changed little between 2018 and 2019, accounting for 16% of deaths of people with learning disabilities in 2019. The proportion in 2020 was masked by the high proportion of deaths from COVID-19. Aspiration pneumonia is categorised by ONS[86] as a preventable medical cause of death.

In our last two annual reports, we have recommended the need for focused guidance about the prevention, diagnosis, and management of aspiration in adults and children (See Appendix 6). The audiences for these recommendations were NICE, the Department of Health and Social Care, and NHS England. We acknowledge that the COVID-19 pandemic may have affected people's ability to progress this work, but it is disappointing that there has not yet been a progress update on the work by some of the agencies involved.

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[86] https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/bulletins/avoidablemortalityinenglandandwales/latest

Appendices

Sarah McGreevy, Two full moons over two houses

Appendix 1: Tables and Figures[87]

Chapter 1: Deaths occurring in 2018, 2019 and 2020

Table A1: The number deaths of people with learning disabilities aged 4 years and over, 2018-2020, by NHS England region

NHS England region	1st Jan. – 31st Dec. 2018			1st Jan. – 31st Dec. 2019			1st Jan. – 31st Dec. 2020			Total No. 2018-2020
	Child 4-17	Adult 18 +	Total	Child 4-17	Adult 18 +	Total	Child 4-17	Adult 18 +	Total	
East of England	21	313	334	22	292	314	16	360	376	1,024
London	22	284	306	36	287	323	35	428	463	1,092
Midlands	42	484	526	55	550	605	38	688	726	1,857
North East & Yorkshire	33	395	428	27	472	499	33	539	572	1,499
North West	36	334	370	36	386	422	20	478	498	1,290
South East	34	444	478	39	413	452	21	516	537	1,467
South West	21	225	246	12	264	276	23	336	359	881
Total No.	*209*	*2,479*	*2,688*	*227*	*2,664*	*2,891*	*186*	*3,345*	*3,531*	*9,110*

Chapter 2: Demographic information about people who died 2018-2020

Table A2: The gender of adults and children, by year of death

Gender	Year of death			Total No.
	2018	2019	2020	
Children and adults				
Males	58%	57%	57%	5,214
Females	42%	43%	43%	3,891
Other	◆	◆	◆	◆
Total No. [+]	*2,688*	*2,891*	*3,530*	*9,109*
Adults				
Males	58%	57%	57%	4,858
Females	42%	43%	43%	3,625
Other	◆	◆	◆	◆
Total No.	*2,479*	*2,664*	*3,344*	*8,487*
Children				
Males	54%	57%	61%	356
Females	46%	43%	39%	266
Other	0%	0%	0%	0
Total No.	*209*	*227*	*186*	*622*

[+] The gender of 1 person is unknown.

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[87] ◆ signifies that the number is less than 10 and has therefore been suppressed

Table A3: The ethnicity of adults and children whose deaths were notified, by year of death

Ethnic group	Year of death			Total No.
	2018	2019	2020	
Adults and children				
White British	91%	90%	89%	7,730
Asian/Asian British	5%	5%	5%	407
Black/African/Caribbean/Black British	2%	2%	2%	185
Mixed/Multiple ethnic groups	1%	1%	1%	72
Other ethnic groups	2%	2%	3%	191
Total number	*2,572*	*2,731*	*3,282*	*8,585*[†]
Adults				
White British	93%	93%	91%	7,426
Asian/Asian British	3%	3%	4%	280
Black/African/Caribbean/Black British	2%	1%	2%	144
Mixed/Multiple ethnic groups	1%	1%	1%	49
Other ethnic groups	2%	2%	2%	155
Total number	*2,400*	*2,537*	*3,117*	*8,054*
Children				
White British	59%	59%	54%	304
Asian/Asian British	26%	22%	25%	127
Black/African/Caribbean/Black British	7%	8%	9%	41
Mixed/Multiple ethnic groups	◆	6%	◆	23
Other ethnic groups	6%	6%	9%	36
Total No.	*172*	*194*	*165*	*531*

[†] The ethnicity for 525 people is missing.

Chapter 3: Potential influences of age at death

Table A4: The number of long-term health conditions in adults, by year of death

Number of long-term health conditions	Year of death						
	2018		2019		2020		2018-2020
	No.	%	No.	%	No.	%	%
0	22	1%	◆	◆	◆	◆	<1%
1-2	124	5%	50	2%	31	2%	3%
3-4	299	13%	144	6%	88	5%	8%
5-6	430	18%	341	14%	278	14%	15%
7-8	495	21%	596	24%	441	23%	23%
9-10	478	20%	596	24%	471	24%	23%
11-12	306	13%	441	18%	395	20%	17%
13 or more	208	9%	303	12%	234	12%	11%
Total No.	*2,362*	*100%*	*2,473*	*100%*	*1,940*	*100%*	*100%*

Table A5: Most frequently reported types of long-term health conditions† for adults, by year of death from 2018-2020, occurring in at least 40% of deaths in any one year								
Year of death								
2018 (n=2,362)			2019 (n=2,473)			2020 (n=1,940)		
Condition	No.	%	Condition	No.	%	Condition	No.	%
Mobility impairment	1,528	65%	Mobility impairment	1,890	76%	Mobility impairment	1,490	77%
Respiratory conditions	1,397	59%	Incontinence	1,658	67%	Incontinence	1,319	68%
Incontinence	1,313	56%	Respiratory conditions	1,582	64%	Respiratory conditions	1,220	63%
Epilepsy	1,175	50%	Skin conditions	1,429	58%	Skin conditions	1,158	60%
Sensory impairment	1,149	49%	Mental health needs	1,384	56%	Sensory impairment	1,122	58%
Mental health needs	1,149	49%	Sensory impairment	1,356	55%	Mental health needs	1,120	58%
Skin conditions	1,081	46%	Constipation	1,351	55%	Constipation	1,062	55%
Constipation	1,075	46%	Epilepsy	1,276	52%	Epilepsy	907	47%
Falls	838	35%	Falls	1,023	41%	Falls	861	44%
Cardiovascular problems	740	31%	Gastric Reflux	848	34%	Gastric Reflux	706	36%
†This excludes the 'Other Condition' category, which was in the top 10 in each year, but is not a specific condition.								

Note: Table A6 is on the following page.

Table A7: Proportion of different types of usual living arrangements of adults, by year of death					
Living arrangements	**2018**	**2019**	**2020**	**2018-2020**	**Total No.**
Residential home	31%	29%	30%	30%	1,821
Supported living	28%	28%	30%	29%	1,731
Own or family	25%	27%	23%	25%	1,519
Nursing home	14%	15%	15%	15%	910
Other	2%	1%	2%	2%	96
Total No.†	*1,671*	*2,470*	*1,936*		*6,077*
†This information is available for adults with completed reviews on IR10[88] (n=6087) and is unknown for 10 adults.					

Table A8: Main form of support adults received prior to their death, by year of death					
Form of support	**2018**	**2019**	**2020**	**2018-2020**	**Total No.**
Paid carer	82%	81%	85%	83%	5,025
Family member/ informal carer	16%	17%	13%	16%	948
None	2%	2%	2%	2%	113
Total No.†	*1,674*	*2,473*	*1,939*		*6,086*
†This information is available for adults with completed reviews on IR10 (n=6087) and is unknown for 1 adult.					

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[88] IR10 is the 10th version of the Initial Review form which was introduced in 2018.

Table A6: The ten most frequently reported combinations of long-term health conditions in adults, by year of death

Year of death											
2018 (n=2,362)				2019 (n=2,473)				2020 (n=1,940)			
Condition 1	**Condition 2**	**No.**	**%**	**Condition 1**	**Condition 2**	**No.**	**%**	**Condition 1**	**Condition 2**	**No.**	**%**
Incontinence	Mobility impairment	1,098	43%	Incontinence	Mobility impairment	1,452	55%	Incontinence	Mobility impairment	1,175	60%
Respiratory conditions	Mobility impairment	1,027	40%	Respiratory conditions	Mobility impairment	1,302	49%	Respiratory conditions	Mobility impairment	1,005	51%
Respiratory conditions	Incontinence	890	35%	Skin conditions	Mobility impairment	1,188	45%	Skin conditions	Mobility impairment	939	48%
Sensory impairment	Mobility impairment	869	34%	Respiratory conditions	Incontinence	1,156	44%	Constipation	Mobility impairment	906	46%
Epilepsy	Mobility impairment	865	34%	Constipation	Mobility Impairment	1,142	43%	Sensory Impairment	Mobility Impairment	905	46%
Constipation	Mobility impairment	828	32%	Sensory impairment	Mobility impairment	1,120	42%	Respiratory conditions	Incontinence	884	45%
Skin conditions	Mobility impairment	827	32%	Skin conditions	Incontinence	1,078	41%	Skin conditions	Incontinence	869	44%
Constipation	Incontinence	779	31%	Constipation	Incontinence	1,070	41%	Mobility impairment	Mental health needs	835	43%
Epilepsy	Respiratory conditions	774	30%	Epilepsy	Mobility impairment	1,059	40%	Constipation	Incontinence	834	43%
Epilepsy	Incontinence	756	30%	Mobility impairment	Mental health needs	1,016	38%	Incontinence	Sensory impairment	793	40%

Table A9: The number of usual medications prescribed, by year of death

Number of medications	Year of death					
	2018		2019		2020	
	People prescribed this (No.)	People prescribed this (%)	People prescribed this (No.)	People prescribed this (%)	People prescribed this (No.)	People prescribed this (%)
0	69	3%	35	1%	30	2%
1	113	5%	102	4%	69	4%
2	161	7%	167	7%	113	6%
3	203	9%	211	9%	182	10%
4	265	11%	276	11%	183	10%
5	256	11%	260	11%	208	11%
6	287	12%	274	11%	255	13%
7	246	11%	265	11%	194	10%
8	184	8%	230	9%	169	9%
9	163	7%	180	7%	143	8%
10 or more	393	17%	445	18%	360	19%
Total No.	*2,340*	*100%*	*2,445*	*100%*	*1,906*	*100%*

Table A10: Categories of the most frequently prescribed[89] usual medications (prescribed for at least 20% of adults) and the number of adults prescribed them, by year of death

BNF Medicine Category (chapter number in parentheses)	2018		2019		2020	
	No.	%	No.	%	No.	%
(4) Central nervous system	**1,957**	**84%**	**2,047**	**84%**	**1,570**	**82%**
Antiepileptic drugs	1,106	47%	1,216	50%	888	47%
Analgesics	752	32%	780	32%	567	30%
Antidepressant drugs	625	27%	683	28%	547	29%
Drugs used in psychoses and related disorders	569	24%	567	23%	452	24%
Hypnotics and anxiolytics	494	21%	562	23%	383	20%
(1) Gastro-intestinal system	**1,622**	**69%**	**1,736**	**71%**	**1,370**	**72%**
Antisecretory drugs and mucosal protectants	1,013	43%	1,066	44%	823	43%
Laxatives	862	37%	934	38%	729	38%
(6) Endocrine system	**1,136**	**49%**	**1,220**	**50%**	**1,012**	**53%**
Drugs affecting bone metabolism	510	22%	549	22%	480	25%
Thyroid and antithyroid drugs	444	19%	450	18%	4	20%
(2) Cardiovascular system	**1,121**	**48%**	**1,199**	**49%**	**1,011**	**53%**
Diuretics	506	22%	531	22%	438	23%
Lipid regulating drugs	505	22%	499	20%	477	25%
(9) Nutrition and blood	**955**	**41%**	**1055**	**43%**	**822**	**43%**
Vitamins	592	25%	636	26%	535	28%
Anaemias and some other blood disorders	445	19%	495	20%	386	20%
(13) Skin	**946**	**40%**	**1028**	**42%**	**803**	**42%**
(3) Respiratory system	**709**	**30%**	**795**	**33%**	**602**	**32%**
(12) Ear, nose and oropharynx	**533**	**23%**	**640**	**26%**	**498**	**26%**

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[89] https://openprescribing.net/bnf/

Table A11: The ten most frequently prescribed usual medications and the number of adults prescribed them, by year of death

2018			2019			2020		
Name of medication	**No.**	**%**	**Name of medication**	**No.**	**%**	**Name of medication**	**No.**	**%**
Valproate	588	25%	Valproate	585	24%	Colecalciferol	493	26%
Colecalciferol	522	22%	Colecalciferol	562	23%	Lansoprazole	458	24%
Levothyroxine	477	20%	Lansoprazole	496	20%	Valproate	450	24%
Lansoprazole	468	20%	Macrogol	477	20%	Levothyroxine	419	22%
Omeprazole	422	18%	Levothyroxine	470	19%	Macrogol	365	19%
Macrogol	397	17%	Omeprazole	441	18%	Omeprazole	319	17%
Paracetamol	372	16%	Paracetamol	420	17%	Paracetamol	304	16%
Carbamazepine	340	15%	Carbamazepine	375	15%	Senna	255	13%
Levetiracetam	311	13%	Levetiracetam	364	15%	Levetiracetam	251	13%
Lactulose	286	12%	Atorvastatin	281	11%	Atorvastatin	249	13%

Table A12: The five most frequently prescribed antipsychotic medications 2018-2020, and reasons for prescribing for cases with available medication data. Reasons occurred in all years, unless noted with a year in brackets.

Name of medication	2018			2019			2020		
	People prescribed this (No.)	% usually prescribed antipsychotic medications	% of all with learning disabilities	People prescribed this (No.)	% usually prescribed antipsychotic medications	% of all with learning disabilities	People prescribed this (No.)	% usually prescribed antipsychotic medications	% of all with learning disabilities
Risperidone	206	36%	9%	189	33%	8%	142	31%	7%
Olanzapine	103	18%	4%	116	20%	5%	88	19%	5%
Quetiapine	65	11%	3%	62	11%	3%	55	12%	3%
Chlorpromazine	63	11%	3%	49	9%	2%	0	0%	0%
Aripiprazole	38	7%	2%	0	0%	0%	45	10%	2%
Haloperidol	0	0%	0%	48	8%	2%	38	8%	2%

Prescribing Reasons

Risperidone	Psychosis/schizophrenia; hallucinations; bipolar disorder/mood stabiliser; depression; anxiety; challenging behaviour; agitation; irritability; obsessive-compulsive behaviour [2018,2019]; autism; sedation; sleep aid [2018,2019]; epilepsy; persistent delusional disorder [2020]
Olanzapine	Psychosis/schizophrenia; bipolar disorder/mood stabiliser; challenging behaviour; agitation; depression; sedation anxiety [2019,2020]; sleep aid [2019]; delirium [2019]; developmental disorder [2019]; hallucinations [2019]; autism [2019]; self-injurious behaviour [2020]
Quetiapine	Psychosis/schizophrenia; bipolar disorder/mood stabiliser; mania; challenging behaviour; agitation; anxiety; depression; sleep aid; irritability; agitation; sedation; autism [2018,2020]; delirium [2019]; paranoia [2019]; hallucinations [2019,2020]; sleep aid; irritability [2019,2020]; sedation [2019,2020]; Parkinson's disease [2020]; hay fever [2020]
Chlorpromazine	Psychosis/schizophrenia; bipolar disorder/mood stabiliser; manage behaviour/challenging behaviour; depression; anxiety; agitation; self-harm [2018]; nausea and vomiting [2018]; sedative [2018]; sleep aid [2019]; hiccups [2019]
Aripiprazole	Psychosis/schizophrenia; bipolar disorder/mood stabiliser; manage challenging behaviour; hallucinations; anxiety [2018]; depression [2018]; self-injurious behaviour [2018]; manage challenging/self-injurious behaviour associated with autism [2018]; schizoaffective disorder [2018]; Tourette's/irritability associated with autism [2020]
Haloperidol	Psychosis/schizophrenia; bipolar disorder/mood stabiliser; hallucinations; challenging behaviour; anxiety; agitation; nausea and vomiting; irritability [2020]; sedation [2020]; hiccups [2020]

Table A13: Binary logistic regression model to predict the likelihood of being prescribed an antipsychotic medication (reference group in parentheses)[90]

Variables	B	Wald	Significance	Odds	Odds 95% Confidence Interval
Mental Health / Criminal Justice System Restrictions (No)					
Yes	1.9	17.9	***	6.5	2.7 - 15.4
Taking Specific Medication (No)					
Taking anti-depressant medication: Yes	1.0	173.3	***	2.8	2.4 - 3.2
Age Groups (18 to 24 years)					
25 to 49 years	0.4	1.7		1.5	0.8 - 2.8
50 to 64 years	0.6	4.3	*	1.9	1 - 3.5
65+ years	0.9	8.4	**	2.5	1.3 - 4.6
Ethnic Groups (White British)					
Asian/ Asian British	-0.1	0.3		0.9	0.5 - 1.4
Black/African/Caribbean/ Black British	0.8	8.4	**	2.2	1.3 - 3.6
Mixed/Multiple ethnic groups	0.6	2.5		1.9	0.9 - 4.2
Other ethnic groups	0.1	0.1		1.1	0.6 - 1.8
Out of Area Placement (No)					
Out of Area Placement: Yes	0.6	25.2	***	1.9	1.5 - 2.5
Learning Disability Level (Mild)					
Moderate	0.0	0.0		1.0	0.8 - 1.2
Severe	0.2	5.6	*	1.3	1 - 1.5
Profound/multiple	-0.7	12.2	***	0.5	0.3 - 0.7
Annual Health Check in Last Year (Yes)					
Health Check in Last Year: No	-0.2	5.6	*	0.8	0.7 - 1
Needs Met (Yes)					
Needs Met: No	0.1	0.4		1.1	0.8 - 1.4
Gender (Male)					
Female	0.0	0.0		1.0	0.9 - 1.2
Index of Multiple Deprivation Quintile (81-100%, Least Deprived)					
1% to 20% (Most Deprived)	0.1	0.6		1.1	0.9 - 1.4
21% to 40%	0.0	0.0		1.0	0.8 - 1.3
41% to 60%	0.0	0.0		1.0	0.8 - 1.3
61% to 80%	-0.1	0.3		0.9	0.7 - 1.2

B is the estimated coefficient in the model. A minus sign indicates that the likelihood of the association is negative.
Wald tests the null hypothesis that the population coefficient is 0. The larger the Wald statistic, the greater the contribution of that variable to the prediction.
Asterisks indicate p-values: *0.05 to 0.01, **0.01 to 0.001, ***less than 0.001.
The measure of likelihood used is the ‘odds ratio’. For ease of reading this report we refer to the likelihood of an occurrence. Odds over 1 indicate a higher likelihood, odds under 1 a lower likelihood, and odds of 1 indicate no change.
Model Summary: Constant=-2.3, Nagelkerke R^2= 0.11, Coefficient Test: $\chi^2(20)=324$, $p<0.001$

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[90] In this Table, and Tables A15, A19, A33 and A59, pink rows signify a statistically significant increased likelihood of the issue under examination. Green rows signify a statistically significant decreased likelihood of the issue under examination.

Table A14: The five most frequently prescribed antidepressant medications 2018-2020, and reasons for prescribing for cases with available medication data. Reasons occurred in all years, unless noted with a year in brackets.

Name of medication	2018			2019			2020		
	People prescribed this (No.)	% of people usually prescribed antidepressant medications	% of all people with learning disabilities	People prescribed this (No.)	% of people usually prescribed antidepressant medications	% of all people with learning disabilities	People prescribed this (No.)	% of people usually prescribed antidepressant medications	% of all people with learning disabilities
Citalopram	157	25%	7%	176	26%	7%	102	19%	5%
Sertraline	123	20%	5%	162	24%	7%	132	24%	7%
Mirtazapine	113	18%	5%	131	19%	5%	122	22%	6%
Fluoxetine	92	15%	4%	90	13%	4%	75	14%	4%
Amitriptyline	54	9%	2%	58	8%	2%	49	9%	3%

Prescribing Reasons

Citalopram	Depression/low mood; anxiety/panic disorder; obsessive compulsive disorder; agitation [2018,2020]; epilepsy [2018,2019]; Fragile X syndrome [2018]; mood stabiliser [2019,2020]; challenging behaviour [2019]
Sertraline	Depression/low mood; anxiety/panic attacks; bi-polar disorder; obsessive compulsive disorder; Asperger’s syndrome [2018]; in place of hormone replacement therapy [2018]; behaviour management [2019]; post-traumatic stress disorder [2019]; Parkinson’s disease [2019]; mood stabiliser [2020]; challenging behaviour [2020]; dementia [2020]; autism [2020]
Mirtazapine	Depression/low mood; anxiety; obsessive compulsive disorder; agitation; sedation; promote appetite [2018,2020]; bi-polar disorder [2019,2020]; sleep aid [2019,2020]; mental health management [2019]; antipsychotic [2019]; challenging behaviour [2020]
Fluoxetine	Depression/low mood; anxiety; mood stabiliser; obsessive compulsive disorder; restlessness [2018]; bulimia [2018]; premenstrual syndrome [2019]; epilepsy [2019]; challenging behaviour [2020]; autism [2020]
Amitriptyline	Depression; anxiety; analgesic; sleep aid; epilepsy [2018]; agitation [2019]; excess salivation [2019,2020]; muscle relaxant [2020]; dementia [2020]

Table A15: Binary logistic regression model to predict the likelihood of being prescribed an antidepressant medication (reference group in parentheses)					
Variables	**B**	**Wald**	**Significance**	**Odds**	**Odds 95% Confidence Interval**
Age Groups (18 to 24 years)					
25 to 49 years	1.0	7.7	**	2.8	1.3 - 5.6
50 to 64 years	1.1	9.6	**	3.0	1.5 - 6.2
65+ years	1.1	9.0	**	2.9	1.5 - 6
Taking Specific Medication (No)					
Taking antipsychotic medication: Yes	1.0	172.8	***	2.8	2.4 - 3.2
Gender (Male)					
Female	0.3	15.4	***	1.3	1.2 - 1.5
Ethnic Groups (White British)					
Asian/ Asian British	-0.5	3.8	*	0.6	0.4 - 1
Black/African/Caribbean/ Black British	-0.6	3.4		0.6	0.3 - 1
Mixed/Multiple ethnic groups	-0.6	1.7		0.5	0.2 - 1.4
Other ethnic groups	-0.4	1.7		0.7	0.4 - 1.2
Learning Disability Level (Mild)					
Moderate	-0.3	11.7	**	0.8	0.6 - 0.9
Severe	-0.8	72.2	***	0.4	0.4 - 0.5
Profound/multiple	-1.2	42.2	***	0.3	0.2 - 0.4
Out of Area Placement (No)					
Out of Area Placement: Yes	0.1	0.4		1.1	0.8 - 1.4
Annual Health Check in Last Year (Yes)					
Health Check in Last Year: No	-0.1	0.5		0.9	0.8 - 1.1
Mental Health / Criminal Justice System Restrictions (No)					
Yes	0.4	1.1		1.5	0.7 - 3.4
Index of Multiple Deprivation Quintile (81-100%, Least Deprived)					
1% to 20% (Most Deprived)	0.1	0.8		1.1	0.9 - 1.4
21% to 40%	0.0	0.0		1.0	0.8 - 1.3
41% to 60%	0.2	2.0		1.2	0.9 - 1.5
61% to 80%	0.0	0.0		1.0	0.7 - 1.2
Needs Met (Yes)					
Needs Met: No	0.1	1.2		1.1	0.9 - 1.5

B is the estimated coefficient in the model. A minus sign indicates that the likelihood of the association is negative.
Wald tests the null hypothesis that the population coefficient is 0. The larger the Wald statistic, the greater the contribution of that variable to the prediction.
Asterisks indicate p-values: *0.05 to 0.01, **0.01 to 0.001, ***less than 0.001.
The measure of likelihood used is the 'odds ratio'. For ease of reading this report we refer to the likelihood of an occurrence. Odds over 1 indicate a higher likelihood, odds under 1 a lower likelihood, and odds of 1 indicate no change.
Model Summary: Constant=-2, Nagelkerke R^2= 0.12, Coefficient Test: $\chi^2(20)$=388, p<0.001

Table A16: Proportion of adults who have had a learning disability annual health check in the year before they died, by year of death

Learning disability annual health check in the year before the person died	2018	2019	2020	2018-2020	No.
Yes	74%	73%	76%	74%	4,347
No	26%	27%	24%	26%	1,503
Total No.†	*1,982*	*2,163*	*1,705*		*5,850*

† This information is missing for 925 adults.

Table A17: Proportion of adults for whom the reviewer reported whether the care package provided had met the needs of the person, by year of death

Care package met needs of the individual	Year of death				Total No.
	2018	2019	2020	2018-2020	
Yes	90%	91%	91%	91%	5,512
No	10%	9%	9%	9%	574
Total No. †	*1,674*	*2,473*	*1,939*		*6,086*

† This information is missing for 1 person.

Table A18: Proportion of adults and children by year of death and the Index of Deprivation

Index of Multiple Deprivation in Quintiles	*Year of death*				Total No.
	2018	2019	2020	2018-2020	
Adults and children					
1% to 20% (Most Deprived)	25%	27%	27%	27%	2,230
21% to 40%	22%	22%	23%	22%	1,882
41% to 60%	21%	21%	20%	21%	1,733
61% to 80%	17%	17%	17%	17%	1,448
81% to 100% (Least deprived)	14%	13%	12%	13%	1,098
Total No.	*2,513*	*2,663*	*3,215*		*8,391*
Adults					
1% to 20% (Most Deprived)	25%	26%	27%	26%	*2,035*
21% to 40%	22%	22%	23%	23%	*1,767*
41% to 60%	22%	21%	20%	21%	*1,642*
61% to 80%	17%	18%	18%	18%	*1,369*
81% to 100% (Least deprived)	14%	13%	12%	13%	*1,026*
Total No.†	*2,331*	*2,456*	*3,052*		*7,839*
Children					
1% to 20% (Most Deprived)	34%	40%	32%	35%	195
21% to 40%	22%	16%	25%	21%	115
41% to 60%	17%	15%	18%	17%	91
61% to 80%	15%	16%	12%	14%	79
81% to 100% (Least deprived)	13%	14%	12%	13%	72
Total No.‡	*182*	*207*	*163*		*552*

†This information is not available for 649 adults. ‡ This information is not available for 70 children.

Table A19: Binary logistic regression model to predict the odds of dying aged 18-49 years. (Reference groups in parentheses).

Variables	B	Wald	Significance	Odds	Odds 95% Confidence Interval
Ethnic Groups (White British)					
Asian/ Asian British	2.2	122.7	***	9.2	6.2 - 13.6
Black/African/Caribbean/ Black British	1.3	23.7	***	3.6	2.1 - 5.9
Mixed/Multiple ethnic groups	1.4	12.6	***	3.9	1.8 - 8.4
Other ethnic groups	0.3	0.8		1.3	0.8 - 2.2
Learning Disability Level (Mild)					
Moderate	0.0	0.0		1.0	0.8 - 1.3
Severe	0.7	37.2	***	2.0	1.6 - 2.4
Profound/multiple	1.9	161.2	***	6.4	4.8 - 8.5
Mental Health / Criminal Justice System Restrictions (No)					
Yes	1.5	11.8	***	4.3	1.9 - 9.8
Annual Health Check in Last Year (Yes)					
Health Check in Last Year: No	0.4	22.6	***	1.5	1.3 - 1.9
Taking Specific Medication (No)					
Taking anti-depressant medication: Yes	-0.2	2.6	*	0.9	0.7 - 1
Taking anti-psychotic medication: Yes	-0.4	13.6	***	0.7	0.5 - 0.8
Gender (Male)					
Female	0.0	0.0		1.0	0.8 - 1.2
Out of Area Placement (No)					
Out of Area Placement: Yes	0.0	0.0		1.0	0.7 - 1.4
Needs Met (Yes)					
Needs Met: No	0.0	0.0		1.0	0.7 - 1.3
Index of Multiple Deprivation Quintile (81-100%, Least Deprived)					
1% to 20% (Most Deprived)	-0.1	0.2		0.9	0.7 - 1.2
21% to 40%	-0.2	2.0		0.8	0.7 - 1.2
41 to 60%	0.0	0.0		1.0	0.6 - 1.1
61 to 80%	0.0	0.0		1.0	0.8 - 1.3

B is the estimated coefficient in the model. A minus sign indicates that the likelihood of the association is negative. Wald tests the null hypothesis that the population coefficient is 0. The larger the Wald statistic, the greater the contribution of that variable to the prediction.

Asterisks indicate p-values: *0.05 to 0.01, **0.01 to 0.001, ***less than 0.001.

The measure of likelihood used is the ‘odds ratio’. For ease of reading this report we refer to the likelihood of an occurrence. Odds over 1 indicate a higher likelihood, odds under 1 a lower likelihood, and odds of 1 indicate no change.

Model Summary: Constant=-1.9, Nagelkerke R^2= 0.17, Coefficient Test: $\chi^2(18)=488$, $p<0.001$

Chapter 4: Causes of death

Table A20: ICD-10 chapters for the most frequently reported underlying causes of death of children and adults by year of death and gender[91]

Underlying cause of death ICD-10 chapter	People with learning disabilities							General population (2019)[92]	
	Year of death						Total No.		
	2018		2019		2020				
	M	F	M	F	M	F		M	F
Adults and children									
Respiratory system	21%	20%	19%	20%	13%	15%	1,507	14%	14%
Circulatory system	17%	13%	14%	16%	14%	13%	1,218	26%	23%
Congenital & chromosomal	13%	14%	15%	14%	10%	11%	1,071	<1%	<1%
Neoplasms	12%	15%	15%	14%	10%	12%	1,065	31%	27%
Nervous system	13%	13%	14%	13%	11%	9%	1,013	6%	8%
COVID-19					24%	21%	720		
Digestive system	8%	6%	7%	6%	6%	5%	535	5%	5%
Mental behavioural & neuro-develop'l	4%	5%	4%	5%	3%	5%	371	7%	11%
Endocrine, nut'ion and metabolic	3%	3%	2%	2%	2%	2%	192	2%	2%
External causes	4%	2%	3%	2%	2%	1%	200	5%	2%
Genitourinary	2%	3%	2%	2%	2%	2%	199	2%	3%
Infections	1%	2%	2%	2%	1%	1%	130	1%	1%
All other causes	2%	3%	3%	4%	2%	2%	237	2%	5%
Total number	*1,477*	*1,091*	*1,538*	*1,191*	*1,800*	*1,361*	*8,458*†	*263,677*‡	*264,232*
Adults									
Respiratory system	21%	21%	19%	20%	13%	15%	1,451	14%	14%
Circulatory system	17%	14%	15%	16%	14%	13%	1,202	26%	23%
Congenital & chromosomal	14%	13%	15%	14%	10%	11%	1,025	<1%	<1%
Neoplasms	12%	15%	15%	14%	10%	12%	1,039	31%	27%
Nervous system	12%	12%	13%	12%	11%	8%	908	6%	7%
COVID-19					25%	21%	717		
Digestive system	8%	7%	7%	6%	6%	5%	517	5%	5%
Mental behavioural & neuro-develop'l	4%	6%	4%	5%	3%	5%	366	7%	11%
Endocrine, nut'ion and metabolic	2%	3%	2%	2%	1%	2%	159	2%	2%
External causes	4%	2%	3%	2%	2%	1%	187	5%	3%
Genitourinary	2%	3%	2%	2%	3%	3%	195	1%	2%
Infections	1%	2%	2%	2%	1%	1%	108	<1%	1%
All other causes	2%	3%	3%	4%	2%	3%	216	3%	5%
Total number	*1,413*	*1,020*	*1,458*	*1,127*	*1,745*	*1,326*	*8,089*†	*263,361*	*263,988*

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[91] When reading this table, note should be made of the proportion of deaths from COVID-19 in 2020, and the effect of this on the proportion of deaths from other causes in that year. Thus, the proportions in each ICD-10 chapter in 2020 are not directly comparable with other years.

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

Children									
Respiratory system	16%	16%	14%	22%	◆	◆	56	8%	12%
Circulatory system	◆	◆	◆	◆	◆	0%	17	3%	4%
Congenital & chromosomal	◆	17%	◆	◆	◆	◆	46	8%	9%
Neoplasms	◆	◆	◆	◆	◆	◆	26	30%	28%
Nervous system	33%	23%	31%	28%	26%	31%	105	13%	12%
COVID-19					◆	◆	◆		
Digestive system	◆	◆	◆	◆	◆	◆	18	4%	2%
Mental behavioural & neuro-develop'l	0%	◆	0%	◆	◆	◆	◆	<1%	<1%
Endocrine, nut'ion and metabolic	◆	◆	◆	◆	20%	◆	33	6%	6%
External causes	◆	◆	◆		0%	◆	13	19%	14%
Genitourinary	0%	◆	0%	◆	0%	0%	◆	<1%	<1%
Infections	◆	◆	◆	◆	◆	◆	22	6%	6%
All other causes	◆	◆	◆	◆	◆		21	4%	5%
Total No.	*64*	*71*	*80*	*64*	*55*	*35*	*369*	*316**	*244**

*children in general population aged 5-14 years; LeDeR data has been grouped to reflect this definition
†the gender was missing for 3 adults
‡adults in general population aged 15 years and over; LeDeR data has been grouped to reflect this definition

Table A21: The most frequently reported underlying causes of death, by chapter, and by age group

Underlying cause of death	**Aged 15 – 49**			**Aged 50 – 64**			**Aged 65 and over**		
	2018	**2019**	**2020**	**2018**	**2019**	**2020**	**2018**	**2019**	**2020**
Respiratory system	19%	18%	11%	16%	15%	10%	27%	25%	18%
Circulatory system	9%	10%	12%	16%	15%	13%	20%	19%	14%
Congenital and chromosomal	11%	13%	10%	22%	24%	17%	7%	8%	5%
Neoplasms	10%	12%	9%	16%	16%	11%	13%	15%	12%
Nervous system	24%	26%	22%	11%	10%	8%	6%	6%	6%
COVID-19			20%			23%			25%
Digestive system	7%	7%	7%	7%	5%	6%	7%	8%	4%
Mental behavioural & neuro-develop'l	2%	2%	◆	3%	3%	3%	8%	8%	7%
Endocrine, nut'ion and metabolic	5%	3%	3%	2%	2%	1%	2%	1%	2%
External causes	6%	4%	◆	3%	3%	2%	2%	2%	1%
Genitourinary	3%	◆	◆	2%	2%	2%	3%	3%	3%
Infections	2%	◆	0%	◆	2%	1%	2%	2%	1%
All other causes	3%	5%	3%	2%	2%	2%	3%	3%	3%
Total No.†	*539*	*617*	*598*	*895*	*919*	*1,104*	*1,000*	*1,050*	*1,370*

† The age of one person who died in 2020 is unknown.

Table A22: The most frequently reported underlying causes of death, by chapter, by ethnic group

Underlying cause of death	White British			Minority ethnic groups		
	2018	2019	2020	2018	2019	2020
Respiratory system	21%	20%	14%	20%	17%	8%
Circulatory system	16%	15%	14%	13%	15%	10%
Congenital and chromosomal	14%	15%	11%	8%	11%	8%
Neoplasms	14%	15%	11%	10%	11%	10%
Nervous system	12%	12%	10%	22%	23%	16%
COVID-19			22%			28%
Digestive system	7%	7%	6%	6%	7%	5%
Mental behavioural & neuro-developmental	5%	5%	5%	◆	◆	◆
Endocrine, nutritional and metabolic	2%	2%	2%	9%	◆	6%
External causes	3%	3%	2%	5%	◆	◆
Genitourinary	2%	2%	2%	◆	◆	◆
Infections	2%	2%	1%	◆	◆	◆
All other causes	3%	3%	2%	◆	5%	4%
Total No.†	*2,252*	*2,360*	*2,672*	*221*	*234*	*296*

†Ethnic group was not known for 455 of those for whom ICD-10 codes for cause of death were available.

Table A23: The most frequently reported underlying causes of death, by chapter, by level of learning disabilities

Underlying cause of death	Mild / Moderate			Severe / Profound & Multiple		
	2018	2019	2020	2018	2019	2020
Respiratory system	19%	18%	14%	26%	23%	16%
Circulatory system	19%	18%	15%	9%	9%	8%
Congenital and chromosomal	13%	14%	10%	14%	16%	11%
Neoplasms	17%	18%	12%	7%	9%	8%
Nervous system	7%	8%	6%	21%	21%	18%
COVID-19			25%			24%
Digestive system	8%	7%	5%	7%	7%	4%
Mental behavioural & neuro-developmental	5%	5%	4%	5%	5%	5%
Endocrine, nutritional and metabolic	2%	2%	1%	3%	2%	◆
External causes	3%	3%	1%	3%	3%	2%
Genitourinary	3%	2%	2%	3%	2%	2%
Infections	2%	2%	1%	◆	2%	◆
All other causes	3%	3%	3%	2%	3%	◆
Total No.†	*1,419*	*1,487*	*1,382*	*834*	*846*	*655*

†Level of learning disability was not recorded for 1,867 of those for whom ICD-10 codes for cause of death were available.

Table A24: The most frequently recorded condition-specific underlying causes of death for people with learning disabilities in 2018, 2019 and in 2020 and for the general population in 2019

Age group	**Year of death**			
	LeDeR data			**General population data 2019[93]**
	2018	**2019**	**2020**	
Males				
5-19	Cerebral palsy	Cerebral palsy	Cerebral palsy	Suicide and injury or poisoning of undetermined intent
20-34	Cerebral palsy	Epilepsy	Cerebral palsy	Suicide and injury or poisoning of undetermined intent
35-49	Bacterial pneumonia	Bacterial pneumonia	COVID-19	Suicide and injury or poisoning of undetermined intent
50-64	Down’s syndrome	Down’s syndrome	COVID-19	Ischaemic heart diseases
65-79	Bacterial pneumonia	Bacterial pneumonia	COVID-19	Ischaemic heart diseases
80+	◆	Bacterial pneumonia	COVID-19	Dementia and Alzheimer disease
All males	*Down’s syndrome*	*Down’s syndrome*	*COVID-19*	*Ischaemic heart diseases*
Females				
5-19	◆	Cerebral palsy	Cerebral palsy	Suicide and injury or poisoning of undetermined intent
20-34	◆	Bacterial pneumonia	COVID-19	Suicide and injury or poisoning of undetermined intent
35-49	Bacterial pneumonia	Bacterial pneumonia	COVID-19	Malignant neoplasm of breast
50-64	Down’s syndrome	Down’s syndrome	COVID-19	Malignant neoplasm of breast
65-79	Bacterial pneumonia	Bacterial pneumonia	COVID-19	Malignant neoplasm of trachea, bronchus & lung
80+	Bacterial pneumonia	Bacterial pneumonia	COVID-19	Dementia and Alzheimer disease
All females	*Bacterial pneumonia*	*Bacterial pneumonia*	COVID-19	Dementia and Alzheimer disease
Total	***Bacterial pneumonia***	***Down’s syndrome***	***COVID-19***	***Dementia and Alzheimer disease***

◆ signifies that the number is less than 10 and the category name has therefore been suppressed

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[93] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2019#leading-causes-of-death

Table A25: Leading underlying causes of death by geographical region and CCG for deaths from 2018 to 2020 for which ICD-10 codes are available

NHS Region and CCG[†]	**Total No. of deaths[i]**	***Leading underlying cause of death by year of death***		
		2018 -2019	**2020**	**2018-2020**
EAST OF ENGLAND	**952**	**Down syndrome**	**COVID-19**	**Down syndrome**
NHS NORFOLK & WAVENEY CCG	166	Down syndrome	◆	Down syndrome
NHS CAMBRIDGESHIRE AND PETERBOROUGH CCG	108	Down syndrome	◆	Bacterial pneumonia
NHS HERTS VALLEYS CCG	105	◆	COVID-19	COVID-19
NHS NORTH EAST ESSEX CCG	95	Down syndrome	◆	Down syndrome Bacterial pneumonia
NHS EAST AND NORTH HERTFORDSHIRE CCG	79	◆	◆	Down syndrome
LONDON	**1,008**	**Bacterial pneumonia**	**COVID-19**	**COVID-19**
NHS S.W. LONDON CCG	222	Bacterial pneumonia	COVID-19	COVID-19
NHS N.C. LONDON CCG	178	Bacterial pneumonia	COVID-19	COVID-19
NHS S.E. LONDON CCG	166	Down syndrome	COVID-19	Down syndrome
MIDLANDS	**1,755**	**Down syndrome**	**COVID-19**	**Down syndrome**
NHS NOTTINGHAM AND NOTTINGHAMSHIRE CCG	210	Bacterial pneumonia	COVID-19	COVID-19
NHS BIRMINGHAM AND SOLIHULL CCG	194	Down syndrome	COVID-19	COVID-19
NHS DERBY & DERBYSHIRE CCG	178	Epilepsy	COVID-19	Down syndrome
NHS LINCOLNSHIRE CCG	159	Bacterial pneumonia	◆	Dementia & Alzheimer
NHS HEREFORDSHIRE AND WORCESTERSHIRE CCG	130	Bacterial pneumonia	◆	Bacterial pneumonia
NHS SANDWELL AND WEST BIRMINGHAM CCG	104	Down syndrome	COVID-19	Down syndrome
NHS NORTHAMPTONSHIRE CCG	97	◆	◆	Down syndrome
NHS COVENTRY & RUGBY CCG	82	◆	◆	◆
NHS LEICESTER CITY CCG	80	◆	◆	◆
NHS DUDLEY CCG	65	◆	COVID-19	COVID-19
NORTH EAST AND YORKSHIRE	**1,390**	**Down syndrome**	**COVID-19**	**Down syndrome**
NHS TEES VALLEY CCG	117	Down syndrome	◆	Q90 - Down syndrome
NHS COUNTY DURHAM CCG	116	Bacterial pneumonia	COVID-19	Bacterial pneumonia
NHS SHEFFIELD CCG	108	◆	COVID-19	COVID-19
NHS BRADFORD DISTRICT AND CRAVEN CCG	103	◆	◆	◆
NHS LEEDS CCG	90	◆	COVID-19	COVID-19
NHS NEWCASTLE GATESHEAD CCG	86	◆	◆	◆
NHS NORTH YORKSHIRE CCG	82	◆	◆	◆
NHS WAKEFIELD CCG	64	◆	◆	◆
NHS SUNDERLAND CCG	62	◆	◆	◆
NORTH WEST	**1,188**	**Bacterial pneumonia**	**COVID-19**	**Bacterial pneumonia**
NHS LIVERPOOL CCG	100	◆	COVID-19	Bacterial pneumonia
NHS MANCHESTER CCG	88	◆	COVID-19	COVID-19
NHS CHESHIRE CCG	76	◆	◆	◆
NHS EAST LANCASHIRE CCG	66	◆	◆	◆
NHS STOCKPORT CCG	66	◆	◆	◆
SOUTH EAST	**1,379**	**Bacterial pneumonia**	**COVID-19**	**Bacterial pneumonia**

NHS KENT AND MEDWAY CCG	310	Bacterial pneumonia	COVID-19	Bacterial pneumonia
NHS SURREY HEARTLANDS CCG	196	Bacterial pneumonia	COVID-19	Bacterial pneumonia
NHS OXFORDSHIRE CCG	135	Down syndrome	◆	Down syndrome
NHS WEST SUSSEX CCG	121	Bacterial pneumonia	◆	Bacterial pneumonia Down syndrome
NHS EAST SUSSEX CCG	101	Bacterial pneumonia	◆	Bacterial pneumonia
NHS BERKSHIRE WEST CCG	84	◆	◆	Bacterial pneumonia
NHS BUCKINGHAMSHIRE CCG	74	Down syndrome	◆	Down syndrome
NHS WEST HAMPSHIRE CCG	60	◆	◆	◆
SOUTH WEST	**818**	**Down syndrome**	**COVID-19**	**Down syndrome**
NHS BRISTOL, N. SOMERSET AND S. GLOUCESTERSHIRE CCG	149	Down syndrome	COVID-19	Down syndrome
NHS DEVON CCG	140	Bacterial pneumonia	◆	Bacterial pneumonia
NHS GLOUCESTERSHIRE CCG	131	Down syndrome	◆	Down syndrome
NHS BATH AND N.E. SOMERSET, SWINDON AND WILTSHIRE CCG	112	Bacterial pneumonia	◆	Bacterial pneumonia
NHS DORSET CCG	101	Down syndrome	◆	Down syndrome
NHS SOMERSET CCG	100	◆	◆	Down syndrome
NHS KERNOW CCG	85	Bacterial pneumonia Down syndrome	◆	Down syndrome

[i] Includes deaths which occurred in 2018-2020 for which an ICD-10 code is available.

† Due to small numbers, those CCGs which have had more than 60 deaths in total are presented in this table.

◆ signifies that the number is less than 10 and the category name has therefore been suppressed.

Table A26: The ten conditions most frequently cited in Part I of the MCCD 2018-2020

2018			2019			2020		
Condition	**No.**	**%**	**Condition**	**No.**	**%**	**Condition**	**No.**	**%**
Bacterial pneumonia	626	24%	Bacterial pneumonia	633	23%	COVID-19	724	23%
Aspiration pneumonia	379	15%	Aspiration pneumonia	439	16%	Bacterial pneumonia	609	19%
Down's syndrome	268	10%	Down's syndrome	298	11%	Aspiration pneumonia	354	11%
Dementia & Alzheimer's disease	226	9%	Dementia & Alzheimer's disease	255	9%	Dementia & Alzheimer's disease	265	8%
Sepsis	180	7%	Epilepsy	189	7%	Down's syndrome	236	7%
Ischaemic heart disease	170	7%	Sepsis	180	7%	Ischaemic heart disease	169	5%
Epilepsy	143	6%	Ischaemic heart disease	164	6%	Cerebral palsy	142	4%
Cerebral palsy	131	5%	Cerebral palsy	138	5%	Acute lower respiratory infections	142	4%
Acute lower respiratory infections	111	4%	Acute lower respiratory infections	121	4%	Epilepsy	139	4%
DVT / PE	91	4%	Heart failure	101	4%	Sepsis	128	4%
Total No.	*2,582*		*Total*	*2,738*		*Total*	*3,170*	

Table A27: The conditions most frequently cited in Part I of the MCCD from 2018-2020 by age group and gender

Age group	2018			2019			2020		
	Condition	**N**	**%**	**Condition**	**N**	**%**	**Condition**	**N**	**%**
Male									
5-19	Bacterial pneumonia	17	16%	Bacterial pneumonia	28	20%	Cerebral palsy	12	13%
20-34	Bacterial pneumonia	26	21%	Bacterial pneumonia	29	24%	Bacterial pneumonia	36	33%
35-49	Bacterial pneumonia	35	24%	Bacterial pneumonia	38	23%	COVID-19	42	22%
50-64	Bacterial pneumonia	121	25%	Bacterial pneumonia	115	22%	COVID-19	145	23%
65-79	Bacterial pneumonia	147	28%	Bacterial pneumonia	122	25%	COVID-19	175	27%
80+	Bacterial pneumonia	17	20%	Bacterial pneumonia	31	29%	COVID-19	56	38%
All	*Bacterial pneumonia*	*363*	*25%*	*Bacterial pneumonia*	*363*	*24%*	*COVID-19*	*441*	*25%*
Female									
5-19	Bacterial pneumonia	18	20%	Bacterial pneumonia	15	15%	Cerebral palsy	17	19%
20-34	Bacterial pneumonia	18	24%	Bacterial pneumonia	24	25%	Bacterial pneumonia	21	24%
35-49	Bacterial pneumonia	34	26%	Bacterial pneumonia	30	21%	COVID-19	33	21%
50-64	Bacterial pneumonia	96	24%	Down’s syndrome	89	22%	COVID-19	114	24%
65-79	Bacterial pneumonia	76	24%	Bacterial pneumonia	98	27%	COVID-19	89	21%
80+	Bacterial pneumonia	19	23%	Bacterial pneumonia	20	23%	COVID-19	23	15%
All	*Bacterial pneumonia*	*261*	*24%*	*Bacterial pneumonia*	*268*	*23%*	*COVID-19*	*283*	*21%*
All									
5-19	Bacterial pneumonia	35	18%	Bacterial pneumonia	43	19%	Cerebral palsy	29	19%
20-34	Bacterial pneumonia	44	22%	Bacterial pneumonia	53	23%	Bacterial pneumonia	57	29%
35-49	Bacterial pneumonia	69	25%	Bacterial pneumonia	68	22%	COVID-19	75	22%
50-64	Bacterial pneumonia	217	24%	Down’s syndrome	203	22%	COVID-19	259	23%
65-79	Bacterial pneumonia	223	27%	Bacterial pneumonia	220	26%	COVID-19	264	25%
80+	Bacterial pneumonia	36	22%	Bacterial pneumonia	51	26%	COVID-19	79	27%
All	*Bacterial pneumonia*	*624*	*24%*	*Bacterial pneumonia*	*631*	*23%*	*COVID-19*	*724*	*23%*

Table A28: Preventable, treatable and overall avoidable medical causes of death in 2018, 2019 and 2020, by region

Region	2018						2019						2020					
	Preventable		Treatable		Overall avoidable		Preventable		Treatable		Overall avoidable		Preventable		Treatable		Overall avoidable	
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
All (ages 4-74)																		
East of England	70	24%	119	41%	156	53%	51	22%	97	41%	123	52%	47	22%	71	33%	98	45%
London	57	23%	109	45%	136	56%	54	21%	101	39%	130	50%	50	23%	88	40%	114	52%
Midlands	93	22%	172	40%	230	53%	106	22%	210	43%	271	56%	94	21%	177	40%	214	49%
North East & Yorks	87	25%	142	40%	185	52%	93	24%	134	34%	182	46%	73	22%	121	37%	156	47%
North West	76	24%	126	40%	167	54%	88	26%	141	42%	188	56%	68	25%	100	37%	138	51%
South East	84	22%	163	42%	208	54%	71	20%	134	36%	176	47%	74	24%	117	38%	155	51%
South West	38	20%	60	31%	79	41%	48	22%	87	39%	112	51%	47	20%	84	36%	99	42%
Total	*505*	*23%*	*891*	*40%*	*1,161*	*53%*	*511*	*22%*	*904*	*39%*	*1,182*	*51%*	*453*	*22%*	*758*	*38%*	*974*	*48%*
Adults (age 20-74)																		
East of England	69	25%	112	41%	148	54%	47	22%	86	40%	111	52%	46	23%	66	34%	92	47%
London	54	24%	101	46%	126	57%	51	22%	93	40%	119	52%	48	24%	82	41%	106	53%
Midlands	87	23%	157	41%	211	56%	102	24%	192	45%	249	58%	92	23%	170	42%	206	51%
North East & Yorks	82	26%	132	42%	170	54%	89	24%	127	35%	171	47%	72	24%	118	39%	152	50%
North West	73	26%	117	42%	156	57%	83	28%	129	43%	173	58%	68	26%	96	37%	134	52%
South East	82	23%	151	43%	196	55%	66	20%	121	36%	159	48%	73	25%	114	39%	151	52%
South West	37	21%	56	32%	75	43%	46	22%	81	39%	104	50%	45	21%	79	37%	94	44%
Total	*484*	*24%*	*826*	*41%*	*1,082*	*54%*	*484*	*23%*	*829*	*40%*	*1,086*	*52%*	*444*	*24%*	*725*	*39%*	*935*	*50%*
Children (age 4-19)	**2018 – 2020**																	
East of England	◆	◆	23	37%	26	42%												
London	◆	◆	22	29%	29	38%												
Midlands	12	9%	40	30%	49	37%												
North East & Yorks	10	11%	20	23%	30	34%												
North West	◆	◆	25	28%	30	34%												
South East	◆	◆	28	32%	33	38%												
South West	◆	◆	15	28%	17	32%												
Total	*57*	*10%*	*173*	*29%*	*214*	*36%*												

For comparison with data published by ONS, the category of 'children' includes those aged 4-19 years. Data for children has been merged for 2018-2020 in this table because of the small numbers in some regions.

Chapter 5: Circumstances of deaths

Table A29: Place of death of children and adults by year of death, and comparison data for the general population

Place of death	**Year of death**			**Total No.**	**General population[94] (2019)**
	2018	**2019**	**2020**		
Children and adults (age 5 years and over)					
Hospital	60%	57%	59%	5,223	46%
Usual place of residence	32%	35%	34%	3,003	45%
Hospice/palliative care unit	3%	3%	2%	251	6%
Other	4%	5%	4%	368	3%
Total No. [i]	*2,622*	*2,801*	*3,422*	*8,845*	*517,909*
Adults (age 15 years and over)					
Hospital	60%	57%	60%	4,961	46%
Usual place of residence	33%	36%	35%	2,896	46%
Hospice/palliative care unit	3%	2%	2%	202	6%
Other	4%	5%	4%	353	3%
Total No.	*2,474*	*2,642*	*3,296*	*8,412*	*517,349* ‡
Children (age 5-14 years)					
Hospital	62%	63%	56%	262	64%
Usual place of residence	25%	23%	27%	107	23%
Hospice/palliative care unit	12%	11%	11%	49	9%
Other	◆	◆	◆	15	4%
Total No.	*148*	*159*	*126*	*433*	*560* †

[i] Place of death is not recorded for 231 people aged 5 and over.

‡ adults in general population aged 15 years and over; LeDeR data has been grouped to reflect this age grouping.

†children in general population aged 5-14 years; LeDeR data has been grouped to reflect this age grouping.

Table A30: Proportion of adults subject to Deprivation of Liberty safeguards (DoLS), by year of death from 2018-2020

	Year of death			**Total number**
	2018	**2019**	**2020**	
DoLS – approved	25%	26%	25%	1,557
DoLS – applied for	10%	10%	9%	607
Total No.	*764*	*788*	*612*	*2,164*

‡ Information on DoLS was not recorded in 557 reviews (of the 6,775 completed reviews of adult deaths)

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

Table A31: Number of adults subject to restricted liberty at time of death or within 5 years of death

	Number 2018-2020
Within the criminal justice system	
Restrictions at time of death	26
Restrictions during the five years prior to death (but not at time of death)	◆
Restricted by mental health legislation	
Restrictions at time of death	13
Restrictions during the five years prior to death (but not at time of death)	◆

Table A32: Proportion of adults with a DNACPR decision at the time of their death, by year of death

DNACPR decision at the time of death	**Year of death**			**Total No.**
	2018	**2019**	**2020**	
Yes	71%	70%	73%	4,785
No	29%	30%	27%	1,931
Total No.	*2,304*	*2,473*	*1,939*	*6,716*

‡ Information about whether someone had a DNACPR decision in place at the time of their death was not recorded for 59 people.

Note: Table A33 appears on the following page

Table A34: Proportion of adults with a DNACPR decision at the time of their death, for whom documentation was correctly completed and/or followed, by year of death

DNACPR decision correctly completed or followed	**Year of death**			**Total No.**
	2018	**2019**	**2020**	
Yes	76%	73%	71%	3,500
No	4%	4%	6%	208
Not known by reviewer	20%	23%	23%	1,066
Total No.	*1,624*	*1,726*	*1,424*	*4,774*

‡ Information about whether DNACPR documentation was correctly completed and/or followed was not recorded for 11 people.

Table A35: Reasons why reviewers thought that the DNACPR decision had not been correctly made

Reasons given by reviewers	**2018**		**2019**		**2020**	
	%	**No.**	**%**	**No.**	**%**	**No.**
No evidence of proper decision-making process documented	29%	14	40%	27	40%	25
Problems with the documentation itself (e.g., incomplete fields, illegible handwriting)	31%	15	29%	20	26%	16
Reason given for the decision was an inappropriate medical condition	27%	13	18%	12	23%	14
Other reasons	◆	◆	◆	◆	◆	◆
Total number of reasons given		*49*		*68*		*62*

Table A33: Binary logistic regression model to predict the likelihood of having a DNACPR decision in place (reference groups in parentheses)

Variables	B	Wald	Significance	Odds	Odds 95% Confidence Interval
Living Arrangement (own or family home)					
Supported Living	0.18	1.38		1.2	0.9 - 1.6
Residential home	0.82	22.29	***	2.3	1.6 - 3.2
Nursing home	1.31	31.17	***	3.7	2.3 - 5.9
Other	0.01	0.00		1.0	0.5 - 2.2
Age groups (18-24 years)					
25 - 49 years	0.08	0.04		1.1	0.5 - 2.4
50 - 64 years	0.67	2.75		2.0	0.9 - 4.3
65 years and over	0.90	4.76	*	2.5	1.1 - 5.5
Level of Learning Disability (mild)					
Moderate	0.43	9.04	***	1.5	1.2 - 2.0
Severe	0.41	6.86	*	1.5	1.1 - 2.1
Profound/multiple	0.91	9.93	***	2.5	1.4 - 4.4
Coronavirus (COVID-19 death not included on MCCD)					
COVID-19 death	0.60	15.64	***	1.8	1.4 - 2.4
Out of area placement (not placed ‘out-of-area’)					
Placed 'out-of-area'	-0.53	5.45	*	0.6	0.4 - 0.9
Gender (male)					
Female	0.18	2.24		1.2	1.0 - 1.5
Ethnic group (White British)					
Asian/ Asian British	-0.21	0.49		0.8	0.5 - 1.5
Black/African/Caribbean/ Black British	-0.22	0.37		0.8	0.4 - 1.6
Mixed/Multiple ethnic groups	-0.52	0.53		0.6	0.2 - 2.4
Other ethnic groups	0.10	0.06		1.1	0.5 - 2.5
Index of Multiple Deprivation Quintile (81-100%: least deprived)					
1% to 20% (Most Deprived)	-0.24	1.36		0.8	0.5 - 1.2
21% to 40%	0.06	0.07		1.0	0.7 - 1.6
41% to 60%	-0.04	0.03		1.0	0.6 - 1.5
61% to 80%	-0.26	1.35		0.8	0.5 - 1.2

B is the estimated coefficient in the model. A minus sign indicates that the likelihood of the association is negative.
Wald tests the null hypothesis that the population coefficient is 0. The larger the Wald statistic, the greater the contribution of that variable to the prediction.
Asterisks indicate p-values: *0.05 to 0.01, **0.01 to 0.001, ***less than 0.001.
The measure of likelihood used is the ‘odds ratio’. For ease of reading this report we refer to the likelihood of an occurrence. Odds over 1 indicate a higher likelihood, odds under 1 a lower likelihood, and odds of 1 indicate no change.
Model Summary: Constant = -0.34, Cases included in Analysis: 1,693, Nagelkerke R^2: 0.13,
Coefficient Test: $\chi^2(21) = 153$, $p<0.001$.

Table A36: Proportion of deaths reported to a coroner by year of death, and comparison with all referrals to a coroner in 2018 and 2019

Deaths reported to a coroner	**People with learning disabilities (LeDeR Programme Data)**				**All referrals to a coroner**[95]			
	Year of death				**2018**		**2019**	
	2018	**2019**	**2020**‡	**Total No.**	**%**	**Total No.**	**%**	**Total No.**
Adults and children	33%	31%	22%	2,545	41%	220,648	40%	210,912
Adults	32%	29%	21%	2,256	n/a	n/a	n/a	n/a
Children	46%	53%	39%	289	n/a	n/a	n/a	n/a
Total No.	*894*	*887*	*764*	*2,545*				*210,912*

‡ Data from 2020 are incomplete and therefore may not be an accurate representation of the proportion of deaths referred to a coroner in that year.

Table A37: Proportion of deaths of adults reported to a coroner for which there was a post-mortem examination undertaken or an inquest opened by year of death and comparison with all referrals to a coroner in 2018 and 2019

Adults with learning disabilities with completed review (LeDeR Programme Data)					**All referrals to a coroner**[96]			
Deaths reported to a coroner	**Year of death**				**Year of death**			
					2018		**2019**	
	2018	**2019**	**2020**‡	**Total No.**	**%**	**Total No.**	**%**	**Total No.**
Of those reported to a coroner, deaths for which there was a post-mortem examination	50%	55%	51%	948	*39%*	*85,593*	*39%*	*82,072*
Of those reported to a coroner, deaths for which an inquest was opened	28%	34%	35%	599	*13%*	*29,094*	*14%*	*29,969*

NB. Post-mortem examinations and opened inquests are assessed separately, so the percentage across those does not total 100%.

‡ Data from 2020 are incomplete and therefore may not be an accurate representation of the proportion of deaths for which a post-mortem examination was undertaken or an inquest opened in that year.

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[95] https://www.gov.uk/government/statistics/coroners-statistics-2019

[96] https://www.gov.uk/government/statistics/coroners-statistics-2019

Table A38: Most frequently reported factors intrinsic to a child considered to contribute to vulnerability, ill-health or death[97]		
	No.	**%**
Disability or impairment - learning disabilities	152	24%
Chronic long-term illness (excl. asthma, epilepsy, diabetes)	144	23%
Pre-existing medical condition	132	21%
Acute sudden illness/onset of event	112	18%
Other disability or impairment (excl. genetic, learning disability, motor, sensory, emotional/behavioural, allergies, alcohol/substance misuse)	95	15%
Disability or impairment – motor impairment	81	13%
Chronic long-term illness - epilepsy	79	12%
Disability or impairment – sensory impairment	55	9%
Child in Need plan	39	6%

Table A39: The broad themes of the most frequently reported potentially modifiable factors in deaths of children		
Order of frequency	**Broad theme**	**Examples of comments in child death reports**
1	Direct provision of care	• 'Lack of blood pressure measurement'. • 'Life was limited by poor clinical care at birth'. • 'Increased scrutiny of repeat prescriptions of medication'.
2	Preventative measures	• 'Parental smoking' • 'Child had not received flu vaccination'.
3	Responsiveness of care provision	• 'Red flags for [health condition] not recognised at school or first contact with ambulance service'. • 'Delayed attendance by the out-of-hours service as well as the failure to automatically arrange an urgent GP review in the morning'. • [Need to] lower thresholds for escalation of care in children with a learning disability.
4	Consanguinity	• 'Parents are first cousins'.
5	Broader issues	• 'Seizure detection devices - currently no evidence for effectiveness - ongoing national medical and technical evaluation [needed]'.

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[97] Note that a child may have had more than one factor identified on the Child Death Analysis Form.

Chapter 6: Indicators of the quality of care provided

Table A40: Most frequently reported types of problems with organisational systems and processes, by year of death

Type of problem with organisational systems and processes	2018	2019	2020
Coordination of care	20%	18%	20%
Deviation from recognised care pathways	8%	9%	10%
Documentation	7%	7%	9%
Training requirements of staff	7%	5%	4%
Lack of availability of service	4%	5%	10%
Funding for social care	4%	7%	5%
Staff availability and roles	4%	3%	5%
Decision-making processes	4%	3%	1%
Discharge from hospital	3%	5%	8%
Total No.	*401*	*374*	*279*

Table A41: The most frequently reported delays in a person's care or treatment, by year of death

Type of delay	2018	2019	2020
Investigation and diagnosis of signs and symptoms of illness	26%	19%	19%
Referral to specialist care	20%	16%	15%
Instigating treatment	16%	12%	12%
The provision of general care (e.g., nutrition, prevention of pressure sores, attendance at health screening etc)	8%	7%	10%
Escalating concerns about a person	6%	11%	10%
Decision-making	6%	3%	4%
Follow-up after medical attention received	5%	6%	6%
Social care arrangements/placements	4%	4%	8%
Emergency response	2%	3%	5%
Total No.	*380*	*334*	*239*

Table A42: The individual or agency that raised concerns about deaths, by year of death

The individual or agency that raised concerns	2018	2019	2020
Family member(s)	35%	38%	42%
Health/social care professional(s)	15%	22%	21%
Paid carer(s)/care home manager	19%	17%	20%
A review process (e.g., LeDeR; safeguarding review; Structured Judgement Review; Coroner's report)	16%	10%	8%
Other	15%	13%	9%
Total No.	*243*	*236*	*168*

Table A43: The most frequently reported concerns raised about a death, by year of death

Type of concern	**2018**	**2019**	**2020**
Quality of care provided	40%	44%	50%
Late diagnosis and treatment	17%	23%	24%
Poor communication (with families and between different agencies)	9%	13%	12%
Concerns about the accuracy of the cause of death on the MCCD	8%	2%	9%
Total No.	*275*	*276*	*192*

Table A44: Most frequently reported types of gaps in service provision that may have contributed to the person's death, by year of death

Type of gap in service provision	**2018**	**2019**	**2020**
Staff availability, skills or training (other than specialist learning disability services)	10%	7%	12%
The availability of a specialist learning disability services	8%	4%	2%
The provision of proactive care, including care planning, health screening and health checks	8%	5%	1%
A lead physician or appropriate care coordination	6%	7%	4%
Gaps in specific service provision (other than specialist learning disability services) e.g., advocacy, housing, dietetics, 'step down' care after an acute hospital stay etc)	6%	10%	3%
Total No.	*208*	*164*	*117*

Chapter 7: Deaths of people from minority ethnic groups

Note: Table A45 is on the following page

Table A46: The proportion adults with long-term health conditions, by ethnic group

Ethnic group	**Number of long-term health conditions**								**Total No.**
	0	**1-2**	**3-4**	**5-6**	**7-8**	**9-10**	**11-12**	**13 or more**	
White British	0%	3%	8%	15%	22%	23%	17%	11%	6,008
Asian/Asian British	0%	6%	7%	16%	23%	24%	15%	8%	222
Black/African/ Caribbean/ Black British	2%	9%	12%	19%	18%	21%	14%	7%	117
Mixed/Multiple ethnicities	0%	3%	8%	18%	23%	23%	13%	15%	40
Other ethnic groups	1%	4%	4%	13%	28%	19%	18%	14%	125
Column total No.	*25*	*197*	*511*	*1,011*	*1,459*	*1,490*	*1,103*	*716*	*6,512*
Column %	*0%*	*3%*	*8%*	*16%*	*22%*	*23%*	*17%*	*11%*	*100%*

Table A45: Median age at death, taking into account different characteristics of adults and children

Characteristics	Median Age	Total number
Adults		
Male, ‘Other’ ethnic groups, mild/moderate learning disabilities (LD)	68	43
Female, ‘Other’ ethnic groups, mild/moderate LD	66	36
Male, white British, mild/moderate LD	64	2,348
Female, white British, mild/moderate LD	64	1,722
Male, white British, severe, profound & multiple LD	59	1,133
Female, ‘Other’ ethnic groups, profound & multiple LD	59	26
Female, white British, severe, profound & multiple LD	57	882
Male, Black African/Caribbean/Black British, mild/moderate LD	55	42
Male, ‘Other’ ethnic groups, profound & multiple LD	54	30
Male, Mixed/Multiple ethnicities, profound & multiple LD	54	15
Male, Asian/Asian British, mild/moderate LD	52	54
Female, Asian/Asian British, mild/moderate LD	50	41
Female, Black African/Caribbean/Black British, prof & multiple LD	50	19
Female, Mixed/Multiple ethnicities, mild/moderate LD	49	10
Female, Black African/Caribbean/Black British, mild/moderate LD	48	31
Male, Mixed/Multiple ethnicities, mild/moderate LD	47	◆
Female, Asian/Asian British, profound & multiple LD	43	64
Female, Mixed/Multiple ethnicities, profound & multiple LD	41	◆
Male, Black African/Caribbean/Black British, profound & multiple LD	33	31
Male, Asian/Asian British, profound & multiple LD	30	74
Total number		*6,619*
Children		
Male, white British	11	171
Female, white British	11	133
Male, Asian/Asian British	10	69
Female, Asian/Asian British	10	58
Male, Black African/Caribbean/Black British	10	25
Male, ‘Other’ ethnic groups	10	21
Female, Black African/Caribbean/Black British	10	16
Female, ‘Other’ ethnic groups	10	15
Male, Mixed/Multiple ethnicities	9	15
Female, Mixed/Multiple ethnicities	9	◆
Total number		*531*

Table A47: Living arrangements for adults, by ethnicity

Ethnic group	Own/ family home	Supported Living	Residential Home	Nursing Home	Other	Total No.
White British	23%	30%	31%	16%	2%	5380
Asian/Asian British	67%	10%	14%	9%	◆	195
Indian	47%	◆	28%	◆	0%	64
Pakistani	84%	◆	◆	◆	0%	79
Bangladeshi	84%	0%	◆	0%	◆	19
Black/African/ Caribbean/Black British	44%	21%	21%	◆	◆	94
Black African	68%	◆	◆	0%	◆	22
Black Caribbean	37%	25%	22%	◆	◆	59
Mixed/Multiple ethnicities	42%	◆	34%	◆	0%	38
Other ethnic groups	28%	21%	32%	17%	◆	111
White Irish	◆	◆	45%	◆	◆	31
Column total No.†	*1,442*	*1,666*	*1,736*	*880*	*94*	*5,818*
Column total %	*25%*	*29%*	*30%*	*15%*	*2%*	*100%*

† This information was not recorded for 9 adults of those for whom their ethnicity is known.

Table A48: Main source of support received by adults, by ethnicity

Ethnic group	Family member or informal carer	Paid Carer	None	Total No.
White British	14%	84%	2%	5,386
Asian/Asian British	49%	51%	0%	196
Indian	38%	63%	0%	64
Pakistani	64%	36%	0%	80
Other Asian	43%	57%	0%	28
Black/African/Caribbean/Black British	26%	74%	0%	95
Black African	◆	61%	0%	23
Mixed/Multiple ethnicities	35%	63%	◆	38
Other ethnic groups	20%	78%	◆	111
White Irish	◆	90%	0%	31
Column total No.†	*898*	*4,821*	*107*	*5,826*
Column total %	*15%*	*83%*	*2%*	*100%*

† This information was not recorded for 1 person of those for whom their ethnicity is known.

Table A49: The ten most frequently prescribed usual medications and the number of people prescribed them for 2018-2020, by ethnicity														
Ethnicity														
White British			Asian/Asian British			Black/African/Caribbean/ Black British			Mixed/Multiple ethnicities			Other ethnic groups		
Name of medication	No.	%	Name of medication	No.	%	Name of medication	No.	%	Name of medication	No.	%	Name of medication	No.	%
Valproate	1,430	24%	Valproate	66	29%	Colecalciferol	29	24%	Colecalciferol	14	35%	Valproate	38	30%
Colecalciferol	1,396	24%	Colecalciferol	55	24%	Valproate	28	24%	Macrogol	10	25%	Levothyroxine	30	24%
Lansoprazole	1,278	22%	Lansoprazole	49	22%	Omeprazole	21	18%	Levetiracetam	◆	◆	Colecalciferol	26	21%
Levothyroxine	1,243	21%	Omeprazole	39	17%	Carbamazepine	18	15%	Lansoprazole	◆	◆	Levetiracetam	25	20%
Macrogol	1,102	19%	Baclofen	37	16%	Metformin	18	15%	Insulin	◆	◆	Lansoprazole	24	19%
Omeprazole	1,051	18%	Carbamazepine	37	16%	Levetiracetam	18	15%	Omeprazole	◆	◆	Macrogol	24	19%
Paracetamol	989	17%	Macrogol	35	16%	Levothyroxine	16	13%	Levothyroxine	◆	◆	Omeprazole	19	15%
Carbamazepine	849	14%	Levetiracetam	31	14%	Paracetamol	16	13%	Furosemide	◆	◆	Carbamazepine	17	13%
Levetiracetam	816	14%	Paracetamol	30	13%	Risperidone	15	13%	Bisoprolol	◆	◆	Furosemide	17	13%
Senna	704	12%	Calcium carbonate	28	12%	Macrogol	15	13%	Valproate	◆	◆	Senna	17	13%

Table A50: The most frequently prescribed medications from 2018-2020 organised by BNF chapter and subchapter, by ethnicity

BNF Medicine Category (chapter number in parentheses)	White British		Asian/Asian British		Black/African/ Caribbean/ Black British		Mixed/ Multiple ethnicities		Other ethnic groups	
	No.	%	No.	%	No.	%	No.	%	No.	%
(4) Central nervous system	**4,943**	**83%**	**184**	**82%**	**98**	**82%**	**32**	**80%**	**102**	**81%**
Antiepileptic drugs	2,820	48%	122	54%	53	45%	19	48%	66	52%
Analgesics	1,889	32%	65	29%	33	28%	◆	◆	32	25%
Antidepressant drugs	1,702	29%	32	14%	19	16%	◆	◆	23	18%
Drugs used in psychoses and related disorders	1,422	24%	38	17%	34	29%	13	33%	27	21%
Hypnotics and anxiolytics	1,276	22%	54	24%	26	22%	14	35%	27	21%
(1) Gastro-intestinal system	**4,200**	**71%**	**150**	**67%**	**74**	**62%**	**29**	**73%**	**89**	**71%**
Antisecretory drugs and mucosal protectants	2,592	44%	100	44%	43	36%	18	45%	45	36%
Laxatives	2,252	38%	71	32%	33	28%	19	48%	47	37%
(6) Endocrine system	**3,002**	**51%**	**96**	**43%**	**60**	**50%**	**19**	**48%**	**63**	**50%**
Drugs affecting bone metabolism	1,364	23%	52	23%	27	23%	12	30%	27	21%
Thyroid and antithyroid drugs	1,162	20%	26	12%	17	14%	◆	◆	28	22%
(2) Cardiovascular system	**3,005**	**51%**	**91**	**40%**	**53**	**45%**	**17**	**43%**	**59**	**47%**
Diuretics	1,330	22%	36	16%	22	18%	◆	◆	24	19%
Lipid regulating drugs	1,334	23%	41	18%	17	14%	◆	◆	30	24%
(9) Nutrition and blood	**2,513**	**42%**	**102**	**45%**	**52**	**44%**	**19**	**48%**	**48**	**38%**
Vitamins	1,554	26%	69	31%	32	27%	13	33%	31	25%
Anaemias and some other blood disorders	1,190	20%	39	17%	28	24%	◆	◆	21	17%
(13) Skin	**2,464**	**42%**	**91**	**40%**	**40**	**34%**	**16**	**40%**	**59**	**47%**
(3) Respiratory system	**1,850**	**31%**	**69**	**31%**	**39**	**33%**	**17**	**43%**	**39**	**31%**
(12) Ear, nose and oropharynx	**1,483**	**25%**	**60**	**27%**	**33**	**28%**	◆	◆	**26**	**21%**

Table A51: Place of death for adults and children who died between 2018-2020[98], by ethnicity

Ethnic group	Adults & Children					Adults (18yrs and over)					Children (4-17yrs)				
	Hospital	Usual place residence	Hospice/ p. care unit	Other	Total number	Hospital	Usual place residence	Hospice/ p. care unit	Other	Total number	Hospital	Usual place residence	Hospice/ p. care unit	Other	Total number
White British	58%	35%	3%	4%	7,562	59%	35%	2%	4%	7,259	51%	29%	16%	4%	303
Asian/Asian British	68%	24%	3%	5%	401	67%	26%	◆	5%	277	71%	19%	◆	◆	124
Indian	55%	36%	0%	◆	105	52%	39%	0%	◆	84	67%	◆	0%	◆	21
Pakistani	76%	16%	◆	◆	184	77%	17%	◆	◆	113	75%	16%	◆	◆	71
Other Asian	66%	30%	◆	◆	61	67%	28%	◆	0%	43	61%	◆	0%	◆	18
Black/African/Caribbean/ Black British	61%	28%	◆	7%	181	60%	30%	◆	7%	140	66%	◆	◆	◆	41
Black African	59%	30%	◆	◆	54	52%	41%	0%	◆	29	68%	◆	◆	◆	25
Other Black	77%	◆	0%	◆	26	79%	◆	0%	◆	19	◆	◆	0%	0%	◆
Mixed/Multiple ethnicities	59%	35%	◆	◆	71	52%	44%	◆	◆	48	74%	◆	◆	0%	23
White and Black Caribbean	46%	54%	0%	0%	24	◆	60%	0%	0%	20	◆	◆	0%	0%	◆
Other Mixed	72%	◆	0%	0%	25	63%	◆	0%	0%	16	◆	◆	0%	0%	◆
Other ethnic groups	55%	36%	◆	8%	185	54%	37%	◆	8%	150	57%	29%	◆	◆	35
White Other	56%	37%	◆	6%	116	54%	38%	◆	◆	92	63%	◆	0%	◆	24
Column total No. †	*4,936*	*2,874*	*239*	*351*	*8,400*	*4,630*	*2,740*	*178*	*326*	*7,874*	*306*	*134*	*61*	*25*	*526*
Column total %	*59%*	*34%*	*3%*	*4%*	*100%*	*59%*	*35%*	*2%*	*4%*	*100%*	*58%*	*26%*	*12%*	*5%*	*100%*

†The place of death is not recorded for 185 people (180 adults, 5 children) of those for whom their ethnicity is known.

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[98] The impact of COVID-19 on place of death in 2020 is addressed in Chapter 8.

Table A52: Proportion of adults with a DNACPR decision at the time of their death, by ethnicity

Ethnic group	DNACPR decision in place	No DNACPR decision	Total No.
White British	73%	27%	5,956
Asian/Asian British	61%	39%	222
Bangladeshi	54%	46%	24
Other Asian	69%	31%	35
Black/ African/Caribbean/Black British	50%	50%	112
Mixed/Multiple ethnicities	58%	43%	40
Other ethnic groups	67%	33%	123
White Other	73%	27%	70
Column total No. †	*4,619*	*1,834*	*6,453*

†This information was not recorded for 59 adults for whom their ethnicity is known and a review was completed.

Table A53: Proportion of deaths of adults and children from 2018-2020 which were reported to a coroner,[99] by ethnicity

Ethnic group	Deaths reported to a coroner					
	Adults and children		Adults		Children	
	No.	%	No.	%	No.	%
White British	2,074	27%	1,939	26%	135	44%
Asian/Asian British	143	35%	80	29%	63	50%
Pakistani	57	31%	23	20%	34	48%
Bangladeshi	16	40%	◆	◆	◆	◆
Other Asian	27	42%	17	40%	10	48%
Black/African/Caribbean/Black British	73	40%	53	37%	20	49%
Other Black	16	59%	11	55%	◆	◆
Mixed/Multiple ethnicities	34	47%	19	39%	15	65%
White and Black Caribbean	12	50%	10	50%	◆	◆
Other ethnic groups	67	35%	53	34%	14	39%
Other White	36	30%	26	28%	10	40%
Column total No. and %	*2,391*	*28%*	*2,144*	*27%*	*247*	*47%*

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[99] This data is collected when a notification of death is made to the LeDeR programme and later checked and amended by a reviewer as part of the review process.

Table A54: The most frequently reported underlying causes of death, for adults and children, by ICD-10 chapter, by ethnicity					
Underlying cause of death	**White British**	**Asian/ Asian British**	**Black/ African/ Caribbean/ Black British**	**Mixed/ Multiple ethnicities**	**Other ethnic groups**
Respiratory system	18%	15%	14%	◆	14%
Circulatory system	15%	9%	15%	21%	14%
Congenital and chromosomal	13%	8%	8%	◆	14%
Neoplasms	13%	7%	16%	◆	11%
Nervous system	11%	25%	18%	◆	11%
COVID-19	8%	12%	12%	◆	9%
Digestive system	6%	4%	◆	◆	10%
Mental behavioural & neuro-developmental	5%	◆	◆	0%	◆
Endocrine, nutritional and metabolic	2%	9%	◆	0%	◆
External causes	2%	3%	◆	◆	◆
Genitourinary	2%	◆	◆	◆	◆
Infections	2%	◆	0%	◆	◆
All other causes	3%	4%	◆	◆	◆
Column total No.	*7,284*	*369*	*156*	*58*	*168*

Table A55: Indicators of the quality of care, for adults with completed review, by ethnicity					
Ethnic group	**Examples of best practice**	**Concerns about the death**	**Delays in care or treatment**	**Problems with systems/ processes**	**Gaps in service provision**
White British	64%	10%	14%	15%	7%
Asian/Asian British	59%	16%	15%	19%	10%
Indian	66%	16%	21%	18%	◆
Other Asian	51%	◆	◆	◆	◆
Black/African/Caribbean/ Black British	61%	17%	20%	22%	8%
Black Caribbean	51%	13%	18%	21%	◆
Black African	74%	◆	◆	◆	◆
Other Black groups	93%	◆	◆	◆	◆
Mixed/Multiple ethnicities	70%	23%	18%	15%	20%
Other mixed groups	79%	◆	0%	0%	◆
Other ethnic groups	61%	18%	16%	23%	11%
White Other	69%	16%	◆	16%	◆
White Irish	55%	◆	◆	29%	◆
Column total No.	*4,135*	*706*	*909*	*1,015*	*463*
NB. Each indicator is assessed separately, so the percentage across all indicators does not total 100%					

Table A56: Overall grading of care as determined by LeDeR reviewers, by ethnicity

Ethnic group	Met or exceeded good practice	Fell short of current good practice in minor ways	Fell short of expected good practice in significant ways	Fell short of expected good practice with significant impact on well-being or potential to cause death	Fell far short of expected good practice and contributed to death
White British	54%	29%	13%	3%	1%
Asian/Asian British	45%	35%	14%	6%	◆
Indian	39%	41%	16%	◆	0%
Pakistani	49%	36%	◆	◆	0%
Bangladeshi	54%	◆	◆	◆	◆
Black/African/ Caribbean/Black British	52%	24%	15%	◆	◆
Black African	58%	◆	◆	◆	0%
Mixed/ Multiple ethnicities	50%	◆	◆	◆	◆
Other ethnic groups	51%	30%	14%	◆	◆
Column total No.[†]	*3,478*	*1,864*	*881*	*222*	*65*
Column total %	*53%*	*29%*	*14%*	*3%*	*1%*

[†] The grading of care was missing for 2 adults of those who have had a completed review and their ethnicity is known.

Chapter 8: Deaths of adults from COVID-19

Table A57: Number of deaths of adults notified to the LeDeR Programme with COVID-19 included as a cause of death on the MCCD, by month of death in 2020

COVID-19 Status	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Total No.
COVID-19 as cause of death	0	0	76	358	73	25	◆	◆	◆	33	60	79	718
Not identified as COVID-19 death	248	210	260	250	200	154	176	188	167	196	134	134	2,317
Total No. (column)	248	210	336	608	273	179	179	193	173	229	194	213	3,035

Table A58: Demographic information about adults who died from COVID-19 and those who died from other causes in 2020

	Deaths notified to the LeDeR programme			England and Wales General population 2020: Deaths from COVID-19 aged 20[100,101]
	COVID-19	Other causes	All deaths	
Gender				
Male	61%	55%	57%	55%
Female	39%	45%	43%	45%
Total number†	*718*	*2,316*	*3,034*	*84,429*
Age group				
18-49	16%	19%	19%	2%
50-69	49%	50%	50%	14%
70-84	31%	27%	28%	42%
85 and over	4%	4%	4%	42%
Total number	*718*	*2,317*	*3,035*	*84,429*
Ethnicity				
White British	88%	93%	94%	89%
Asian/Asian British	6%	3%	4%	6%
Black African/Caribbean/Black British	3%	2%	2%	4%
Mixed/Multiple ethnicities	3%	3%	3%	1%
Total number†	*667*	*2,179*	*2,846*	*37,956*
Level of learning disabilities				Not available
Mild/moderate	68%	68%	68%	
Severe/profound & multiple	32%	32%	32%	
Total number‡	*451*	*1,262*	*1,713*	
Usual place of residence				Not available
Own or family home	17%	25%	23%	
Supported living	32%	29%	30%	
Residential home	31%	30%	30%	
Nursing home	19%	14%	16%	
Other	2%	2%	2%	
Total number‡	*467*	*1,358*	*1,834*	

N.B. Due to rounding, percentages may not total 100%.

† Total number of notifications for which this information is available.

‡ The information is collected as part of the review process, rather than at notification of the death, so the number relates to completed reviews only.

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[100] Provisional data. See: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/weeklyprovisionalfiguresondeathsregisteredinenglandandwales

[101] Data for ethnicity in the general population is for people in England and Wales who died between 2nd March and 15th May 2020. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbyethnicgroupenglandandwales/2march2020to15may2020

Table A59: Binary logistic regression model to predict the likelihood of dying from COVID-19 in the sample of people with learning disabilities (reference groups in parentheses)

Variables	B	Wald	Significance	Odds	Odds 95% Confidence Interval
Ethnic Group (White British)					
Asian/ Asian British	1.1	16.9	***	3.0	1.8 - 5
Black/African/Caribbean/ Black British	0.5	1.8		1.6	0.8 - 3.2
Mixed/Multiple ethnic groups	0.7	1.5		2.0	0.7 - 5.9
Other ethnic groups	0.2	0.5		1.3	0.7 - 2.4
Usual Place of Residence					
Supported Living	0.5	10.0	**	1.7	1.2 - 2.4
Residential Home	0.4	5.3	*	1.5	1.1 - 2.1
Nursing Home	0.7	12.6	***	2.0	1.4 - 3
Other	0.6	2.1		1.8	0.8 - 3.1
Gender (Male)					
Female	-0.2	4.1	*	0.8	0.6 - 1
Age Group (18-49)					
50-69	-0.1	0.1		1.0	0.7 - 1.3
70-84	-0.1	0.2		0.9	0.6 - 1.3
85 and over	-0.2	0.4		0.8	0.4 - 1.5
Learning Disability Level (Mild)					
Moderate	0.0	0.0		1.0	0.8 - 1.3
Severe	-0.2	1.7		0.8	0.6 - 1.1
Profound/multiple	-0.1	0.1		0.9	0.6 - 1.5
Index of Multiple Deprivation Quintile (81-100% Least Deprived)					
1% to 20% (Most Deprived)	0.2	1.0		1.2	0.8 - 1.8
21% to 40%	0.0	0.1		1.0	0.7 - 1.6
41% to 60%	0.0	0.0		1.0	0.7 - 1.5
61% to 80%	0.3	2.4		1.4	0.9 - 2

B is the estimated coefficient in the model. A minus sign indicates that the likelihood of the association is negative.
Wald tests the null hypothesis that the population coefficient is 0. The larger the Wald statistic, the greater the contribution of that variable to the prediction.
Asterisks indicate p-values: *0.05 to 0.01, **0.01 to 0.001, ***less than 0.001.
The measure of likelihood used is the ‘odds ratio’. For ease of reading this report we refer to the likelihood of an occurrence. Odds over 1 indicate a higher likelihood, odds under 1 a lower likelihood, and odds of 1 indicate no change.
Model Summary: Model Coefficients: $\chi^2(19)=39$, p=0.005, constant=-1.6, Nagelkerke R2=0.03

Table A60: Statistically significant differences in long-term health conditions between deaths in 2020 from COVID-19 and deaths from other causes

Long-term health condition	COVID-19		Other causes of death	
	People with this condition (No.)	People with this condition (%)	People with this condition (No.)	People with this condition (%)
Obesity	154	34%	293	21%
Cancer	55	12%	314	22%

Table A61: The most frequently reported symptoms of illness in those who died from COVID-19

Symptom	No.	%
Cough / ‘chesty’	159	52%
Fever	155	51%
Difficulty breathing	114	37%
Loss of sense of smell or taste	0	0%
One of the above symptoms only	143	47%
Two of the above symptoms	99	32%
Three of the above symptoms	29	9%
All four of the above symptoms	0	0%
Lethargy/tiredness	47	15%
Diarrhoea or vomiting	40	13%
Loss of appetite	38	12%

Table A62: Indicators of the quality of care reported by LeDeR reviewers for the deaths of people from COVID-19 and other causes

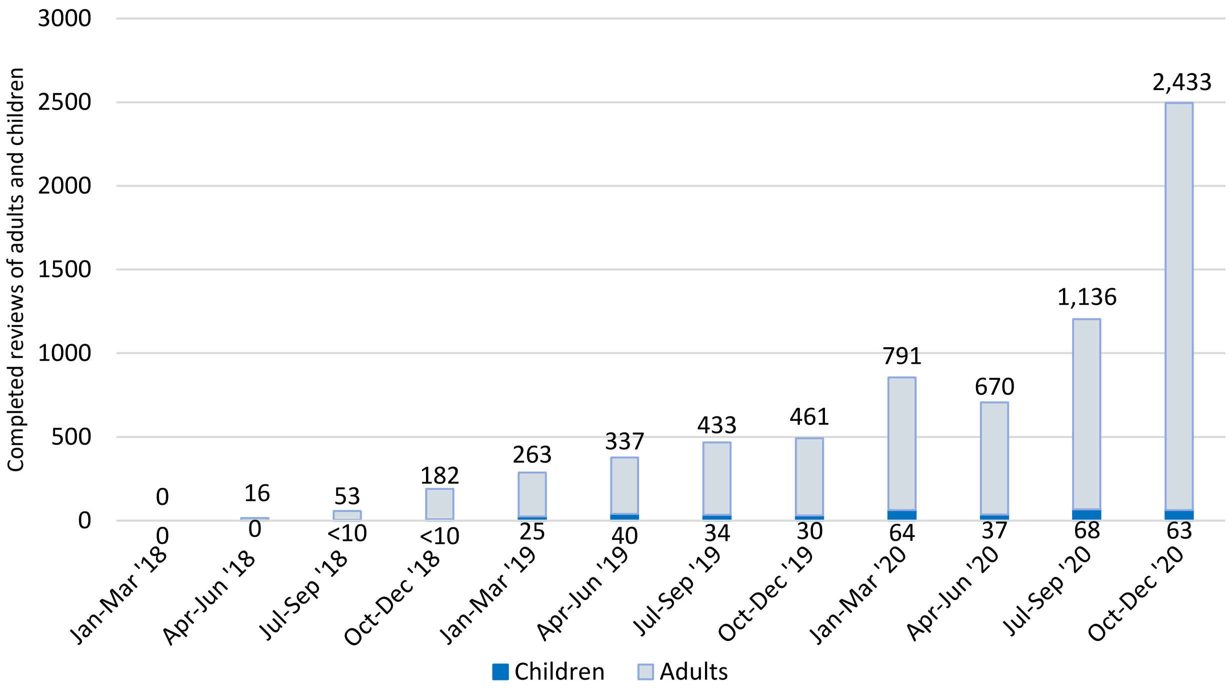
Indicator of quality of care	COVID-19 deaths		Deaths from other causes	
	No.	%	No.	%
Best practice at any time for the person	343	72%	970	71%
Problems with organisational systems and processes	84	18%	181	13%
Delays in the person’s care or treatment	75	16%	149	11%
Concerns about the death	53	11%	120	9%
Gaps in service provision	33	7%	75	6%

NB. Each indicator is assessed separately, so the percentage across all indicators does not total 100%

Figures

Chapter 1: Deaths occurring in 2018, 2019 and 2020

Figure A1. The number of completed reviews each quarter from 1st January 2018 – 31st December 2020



Appendix 2: Causes of death and their ICD-10 codes

Cause of death	ICD-10 codes[102]
Acute lower respiratory infections	J20 – J22
Aspiration pneumonia	J69
Bacterial pneumonia	J12 – J18
Cardiac arrest	I46
Cerebral palsy	G80
COVID-19	U07.1 – U07.2
Dementia & Alzheimer’s disease	F01 – F03, G30
Down’s syndrome	Q90
DVT / PE	I26, I80.2
Epilepsy	G40 – G41
Heart failure	I50
Influenza	J09-J11
Ischaemic heart disease	I20 – I25
Other disorders of the nervous system	G90 – G99
Sepsis	A40 – A41, R65.2

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[102] https://icd.who.int/browse10/2015/en

Appendix 3: Brief introduction to the LeDeR programme

The LeDeR programme is now established throughout England and supports local reviews of deaths of people with learning disabilities aged 4 years and over. The definition of 'learning disabilities' as used by LeDeR is the presence of: 'A significantly reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently, which started before adulthood, with a lasting effect on development.'

The review process

Deaths of children with learning disabilities are reviewed by the statutory Child Death Review programme; completed reviews are shared with the LeDeR programme. The LeDeR review process as applied to reviewing deaths of adults with learning disabilities is described on the LeDeR programme website at www.bristol.ac.uk/sps/leder. From 1st June 2021 it will be available at: https://leder.nhs.uk

Delivery of the LeDeR programme

The LeDeR programme is delivered by a number of partners, each with different responsibilities. Until 31st May 2021, the University of Bristol has been responsible for:

- The process for being notified about deaths of people with learning disabilities, via a secure web link or a confidential phoneline, and informing relevant local areas about the death.
- Developing the online LeDeR review system.
- Providing a secure electronic platform which is used for allocating notifications of deaths to reviewers, monitoring the progress of reviews, and storing review documents and reports.
- Supporting CCGs to complete reviews.
- Coding[103], collating and reporting on the findings of completed reviews, through regular themed review reports for NHS England, and the LeDeR programme annual report.

The University of Bristol's involvement with the LeDeR programme as described above will come to a planned end on 31st May 2021.

NHS England and NHS Improvement funds the LeDeR programme. It is responsible for:

- Supporting local agencies and health and care professionals to complete the reviews.
- Using the learning obtained to influence and contribute to service improvements as indicated.

CCGs are responsible for:

- Ensuring that the actions agreed from LeDeR reviews are delivered in their local area so that local services are improved to meet the needs of people with a learning disability.

As part of their support to local areas for the timely completion of reviews of deaths, in 2019 NHS England

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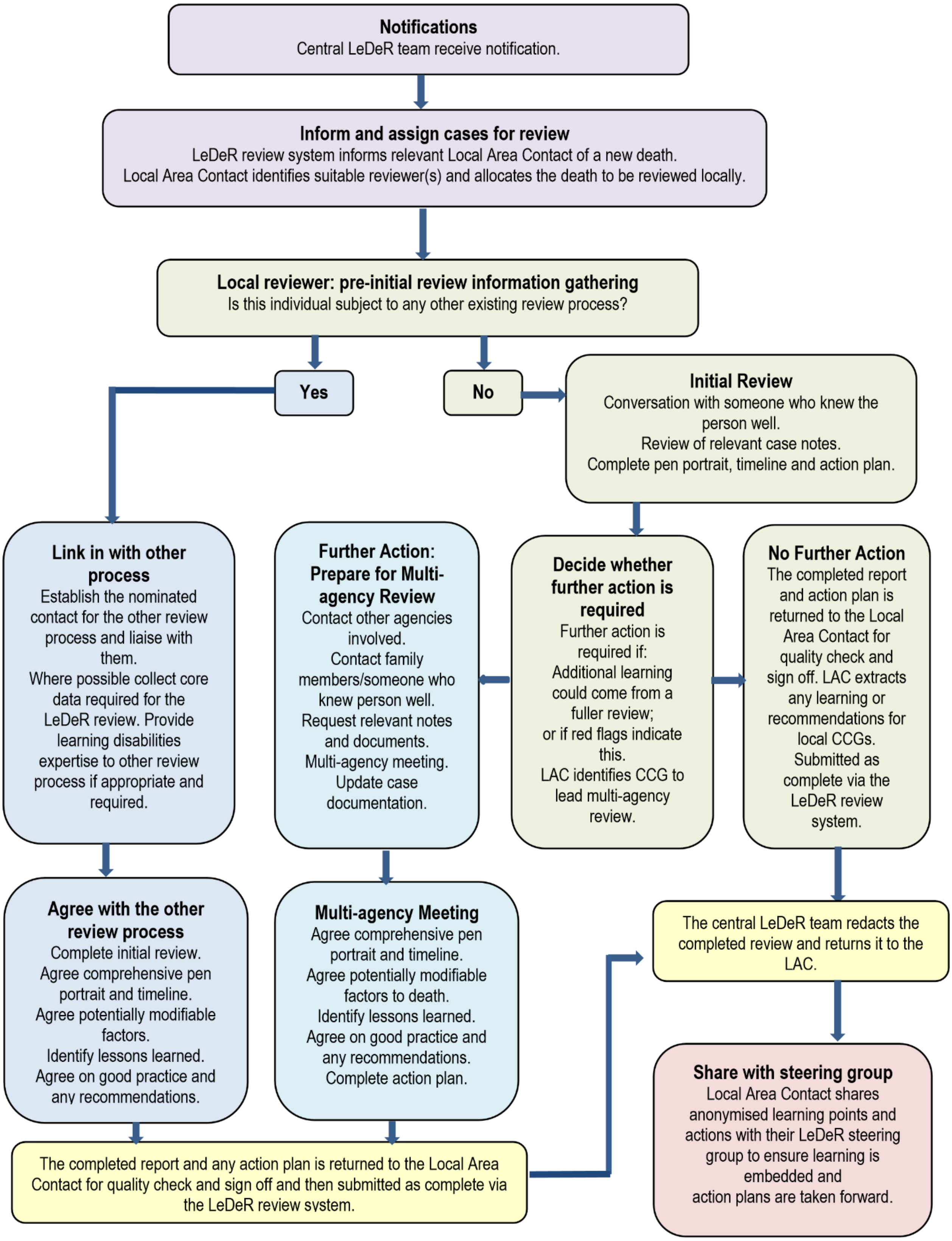
[103] The University of Bristol responsibility for coding and redacting reports transferred to South, Central and West Commissioning Support Unit in June 2020.

commissioned the North East Commissioning Support Unit (NECS) to undertake some reviews of deaths.

In 2020 the South Central and West Commissioning Support Unit (SCW) was appointed to develop a new web-based platform to enable notifications of deaths and completion of reviews. In 2021 a new academic partner will be commissioned to provide independent academic support to the programme.

The LeDeR review process (2018-2020)



Notifications
Central LeDeR team receive notification.

Inform and assign cases for review
LeDeR review system informs relevant Local Area Contact of a new death.
Local Area Contact identifies suitable reviewer(s) and allocates the death to be reviewed locally.

Local reviewer: pre-initial review information gathering
Is this individual subject to any other existing review process?

Initial Review
Conversation with someone who knew the person well.
Review of relevant case notes.
Complete pen portrait, timeline and action plan.

Link in with other process
Establish the nominated contact for the other review process and liaise with them.
Where possible collect core data required for the LeDeR review. Provide learning disabilities expertise to other review process if appropriate and required.

Further Action: Prepare for Multi-agency Review
Contact other agencies involved.
Contact family members/someone who knew person well.
Request relevant notes and documents.
Multi-agency meeting.
Update case documentation.

Decide whether further action is required
Further action is required if:
Additional learning could come from a fuller review;
or if red flags indicate this.
LAC identifies CCG to lead multi-agency review.

No Further Action
The completed report and action plan is returned to the Local Area Contact for quality check and sign off. LAC extracts any learning or recommendations for local CCGs.
Submitted as complete via the LeDeR review system.

Agree with the other review process
Complete initial review.
Agree comprehensive pen portrait and timeline.
Agree potentially modifiable factors.
Identify lessons learned.
Agree on good practice and any recommendations.

Multi-agency Meeting
Agree comprehensive pen portrait and timeline.
Agree potentially modifiable factors to death.
Identify lessons learned.
Agree on good practice and any recommendations.
Complete action plan.

The completed report and any action plan is returned to the Local Area Contact for quality check and sign off and then submitted as complete via the LeDeR review system.

The central LeDeR team redacts the completed review and returns it to the LAC.

Share with steering group
Local Area Contact shares anonymised learning points and actions with their LeDeR steering group to ensure learning is embedded and action plans are taken forward.

Appendix 4: Selected aspects of best practice noted by reviewers

It is important that a programme such as LeDeR shares good practice so that different parts of the country can learn from one another and improve services. This appendix aims to share some of the good practice examples we have found in reviewing LeDeR cases, so that this can contribute to the learning more widely. They demonstrate ways of working with people with learning disabilities that could be replicated elsewhere, to achieve well-coordinated, person-centred care that was proactive as well as reactive. Each of the comments is a direct quote from a reviewer.

Well-coordinated care

Deaths occurring in 2018

- From the point of diagnosis to the point of death, Madeleine received good quality, coordinated care from the right services and specialists. Every professional or specialist service involved knew their roles and followed up on actions to ensure that her needs were meet appropriately.
- Prior to Kathryn being discharged from [care home in Place A], there were several care planning meetings between the community learning disability teams in [Place A] and [Place B – 'out of area'] to ensure a safe discharge and transitioning of her care needs. The [Place A] community learning disabilities team followed up with several reviews once Kathryn was actually a resident and transferred to Place B.
- There is strong evidence of effective communication between all professionals and an excellent understanding of good practice and each other's roles and responsibilities, promoting clarity, effective communication and good practice.

Deaths occurring in 2019

- Collaborative working between the community learning disability team, GP, rapid response team, care home staff and district nursing service. The care home had special links to the rapid response team which meant they had access to IV antibiotic treatment and IV fluids which prevented the need for hospital admissions. The GP acted as the care co-ordinator.
- …effective communication with all professionals including the GP, district nursing team and the palliative care team. This ensured that everyone knew what they were responsible for. Carers knew exactly who to go to for the different support components. All professionals responded as needed to the carers requesting support as needs changed.
- There was clear evidence of a single lead practitioner/key worker being the point of contact for family members and that Mark's family were listened to, actively involved and valued as key members of his caring network when it came to planning and delivering his current and future care and support.

Deaths occurring in 2020

- The different teams collaborated well together to help Nafisa access health interventions with the intended outcome of enabling her to have dialysis and manage her kidney condition. When that was not possible, the teams quickly organised themselves around enabling her to be comfortable. The family were very well engaged in the process.
- The learning disability team appeared to co-ordinate the care which brought everything together. There was a clear and concise integrated care plan with evidence of NICE

guidelines. The actions were very well articulated with named person responsible. This was a live document.
- Availability of the learning disability virtual discharge team who became involved in Sheralyn's care during COVID-19. Team supported discharge and transition, ensuring timely sharing of information, involvement of the relevant health professionals and that care decisions were being made appropriately. The hospital ward team that supported Sherlyn the longest during her admission placed a section within her discharge notification about her health and support needs and what was important for others to know. This was particularly valuable …as limited professionals had been able to visit.

Person centred care

Deaths occurring in 2018
- Incorporation of dental treatment into best interest decision making to limit risks of repeat general anaesthetics.
- The provider had emailed a number of mosques to request support for him to attend from mosque volunteers.
- His environment was adapted to meet his changing needs rather than he had to move to have his needs accommodated.

Deaths occurring in 2019
- The hospital chef continued to make Adrian his favourite milkshake, despite him not being on that ward anymore, but the chef being aware of what a difference it was making for Adrian.
- His community nurse recognised that transport (trains) motivated Eric and produced a certificate with a train on it to recognise Eric attending his first podiatry appointment.
- Peter’s care was commissioned to facilitate attending [his long-standing] social club and so to remain in the social circle he had known and valued for over 50 years. Even when he became physically dependent and it was clear he would need nursing care, they made a commitment to find a way to ensure he could continue to participate.

Deaths occurring in 2020
- The doctor met with Gwylim’s mother and carers to try to establish a normal baseline for Gwylim. The carer from the home was able to show a video of how Gwylim would usually interact and behave; this enabled the medical team to understand how much Gwylim had deteriorated.
- The GP took Mr Sleeman's blood sample in the car as Mr Sleeman did not want to get out due to anxiousness around COVID-19.
- The district nurse would change into a t-shirt when she went to the unit to administer Derek's insulin because of his dislike of uniforms and subsequent non-compliance.

Proactive rather than reactive care, including the provision of reasonable adjustments

Deaths occurring in 2018
- The urology team developed a 'fast track 'pathway for Lee so he could go straight to the ward rather than wait in the emergency department when his catheter dislodged.
- The care home used desensitisation to enable Richard to access an ultrasound scan; ‘simulating’ the process of what it would be like, applying gel to his stomach and using an object similar to what a scope would feel like, this was also carried out when he had a full bladder to get used to the feeling. Richard was able to consent to this.
- Martin liked to go away on holiday so even in the last year of his life the carers made sure he could still go rather than be left behind. They took all his equipment with them, including his hoist and special bed. They hired a special van that was big

enough to take all his equipment and Martin in his wheelchair.

Deaths occurring in 2019

- The diabetes nurse realised that a talking blood glucose machine would be beneficial to Jenny as Jenny was struggling to read the numbers on her old machine.
- Adaptations were made in the home to help keep Dave safe. e.g hallway was repainted, so the floor and walls were easily distinguishable for people experiencing visual perceptual difficulties associated with dementia.
- There was appropriate pre-planning to ensure that when she attended appointments she was well-prepared. Clear plans were always in place and when attending hospital quiet areas were prepared in advance and she was taken straight to the area rather than waiting around.

Deaths occurring in 2020

- An autism profile completed by the provider agency specified in detail how to support Bill and ensure his needs as an individual with autism were central to his care and support. This included how to support his specific interests, how to minimise his extensive anxieties and both proactive and reactive strategies for behaviours of concern.
- The supported care manager had invested in a heart rate monitor and oxygen saturation monitor to monitor residents if they were showing signs or symptoms of COVID-19.
- Mum told the story of a social worker who came to chat to her, who broached the subject of where Graham should live if mum died before him. Mum says she was so relieved to have this conversation and was happy that the social worker had some suggestions that she thought might work for Graham.

Decision-making

Deaths occurring in 2018

- Enid became seriously underweight in 2016. Her care team referred her to the Community Learning Disability team who came to [the care provider] and held a multidisciplinary meeting to review all aspects of Enid's health and social care needs and agree a plan to assist her with eating. This meeting was chaired by a psychologist and considered her physical health needs and any possible cognitive and behavioural aspects that might have been impacting on her eating. The care staff praised this meeting and said it was excellent to have the doctor, social workers, therapists and care staff and Enid's family round the table together. Everyone was able to contribute and provide a full assessment of Enid's problems.
- Before instituting DNACPR, the decision was discussed several times with her parents. They were given the time they needed to consider the decision and its implications. Evidence shows that they were not rushed into agreeing to a DNARCPR decision but were supported to arrive at their own decision. Only after the parents agreed to the DNACPR decision was it put in place.
- A visit was arranged for Susan to visit [the nursing home] whilst she was still in hospital. This enhanced her capacity to make a decision about where she wanted to receive her care and treatment going forward.

Deaths occurring in 2019

- All efforts were made by Robert's multi-disciplinary care team to support his understanding of his chronic renal disease and its possible progression and treatment options. This included the speech and language therapist liaising with specialist services, developing specific easy read information, and on-going contact over a

period of time to establish the limits of Robert's level of understanding and plans for future decisions about his care.
- Margaret refused assessment and treatment of a suspected fractured femur…Margaret did not wish to go into hospital for an x-ray, so alternative arrangements were made for this to happen at one of the local medical centres. Margaret then refused further assessment and treatment in hospital and …did not want to undergo an operation on her thigh. A capacity assessment was completed, and Margaret was found to have capacity to make this decision. Rather than discharge Margaret at this point, it was suggested that she should remain in hospital for pain management and discussions would be re-visited. As such, Margaret changed her mind about having the operation. Records indicate excellent application of Mental Capacity Act principles throughout, which acknowledge that Margaret had a learning disability but also that she had capacity and the right to make her own decisions about her care and treatment.
- Easy read info on cancer was provided and the psychiatrist spent time ensuring David`s understanding of his illness and prognosis.

Deaths occurring in 2020
- Tom was consulted and listened to in relation to decisions about where he lived - he was supported to go and look at one home which he did not like as it was too big. An alternative was sought, and he was supported to visit before deciding he would move there.
- Good evidence of Mental Capacity Act principles supporting practice. It had been determined that Jack did not have capacity to determine his residence and care arrangements. A best interests agreement had been made for Jack should he become unwell that he would remain where he was living as long as possible and a prepaid funeral plan had been arranged for him. There was a pre-planned COVID-19 plan for Jack, given he could not make decisions about protecting himself from this illness - it was clearly written down and relatives felt that they had been appropriately consulted.

- The role of the hospital learning disability liaison nurse was significant in identifying the inappropriate DNACPR and ensuring this was corrected and also ensuring reasonable adjustments were made.

Documentation

Deaths occurring in 2018
- The documentation at the care home was comprehensive - the detailed communication record showed photographs of Billy displaying each of his unique hand and arm signage and describing what each meant.
- Following the best interest agreement to insert a PEG, the acute learning disability team provided a personalised pictorial guide as to how the PEG would be inserted and how the PEG would continue to work - it explained the benefits and possible problems to Billy in a simple but clear way. Once a general anaesthetic had been deemed the only option for Billy, the acute learning disability team made the same clear pictorial guide about the general anaesthetic so Billy, his family and carers were fully aware of the process. The information all featured and named Billy as the person having the procedure.
- The provider has clear "record of health appointment" logs in place. This covers the following topics - "details", "reason for appointment" and "outcome of appointment” (to be completed by health professional where possible). The records of health appointments read by the reviewer were detailed, gave a good explanation of the reasons for appointments and their

outcomes; they were clear and easy to follow.

Deaths occurring in 2019
- Following John's admission and subsequent death, managers felt that they needed to write a local protocol for hospital admission/discharge. This protocol incorporates travel, administration needs, discharge and what needs to happen after discharge from hospital, and a checklist for staff. The area manager advised that the communication between hospital staff and carers was poor and they needed to address this issue in case of any future admissions.
- The organisation created their own internal pre-annual health check forms to help focus the reviews and help to ensure they are meaningful.
- ITU kept a diary for Jacqueline so that she would know what had happened to her when she woke up, this included who was looking after her, any medical interventions she had had and what sort of day she had had. It was written in the form of a letter to her and was very positive and caring.

Deaths occurring in 2020
- The hospital scanned her hospital passport onto the electronic patient record so that it could not be lost and was accessible to everyone involved in her care.
- The local GP service provides an easy read leaflet called 'Get Checked out' for people with learning disabilities to complete prior to attending for their annual health check.
- The practice nurse used videos to demonstrate good inhaler technique.

Bereavement support

Deaths occurring in 2018
- The care staff received bereavement counselling following Johnny's death. I was told how helpful this had been because it was the first death they had managed in the care home.
- Care home staff were proactive in seeking speech and language therapist support to obtain accessible information following Debbie’s death to support her fellow residents.
- The impact of Trevor's death on the two other clients that lived with him was obviously quite significant. Staff demonstrated best practice in bereavement care by supporting these clients to attend Trevor's funeral; and the staff and clients talked openly about Trevor in a way that was appropriate to the cognitive needs of the client group.

Deaths occurring in 2019
- His sister had visited him every Tuesday for 30 years and she felt that there was a huge gap to fill on a Tuesday and found herself gravitating to the home. They have welcomed her visits and enjoyed a cup of tea and a chat and allowed her to sit in his room for a while.
- After Lexi's death her old downstairs bedroom was transformed into a lounge/games room. Pictures of Lexi were on the wall - it was clearly a room that was valued by residents and staff.
- On the day of Shaun's death, his support worker drove to his family's home and brought his brother to the hospital, as she recognised that Shaun's death was imminent. Had she not done so it is likely that he would not have had the opportunity to be with Shaun when he died.

Deaths occurring in 2020
- A 'remembrance display' has been created with photographs and crafts such as a rainbow and a dove that Stephanie made as a positive memorial for staff and residents.
- There is an end-of-life champion at the home who has received Level 3 end-of-life training and education.

- Trevor's co-tenants and staff team could not attend his funeral due to government restrictions concerning potential spread of Coronavirus. Each tenant and staff member released balloons into the air to remember Trevor at the point his funeral took place. Trevor loved balloons in life.

Training

Deaths occurring in 2018

- The care staff all received training in Makaton signing so they could communicate with Mark.
- The introduction of digital equipment and social care staff training in the use of the NEWS tool was fundamental and on two occasions alerted the staff team to Brenda's deterioration in health and requiring hospital admission.
- The care provider supported all the staff from David's house to attend a full days training around end-of-life care, with David being the primary focus for this training and the aim to support him at home to the best of the team’s ability when his health started to deteriorate further.

Deaths occurring in 2019

- Providing training to all staff that were involved in Kayleigh's care prior to her discharge with a tracheostomy was excellent practice. I believe this reduced any complications with the management of the tracheostomy. In-depth training was also provided to the nursing staff which enabled them to train any new staff that came into the home.
- The epilepsy nurse provided training to carers supporting Nicole about basic epilepsy awareness and use of the vagal nerve stimulator…Nicole attended a social club once weekly and a social worker who was a leader at the club contacted the epilepsy nurse for advice about using the vagal nerve stimulator. Training in epilepsy awareness and use of the vagal nerve stimulator was provided to social club staff.
- All members of staff, including the junior members of staff who were involved in Rachel's care, were trained to have dysphagia awareness, which enabled them to understand the dietary requirements that they had to adhere to, and to pick up any early signs of aspiration.

Deaths occurring in 2020

- Staff were provided with epilepsy awareness training from the community epilepsy service. The training included diagnosis, seizures types, seizure management, medications and personal safety and directly related to Alan and the care he required.
- Supported living staff were trained on some nursing care aspects - not the remit of supported accommodation staff, but they did this in order to keep him at home which is what he wanted.
- The learning disability team were involved to help Ann's team understand how to identify and manage her pain.

Appendix 5: Examples from the range of recommendations made by multi-agency review panels and Child Death Review panels

Deaths of adults

Recommended changes to local practice

A total of 275 recommendations were made by multi-agency review panels regarding changes to local practice across 2018 - 2020. Of these, 116 recommendations were made with regards to deaths occurring in 2018, 110 in 2019, and 49 in 2020[104]. (Table 1 Appendix 5). The recommendations were analysed and are reported here in 9 themes:

1. Training and development (22%; n=61).
2. Joint working (17%; n=48).
3. Documentation and systems (15%; n=42).
4. Communication and information sharing (12%; n=34).
5. Proactive care and planning (9%; n=24).
6. Clinical assessment and delivery of care (7%; n=20).
7. Broader systems issues (7%; n=19).
8. Provision of reasonable adjustments (5%; n=15).
9. Person centred planning (4%; n=12).

Table 1 Appendix 5: The most frequently reported categories of recommended changes to local practices made by multi-agency panels and reviewers

Year	Training and development	Joint working	Documentation and systems	Communication and information sharing	Proactive care and planning	Clinical assessment and delivery of care	Broader systems issues	Provision of Reasonable Adjustments	Person centred planning	Total No.
2018	21	21	21	19	9	6	10	5	4	*116*
2019	23	21	14	9	13	8	7	8	7	*110*
2020	17	6	7	6	2	6	2	2	1	*49*
Total	*61*	*48*	*42*	*34*	*24*	*20*	*19*	*15*	*12*	*275*

Excluding 2020 as the data is largely incomplete, the three categories of most frequently reported recommendations were similar in 2019 and 2019.

The most frequently reported recommendations to local practice were categorised as **training and development needs**, and included general learning disability awareness, training about the Mental Capacity Act, about specific medical conditions and safeguarding protocols.

Deaths occurring in 2018

- Introduction of the NEWS (National Early Warning Score) digital kit and training for staff team on using it to provide an opportunity to recognise signs of deterioration in physical health.

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[104] A small number of reviews of people who had died since June 2020 would have been completed, so 2020 data is incomplete.

- Further training in Mental Capacity Act legislation, including best interests decision making processes.
- Awareness should be raised with health professionals on raising a safeguarding alert for individuals at risk of self-neglect.
- There needs to be reflective practice sessions and ensure that there is further curiosity on the care and treatment when something isn't working. There needs to be a cultural shift on the physical health needs rather than challenging behaviours.

Deaths occurring in 2019

- Learning from…LeDeR review and SJR process to be shared across the relevant medical directorates including X-ray departments, Moving and Handling and with the EOL Team for wider dissemination through training.
- Training on sepsis awareness, diagnosis and management for residential home staff and medical professionals.
- Improve education and training for the care provider in relation to falls management and epilepsy training.
- Providers should be aware of what action to take if a person becomes unwell out of area and how they can be promptly transported back to the local hospitals if required. A clear pathway for this should be developed. Providers/Local authorities should consider this as part of their risk assessments when service users are going on holiday.

Deaths occurring in 2020

- Trust to include the subject of 'bias' within annual development days in order to continue to raise awareness of the impact of bias in clinical assessments.
- To consider wider training on reasonable adjustments.
- Promote bowel management/dysphagia training throughout all services.
- GPs to have greater awareness of specialist community learning disabilities teams and when they could/should refer.

The second most frequently reported category of recommendations was in relation to **joint working,** which included involving community learning disability teams in care planning meetings, having a named care coordinator, and following-up on referrals.

Deaths occurring in 2018

- Where community care services continue to offer support to an individual after their admission to hospital, this should be on the basis of a clearly defined 'carers contract' so that the boundaries and expectations of all parties is clear, and the potential for misunderstandings or failures in communication is minimised.
- Need for multi-disciplinary team discharge meetings with providers if there is likely to be a change in the person's level of need on discharge from hospital.
- Hospital staff should ensure that when patients with learning disabilities are admitted to hospital because of concerns around seizure activity, that their neurologist/epilepsy nurse is made directly aware of this.
- Identification of key person/health professional to co-ordinate care as a person's health status is changing.

Deaths occurring in 2019

- To consider an automatic referral for support to Community Learning Disability Services following repeated non-attendance at annual health checks.
- GP to consider a referral to the health facilitator for difficult to contact patients with a learning disability.
- A named person should be responsible for the co-ordination of care of people with complex needs.
- Development of multi-agency risk assessment/risk management processes

as well as the development of multi-agency pain assessment tools.

Deaths occurring in 2020
- Community learning disability teams to joint work for a period to ensure that people with mild learning disability have the correct support from mental health services.
- Any changes to the priority of a referral should be notified to the referrer to inform them of the actions they have taken and the rationale for doing so.
- Consider how care coordination can be implemented for individuals with long-term conditions/unmet physical health needs.

The third most frequently reported category of recommendations was in relation to **documentation and systems,** which included ensuring all involved in a person's care could access the same information, systems being in place that ensure referrals and follow-up appointments are monitored, and people with learning disabilities being 'flagged' in hospital systems.

Deaths occurring in 2018
- Acute trust should consider documenting best interests discussions better.
- Equipment should be linked to the person so that if it is lost it can easily be re-united with the owner.
- For people with complex health needs, prior to transfer of the records there should be a summary of medical history and treatment in the GP records, that includes any referrals that have been made or are required to specialists.
- For all hospital admissions/contacts, the nursing Home to receive a copy of the discharge letters for the people under their care.

Deaths occurring in 2019
- Better documentation of whether mental capacity assessments have taken place and how best interests decisions are made.
- The flagging system for people with learning disabilities in the acute hospitals to be reviewed [in the light of Mark's admissions being missed twice].
- Digitalisation of the hospital passport with an electronic alert on admission to let the liaison nurse know that a person with a learning disability has been admitted to A&E.
- System to be established for Liaison Nurses to alert community learning disability teams of people with learning disabilities who have been admitted to an acute hospital.

Deaths occurring in 2020
- There needs to be clearer processes for communication between the hospital, primary care, the care home and relatives to enable more joined up discharge planning for people with learning disabilities.
- Services should not reduce the priority of an urgent referral that has been made by a GP, especially when this has been done without contact with the patient/family.
- There needs to be sufficient detail in all care and support plans to ensure that there is clarity about who completes which task, and how tasks will be undertaken, measured and monitored.

Wider recommendations made by multi-agency review panels

A total of 143 wider recommendations were made by multi-agency review panels between 2018-2020. Of these, 53 recommendations were made in 2018, 58 in 2019, and 32 in 2020[105] (Table 2, Appendix 5).

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[105] A small number of reviews of people who had died since June 2020 would have been completed, so 2020 data is incomplete.

The recommendations are divided into 7 themes:

1. Care coordination (22%; n=31).
2. Communication and information sharing (20%; n=28).
3. Training (17%; n=24).
4. Person centred planning (15%; n=21).
5. Proactive care (11%; n=15).
6. Provision of reasonable adjustments (8%; n=12).
7. Documentation (8%; n=11).

Table 2 Appendix 5: The most frequently reported categories of wider recommendations made by multi-agency panels and reviewers

Year	**Care coordination**	**Communication and information**	**Training and development**	**Person centred planning**	**Proactive care planning**	**Reasonable Adjustments**	**Documentation and systems**	***Total***
2018	9	9	12	11	4	4	4	*53*
2019	14	12	7	7	9	5	4	*58*
2020	8	7	5	3	2	3	4	*32*
Total	*31*	*28*	*24*	*21*	*15*	*12*	*12*	*143*

Excluding 2020 as the data is largely incomplete, the number of recommendations about care coordination, information sharing, and proactive planning increased from 2018 - 2019.

The most frequently reported wider recommendations were regarding **care coordination**, which included the need for a single point of contact or a named individual, particularly for people with the most complex needs.

Care coordination

- Implementation of care co-ordination including input from acute services when necessary.
- Care coordinator needs assigning on patient admission.
- There is a local and national requirement for a named healthcare coordinator to be allocated to people with complex or multiple health needs, or two or more long-term conditions.
- Joint protocols for clinical lead and team leaders to be formulated and shared.

The second most frequently reported category of wider recommendations was in relation to **communication and information-sharing**, which included enhanced IT systems that allow information sharing across different settings, shared documentation and proactive communications.

- For hospitals to consider the process of death notification in the event that an individual has health appointments that need to be cancelled.
- Investigate whether IT system can flag where more than one vulnerable person lives at the same address.
- In relation to Mental Capacity Act assessments and best interest decision-making, clinical teams should use joint paperwork and record-keeping systems, to promote shared understanding.
- Automatically pulling through reasonable adjustments from the NHS Spine, onto all records and referrals would be highly

beneficial - it will allow services to anticipate challenges in advance.

The third most frequently reported category of wider recommendations was in relation to **training and development,** which included training about the Mental Capacity Act and aspects of care provision for people with learning disabilities.

- Families of people with a learning disability should be given information and advice about the Mental Capacity Act 2005.
- Improve use of pain assessment and other tools when working with people with learning disabilities who are nonverbal.
- Greater support is required for non-mental health trained support staff about supporting people with learning disabilities with specific mental health issues.
- Staff in hospitals and other care environments to be made more aware of Lasting Power of Attorney and what is means.

The fourth most frequently reported category of wider recommendations was in relation to **person-centered planning**, which referred to the provision of advocacy, timely proactive planning of care and shared care plans.

- The wider promotion and use of non-statutory advocates.
- When people with a learning disability have a terminal illness there should be consideration of whether additional care can be commissioned to enable them to have end-of-life care in their own home, and prevent a placement move.
- Provision of long-term care planning for those people with learning disabilities who are older, frail and their health is deteriorating and their care provision may need to be change to suit their needs.
- Consideration of the assumptions of culture in relation to apparent expectations of family care provision.

Deaths of children

The Child Death Review Analysis form summarises the learning and recommendations related to local, regional and national agencies that have been agreed by the Child Death Overview Panel. We have combined these with the findings from the few LeDeR reviews of deaths of children to consider the overall learning and recommendations from the reviews.

The majority of recommendations were specific to local agencies. Table 3 Appendix 5, indicates the 6 broad themes of the most frequently made recommendations and actions.

The themes related to the coordination of care; the delivery of care; gaps in service delivery; information sharing; training provision; and working with families and paid carers.

Table 3 Appendix 5: The broad themes of the most commonly made recommendations made and actions agreed to be taken as reported in child death review reports

Broad theme	Example recommendations	Example actions agreed to be taken
Coordination of care	'Paediatric intensive care unit to attend weekly neuro-oncology multi-disciplinary team meeting when relevant.' 'Opportunities to be created for Health and [children and young people] practitioners to come together to explore how they better support and prioritise the needs of children and young people with complex health needs and improve their practice as an outcome.' 'Housing to be invited to multiagency meetings for children when there is an unmet housing need.'	'Chair of meeting emailed head of surgical governance to discuss adding consultant neurosurgical workload and working hours onto the hospital risk register at the next surgical clinical governance meeting.' 'It was important that the paediatric team were aware that sepsis had been triggered but as it was not recorded electronically there was a lack of communication between the two departments…This electronic communication problem has been resolved.' 'Hospital paediatricians have agreed to provide guidance for adult wards/ITU when requested.'
Delivery of care	'All providers ensure that their [Advanced Clinical Practice] pathways enable a timely review as appropriate.' 'Blood Pressure should be taken more regularly when septic shock is indicated' 'Standard operating procedure for planned compassionate extubation in hospice or home to be developed by [Primary Care Commissioning] team'	'Dr D Vasiliadis to write to CDOP to confirm that A&E has clear pathways and guidance in place with regard to the sepsis protocol.' 'Chair to consider discussion with the tertiary Emergency Department about how children with complex needs are managed in the department should they want to leave before being assessed.' 'Paediatric neuro-surgeon is discussing the introduction of a medic alert bracelet.'
Gaps in service delivery	'All areas should have provision for a specialist epilepsy nurse.' 'Children with autism or [learning disabilities] require full assessment and review as all children do' 'Need for timely [Education, Health and Care Plan] and a process to identify/escalate cases where they are delayed and impacting on quality of life.'	'[Clinical Commissioning Groups] and [local authorities] to consider a review of short break capacity.' 'Check whether palliative care support was offered in relation to the deceased.' 'CDOP to raise with GP's the profile of the learning disability register through the clinical lead for learning disabilities and via the CCG primary care bulletin.'

Information sharing	‘All commissioners of NHS provider services to ensure that providers are meeting the NHS communication standards’ ‘Have a compulsory yes/no box on discharge summary to prompt letters to be sent to community team.’ ‘Ensure there is a system in place within the community team for all e-mailed discharge summaries to go to the nursing team as well as the medical team.’	‘Specialist safeguarding lead to notify relevant agencies regarding new policy for young carers’. ‘Chair, designated doctor, head of safeguarding…and hospice medical director to progress Child and Family Wishes document for ambulance service.’ ‘Current audit within community team about vitamin D supplementation in children on long term anticonvulsant therapy to be shared with acute team once results available.’
Training provision	**‘**Ensure that all practitioners in health and children’s services are clear about when to use an Independent Mental Capacity Advocate for over 18s under the MCA and for children under the 1989 Children’s Act. Practitioners should understand the role of the advocate.’ ‘All practitioners in health and children’s and adult services to be knowledgeable about trauma informed care/ACE and the implications of this for their work with families.’	‘Dr Farmer and Martin to scope protected learning time for professionals on acute grief.’ ‘Half day session on complex needs so that GPs understand that bereavement is different, and that care of family doesn’t end after a child’s death.’
Working with families/paid carers	‘Reminder to be given to all paediatric and emergency department staff that parents may change their mind about the advanced care planning.’ ‘Where an organisation is taking out action against a service user under the zero-tolerance policy, they need to take into consideration the impact that might have on the wider family, particularly if they have parenting or caring responsibilities.’ ‘Discuss methods of sharing coronial information with families and how better to support families with the information when they are unprepared.’	‘Seek reassurance that there is appropriate support in place and effective working with the family for the child's younger sibling who has the same medical condition.’ ‘Community paediatrician is going to meet with the family again next week to ensure feedback of any issues.’ ‘LeDeR programme manager will meet with the child's grandmother to explore her experiences of the values and attitudes of some professionals in providing care to a child with severe and profound learning disabilities.’

Appendix 6: Summary of some recommendations made in previous reports about deaths of people with learning disabilities, and government responses to these

Many issues have been raised and recommendations made in previous reports and inquiries about deaths of people with learning disabilities. There is a danger in viewing these in isolation, rather than as a whole. Here, identify some of the key issues raised in previous mortality reports, summarise the recommendations made in those reports, and note any published responses to these recommendations. It should be noted that actions may have been taken in response to recommendations but not included in any published response. In addition, the global COVID-19 pandemic in 2020 may have affected progress in taking forward some of the recommendations.

Poor care coordination and communication between agencies

Recommendations made

Learning Disabilities Mortality Review (LeDeR) programme. Fourth Annual Report 2019 (published in 2020).
Recommendation 4.
Consider the recommendations from the 'Best practice in care coordination for people with a learning disability and long-term conditions' (March 2019) report and:

- Establish and agree a programme of work to implement the recommendations.
- Liaise with NIHR regarding the importance of commissioning a programme of work that develops, pilots and evaluates different models of care coordination for adults and children with learning disabilities.

Learning Disabilities Mortality Review (LeDeR) programme. Third Annual Report 2018.
Recommendation 7.
Guidance continues to be needed on care-coordination and information sharing in relation to people with learning disabilities, at individual and strategic levels.

Learning Disabilities Mortality Review (LeDeR) programme. Second Annual Report 2017.
Recommendation 4.
All people with learning disabilities with two or more long-term conditions (related to either physical or mental health) should have a local, named health care coordinator.

CIPOLD (2013)
http://www.bris.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf
Recommendation 4.
A named healthcare coordinator to be allocated to people with complex or multiple health needs, or two or more long-term conditions.

Michael, J. (2008) Healthcare for All
https://webarchive.nationalarchives.gov.uk/20130105064250/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099255
Recommendation 3.
Family and other carers should be involved as a matter of course as partners in the provision of treatment and care, unless good reason is given, and Trust Boards should ensure that reasonable adjustments are made to enable them to do this effectively. This will include the provision of information but may also involve practical support and service co-ordination.

Published responses to recommendations made

NHS England Action from Learning report 2020
https://www.england.nhs.uk/publication/leder-action-from-learning-report/
The Voluntary Organisations Disability Group (VODG) hosted three conferences for social care providers to share learning and spread best practice about how better partnership working across health and social care can improve outcomes and experience.

Department of Health and Social Care (2020) The Government response to the third annual Learning Disabilities Mortality Review (LeDeR) Programme report[106].
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/865288/government-response-to-leder-third-annual-report.pdf
2.35 In the Government's response to the 2018 LeDeR report, we committed to 'Undertake a rapid review of best practice in care co-ordination/key working for people with a learning disability, focused on health and wellbeing, to inform guidance for the NHS on care-co-ordination.'
2.36 We are working with the Institute of Public Care at Oxford Brookes University to gather existing evidence and case studies of care co-ordination for people with learning disabilities. The IPC held focus groups with people with learning disabilities and their families and carers. Evidence from a number of different approaches to care co-ordination have been identified. Examples from across the country have also been drawn together to demonstrate best practice.

2.37 Care co-ordination is a complex area, particularly in the specific context of improving health and wellbeing of people with learning disabilities. It is therefore important that we properly understand the challenges and issues faced prior to establishing next steps. DHSC will publish an evidence review of care co-ordination for people with learning disability, focused on health and wellbeing. Once this work is complete, we will be better placed to understand how this can be used to inform how care co-ordination is delivered across the health and social care sector for people with a learning disability, particularly in regards to developing guidance. Action: DHSC to publish an evidence review of care co-ordination for people with learning disability, focused on health and wellbeing. By summer 2020.

The Government response to the Learning Disabilities Mortality Review (LeDeR) Programme Second Annual Report (2018)
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/739560/government-response-to-leder-programme-2nd-annual-report.pdf

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[106] The government has not yet responded to the Fourth Annual Report 2019 (published in 2020).

We agree that coordinating care across and within health and care services is a crucial determinant of outcomes. We will be reviewing best practice on care coordination to identify approaches that work best for people with a learning disability with two or more long-term conditions.
Action 2: NHS England to report annually to the DHSC on progress made on the learning into action workstream regarding improvements in interagency communication achieved through local action. By March 2019.
Action 8. Undertake a rapid review of best practice in care-coordination / key working for people with a learning disability, focused on health and wellbeing, to inform guidance for the NHS on care-co-ordination. DHSC. March 2019.

Department of Health (2014) Premature Deaths of People with Learning Disabilities: Progress Update
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/356229/PUBLISH_42715_2902809_Progress_Report_Accessible_v04.pdf
3.2. An overarching national initiative to address the fragmentation of care is the Better Care Fund. This provides an opportunity for local services to improve the lives of some of the most vulnerable people in our society. It ensures closer integration between health and social care services to work more closely together in local areas, based on a plan agreed between the NHS and local authorities. Local plans were submitted in April.
3.4. Published on April 14th, Transforming Primary Care sets out the Department and NHS England's joint vision for safe, proactive, personalised care for those who need it most. From September 2014, over 800,000 people with the most complex needs will experience a step change in their care, with GPs developing a proactive and personalised programme of care and support tailored to their needs and views – the Proactive Care Programme.
3.5. The Programme will be provided for at least two per cent of adults on GPs' practice list with the most complex needs. The decision about who is identified to receive the Programme is ultimately up to general practitioners' discretion. However, we anticipate that the cohort of people will contain a number of people with learning disabilities.

Government response to the recommendations in the Confidential Inquiry into premature deaths of people with learning disabilities (2013).
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/212077/Government_Response_to_the_Confidential_Inquiry_into_Premature_Deaths_of_People_with_Learning_Disabilities_-_full_report.pdf
The DH agrees with this recommendation and this is also a core aim of NHS England. In particular, domain 2, 'Improving the quality of life for people with long term conditions', is aiming to have a known contact for individuals who have multiple long-term conditions who can:

- Coordinate a person's care.
- Communicate with other health professionals.
- Be involved in care planning with the individual for future needs.

23. NHS England will make care coordination a central part of its strategy to help people with more complex healthcare needs benefit from personalised care and know who to turn to for advice in the event of deterioration in their condition. This will include approaches to identify those people who need disease or case management to manage their condition.

24. NHS England will support named healthcare coordinators, usually located in primary and community care settings, being available to people so they know who to turn to when they need them. In particular, NHS England will:

- work with the Association of Directors of Adult Social Services (ADASS) and the Association of Directors of Children's Services (ADCS), to develop practical resources for commissioners of services for people with learning disabilities of all ages, including children and young people; and,
- examine the potential for tighter requirements in the NHS Standard Contract for the provision of named healthcare coordinators for people with learning disabilities. This will be done by the new clinical lead for learning disabilities, who will be recruited to work on domain 2 in NHS England by August 2013. NHS England will publish further details later in 2013.

HM Government (2009). Valuing People Now: a new three-year strategy for people with learning disabilities. A response to Michael's Healthcare for All (2008)
https://webarchive.nationalarchives.gov.uk/20130105064234/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093375.pdf
Recommendation 3. Response: we accept this recommendation.

Delays in the diagnosis and treatment of illness

Recommendations made

Learning Disabilities Mortality Review (LeDeR) programme. Fourth Annual Report 2019.
Recommendation 5
Adapt (and then adopt) the National Early Warning Score 2 regionally, such as the Restore2TM in Wessex83, to ensure it captures baseline and soft signs of acute deterioration in physical health for people with learning disabilities by:

- Involving people with learning disabilities, their families and professional organisations.
- Disseminating for use across acute, primary and community settings.

Recommendation 6
Consider developing, piloting and introducing:

- Specialist physicians for people with learning disabilities who would work within the specialist multidisciplinary teams.
- A Diploma in Learning Disabilities Medicine.
- Making 'learning disabilities' a physician speciality of the Royal College of Physicians.

Recommendation 7
Consider the need for timely, NICE evidence-based guidance that is inclusive of prevention, diagnosis and management of aspiration pneumonia in adults and children. The outcome of such considerations should be shared with DHSC and NHSE.
Recommendation 8
RightCare to provide a toolkit to support systems to improve outcomes for adults and children at risk of aspiration pneumonia.
Recommendation 9

For safety of people with epilepsy to be prioritised. The forthcoming revision of the NICE Guideline 'Epilepsies in children, young people and adults' to include guidance on the safety of people with epilepsy, and safety measures to be verified in Care Quality Commission inspections.
Recommendation 10
For a national clinical audit of adults and children admitted to hospital for a condition related to chronic constipation. The National Clinical Audit and Patient Outcomes Programme is one way this could happen.

Learning Disabilities Mortality Review (LeDeR) programme. Third Annual Report 2018.
Recommendation 6.
The Department of Health and Social Care, working with a range of agencies and people with learning disabilities and their families, to prioritise programmes of work to address key themes emerging from the LeDeR programme as potentially avoidable causes of death. The recommended priorities for 2019 include: i) recognising deteriorating health or early signs of illness in people with learning disabilities and ii) minimising the risks of pneumonia and aspiration pneumonia.

CIPOLD (2013)
http://www.bris.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf
Recommendation 7.
People with learning disabilities to have access to the same investigations and treatments as anyone else, but acknowledging and accommodating that they may need to be delivered differently to achieve the same outcome.

Published responses to recommendations made

NHS England Action from Learning report 2020.
https://www.england.nhs.uk/publication/leder-action-from-learning-report/
NHS England and NHS Improvement are working with NHS Digital to roll out an adaptation to the summary care record system. The digital 'fag' will alert NHS providers that a particular patient needs 'reasonable adjustments' (defined by the Equality Act 2010) in order to be able to access healthcare on a fair basis.

Department of Health and Social Care (2020) The Government response to the third annual Learning Disabilities Mortality Review (LeDeR) Programme report.
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/865288/government-response-to-leder-third-annual-report.pdf
2.29 We agree that key themes identified in LeDeR reports should inform the prioritisation of programmes of work. NHS England have set out the work underway in response to national themes identified in the LeDeR reviews, including relating to the recommended priorities above in their Action from Learning report (2019).
2.30 The LeDeR report highlighted a number of issues related to the quality of care of people with learning disabilities, including delays in identifying that a person was ill, recognising further deterioration, and accessing and receiving appropriate medical care. Failure to recognise or act on

signs a patient is deteriorating can result in missed opportunities to provide the necessary care to give the best possible chance of survival.

2.31 The 2019 Action from Learning report was the first report on work to translate learning into action in relation to the LeDeR programme and set out work relating to the specific issues of acute deterioration, including sepsis and aspiration pneumonia.

Action: NHS England will publish another Action from Learning report to demonstrate the range of changes that have taken place as a result of the learning from LeDeR reviews. Spring 2020.[107]

Government response to the recommendations in the Confidential Inquiry into premature deaths of people with learning disabilities (2013).

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/212077/Government_Response_to_the_Confidential_Inquiry_into_Premature_Deaths_of_People_with_Learning_Disabilities_-_full_report.pdf

30. NHS England is committed to reducing inequalities in outcomes for people with learning disabilities. The Mandate set by the Government requires NHS England to deliver improved outcomes for all people. Success will be measured not only by the average level of improvement but also by progress in reducing health inequalities and unjustified variation in outcomes, including for people with learning disabilities.

31. The factors that contribute to inequalities in outcomes are complex and it is clear that a number of approaches to addressing and improving these are needed. NHS England is currently developing its approach to reducing premature mortality. As part of this it is working with learning disabled people and family carers to understand the factors that impact on their ability to access services in the same way as the rest of the population. NHS England is clear that if it can improve the way that services respond to the needs of the most vulnerable in society, then those improvements are also likely to deliver broader benefits for the general population.

32. NHS England will continue to develop its overall approach to supporting people with learning disabilities and family carers. In the meantime, NHS England will:

- Work with Association of Directors of Adult Social Services (ADASS) and Association of Directors of Children's Services (ADCS) to develop practical resources for commissioners of services for people with learning disabilities, including children and young people with the potential for new NHS contract specifications for specialist learning disability services and for models for rewarding best practice through the Commissioning for Quality and Innovation (CQUIN) framework.
- Support CCGs in their work with local authorities to ensure that people of all ages in vulnerable circumstances, particularly those with learning disabilities and autism, receive safe, appropriate and high-quality care. This includes supporting effective, integrated education, health and care planning for children and young people with a learning disability who have special educational needs.
- Monitor the progress of the NHS in improving outcomes for all people and reducing variation in outcomes, including for those with learning disabilities, in England.

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[107] The 'Learning Disability Mortality Review (LeDeR) programme: Action from Learning Report 2019/2020' was published in July 2020: Action from learning report (england.nhs.uk)

- Assess scope for publishing comparable practice level data and as part of this work consider what scope there is for capturing data in relation to people with learning disabilities.

Application of the Mental Capacity Act

Recommendations made

Learning Disabilities Mortality Review (LeDeR) programme. Fourth Annual Report. 2019.
Recommendation 3
(Repeated from the House of Lords Select Committee on the Mental Capacity Act 2005).
The standards against which the Care Quality Commission inspects should explicitly incorporate compliance with the Mental Capacity Act as a core requirement that must be met by all health and social care providers.

Learning Disabilities Mortality Review (LeDeR) programme. Second Annual Report. 2017.
Recommendation 8.
Local services strengthen their governance in relation to adherence to the MCA, and provide training and audit of compliance 'on the ground' so that professionals fully appreciate the requirements of the Act in relation to their own role.

Select Committee on the Mental Capacity Act 2005. Mental Capacity Act 2005: post-legislative scrutiny (2014).
https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/13902.htm
Recommendation 1.
In the first instance we recommend that the Government address as a matter of urgency the issue of low awareness among those affected, their families and carers, professionals and the wider public. (paragraph 109.)
Recommendation 3
We recommend that overall responsibility for implementation of the Mental Capacity Act be given to a single independent body. This does not remove ultimate accountability for its successful implementation from Ministers, but it would locate within a single independent body the responsibility for oversight, coordination and monitoring of implementation activity across sectors, which is currently lacking. (paragraph 114).
Recommendation 5.
We recommend that the standards against which the CQC inspects should explicitly incorporate compliance with the Mental Capacity Act, as a core requirement that must be met by all health and care providers. Meeting the requirements of the empowering ethos of the Act, and especially in terms of actively enabling supported decision-making, must be given equal status with the appropriate use of the deprivation of liberty safeguards, or their replacement provisions (paragraph 127).
Recommendation 6.
We recommend the Government work with professional regulators and the medical Royal Colleges to ensure that the Act is given a higher profile. This work should emphasise the empowering ethos

of the Act, and the best interests process as set out in section 4 of the Act. In future, we would expect the responsibility for this to sit with the independent oversight body. (paragraph 138).
Recommendation 36.
We recommend as a matter of urgency that the Government take steps to establish regular and dedicated monitoring of implementation of the Act, and that this should include all the sectors across which the Act applies. (paragraph 35).

CIPOLD (2013).
http://www.bris.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf
Recommendation 10.
Mental Capacity Act advice to be easily available 24 hours a day.
Recommendation 12.
Mental Capacity Act training and regular updates to be mandatory for staff involved in the delivery of health or social care.
(i) We recommend the development, by the Department of Health, of an approved e-learning package with worked examples and case studies, supported by individual applied training in the practice environment.
(ii) Training activities regarding the Mental Capacity Act must be monitored by NHS England and Clinical Commissioning Groups as part of their contracts with service providers.

Published responses to recommendations made

NHS England Action from Learning report 2020.
https://www.england.nhs.uk/publication/leder-action-from-learning-report/
NHS England and NHS Improvement have been co-producing with experts by experience some new resources on the Mental Capacity Act for people with a learning disability, their families and carers and professionals. However, this work was paused due to the COVID-19 response.

The Government response to the Learning Disabilities Mortality Review (LeDeR) Programme Second Annual Report (2018)
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/739560/government-response-to-leder-programme-2nd-annual-report.pdf
50. We acknowledge that more needs to be done to embed the principles of the MCA in everyday practice. Every part of the system has a role to play and the Government is showing leadership on this through the National Mental Capacity Forum.
Action 21. The Department of Health and Social Care to update on progress regarding the National Mental Capacity Forum. DHSC. 2019.
Action 22. NHS England to distribute additional best practice guidance on the MCA, learning disabilities and urgent care situations. NHS England. November 2018.
Action 23. The CQC to further develop inspection expertise to assess the quality of MCA application and practice. CQC. October 2019.

Department of Health (2014) Premature Deaths of People with Learning Disabilities: Progress Update

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/356229/PUBLISH_42715_2902809_Progress_Report_Accessible_v04.pdf
5.3 … relevant commitments include:

- The Social Care Institute for Excellence (SCIE) has been asked to conduct a review of MCA guidance to identify 'gold standard' materials for the health and care sector by the end of 2014. These materials can then be jointly endorsed by national system partners and their existence advertised. They will be easily available online.
- Health Education England (HEE) is conducting a review of its training programmes to determine their compliance with the principles of the MCA.
- NHS England has agreed to explore best practice in the use of commissioning as a tool for encouraging implementation of the MCA.

5.5. It is important that MCA advice should be available whenever it is needed. Most hospitals and local authorities have a Mental Capacity Lead person, whose job it is to carry out training needs analyses, commission or offer training, and to help with difficult situations. There should be staff trained in the MCA available 24 hours a day, and there should be specialist advice available in all care settings.

5.6. In addition, the Department is commissioning a review of guidance materials on the MCA. This review will ask stakeholders to submit any tools and guidance for review by an independent panel prior to being made available through an online portal.

5.7. HEE is committed to improving the education and training of the NHS workforce by working with the Department of Health, providers, clinical leaders, Royal Colleges and other partners. HEE has signed the Winterbourne View Concordat and will also ensure the findings of the Confidential Inquiry are acted upon as it progresses work on educating and training staff that are treating and caring for people with learning disabilities, autism and challenging behaviour. In particular:

- To develop e-learning resources for those working with children, young people and adults across the full spectrum of disabilities, including those with a learning disability, special educational needs or complex health needs. This will include opportunities for training in how to support individuals in line with the provisions of the MCA.
- In response to the House of Lords report, Health Education England is reviewing its education and training programmes to determine their compliance with the principles of the MCA. Health Education England will also consider the benefit of including MCA compliance as a feature of our standard contract with education providers.

Government response to the recommendations in the Confidential Inquiry into premature deaths of people with learning disabilities (2013).
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/212077/Government_Response_to_the_Confidential_Inquiry_into_Premature_Deaths_of_People_with_Learning_Disabilities_-_full_report.pdf

47. The DH agrees it is important that MCA advice should be available at all times. ..

48. Most hospitals and local authorities have a Mental Capacity Lead person, whose job it is to carry out training needs analyses, commission or offer training, and to help with difficult situations. There should be staff trained in the MCA available 24 hours a day, and there should be specialist advice available in all care settings.

49. CCGs are responsible for commissioning this for the NHS, and all CCGs have a named MCA lead as part of their authorisation process. However, their arrangements for commissioning advice vary, some commission it through access to private lawyers, some through access to their own lawyers, while others rely on their consultants having the required expertise.

56. The DH is working with partners, including relevant Royal Colleges, HEE and Skills for Care to develop e-learning resources for those working with children, young people and adults across the full spectrum of disabilities, including those with a learning disability, special educational needs or complex health need. This will include opportunities for training in how to support individuals in line with the provisions of the MCA.

57. All CCGs have a named MCA lead. These named leads have responsibility for commissioning MCA compliant services and for monitoring that the services meet the requirements of the MCA. CCGs will be held accountable by NHS England, who will be asked to report to the DH on evidence of compliance.

Addressing inequalities

Recommendations made

Learning Disabilities Mortality Review (LeDeR) programme. Fourth Annual Report 2019.
Recommendation 1.
Ensure continued focus on BAME deaths of all adults and children within, but not limited to, the LeDeR programme.
*Recommendation 2**.***
For the DHSC to work with the Chief Coroner to identify the proportion of deaths of people with learning disabilities (and possibly other protected characteristics) referred to a coroner in England and Wales.

Published responses to this recommendation

NHS England Learning from lives and deaths. People with a learning disability and autistic people (LeDeR) policy 2021.
https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf
Focused review
Situations where a focused review will be carried out are:
1. If the individual is from a Black, Asian or Minority Ethnic background, a focused review will automatically be completed due to significant under-reporting and increased health inequalities in these communities. (This may include, for example, and not be limited to, Romany Gypsy, Irish traveller or Jewish communities).
Action Plan
LeDeR steering groups to be asked to identify a BAME lead. We will explore the inclusion of the needs of people with a learning disability from BAME communities in the revised NHS Equality Delivery System.

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