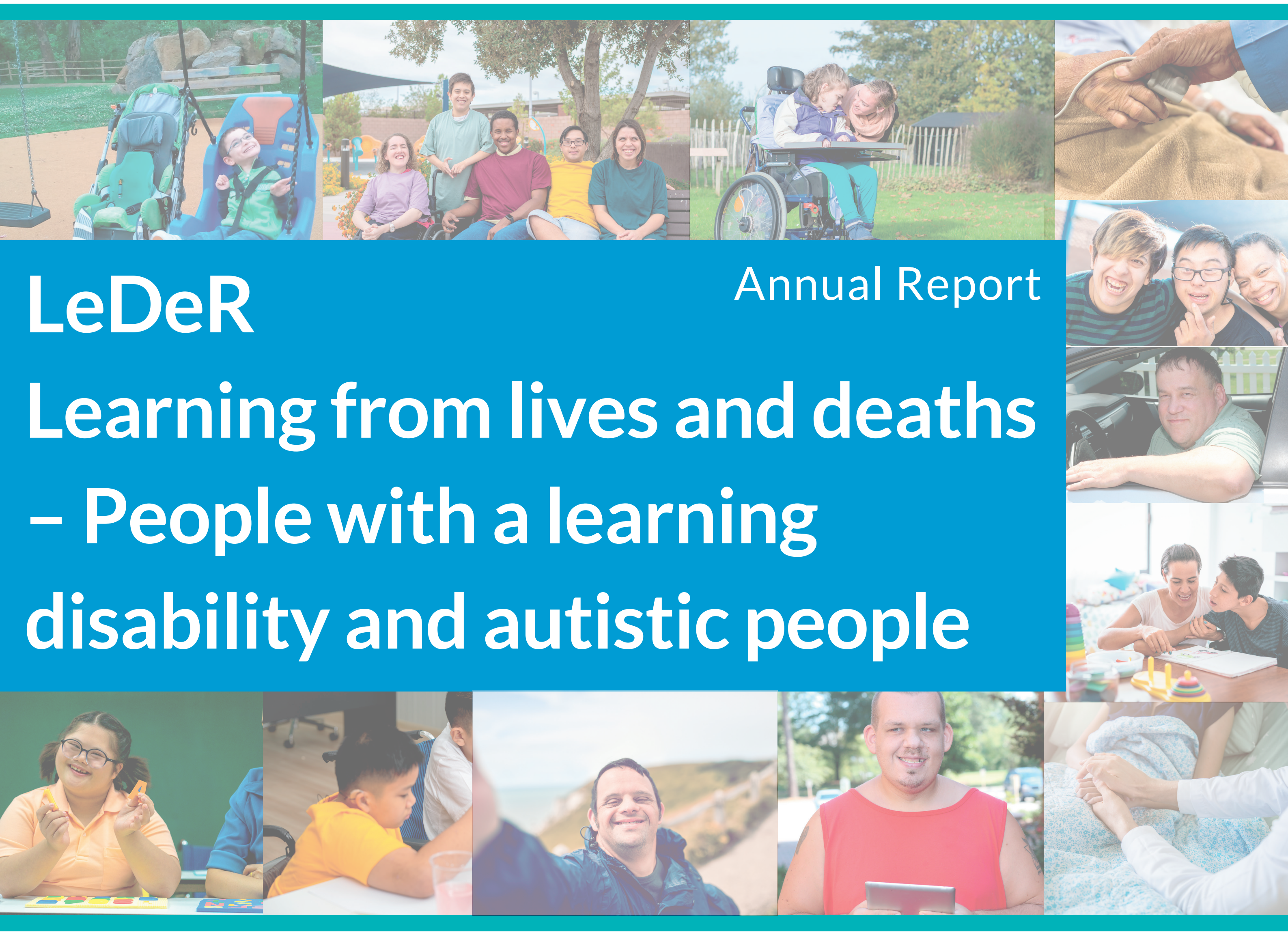

Annual Report

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

2021

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

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White, A; Sheehan, R; Ding, J; Roberts, C; Magill, N; Keagan-Bull, R; Carter, B; Ruane, M;
Xiang, X; Chauhan, U; Tuffrey-Wijne, I; Strydom, A; (2022).
Learning from Lives and Deaths -
People with a learning disability and autistic people (LeDeR) report for 2021
(LeDeR 2021).
Autism and learning disability partnership,
King's College, London

Acknowledgements

These images are entrants to the Staying Alive and Well logo competition. 1. Tamsin, Milton Keynes, 2. Stacey, Wandsworth, 3. Peter, GRASSroots, 4. Louise, Darlington, 5. Charlie, Southwark, 6. Tonbridge and Tonbride Wells day services.

The LeDeR report would not have been possible without the support, commitment and care of the many people and organisations across England who have worked to notify deaths of people with a learning disability, conducted reviews and coded and analysed the information. Most importantly though, we wish to acknowledge the people for whom this report is created; people with a learning disability, their families, friends, colleagues, carers and all staff and service providers, whose lives are affected by this report. In light of the challenges our community and the world is facing today, it is deeply important to acknowledge the strength and care displayed by so many and the love for those who have passed. Whilst far too many cannot be with us today, we hope that this report does justice to their legacy.

We wish to acknowledge and thank the organisations who have been involved in this work; NHS England, in particular the work of the whole LeDeR team; the University of Central Lancashire, Kingston University and St George's, University of London; and the team at South Central and West Commissioning Support Unit (SCW) that had responsibility for processing and managing the data. Professor Pauline Heslop and her team at University of Bristol had a pivotal role in establishing the LeDeR review programme and produced the annual reports from 2015 to 2020. The University of Bristol had responsibility for managing some aspects of the programme until the spring of 2021, and we acknowledge the use of data that was collected and managed by them during the first part of the year, as well as data from earlier years. We would also like to acknowledge our colleagues at Estia Centre at South London and the Maudsley NHS Foundation Trust, the Foundation for People with Learning Disabilities at London Southbank University and Pathways Associates for their assistance with the accessible report.

We are also grateful for the input from our stakeholders (NHS and other organisations) and our advisory board, chaired by Professor Yona Lunsky of the University of Toronto in Canada. Special thanks also goes to our colleague Dr Lukasz Zalewski for his technical support with the data extraction and processing.

Contents

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

Tables

Figures

LeDeR Report 2021

Introduction and Foreword

New ways of collaborating

When the University of Bristol's involvement with LeDeR came to an end, the roles and responsibilities they previously held were redistributed.

The overall responsibility for hosting a custom application that facilitates the submission of notifications to LeDeR has been taken on by South Central and West Commissioning Support Unit (SCW), who launched a new, integrated web platform in June 2021 with the aim of streamlining the process of conducting reviews and improving reviewer training. SCW are responsible for the ongoing management of the software, including de-identification and other data management processes.

New team and partners

2021-2022 has been a pivotal year for LeDeR. Building on the previous work by the University of Bristol, King's College London (KCL) are the new lead academic partner and have been commissioned to analyse and report the latest data and findings of the LeDeR programme. The brief includes the production of 'deep dives' (in-depth explorations of important and relevant topics) and regular digests of new scientific literature. KCL are working with partners at the University of Central Lancashire (UCLan) and Kingston University and St George's, University of London (KStGU), to deliver a high quality, rigorous annual report that meets the needs of the people for who this matters most: people with learning disability, their caregivers, and the professionals who support them.

Updates to the report

With a new team of researchers working at KCL, UCLan and KStGU, changes have been made to the format of the annual report.

Some of these changes include:

- More graphical presentations of the data and findings in a visual format.
- The inclusion of a pull-out infographics with key take away messages of the main findings.
- A focus on making findings easy to understand and interpret.
- An emphasis, where possible, on changes over time.

Changes have also been made to the format of the accessible report to ensure that it is suited to a wider range of people.

These include:

- Summarising the main findings from the report using video presentations, making the report more comprehensible for people who are unable to read.
- Shorter summaries of only the most important information.
- Dividing the accessible report into more digestible sections.

New ways of including people with a learning disability

Working with people with a learning disability is a central part of the LeDeR programme. Our work is informed by a team of people with a learning disability who meet on a regular basis. The group are keen to boost connections with the wider community of people with a learning disability to raise awareness of the report's findings, ensure the people with a learning disability have further opportunities to engage with LeDeR and empower people with a learning disability to advocate for change.

“**It is about time we speak up for ourselves and not let other people speak up for us**” – *Frankie, member of Staying Alive and Well*

The group chose to name themselves the ‘Staying Alive and Well’ group and have run an art project, open to all people with a learning disability in England, to obtain a group logo and artwork to feature in annual reports, deep dives and research digests. The members of the Staying Alive and Well group had the difficult choice of determining the winners. The logo they selected appears to the right of this text.

“**As we are speaking up for ourselves, we are not just doing it for ourselves, we are doing it for everyone else**” – *Lee, member of Staying Alive and Well*

Having helped to establish the Staying Alive and Well group, we ran a series of focus groups asking people with learning disability about their preferences for accessible communication, producing results which fed back into the accessible annual report and its accessible communication.

We will continue to access the contributions of people with a learning disability throughout the ongoing development of the LeDeR project so our research better suits people with a learning disability.

The winning logo of the Staying Alive and Well group by Darren Barnes, Greatstone.

New learning disability and autism partnership team

Prof André Strydom

Dr André Strydom (MRCPsych, MSc, PhD) is a Professor in Intellectual Disabilities at the Institute of Psychiatry, Psychology and Neuroscience at King's College London, where his research is focused on mental disorders in adults with neurodevelopmental conditions, including Down syndrome and other genetic disorders. He was the chief investigator of the LonDownS consortium, a collaboration on various aspects of Alzheimer's disease in Down syndrome, and continues to undertake research to address the burden of ageing associated conditions in people with Down syndrome.

In addition to leading the learning disability and autism partnership funded by NHSE's National Learning Disability and Autism programme, he directs KCL's Neurodevelopmental disorders clinical trials centre which hosts clinical trials of treatments to reduce morbidity associated with intellectual disability and autism. He works as consultant learning disability psychiatrist at South London and the Maudsley NHS Foundation Trust.

Prof Irene Tuffrey-Wijne,

Irene Tuffrey-Wijne (RN, PhD) is Professor of Intellectual Disability & Palliative Care at Kingston University & St George's University of London. She leads the Staying Alive and Well co-production group on this project. Irene has extensive clinical experience in both intellectual disability and palliative care services in the UK. Since 2001, she has led a programme of research around intellectual disability, bereavement and palliative care.

She has published widely and presented her work in the UK and across the world, and is recognised as the leading international expert in the area of palliative care for people with a learning disability. Inclusion of people with a learning disability as study participants and as salaried co-researchers is a key part of her work.

Prof Umesh Chauhan

Professor Umesh Chauhan is a clinical academic based at University of Central Lancashire who is committed to high quality patient centred care working as a GP in a deprived area of East Lancashire for over 25 years. His research has contributed to both improving the knowledge base on tackling health inequality in health care and social care and improving quality of care delivery.

Previously, he has held advisory roles on the work conducted by the Public Health England Observatory for Learning Disability and the Confidential Inquiry into the premature deaths of people with a learning disability, and the subsequent establishment of the LeDeR Programme.

Dr Rory Sheehan

Dr Rory Sheehan (MRCPsych, MSc, PhD) is a senior clinical lecturer in forensic neurodevelopmental psychiatry at the Institute of Psychiatry, Psychology and Neuroscience at King's College London. Dr Sheehan's research cuts across a number of issues in intellectual disability and neurodevelopmental disorders with a particular focus on medication prescribing, health inequalities, and improving healthcare services. Dr Sheehan works clinically as a consultant psychiatrist at the Oxleas NHS Foundation Trust in south-east London.

Adam White

Adam is an experienced research coordinator and mental health advocate with over 15 years of experience, in 3 continents, in both mental health, education and social work. Currently based at KCL after a 10-year hiatus working abroad in Canada and Japan, his previous work has contributed to a diverse range of areas including intellectual disability, autism, bipolar disorder, international relations, suicide prevention, overcoming adversity and CAMHS. He joins the team at King's to work on the LeDeR report and towards increasing advocacy for the lives of people with a learning disability.

Jonathon Ding

Jonathon is helping with the LeDeR project by working as a research assistant and co-ordinator for the Staying Alive and Well co-production group. Before joining the team, he graduated from the Psychological Sciences Master's course at University College London, during which he also helped examine trends in student mental health and provided mental healthcare assistance on CAMHS inpatient wards. He is really looking forward to building upon his additional experience of working at a Special Educational Needs college and is motivated to help improve care for people with a learning disability and / or autism.

Christina Roberts

Christina is a research assistant at UCLan. Christina obtained her integrated Master's in Psychology from the University of York where she specialised in developmental disorders. Following this, she obtained a Master's in Social Science Research from Loughborough University before working as a learning support assistant for young adults with autism/learning disability. She looks forward to contributing to work that will increase awareness of the challenges that can be faced by those with a learning disability and / or autism and support continued improvement in their quality of care.

Richard Keagan-Bull

Richard is a research assistant at Kingston & St George's University. He works on several projects, including Growing Older, Planning Ahead and the LeDeR programme, which helps people with a learning disability to stay alive! He helped decide the name for the Staying Alive and Well group and is delighted to have this job, as it is not easy for a person with a learning disability to get proper employment. Richard enjoys speaking up and is an advocate for people with learning disabilities. He was co-chair of the Lambeth Assembly for People with Learning Disabilities for 10 years and was the Founder Chair of the National Speaking Group for L'Arche (the organisation that provides Richard's support).

Dr Nick Magill

Nick completed a PhD in medical statistics at the Institute of Psychiatry, Psychology and Neuroscience in 2018. He now works as a researcher at the London School of Hygiene and Tropical Medicine. His main areas of interest are in the epidemiology and treatment of mental health illness and in clinical trial design. He has taught on a range of statistics courses and has assisted with many of the statistical analyses for this report.

Dr Ben Carter

Ben is an experienced medical statistician at the Institute of Psychiatry, Psychology and Neuroscience. He leads the mental health clinical trials statistics group at KCL and is the methodological lead for 16 randomised controlled trials. His interests include aging, frailty and neurodevelopmental disorders.

Mollie Ruane

Mollie is a Master's student at the Institute of Psychiatry, Psychology and Neurosciences at King's College London and has worked in community and inpatient psychiatric NHS services since 2019. She joined the LeDeR team to gain an insight into the valuable work being done to improve the lives of autistic individuals and people with a learning disability.

Xinyu Xiang

Xinyu is a Master's student from Institute of Psychiatry, Psychology and Neurosciences at King’s College London. She has been working on the literature review and data analysis for the LeDeR annual report. She graduated from the Education Studies - Psychology course at Durham University. She is interested in neurodevelopmental disorders, especially autism. She has enjoyed the oppourtunity to help improve the quality of care for people with a learning disability and autistic people.

We would also like to acknowledge and thank the atendees of our stakeholder conference and our advisory board whose advice and guidance was invaluable with helping guide the creation of this report:

Cecil Kullu, Charlotte Hammond, Christine Hutchinson, Christine-Koulla Burke, Clive Parry, Gemma Harpin, Kirsten Lamb, Silvana Unigwe, Eddie Chaplin, Helen Booth, Janice Wycherley, John Shaw, Karen Dodd, Ken Courtenay, Mark Ashworth, Michelle Sowden, Oliver Brady, Rohhss Chapman, Ruwani Ampegama, Sarah Wynn, Tony Marson,Yona Lunsky.

Foreword

Learning from Lives and Deaths - people with a learning disability and autistic people (LeDeR), previously known as The English Learning Disabilities Mortality Review (LeDeR) programme, was established as a pilot in 2015 and rolled out nationally in 2017. The aims are to:

1) improve care for people with a learning disability and autistic people
2) reduce health inequalities for people with a learning disability and autistic people and
3) prevent people with a learning disability and autistic people dying prematurely.

Since being established, more than 10,000 deaths of people with a learning disability have been reviewed with the findings presented in the LeDeR annual reports. Action from Learning reports provide examples of changes that have been made to services in response to the findings from LeDeR reviews.

Through its focus on avoidable deaths and by highlighting where the care of people with a learning disability can be improved to address premature deaths, the LeDeR programme has had considerable impact on service provision since its inception, including reasonable adjustments to the provision of services, such as for the implementation of the COVID-19 vaccination programme.

This report is a continuation of the key aims of LeDeR. In particular, we aimed to provide additional insight on premature death, avoidable causes of death, and on excess deaths due to COVID-19 during 2021. We hope that it will also have an impact on improving care of people with a learning disability.

Changes in the LeDeR process during 2021

From summer 2021 the LeDeR review underwent a significant change in the type and detail of data that was collected. Whilst focused reviews continued to be more comprehensive than initial reviews, the data collected during initial reviews after June 2021 differed in some ways to what was done previously.

This has changed the amount and type of data available at different stages of data collection. Where possible we have drawn comparisons over time but have also highlighted where, due to the transition in the system of data collection, this was not possible. Important differences have been signposted in this report.

Although deaths of autistic people are now included in the LeDeR programme, they were not included in this report because this report covers deaths from January 2021 to December 2021 and deaths of autistic people have only been reviewed since January 2022.

See Appendix for further information on important changes that have been made during 2021.

Notes on the 2021 report

This, the sixth annual report utilising data from LeDeR reviews, focuses on the reviews of deaths of people with a learning disability that occurred predominantly in 2021 and uses comparisons with the deaths occurring in 2018, 2019 and 2020. This has allowed us to identify trends over time and highlight the impact of the COVID-19 pandemic during 2020 and 2021. Deaths included in this year's report are based on the year of death, which is consistent with last year's report. In reports prior to 2020 the data was based on year of review. As such, the data used in this report is not directly comparable in all instances but comparisons have been drawn where it is possible to do so. By shifting the focus to year of death, we aim to better identify trends and changes in health and care over time, including the impact of the pandemic.

As with 2020, the pandemic continued into 2021, albeit with the introduction of the vaccination programme. The lives and deaths of the entire population, including people with a learning disability, continued to be affected in multiple ways. As such, comparisons with years prior the pandemic should also be interpreted with some caution.

Notifying a death to LeDeR is not mandatory and, therefore we would not expect LeDeR to have data on all people with a learning disability who have died. Some data contain a relatively small number of cases, particularly the data regarding children and in some sub-categories, so some findings must be interpreted with a degree of caution. We have highlighted this where it’s important to have caution with the results due to these lower numbers. To avoid possible identification of individuals, any number below 5 is replaced with an "*" throughout this report.

The LeDeR process

The LeDeR Process

Deaths of people with a learning disability aged 18 years and over are eligible for a LeDeR review, while child deaths are linked via the national child death review process (CDOP). Following confirmation that the death is within scope of the programme, a trained LeDeR reviewer will gather details on the death and start the review process, with a target for this to be completed within 6 months. For some reviews, this will lead to a more comprehensive “focused” review, looking very closely at the person's life and circumstances of death. These focused reviews, once completed, are then sent to local governance groups with areas of good practice, areas of concern, and wider learning from the case being outlined. The process is outlined in detail on the website https://leder.nhs.uk/about

LeDeR data

In the LeDeR report we use pseudonymised data which reflect different stages of the LeDeR review process. Note: Child deaths follow a separate statutory review process overseen by the Child Death Overview Panels (CDOP), including deaths of children with a learning disability, with relevant information (children aged 4 years or older) being included in the LeDeR data.

Notification data

Anyone can report a death by submitting a notification to LeDeR via the website (Report the death of someone with a learning disability (leder.nhs.uk))[SA1] . The notification form includes basic demographic information about the person who died, such as their name, NHS number, address, date of birth, sex, and ethnicity. The person submitting the form is also asked to provide information about the circumstances of death, including where the death occurred, what they thought caused the death, and whether they had any concerns around the care of the person. During this process, it may become apparent that the notification is not suitable for LeDeR, for example, on further examination the deceased person did not have a diagnosed learning disability in their clinical records. In these cases a LeDeR review is not completed, and the notification is discounted. The notification dataset contains information on more recent deaths and was therefore used for certain analyses, such as in the analysis of deaths associated with COVID-19 where, due to reviewers having 6 months to complete an initial or focused review, and due to the data extraction being 31st December 2020, this was the most up to date available data.

Initial Review Data

If the notification is found to be suitable for inclusion in LeDeR it is then passed to a reviewer for further information gathering. The reviewer gains more information through talking with people who knew or were involved in the care of the person who died, which includes the family of the person who died and clinicians (or their clinical records). The reviewers also look to speak to at least one other person involved in the care of the person who died to build up a clear picture of the person's life and their health and care leading up to the time of their death,
The review data are supplemented by linkage with medical certificate of cause of death (MCCD) data provided by the Office of National Statistics (ONS) and NHS Digital.

Focused Review Data

Focused reviews explore in more detail the life and death of the person and lessons that can be learnt from their care. Deaths are forwarded for a focused review if the reviewer feels that there is significant learning to be gained from the death based on the initial review or the family of the deceased request a focused review.

From summer 2021, if the person was from a minority ethnic group, a focused review was also completed. Reviewers add to data from the initial review by looking further into the health and social care of the person who died and circumstances surrounding their death. More detailed information about their medical history, care and treatment and their social care arrangements are obtained through liaison with professionals involved in their care and accessing additional records.

Scan to find out more about LeDeR

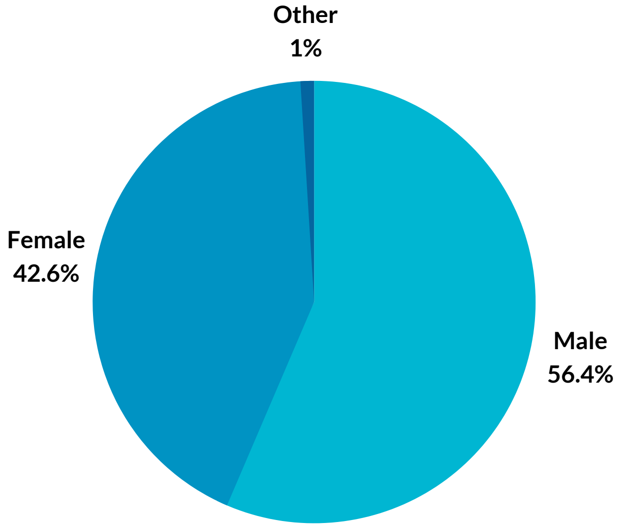
Glossary of Abbreviations

CDOP	Child Death Overview Panels
CI	Confidence interval
DoLS	Deprivation of Liberty safeguards
DNACPR	Do Not Attempt Cardio-Pulmonary Resuscitation
DVT	Deep Vein Thrombosis
GP	General Practitioner
HR	Hazard ratio
ICD-10	International Classification of Diseases version 10
ICS	Intergrated Care System
IMD	Index of Multiple Deprivation
IQR	Inter-quartile range
LTC	Long-term health condition
KCL	King's College, London
KStGU	Kingston University and St George's University of London
LeDeR	Learning from Lives and Deaths review programme
LD	Learning disability
MCA	Mental Capacity Act
MHA	Mental Health Act
MCCD	Medical Certificate of Cause of Death
NHS	National Health Service
NHSE	National Health Service England
NICE	National Institute for Health and Care Excellence
OECD	Organisation for Economic Cooperation and Development
ONS	Office for National Statistics
OR	Odds ratio
PEG	Percutaneous Endoscopic Gastrostomy
ReSPECT	Recommended Summary Plan for Emergency Care and Treatment
SCW	South Central and West Commissioning Support Unit
SD	Standard deviation
SJR	Structured Judgement Review
SMART	Specific Measurable Actionable Realistic Timebound
UCLan	University of Central Lancashire
WHO	World Health Organisation

Chapter 1

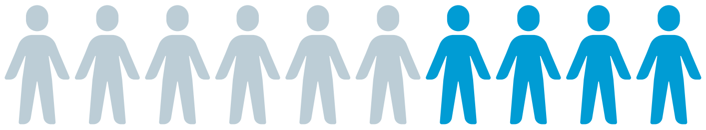
Review of deaths for 2021

KEY TAKEAWAY OF DEMOGRAPHICS

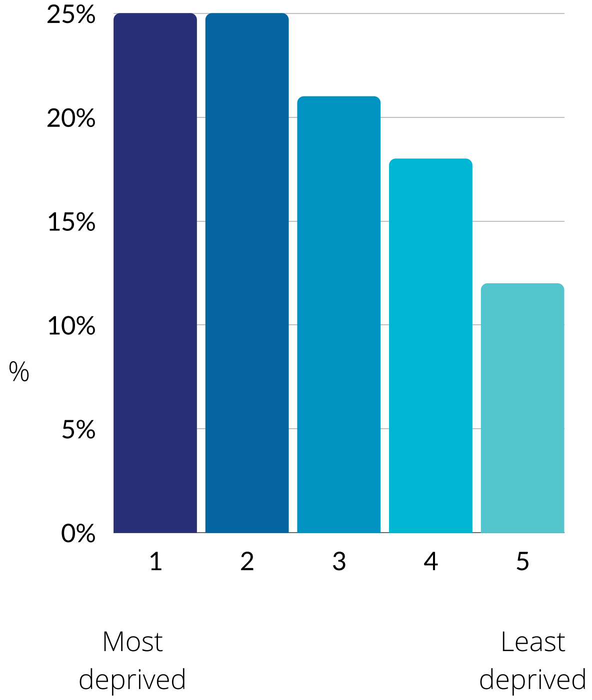


56% of people who were notified to LeDeR in 2021 identified as male.

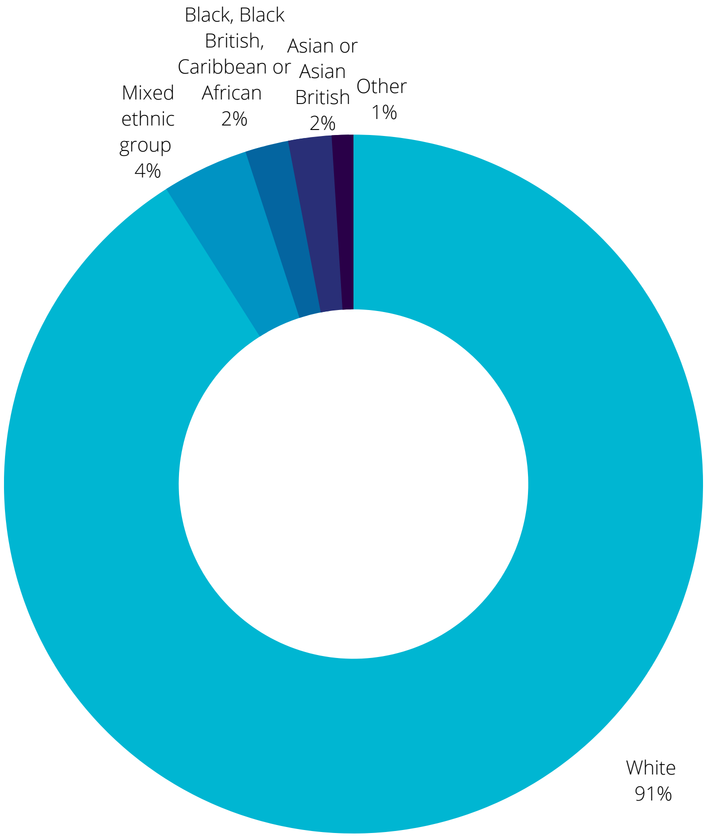
6 out of 10 people living with a learning disability died before they were 65.



On average, males with a learning disability die 22 years younger than males from the general population, and females 26 years younger than females form the general population.



Over 50% of people with a learning disability died in areas rated as some of the most deprived in England.



91% of people who were notified to LeDeR in 2021 were denoted as white.

Review of deaths for 2021

Deaths notified to the LeDeR programme

A total of 3,304 deaths of people with a learning disability[1] were reported to LeDeR during 2021. This includes 208 deaths of children aged 4-17 and 3,096 deaths of adults aged 18 – 98.

We used the most recent data alongside data from 9,094 deaths reported to LeDeR occurring between 2018 and 2020 for comparisons across time.

There was a significant increase in the number of deaths reported during the peak periods of the COVID-19 pandemic, with spikes in deaths occurring during April 2020 and January 2021.

Figure 1.1 shows the number of deaths by month from January 2018 to December 2021 for children and adults.

LeDeR reviews in 2021

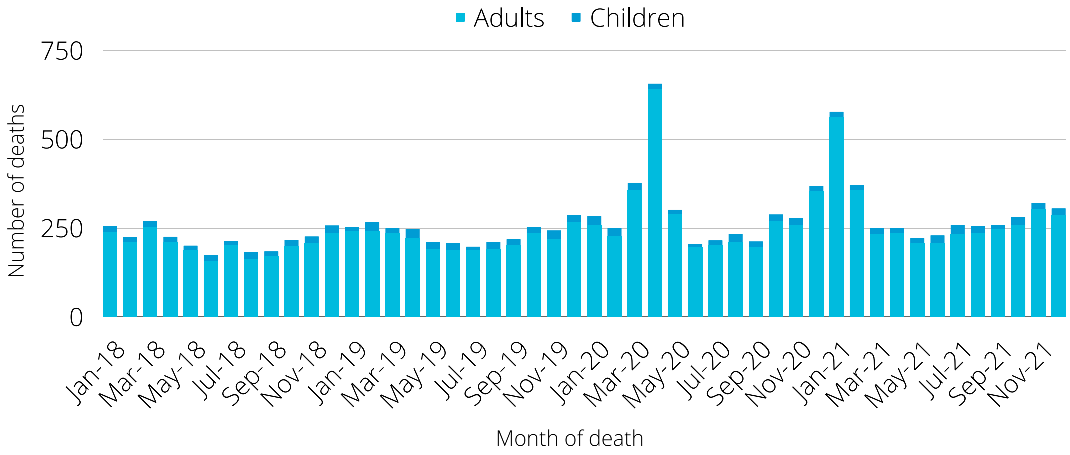
Once a death is reported via the LeDeR web platform and a reviewer is assigned, the reviewer conducts an initial review by talking to family, carers and professionals involved in the person's care.

Focused reviews look in more detail about the life and death of the person and lessons that can be learnt from their care. Previous reports have shown that people from ethnic minority backgrounds have the poorest outcomes of all groups. One of LeDeR's policies is that focused reviews will be completed for every person from a non-white British background.

In addition, based on whether the reviewer has concerns about the care of the person who died or whether the reviewer considers there is either a positive or negative learning to be made, the case may also be progressed to a focused review.

The number of initial reviews completed in 2021 was 2553; plus 109 CDOP reviews for children (aged 4-17).

Figure 1.1: The number of deaths reported to LeDeR by month of death from January 2018 to December 2021.



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[1] 'Learning disability' is defined according to Valuing People Now (2001): Learning disability includes the presence of: A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with; A reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development.

The number of focused reviews completed was 139, including one review for a child*.

Of the people who died who were of minority ethnic backgrounds, 198 initial reviews and 29 focused reviews were completed in 2021. LeDeR's policy states that focused reviews from June 2021 will be completed for every person from a minority ethnic background.

Demographics of the people who died

Table 1.1 (page 16) summarises the demographics for people who died in 2021.

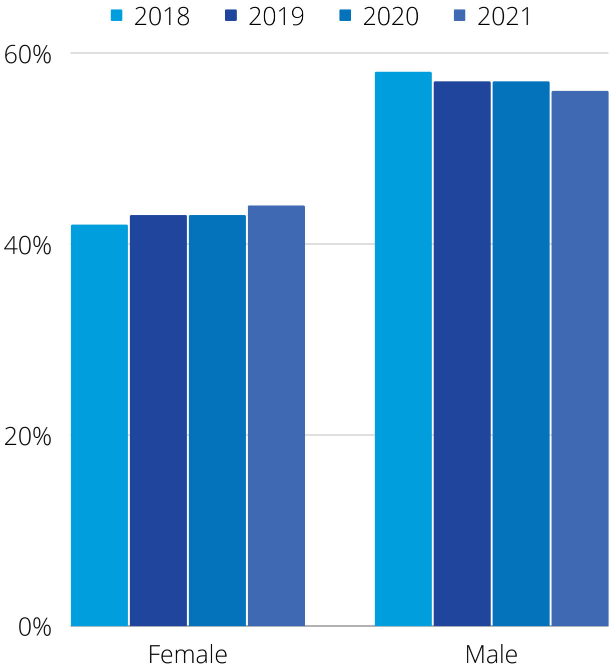
Sex

Sex was reported for 845 children and 11,549 adults who died and were notified to LeDeR between 2018 and 2021.

In 2021, males accounted for 56% of deaths, females accounted for 44% and less than 1% (fewer than 10) people were denoted as identifying 'in another way' to their sex at birth.

Figure 1.2 shows the number of deaths from 2018 – 2021 by sex. The proportion of males and females between 2018 and 2021 has remained stable, with an overall excess of males but with a trend towards increasing proportion of deaths of females.

Figure 1.2: Number of deaths for each year from 2018 to 2021 for males and females, including all ages.



The percentage of deaths for each sex with general population comparison from 2018-2021 is shown in Appendix 1.1.

Age at death

Information on the person's age at death was available for 869 children and 11,915 adults who died and were notified to LeDeR between 2018 and 2021.

The median[2] age at death for 2021 notifications** was 61, which is the same as 2020. The median age at death for males was 61 and 60 for females, based on notifications.

The median age at death has increased by 1 year since 2018 and 2019 when it was 60. For children, the median age at death in 2021 was 12, which is an increase of 1 year since 2020.

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[2] 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.

*Note. It is not usual for a focused review to be carried out for a child as, outlined previously, the child death review process is separate to LeDeR. This was an exception from one local system.

**This is the median age of death from notifications. For further analysis in this report we have used median age from Inital Reviews, which is 62.

Table 1.1: Descriptive statistics for demographics of people who died in 2021 (notifications and initial reviews).

Sex (number of deaths, % of deaths notified)*	**4 to 17**	**18 to 64**	**65+**	**Total No.**
Male	103 (50%)	1009 (56%)	740 (58%)	1,852 (56%)
Female	105 (50%)	802 (44%)	545 (42%)	1,452 (44%)
Total	208	1,811	1,285	3,304
Ethnicity (number of deaths, % deaths notified)				
Asian or Asian British	28 (15%)	60 (4%)	10 (<1%)	98 (3%)
Black, Black British, Caribbean or African	14 (7%)	50 (3%)	*	65 (2%)
Mixed ethnic group	16 (9%)	55 (3%)	10 (<1%)	83 (3%)
White	126 (67%)	1,524 (89%)	1,180 (98%)	2,830 (91%)
Other	*	19 (1%)	6 (<1%)	28 (1%)
Total	187	1,708	1,209	3,104
Index of Multiple Deprivation Quintiles (number of deaths, % of deaths with initial review data)				
1 (most deprived)	32 (29%)	383 (26%)	261 (25%)	676 (25%)
2	23 (21%)	366 (24%)	267 (25%)	656 (25%)
3	20 (18%)	314 (21%)	211 (20%)	545 (21%)
4	20 (18%)	266 (18%)	185 (18%)	471 (18%)
5 (least deprived)	14 (13%)	169 (11%)	131 (12%)	314 (12%)
Total	109	1,498	1,057	2,662
Long-term health conditions (number of deaths with initial review data)				
Epilepsy	7	233	123	363
Cardiovascular conditions	*	167	186	357
Mental health conditions	*	168	185	354
Sensory impairment	*	148	119	269
Dysphagia	*	125	123	250

Table 1.1: Descriptive statistics for demographics of people who died in 2021 (continued).

Long-term health conditions (cont)	**4 to 17**	**18 to 64**	**65+**	**Total No.**
Dementia	*	123	107	230
Kidney problems	*	79	113	194
Diabetes	*	77	87	164
Respiratory conditions	*	81	71	152
Hypertension	*	50	86	136
Osteoporosis	*	30	35	65
Cancer	*	25	38	63
Degenerative conditions	*	28	18	46
DVT	*	25	13	38
Number of long-term health conditions (of deaths with initial review data)**				
0	*	66 (11%)	37 (8%)	104 (10%)
1	*	133 (22%)	86 (18%)	223 (20%)
2	*	153 (26%)	114 (23%)	271 (25%)
3	*	125 (21%)	107 (22%)	234 (21%)
4		70 (12%)	80 (16%)	150 (14%)
5 or more	*	50 (8%)	62 (13%)	112 (10%)
Total	11	597	486	1,094

* This table includes data from the deaths during 2021 notified to LeDeR, with information available about each demographic excluding unrecorded data. 3,304 were notified, 1 had unrecorded sex data.

** Total values with data on LTC's are 1,095, of the 2,662 deaths with initial review data.

General population data has been used to outline how people with learning disability compare to the population as a whole. The data are not directly comparable as the deaths included in LeDeR are only of people from the age of 4 years, whereas general population data includes information about children 0-3 years.

The median age at death in the general population was 83 for males and 86 for females in 2016-2018[3]. For people with a learning disability who died in 2021 and were notified to LeDeR, the median age at death was 61 for males and 60 for females. The disparity between median age at death in people with learning disability and the general population is 22 years for males and 26 years for females.

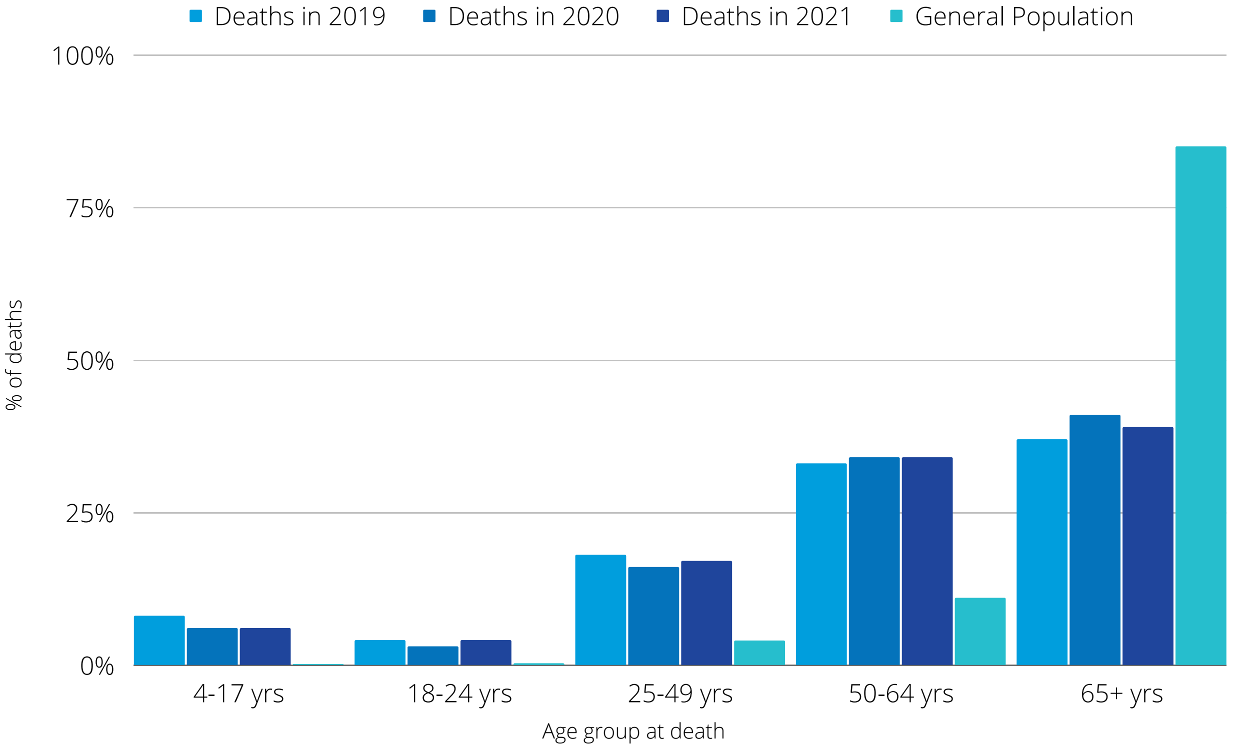
The COVID-19 global pandemic means data from 2020 and 2021 look very different to data from 2018 and 2019. However, comparing trends from these years is useful to look at how the pandemic impacted on age at death for people with learning disability.

Figure 1.3 shows the age group at death for people with learning disability in 2019, 2020 and 2021 compared to the general population in 2020[4].

An in-depth analysis of the impact of COVID-19 on the deaths of people with learning disability in 2020 and 2021 is provided in Chapter 6.

In 2020, 85% of people in the general population died at age 65+. The percentage of people who died at age 65+ with learning disability was 39%, in other words, less than 2 of every 10 people that die in the general population

Figure 1.3: Percentage of deaths of people with a learning disability from 2018 to 2021 by age group at death compared to the general population (2020).



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[3] https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/datasets/averageageatdeathbysexuk

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

will be younger than 65, while 6 in 10 of people with a learning disability that die are under the age of 65.

Since 2019, the percentage of people who died at age 65+ has increased by 2% for people with a learning disability.

Ethnicity

The ethnicity of the person who died was reported in the notifications of 761 deaths of children and 11,138 deaths of adults between 2018 and 2021.

The vast majority (91%) of adults and children with learning disability who died in 2021 were denoted as white. This is the same as the overall percentage of people who died denoted as white between 2018 and 2021 (91%). In comparison, the proportion of people denoted as white in the general population is 85%[5].

This may be due to a difference in population structure of people with a learning disability (with fewer older people from ethnic minority groups), although an underreporting of deaths of people from ethnic minority backgrounds may also be possible.

Given the small percentage of people who were denoted as being of a minority ethnicity (9%), results must be interpreted with caution.

The proportion of children who died in 2021 that were denoted as white (62%) is significantly different to the proportion of adults denoted as white (93%). This may, in parts, reflect the difference in the ethnicity structure of younger compared to older people with a learning disability, but as the number of deaths of children represent 6% of the overall number of deaths in 2021 this needs to be interpreted with caution.

A summary of the number and percentage of deaths for each ethnic group from 2018-2021 with general population comparison can be found in Appendix 1.2.

Deprivation

The Index of Multiple Deprivation (IMD) was used to look at the level of deprivation for the area of residence of the people who died. Residential postcodes were given an IMD score of 1 to 10. IMD scores were grouped into five quintiles from most to least deprived. Lower values indicate higher levels of poverty which is measured by looking at factors such as the average income, employment status, health statistics and crime rates in the area[6].

Deprivation data were available for all people who died in 2021 and had initial review data.

IMD quintile.

Appendix 1.3 shows the distribution of IMD quintile data for 2021.

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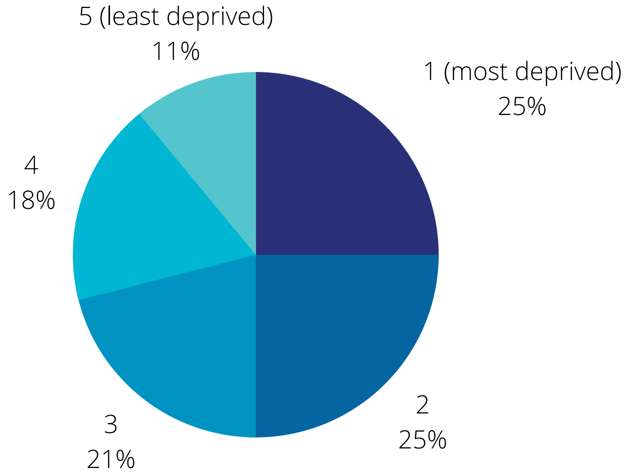
[5] https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/populationestimatesbyethnicgroupandreligionenglandandwales/2019
[6] https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019

Figure 1.4 shows the percentage of deaths of people with a learning disability in 2021 by IMD quintile. Appendix 1.4 shows how this compares to the general population.

Figure 1.4: Percentage of deaths in 2021 by IMD quintile.



Long-term health conditions

When a death is reviewed by a LeDeR reviewer, information may be collected about whether the person had any long-term conditions or health needs. These are referred to in this report as 'long-term health conditions'[7]. Long-term health conditions as described by NICE guidelines usually include learning disability and autism, but for the purpose of this report we have not classed learning disability or autism as long-term health conditions. 14 conditions are included in our definition of long-term health conditions[8].

Information about long-term health conditions is not always accessible to reviewers as it depends on what kind of health records they can obtain. Long-term health condition data was available for 1,095 people who died in 2021 with initial review data.

The five most frequently reported long-term health conditions for people who died in 2021 and received an initial review were:

Epilepsy (33%, n=364)
Cardiovascular conditions (33%, n=357)
Mental health conditions (32%, n=355)
Sensory impairment (25%, n=269)
Dysphagia (23%, n=250)

Table 1.2 (page 21) shows the percentage breakdown of occurrences of each long-term health condition by age group at death. More information about how we define long-term health conditions is in Appendix 1.5.

Multimorbidity

NICE (National Institute for Health and Care Excellence) guidelines define multimorbidity[9] as the presence of two or more long-term health conditions.

Information about multimorbidity was available for the deaths of 1,095 people who died in 2021 with initial review data.

In 2021, the average number of long-term health conditions per person was 2.45 (standard deviation = 1.56).

10% of people were reported to have no long-term health conditions at death. Table 1.3 (page 22) shows the number of long-term health conditions by age group at death.

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

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

[9] https://www.nice.org.uk/guidance/ng56

Table 1.2: Long-term health conditions of people with a learning disability who died in 2021 with initial review data, showing the percentage of people reported to have each condition by age group at death.

Long-term health condition	Overall**	4 to 17	18 to 25	25 to 49	50 to 64	65+	Total No.
Epilepsy	33%	2%	4%	21%	40%	34%	363
Cardiovascular conditions	33%	1%	3%	11%	33%	52%	357
Mental health conditions	32%	0	<1%	12%	35%	52%	354
Sensory impairment	25%	<1%	5%	14%	36%	44%	269
Dysphagia	23%	<1%	2%	11%	37%	49%	250
Dementia	21%	0	0	3%	51%	47%	230
Kidney problems	18%	1%	1%	12%	27%	58%	194
Diabetes	15%	0	1%	10%	35%	53%	164
Respiratory conditions	14%	0	3%	16%	34%	47%	152
Hypertension	12%	0	<1%	8%	28%	63%	136
Osteoporosis	6%	0	3%	17%	26%	54%	65
Cancer	6%	0	0	8%	32%	60%	63
Degenerative conditions	4%	0	9%	20%	33%	39%	46
DVT	4%	0	0	21%	44%	33%	38
Total No. *	1,095	18	59	337	963	1,304	2,681

*Total describes total number of occurrences of each condition, overall totals describe total number of occurrences for all conditions.

**These represent the percentages of people who were denoted as having each LTC of the 1,095 people who had information recorded about LTCs.

Table 1.3: Percentage of people with each number of long-term health conditions by age group at death of people who died in 2021 with initial review data.

Number of long-term health conditions	4 to 17	18 to 25	25 to 49	50 to 64	65+
0	*	*	27 (16%)	35 (9%)	37 (8%)
1	*	7 (23%)	49 (28%)	77 (20%)	86 (18%)
2	*	11 (37%)	44 (25%)	98 (25%)	114 (23%)
3	*	*	26 (16%)	95 (24%)	107 (22%)
4	*	*	17 (10%)	51 (13%)	80 (16%)
5 or more	*	*	10 (6%)	38 (10%)	62 (13%)
Total No.	11	30	173	394	486

Chapter 2

Causes and Circumstances of Death

KEY TAKEAWAY OF CAUSES AND CIRCUMSTANCES OF DEATH

64% of people who died in 2021 had a DNACPR in place at the time of death. Reviewers judged that this was followed appropriately for 60% of the deaths with a DNACPR in place.

61% of deaths occurred in hospital.

1: COVID-19

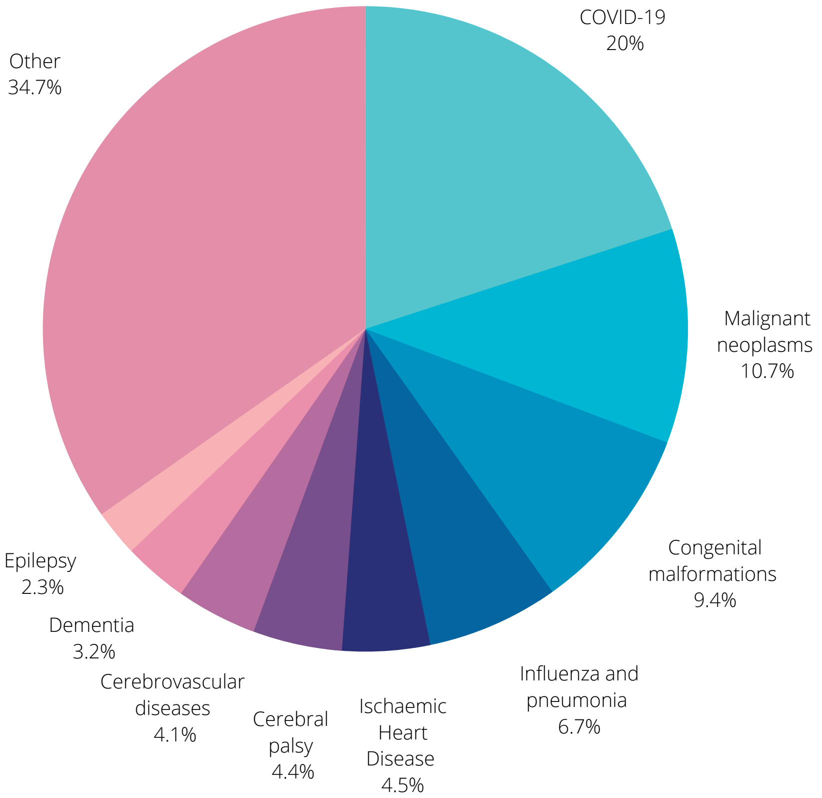
2: Diseases of the Circulatory System

3: Diseases of the Respiratory System

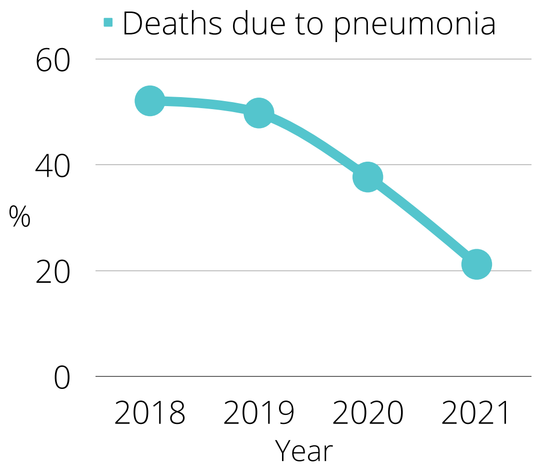
4: Cancers

5: Diseases of the Nervous System

The top 5 ICD-10 categories of cause of death.



The most frequently cited cause of death for all ages.



The percentage of respiratory deaths due to pneumonia decreased from 52% in 2018 to 21% in 2021.

Causes and Circumstances of Death

Introduction

In this chapter, we summarise the circumstances and most common causes of death of people with a learning disability. We have drawn on data from LeDeR initial review and MCCD data for people who died between 2018 and 2021.

MCCD data were available for 95% of initial reviews of adult deaths which occurred in 2021 and 78% of reviews of child deaths which occurred in 2021 (see page 9 for a description of the LeDeR process and an explanation of why availability of data may differ between these groups).

Circumstances of death

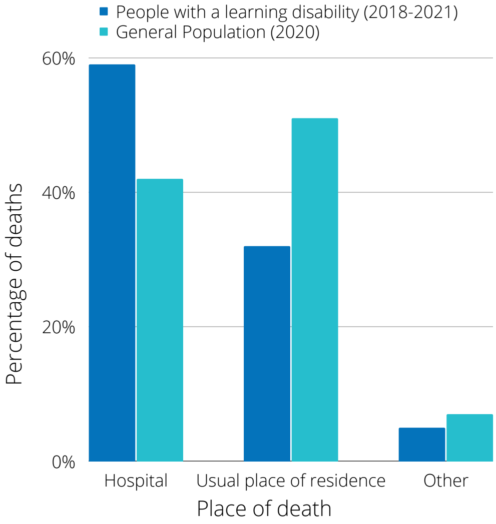
We report where people died, whether their death was reported to a coroner, whether a DNACPR decision was made prior to death, and whether a DNACPR decision was followed correctly.

Place of death

Of the deaths occurring in 2021 which had initial review data, 61% overall (62% adults, 51% children) occurred in hospital. See Appendix 2.1 for comparison with previous years.

In comparison to deaths in the general population (data from 2018), a greater proportion of people with a learning disability die in hospital (59% of people with a learning disability in 2018-2021 vs 42% of the general population in 2020) (Figure 2.1).

Figure 2.1: Place of death for deaths which occurred between 2018 and 2021 and had initial review data compared with the general population (2020).



'Other' includes home of friend or relative, hospice, prison and other.

Compared with the general population, a smaller proportion of people with a learning disability died in their usual place of residence (32% of people with a learning disability vs 51% of the general population in 2020)[10].

Deaths with DNACPR decisions

Of the 2,662 people that died in 2021 and had initial review data, 64% had a DNACPR decision in place at the time of death (see Table 2.1, page 26). This compares to 63%, 63% and 64% in 2018, 2019 and 2020.

Reviewers judged that DNACPR documentation and processes were appropriate for 60% of the deaths in 2021 where a DNACPR was in place.

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[10] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2020

Table 2.1: Percentage of adults with a DNACPR decision that died in 2018, 2019, 2020 and 2021.

DNACPR decisions at time of death	2018	2019	2020	2021
Yes	62.8%	63.1%	64.2%	63.8%
No	26.1%	27.2%	23.6%	24.2%
Not recorded	11.2%	9.8%	12.2%	12%
Total No.	2,537	2,724	3,444	2,662

In comparison to previous years, there was an increase in the proportion of deaths in which the reviewer was unable to determine whether the process for making a DNACPR decision had been correctly followed and a slightly larger proportion with non-compliance to DNACPR protocol around the time of death (see Table 2.2).

Table 2.2: Percentage of adults who died with a DNACPR decision at the time of their death, for whom documentation was completed and/or followed, by year of death.

DNACPR decision correctly completed and followed	2018	2019	2020	2021
Yes	75.4%	72.0%	69.9%	59.5%
No*	3.9%	4.0%	5.5%	7.1%
Not known by reviewer	22.4%	23.9%	24.6%	32.5%
Total No.	1,592	1,718	2,211	1,698

Deaths reported to a coroner

Deaths are reported to a coroner in certain circumstances. These include suspicious deaths, those with an unknown cause, or deaths which have occurred under state detention (see Appendix 2.2 for a full list of circumstances in which a coroner should be notified)[11]. Whether a death is reported to a coroner or not is not an indication of the quality of care a person received[12].

In 2020 and 2021, a lower proportion of deaths were reported to a coroner than in previous years (see Table 2.3). This may partly be explained by an increase in the proportion of deaths that were due to COVID-19, deemed a natural cause of death that is unlikely to have resulted in a referral to a coroner. In 2020, the UK government reported that 34% of all registered deaths were reported to a coroner.

Table 2.3: Percentage of deaths that occurred between 2018 and 2021 that were reported to a coroner.

Deaths reported to a coroner	2018	2019	2020	2021
Adults and children	26.2%	21.2%	16.5%	8.9%
Children (4-17)	42.5%	50.9%	38.0%	14.7%
Adults (18+)	24.9%	18.6%	15.3%	8.7%

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[11] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1062499/registered-medical-practitioners-notification-deaths-regulations-25-march-2022.pdf
[12] https://www.gov.uk/government/statistics/coroners-statistics-2020/coroners-statistics-2020-england-and-wales

Causes of death

Determination of underlying cause of death

When someone dies, a doctor who was involved in the person's care completes an MCCD. This indicates the sequence of conditions which lead to death, including the underlying cause[13]. The World Health Organization (WHO) defines the **underlying cause of death** as the disease or injury that lead to death or the circumstances of the accident or violence that produced the fatal injury[14].

In practice, the underlying cause of death is taken from the lowest completed line of part one of a person's death certificate and assigned one of approximately 14,200 codes according to the International Statistical Classification of Diseases version 10 (ICD-10). Assignment of ICD-10 codes enables comparisons between mortality data from different countries, regions or time periods with a systematic recording framework. A great deal of specificity regarding the cause, site, severity and type of disease or injury is recorded using ICD-10 codes.

Grouping underlying causes of death

Grouping ICD-10 codes enables practical interpretations and provides service leads and policy makers with an appropriate level of detail in order to develop and generate appropriate health interventions, although conclusions may differ between grouping methods. For the purposes of this report, underlying cause of death codes were first grouped by International Statistical Classification of Diseases chapter. This is similar to previous LeDeR reports, with chapters reflecting the general type of injury or disease that caused death (e.g. diseases of the circulatory system).

An additional approach used in this report has been to focus on certain underlying causes of death within particular chapters of the ICD-10 to further describe the most common conditions, such as cancers and respiratory conditions.

Another way in which the ICD-10 codes have been grouped is by **leading cause of death**. This involved using an internationally recognised list developed by the WHO which focuses on certain prevalent conditions, thereby providing a more epidemiologically meaningful picture of common causes of death, and allowing for comparison between populations[15] [16].

It is important to consider that not every condition is assigned to a leading cause of death. A notable example is aspiration pneumonia, which is a prominent cause of death in people with a learning disability but which is not considered a leading cause of death in the WHO classification. Although the WHO leading cause of death classification is useful for comparison with the general population, additional analyses may be required to understand causes of death in people with a learning disability.

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[13] https://www.gov.uk/government/publications/guidance-notes-for-completing-a-medical-certificate-of-cause-of-death
[14] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/methodologies/userguidetomortalitystatisticsjuly2017#cause-of-death-coding
[15] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/methodologies/userguidetomortalitystatistics/leadingcausesofdeathinenglandandwalesrevised2016
[16] https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/articles/leadingcausesofdeathuk/2001to2018

We have also included deaths due to COVID-19 as a leading cause using the following ICD-10 codes: U.071, U.072 and U10.9.

When interpreting findings in the following analyses, it is important to note that we have not reported contributory conditions or causes listed in part 2 of the MCCD.

Most common causes of death by ICD-10 chapter

Table 2.4 shows the 10 most common ICD-10 chapter causes of death for people who died from 2018 to 2021 and had an initial review completed by LeDeR before 31st Dec 2021. See Appendices 2.3.1 to 2.3.4 for breakdowns by age and sex.

The most commonly reported underlying causes of death in 2021 were related to: codes for special purposes (COVID-19), diseases of the circulatory system, diseases of the respiratory system, cancers and diseases of the nervous system. Other than COVID-19, little change in the proportion of deaths from these causes was observed between 2018 and 2021.

In 2021, diseases of the circulatory system surpassed diseases of the respiratory system as the second most frequently recorded cause of death according to ICD-10 chapter. Cancers overtook diseases of the nervous system to become the fourth most frequently reported ICD-10 chapter cause of death. However, the proportion of deaths due to diseases of the circulatory system and cancers remained similar over time.

Table 2.4: The 10 most commonly recorded ICD-10 chapter causes of death for 2018 to 2021 (all ages).

	2018		2019		2020		2021	
ICD-10 chapter	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
Codes for special purposes (COVID-19)	-	-	-	-	750	23.5	532	21.3
Diseases of the circulatory system	378	15.3	389	14.9	415	13.0	356	14.3
Diseases of the respiratory system	519	21.0	513	19.7	443	13.9	300	12.0
Cancers	334	13.5	373	14.3	330	10.3	286	11.4
Diseases of the nervous system	307	12.4	344	13.2	339	10.3	276	11.0
Congenital malformations, deformations and chromosomal abnormalities	337	13.6	379	14.6	329	10.3	251	10.0
Diseases of the digestive system	178	7.2	174	6.7	177	5.5	149	6.0
Mental and behavioural disorders	113	4.6	120	4.6	133	4.2	95	3.8
Endocrine, nutritional and metabolic diseases	68	2.8	58	2.2	64	2.0	65	2.6
Diseases of the genitourinary system	56	2.3	55	2.1	81	2.5	54	2.2

Most common respiratory causes of death

The 3 most common respiratory causes of death for people that died between 2018 and 2021 and had initial review data before 31st Dec 2021 are provided in Table 2.5. More detail can be found in Appendix 2.4.

Unsurprisingly, the leading respiratory cause of death in 2021 was COVID-19, which caused 64% of deaths due to respiratory diseases.

In 2021, 21% of respiratory deaths were caused by pneumonia (organism unspecified), followed by other chronic obstructive respiratory disease (3.5% of respiratory deaths) and aspiration pneumonia (3.1% of respiratory deaths).

There has been a notable reduction in numbers and proportions of deaths due to pneumonia (from 271 (52%) in 2018; to 176 (21%) in 2021). This may in part be due to the effect of measures taken to control COVID-19 (social distancing, face coverings, reduced number of large gatherings), that also had a positive impact on pneumonia, though could also be due to some pneumonia deaths being classified as COVID-19. Pneumonitis due to solids and liquids (aspiration) also reduced over time.

Most common cancers as causes of death

The top 3 cancers reported as an underlying cause of death between 2018 and 2021 are presented in Table 2.6. More detail can be found in Appendix 2.5.

In LeDeR data for 2021, the top 5 were cancers of the: digestive organs (e.g. stomach cancer, 34.7% of deaths from cancer), lymphoid, haematopoietic and related tissue (cancer of the blood forming cells, 11.2% of death from cancer), respiratory and intrathoracic organs (e.g. lung cancers, 8.4% of deaths from cancer), breast (8.4% of deaths from cancer), female genital organs (e.g. ovarian cancer, 8.0% of deaths from cancer).

Table 2.5: The 3 most commonly recorded respiratory causes of death for 2018 to 2021.

2018			2019			2020			2021		
Cause of death	**No.**	**% of rep deaths**	**Cause of death**	**No.**	**% of resp deaths**	**Cause of death**	**No.**	**% of resp deaths**	**Cause of death**	**No.**	**% of resp deaths**
Pneumonia, organism unspecified	271	52.1	Pneumonia, organism unspecified	256	49.8	COVID-19	750	62.9	COVID-19	532	63.9
Pneumonitis due to solids and liquids	88	16.9	Pneumonitis due to solids and liquids	76	14.8	Pneumonia, organism unspecified	211	17.7	Pneumonia, organism unspecified	176	21.2
Unspecified acute lower respiratory infection	39	7.5	Other chronic obstructive pulmonary disease	39	7.6	Pneumonitis due to solids and liquids	75	6.3	Other chronic obstructive pulmonary disease	29	3.5

Table 2.6: The 3 most commonly recorded cancers as causes of death for 2018 to 2021.

2018			2019			2020			2021			
Type of cancer	**No.**	**% of cancer deaths**	**Type of cancer**	**No.**	**% of cancer deaths**	**Type of cancer**	**No.**	**% of cancer deaths**	**Type of cancer**	**No.**	**% of cancer deaths**	**General population (2016-2018) % of cancer deaths**
Digestive organs	134	40.1	**Digestive organs**	126	33.8	**Digestive organs**	119	36.1	**Digestive organs**	99	34.7	-
Most common sub cancers:			Most common sub cancers:			Most common sub cancers:			Most common sub cancers:			
Colon and rectum	47	14.1	Colon and rectum	55	14.7	Colon and rectum	36	10.9	Colon and rectum	39	13.6	10
Oesophagus	26	7.8	Oesophagus	24	6.4	Oesophagus	29	8.8	Oesophagus	19	6.6	5
Pancreas	25	7.5	Pancreas	17	4.6	Pancreas	15	4.5	Pancreas	15	5.2	6
Lymphoid, haematopietic and related tissue	38	11.4	**Lymphoid, haematopietic and related tissue**	44	11.8	**Lymphoid, haematopietic and related tissue**	31	9.4	**Lymphoid, haematopietic and related tissue**	32	11.2	-
Breast	26	7.8	**Ill-defined secondary and unpecified sites**	43	11.5	**Ill-defined secondary and unpecified sites**	31	9.4	**Respiratory and intrathoracic organs.**	24	8.4	-
			Most common sub-cancers: Other and unspecified types of non-Hodgkins lymphoma	14	3.8	Most common sub-cancers: Other and unspecified types of non-Hodgkins lymphoma	9	2.7	Most common sub-cancers: Bronchus and lung	22	7.7	21

Cancer of the colon and rectum (bowel cancer) alone accounted for 13.6% of cancer deaths reported to LeDeR in 2021, while cancer of the oesophagus accounted for 6.6% of deaths.

Bowel cancer and cancer of the oesophagus accounted for a lower percentage of cancer deaths in the UK general population between 2016 and 2018 (bowel cancer: 10% of all cancer deaths; oesophageal cancer: 5% of all cancer deaths) [17] [18]. Lung cancer and prostate cancer caused a higher percentage of cancer deaths in the UK general population between 2016 and 2018 (lung cancer: 21% of all cancer deaths; prostate cancer: 13% of all cancer deaths) compared with those with a learning disability.

The average age of death for the people reported to LeDeR that died of bowel cancer between 2018 and 2021 was 61.7 years. This statistic supports lowering the age threshold for bowel cancer screening for people with a learning disability, as bowel cancer screening is currently offered every two years to all people aged 60 to 74. NHSE has agreed to gradually reduce the age of bowel cancer screening. This process began in April 2021 and will occur over the next 4 years to include all people aged 50 to 59.

The average age of death for people with learning disability who died from breast cancer between 2018 and 2021 was 62.8 years. Breast cancer screening is currently offered every three years to all women aged 50 to 70.

[17] https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/bowel-cancer/mortality#heading-Zero
[18] https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/oesophageal-cancer/mortality#heading-Zero

The overall leading causes of death

Figure 2.2 shows the leading causes of death for people who died from 2018 to 2021 and had a LeDeR initial review completed before 31st December 2021.

In 2020, COVID-19 replaced cancer as the first leading cause of death in people with a learning disability, accounting for 22% of all deaths. The proportion of deaths due to COVID-19 decreased to 20% in 2021, although it remained the leading cause of death of those reviewed by LeDeR. Congenital malformations, deformations and chromosomal abnormalities accounted for a similar number of deaths to cancers and was the third leading cause of death in 2020 and 2021.

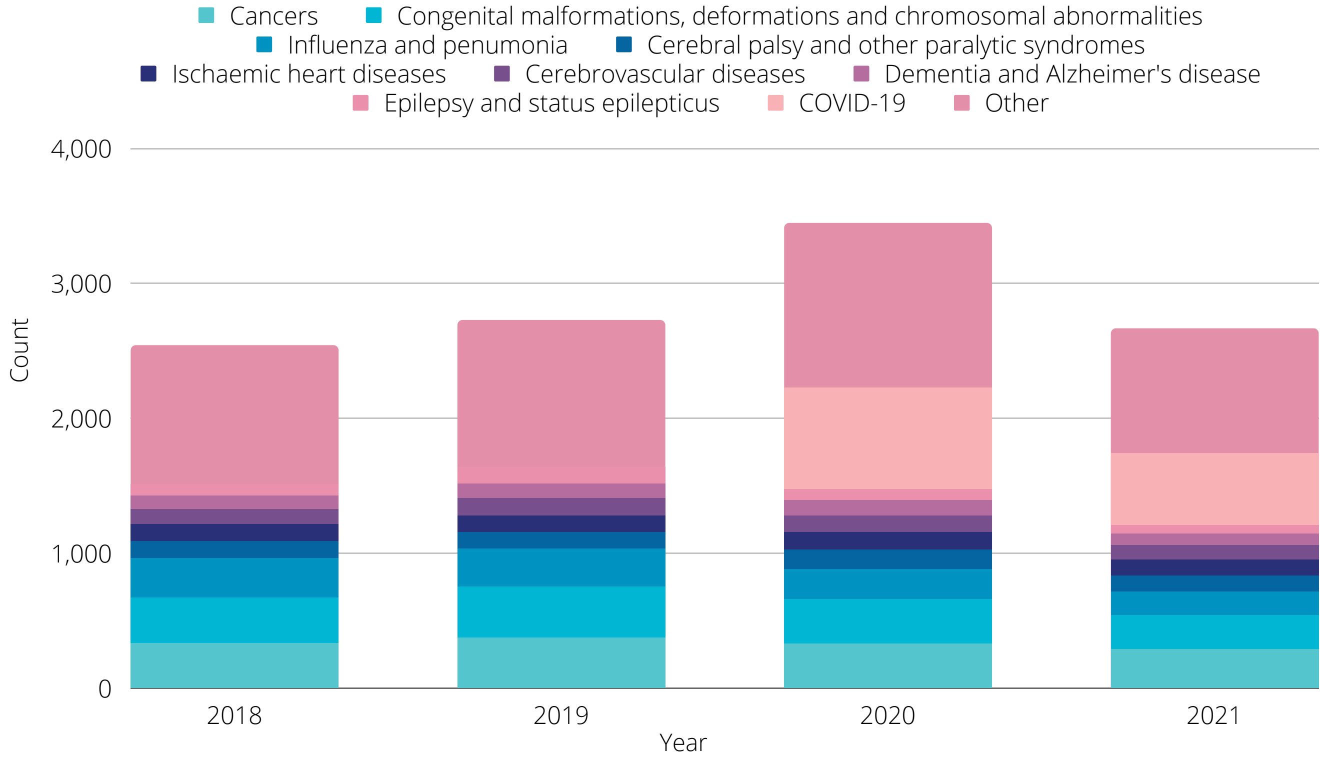
Despite the higher mortality rate due to the spread of COVID-19, no marked increases were observed across leading causes of death other than COVID-19.

COVID-19 was the leading cause of death across all English regions in 2021.

In 2020, the leading cause of death in the general population was COVID-19, which accounted for 12.1% of all deaths. The second leading cause of death was dementia and Alzheimer's disease (11.5% of all deaths). The third and fourth leading causes of death in the general population were ischaemic heart diseases and cerebrovascular diseases, which accounted for 9.2% and 4.9% respectively.

Appendix 2.6 includes more detail about the approach to reporting leading cause of death.

Figure 2.2: Number of deaths which occurred 2018-2021, had initial review and MCCD data available by leading cause of death.



A smaller amount of data were available for child deaths. Therefore, the representativeness of the data presented in this report for child deaths that occurred in 2021 may be limited.

Leading causes of death in children

The 5 most common leading causes of death for 4- to 17-year-olds reported to LeDeR between 2018 and 2021 include: congenital malformations, deformations and chromosomal abnormalities; cerebral palsy and other paralytic syndromes; influenza and pneumonia; epilepsy and status epilepticus; and cancers, Figure 2.3.

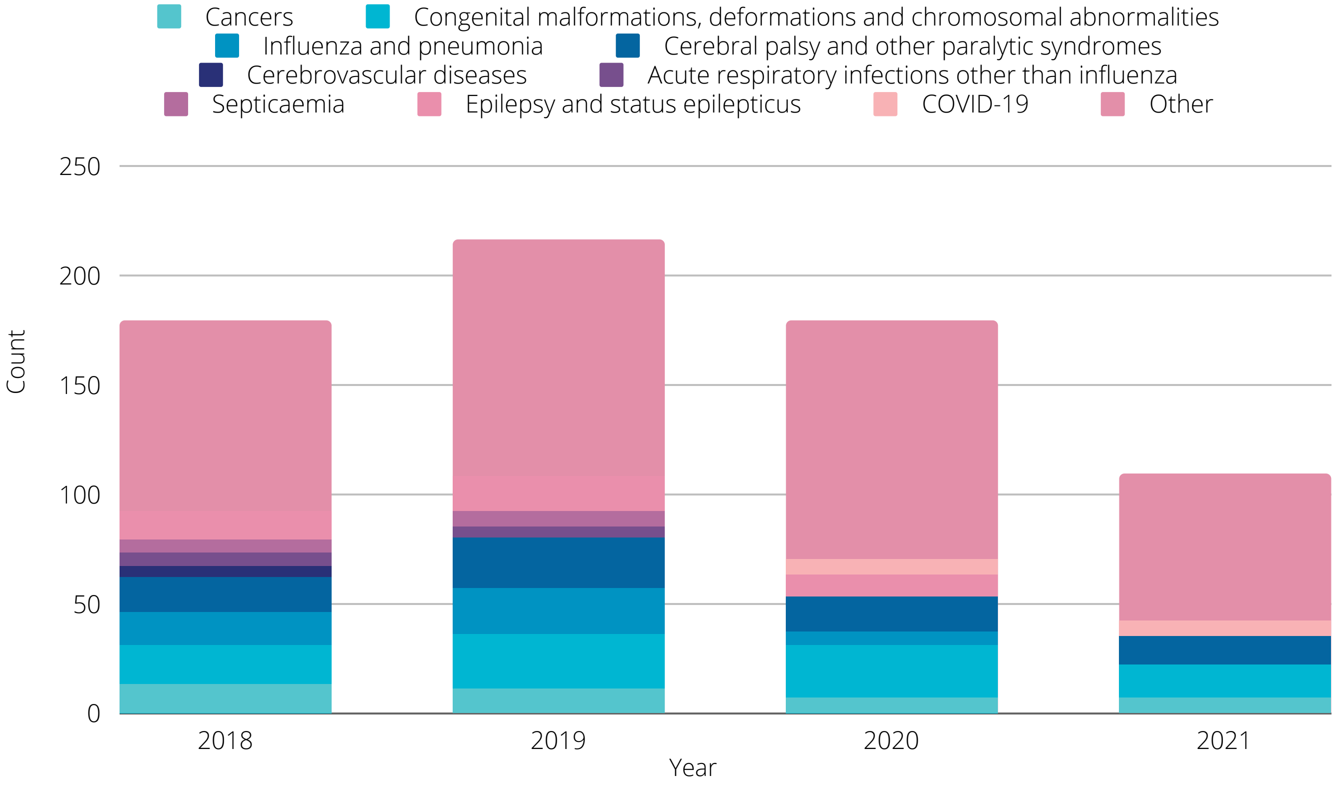
A smaller portion of CDOP reviews are available for the children aged between 4 and 17 who died in 2021. Of 208 notifications of child deaths, 109 had received a review when data collection took place. This is due to the lengthy time to completion for a CDOP report, which is not under LeDeR control, and the subsequent delay in getting the data to LeDeR before extraction. For this reason, caution should be applied when aiming to interpret the most recent leading causes of death for children.

Deaths due to COVID-19 represent a small percentage of all deaths in 4- 17-year-olds. There were no notable increases in the number of non-COVID-19 causes of death in 2020 and 2021. Respiratory associated deaths in children seem to have decreased in number during 2020 and 2021.

In 2020, the leading cause of death in people aged between 5 and 19 from the general population was intentional self-harm; and event of undetermined intent, which accounted for 15.2% of deaths.

This was followed by homicide and probable homicide (7.3%).

Figure 2.3: Number of deaths of children which occurred in 2018-2021, had initial review and MCCD data available by leading cause of death.



In summary, the leading causes of death in children with learning disability were quite different from those in children from the general population[19]. There appears to have been a reduction in deaths due to influenza and pneumonia, and other respiratory infections, during the past two years.

Leading causes of death in adults

For people with a learning diability, in 2020 and 2021 the leading cause of death in 18-to-64-year-olds was COVID-19, which caused 21% of deaths in 2020 and 19% of deaths in 2021 (Figure 2.4).

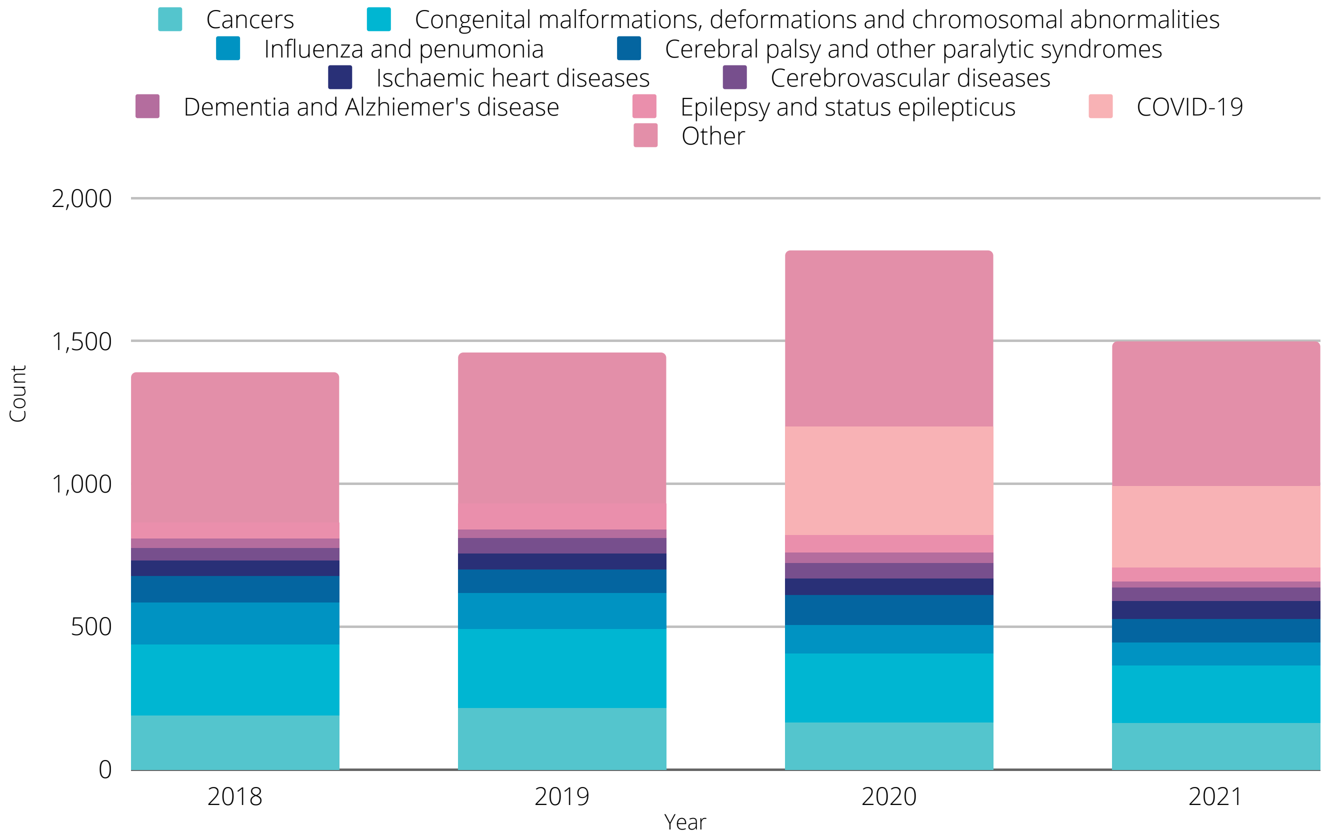
The second most common leading cause was congenital malformations, deformations and chromosomal abnormalities, which showed a decrease in the number of deaths it accounted for.

The results for 2020 and 2021 appear to show a reduction in the proportion of deaths attributed to influenza and pneumonia, which has also been found in children. This is most likely explained by the lower circulation of respiratory viruses (other than COVID-19) due to reduced mixing and the imposition of social distancing measures in response to the pandemic.

Non-COVID-19 leading causes of death did not show an increase during 2020 and 2021.

The leading causes of death for people aged between 20 and 64 in the general population was ischaemic heart diseases, followed by COVID-19, which caused

Figure 2.4: Number of deaths which occurred in 2018-2021, had initial review and MCCD data available, by leading cause of death, 18- to 64-year-olds .



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

8.9% of deaths[19].

In summary, a higher proportion of deaths in adults with learning disability of working age were due to COVID-19 than in the general population, while other causes of death did not show an increase.

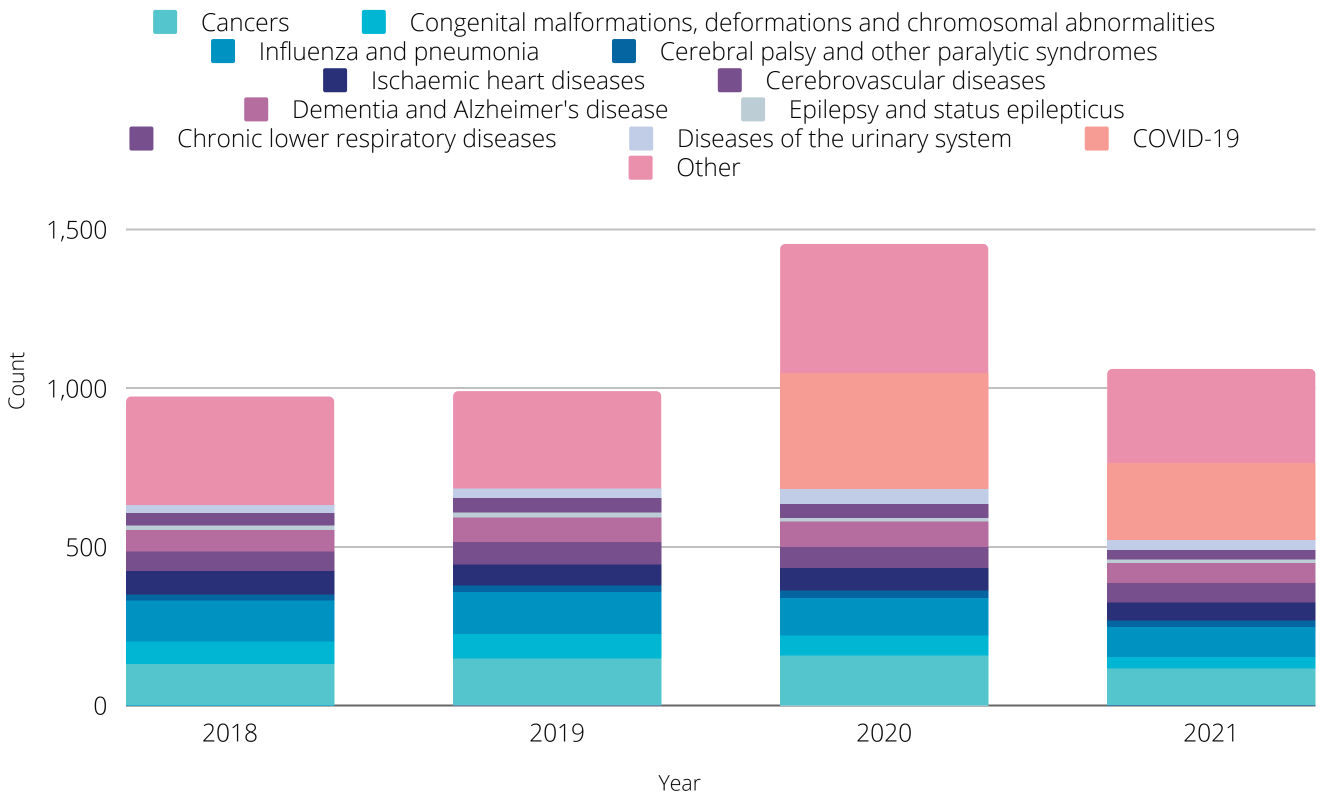
Leading causes of death in older adults (65+)

The leading causes of death for older adults with a learning disability who died between 2018 and 2021 and had initial review data before the 31st of December 2021 are presented in Figure 2.5.

As in the general population, COVID-19 was the leading cause of death in this age group, accounting for 25% of deaths in 2020 and 23% of deaths in 2021. The second leading cause of death in 2021 was cancers, which caused 11% of deaths. The third leading cause of death in 2021 was influenza and pneumonia, which was listed as an underlying cause on 9% of death certificates, although as seen in other age groups, the percentage of deaths attributed to influenza and pneumonia in 2020 and 2021 was less than previous years.

Another finding that was consistent with other age groups was that no increases in deaths due to non-COVID-19 leading causes of death were found in 2020 and 2021.

Figure 2.5: Number of deaths reported to LeDeR by leading cause of death, people aged 65 and over, 2018 to 2021.



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*https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables

Unsurprisingly, a larger portion of deaths were found for dementia and Alzheimer’s disease (6%) and cerebrovascular diseases (6%) than in other age groups. Additionally, chronic lower respiratory diseases (3%) and diseases of the urinary system (3%) accounted for a larger percentage of deaths for over 65s. For a full breakdown of the leading underlying causes of death by age group and sex, see Appendix 2.7 and 2.8.

In 2020, the leading cause of death for people aged between 65 and 79 from the general population was COVID-19, which accounted for 12% of deaths. Ischaemic heart disease was the second leading cause of death, causing 11% of deaths.

Dementia and Alzheimer's disease was the leading cause of death for people aged 80+, accounting for 18% of deaths, while COVID-19 was the second leading cause of death, causing 13% of deaths.

In summary, a higher proportion of deaths in older adults with learning disability were due to COVID-19 than in those from the general population. Older adults also showed higher proportions of deaths due to cancers, and influenza and pneumonia, while deaths due to ischaemic heart disease were lower.

Implications

There are many reasons why a higher proportion of people with learning disability die in hospital compared with the general population. There may be differences in characteristics such as age or causes of death, factors related to a person’s living circumstances, or issues surrounding hospice or palliative care services at home. Further exploration of these factors is necessary.

A concerning finding was that reviewers judged DNACPR documentation and processes to have been correctly followed in only 60% of the deaths in 2021 where a DNACPR was present. Additional work will be necessary to understand where these problems arise, and how this can be improved.

Leading causes of death

In 2020 and 2021, COVID-19 was the leading cause of death, which underlines the importance of vaccination and the need to take an assertive approach to reducing infection rates in people with a learning disability. Chapter 6 focuses on deaths due to COVID-19.

There were no apparent increases in the number of deaths caused by conditions other than COVID-19. This seems to have occurred in spite of the disruption to routine healthcare services that occurred due to the pandemic. However, if the pandemic has had a wider impact on other causes of morbidity and mortality, it may take longer for its effect to be visible within LeDeR data.

As well as analysing outcomes related to death, comparisons of the deterioration in mental and physical health could be made between people with learning disability and people from the general population in future research. This could help to establish whether people with a learning disability have experienced poorer outcomes related to the pandemic.

Moving forward

Research

- Future analyses of mortality statistics in subsequent years are required to determine whether the pandemic has had a wider and longer-term effect on mortality in people with a learning disability.
- Research should seek to establish the barriers and facilitators associated with compliance with current DNACPR procedures to drive practice improvement.
- Ways in which the reduction in deaths due to respiratory infections can be maintained should be explored.
- Research to consider the potential impact of reducing the age of screening for bowel cancer in people with a learning disability could be useful.

Care and services

- How can NHS providers ensure completion and adherence to DNACPR documentation and processes in people with a learning disability?
- How can the NHS and its partners continue efforts to monitor the long-term impact of COVID-19 on people with a learning disability?
- How can caregivers and healthcare professionals be supported to look out for symptoms of cancers of the digestive system and consider investigation if appropriate?

Chapter 3

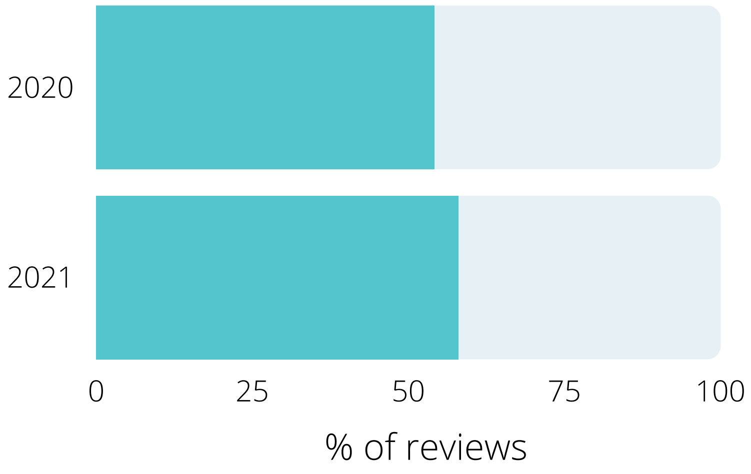
Quality of Care

KEY TAKEAWAY OF QUALITY OF CARE

7 out of 10 reviews indicated evidence of good practice.

9 out of 10 of reviewers indicated that the care package provided met the needs of the individual in deaths that occurred in 2020 and 2021*.

Overall care was rated as 'good' or 'excellent' in 58% reviews of deaths in 2021, increased from 54% in 2020*.



*data taken from reviews conducted with the older LeDeR review system.

Quality of Care

Introduction

The provision of high-quality care for people with a learning disability is paramount in ensuring positive experiences and optimal outcomes. However, there is evidence that people with a learning disability do not always receive good care[20; 21]. As an in-depth review of a person's overall care, rather than being focused on a particular service or episode of care, the LeDeR review process provides a unique opportunity to identify both good practice and areas for improvement across the health and social care pathway, as well as at around the time of death.

Method

Data presented in this chapter are drawn from several questions in LeDeR reviews that report the quality of care that the person received. Reviewers are asked to make judgements about various aspects of a person's overall health and social care based on the information they receive from different sources while conducting the review. Reviewers are not limited to reporting the care received immediately prior to death or to evaluating one organisation's input. Thus, the data here take a patient-centred approach and broadly reflect most aspects of the care that a person with a learning disability who has died had received.

Changes to the LeDeR review process relevant to this chapter

The LeDeR review process changed in May 2021 and this year's annual report contains data gathered using both the older review template and the new version of the review; both span deaths occurring in 2020 and 2021. Because there are some differences in the way that quality of care indicators are collected between the older and the newer versions of the review, we report data gathered from each process separately.

The older LeDeR review (conducted prior to June 2021) contained several questions related to quality of care that are not included in the new LeDeR *initial* review but which are included in the more detailed new LeDeR *focused* review. As described in the foreword of this report, cases progress to a focused review under certain circumstances, guided by the reviewer and the potential for learning from the case. Focused reviews are therefore not representative of all LeDeR reviews, and direct comparisons of results obtained using the old review process and using the new focused review process cannot be made.

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[20] Durrant, Tizard Learning Disability Review 2020;25(2):83-92
[21] McCormick, Marsh, Taggart et al, Health and Social Care in the Community 2021, 29(5):1222-1232

Data analysis

Many of the Quality of Care indicators are closed questions that require the reviewer to choose from a short set of pre-defined responses. These questions have been analysed using descriptive statistics and are tabulated or represented graphically. Results of reviews of deaths occurring in 2020 are presented alongside results of reviews of deaths occurring in 2021.

In this chapter we have also included questions that ask the reviewer to describe areas of good practice or concerns with the care that the person received. These are open, free-text questions. To analyse these responses, we have used a structured form of qualitative analysis that enables us to organise and draw major themes from the data using a systematic method that is suitable for the short comments that the reviewers have typically provided. This process was completed collaboratively by members of our research team and results are presented narratively alongside anonymised quotes from the reviewers.

Results

This chapter reports data from 3,516 of the old type LeDeR review (3,062 deaths occurring in 2020 and 454 deaths occurring in 2021) and from 136 of the new LeDeR focused reviews (28 deaths occurring in 2020 and 108 deaths occurring in 2021). As it takes time for the LeDeR review process to be completed, not all reviews of deaths occurring in 2021 are available at the time of compiling this report; data from these reviews will be reported in subsequent years. The data related to quality of care metrics relates to reviews of deaths of adults aged 18 years and over.

Grading of Quality of Care

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

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

The grading of quality of care question was unchanged between the older LeDeR review and the new LeDeR review, introduced in 2021. However, some readers will notice that the rating scale has been reversed, such that higher numbers on the scale now correspond to higher quality of care. In this report, we reference the updated scale and report results of both review systems according to this scale so that they can be compared more easily.

Older LeDeR review data

The most common reviewer rating of overall quality of care for deaths occurring in 2020 and 2021 was 5, that is "good care that met expected good clinical practice" (Figure 3.1). Only a very small proportion received the lowest ratings, that is, care that contributed to, or had the potential to contribute to, the person's cause of death.

New LeDeR focused review data

Gradings of overall quality of care of deaths that occurred in 2020 or 2021 that were reviewed using the newer LeDeR focused review are shown in figure 3.2. Deaths occurring in 2020 were generally assigned a lower quality of care grade than those occurring in 2021, although it must be recognised that these observations are based on only a small number of reviews.

It also appears that overall care is rated slightly less favourably when comparing results from reviews undertaken using the older LeDeR review (Figure 3.1) and the new LeDeR review (Figure 3.2, page 43). That is, overall care grading was generally lower in the reviews using the new LeDeR focused review. This may be because the new LeDeR focused reviews are undertaken on selected cases, with one of the main reasons for selection being that the reviewer believes lessons could be learned from the case, indicating potential problems with the care that was received.

Figure 3.1: Quality of care (older LeDeR reviews).

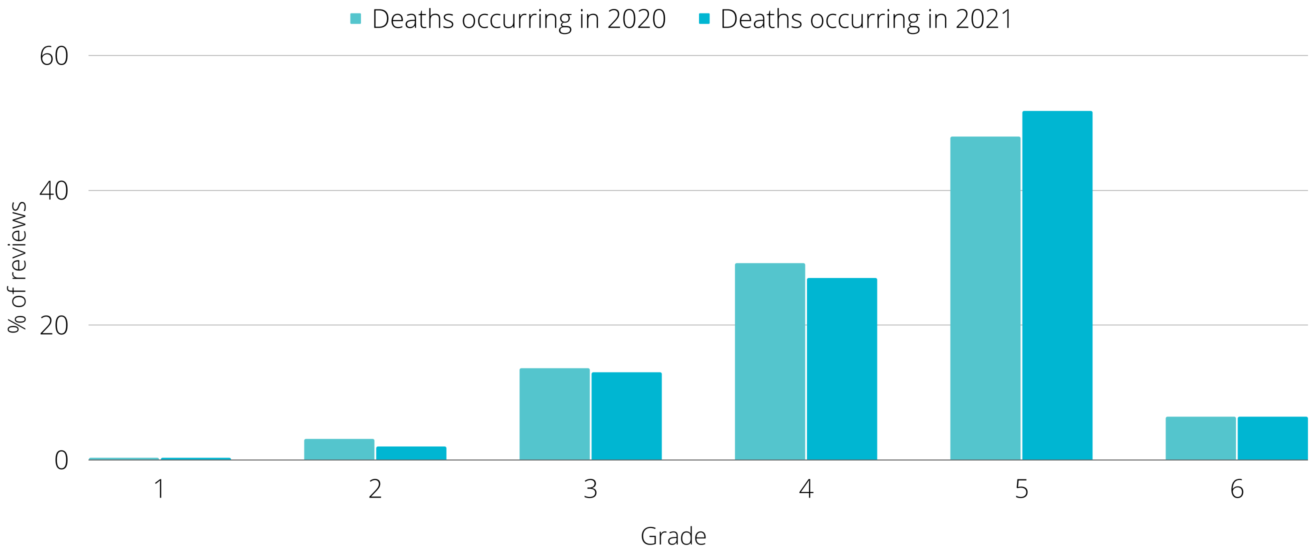
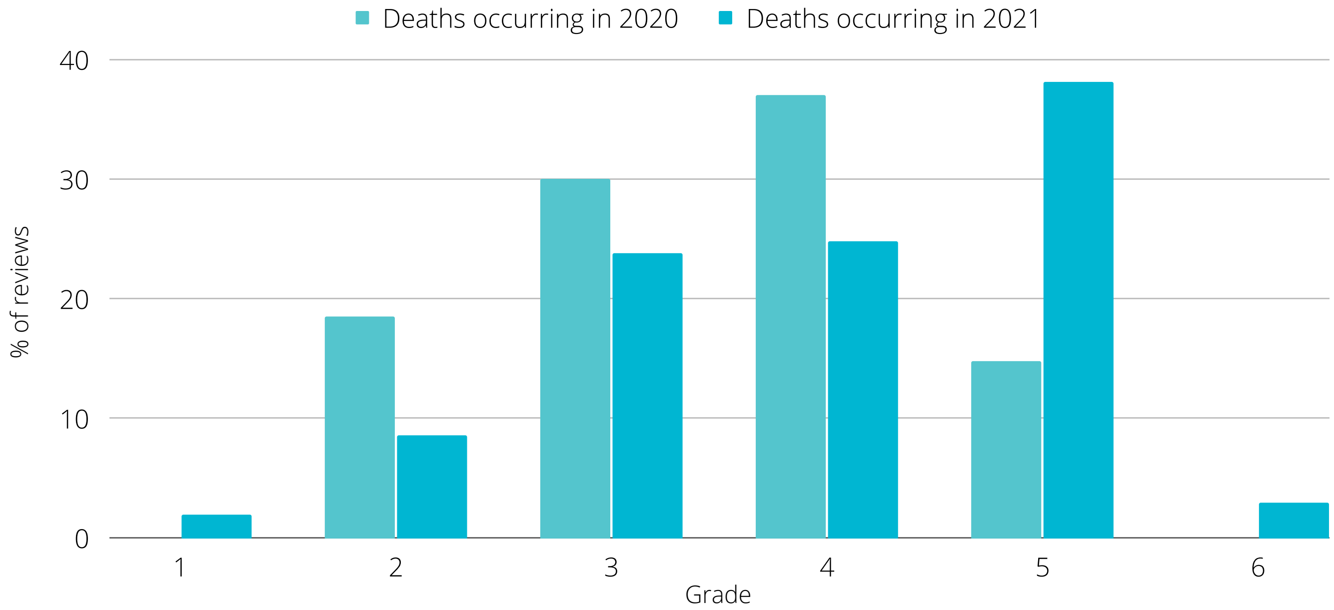


Figure 3.2: Quality of care (new LeDeR focused reviews).



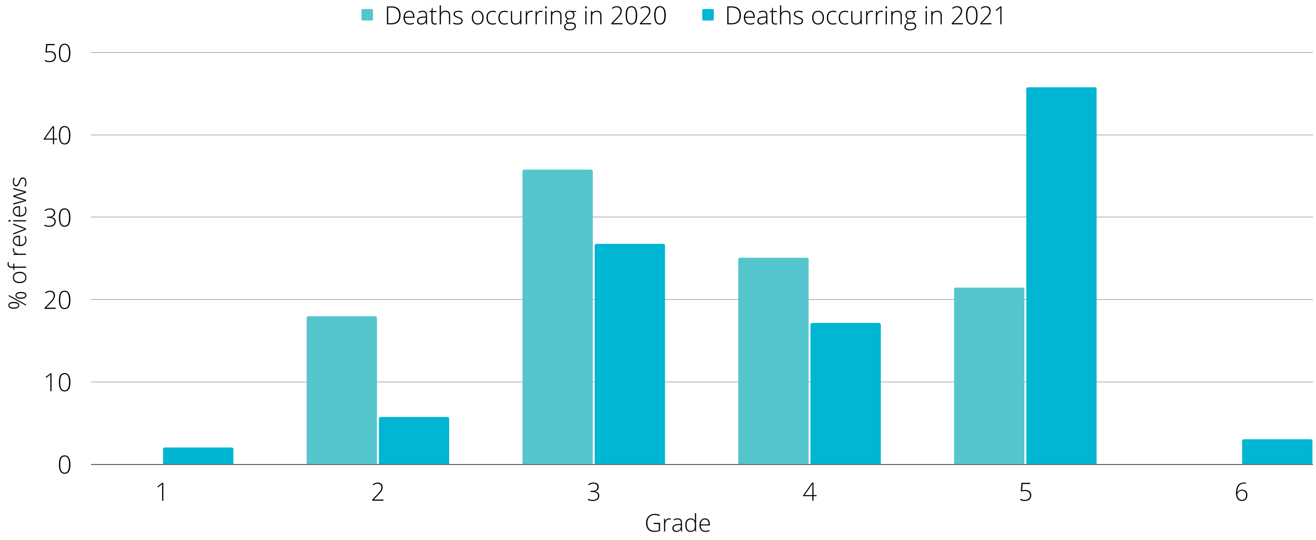
Grading of acceptability and effectiveness of care

The new LeDeR focused review includes an additional question which asks reviewers to grade the availability and effectiveness of services the person received. This is again rated on a six-point scale:

- 1=Availability and effectiveness of services fell far short of the expected standard and this contributed to the cause of death
- 2=Availability and effectiveness of services fell short of the expected standard and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death
- 3=Availability and effectiveness of services fell short of the expected standard and this did impact on the person's wellbeing but did not contribute to the cause of death
- 4=Availability and effectiveness of services fell short of the expected standard in some areas but this did not significantly impact on the person's wellbeing
- 5=Availability and effectiveness of services was good and met the expected standard
- 6=Availability and effectiveness of services was excellent and exceeded the expected standard

The reviewers assigned gradings across the scale, with the majority of reviews falling between grades 3 and 5 (figure 3.3, page 43). Again, there is a difference between results of reviews of deaths occurring in 2020 and deaths occurring in 2021 although the very small number of focused reviews in these years makes it difficult to interpret potential trends in the data.

Figure 3.3: Acceptability and effectiveness of care (new LeDeR focused reviews).



Identification of good practice

Reviewers are asked to indicate whether any good practice was identified in the care the person received.

Whereas this question is asked as a yes/no question in the older LeDeR review, the newer LeDeR focused review requires the reviewer to describe the good practice in a free text box. In this case, we have counted good practice as being present when the text box is completed, and good practice being absent when the text box is left unfilled. It was not possible in the new LeDeR focused reviews to distinguish cases where this question was skipped by the reviewer from an unfilled box due to there being no examples of good practice, and therefore this method may under-estimate the proportion of focused reviews in which good practice was identified. Tables 3.1 and 3.2 show the results of this question by version of the LeDeR review.

Table 3.1: Proportion of reviews with evidence of good practice (older LeDeR reviews).

Good practice identified	Deaths in 2020	Deaths in 2021
Yes	2115 (69.8%)	290 (70.4%)
No	915 (30.2%)	122 (29.6%)
Unrecorded	32	42
Total (valid)	3062 (3030)	454 (412)

Table 3.2: Proportion of reviews with evidence of good practice (new LeDeR focused reviews).

Good practice identified	Deaths in 2020	Deaths in 2021
Yes	19 (67.9%)	77 (71.3%)
No	9 (32.1%)	31 (28.7%)
Unrecorded	0	0
Total (valid)	28 (28)	108 (108)

Concerns with care

The reviewer was asked if anyone had expressed concern about the death. Table 3.4 shows the proportion of cases where concerns had been expressed about the death using the older LeDeR review system is just under 10%. This is similar to the results of deaths occurring in 2018 and 2019, as reported in previous LeDeR annual reports. Results from the same question asked in the new LeDeR review are reported in table 3.4. This shows that concerns were raised about the death in around 3 out of 10 cases. This is higher than under the previous LeDeR review system and most likely reflects the selection of cases that moves to a focused review.

Table 3.3: Proportion of reviews where concern has been expressed about the death (older LeDeR reviews).

Concern expressed about the death	Deaths in 2020	Deaths in 2021
Yes, concerns	300 (9.9%)	30 (7.3%)
No/Not to my knowledge	2730 (90.1%)	382 (92.7%)
Unrecorded	32	42
Total (valid)	3062 (3030)	454 (412)

Table 3.4: Proportion of reviews where concern has been expressed about the death (new LeDeR focused reviews).

Concern expressed about the death	Deaths in 2020	Deaths in 2021
Yes, concerns	8 (28.6%)	33 (30.6%)
No/I don't know	20 (71.4%)	75 (69.4%)
Unrecorded	0	0
Total (valid)	28 (28)	108 (108)

Review of care package

Reviewers were asked to judge whether the care package met the needs of the individual. The care package was deemed to meet the needs of the individual in over 9 out of 10 deaths that were reviewed using the older review process (Table 3.5, page 45). Using the newer LeDeR focused review, a lower proportion of reviewers concluded that the care package met the individual’s needs, with a discrepancy between reviews of deaths occurring in 2020 and deaths occurring in 2021 (Table 3.6, page 45).

Table 3.5: Proportion of reviews where the care package met the needs of the individual (older LeDeR reviews).

Care package meets needs	Deaths in 2020	Deaths in 2021
Yes	2733 (90.2%)	384 (93.2%)
No	297 (9.8%)	28 (6.8%)
Unrecorded	32	42
Total (valid)	3062 (3030)	454 (412)

Table 3.6: Proportion of reviews where the care package met the needs of the individual (new LeDeR focused reviews).

Care package needs met	Deaths in 2020	Deaths in 2021
Yes	15 (53.6%)	88 (81.5%)
No	13 (46.4%)	20 (18.5%)
Unrecorded	0	0
Total (valid)	28 (28)	108 (108)

Specific areas of problems with care

In addition to general questions about quality of care, the LeDeR review asks about specific areas that may impinge on the quality of care that people received. These are:

1. delays in care or treatment
2. problems with organisational systems and processes (including the coordination of care)
3. gaps in service provision
4. recommended diagnostic and treatment guidelines met (included as an additional question in the new LeDeR focused review)

The results of these questions are represented graphically in Figure 3.4 (below) and Figure 3.5 (page 46).

Figure 3.4: Proportion of reviewers reporting problems with different aspects of care (older LeDeR reviews).

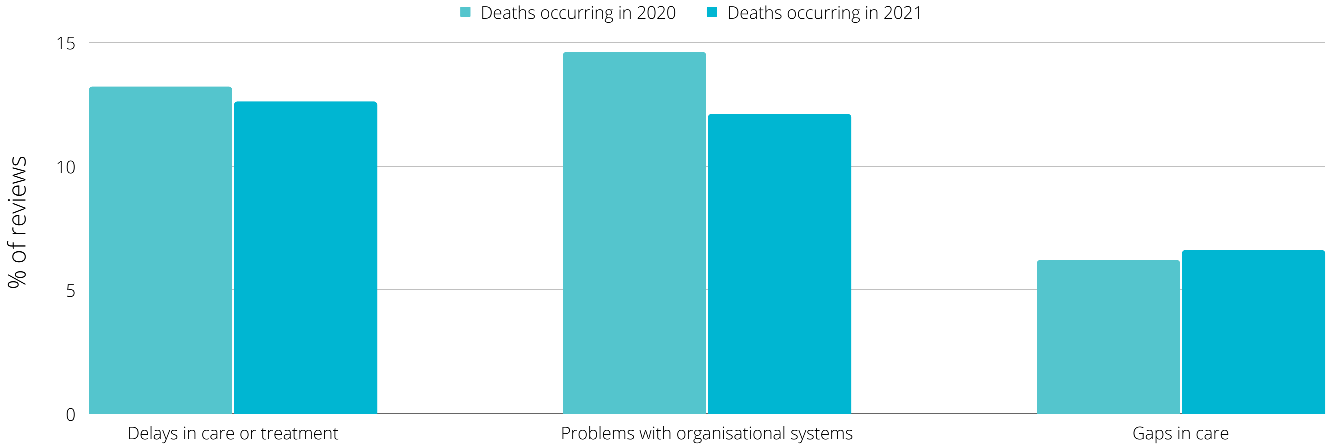
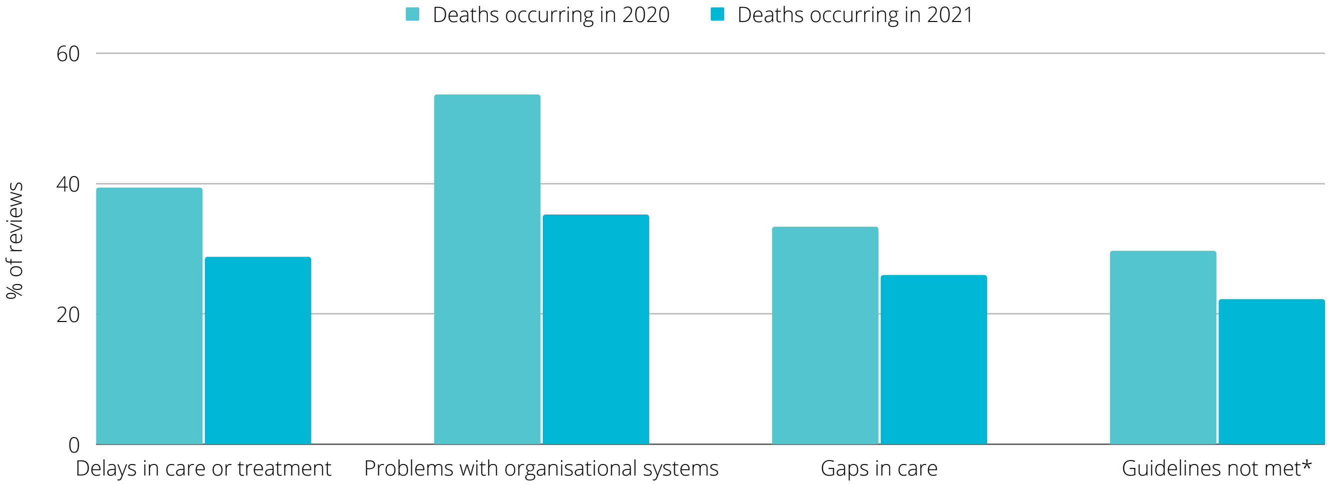


Figure 3.5: Proportion of reviewers reporting problems with different aspects of care (new LeDeR focused reviews).



*The new LeDeR focused review includes an additional question about whether recommended diagnostic and treatment guidelines were met.

The results from new LeDeR focused reviews show higher proportions with problems reported across each of the domains when compared with reviews undertaken using the older LeDeR review. As above, this may be explained by the selection criteria for focused reviews which includes problems in care identified in the early stages of the review and we also need to be mindful that these results are based on a small number of reviews. In future annual reports and with an increased dataset, it will be possible to compare trends over time, including relating these to service changes following the COVID-19 pandemic. As the dataset expands, it will be possible to use the qualitative data that accompanies these questions to further explore the nature of these problems.

Areas of positive practice and areas of concern

In addition to the quantitative data, reviewers are asked to report areas of positive practice and issues or areas of concern. Reviewer responses are written as free text; we have analysed this content using a structured method. We have concentrated this analysis on results from the new LeDeR focused reviews and therefore a relatively smaller number of reviews.

Data related to concerns with care and areas of positive practice are considered separately. We first sorted the text comments into a matrix using care setting as the column header and pre-determined theme categories devised by NHS England as the rows.

The care settings were:

1. Primary and community care (including hospital out-patient services)
2. Hospital in-patient care
3. Social care
4. End-of-life care

The theme categories were:

1. Equality and disability
2. Statutory duties
3. Quality of care
4. Care coordination
5. Information sharing and documentation
6. Skills, knowledge and competency

We have drawn out commonly reported topics and written a short narrative around these, supported by anonymised direct quotations from the reviewers to give a sense of the data. Areas of concern reported by reviewers were often the opposite of positive practice examples.

Equality and disability

Areas of concern

In **primary and community care**, concerns included a lack of preventative healthcare (screening programmes and vaccinations) and difficulties accessing appointments. In some cases this was founded on lack of reasonable adjustments, including not providing information in suitable formats, or discharging a person from a community or out-patient service following a single non-attendance. A small number of reviewers mentioned the person not being consulted about their care and lacking access to advocacy, or care decisions that were made on the basis of the learning disability, rather than other relevant clinical factors. Missed or inadequate learning disability annual health checks were highlighted by some.

Echoing some of the concerns in primary care, lack of reasonable adjustments in **hospital in-patient care** emerged as a theme, including problems with access to specialist equipment, accessible information, advocates, and interpreters.

"Appropriate equipment was not promptly available such as moving and handling equipment (and adaptations to allow the use of her specialist slings), adapted bath or shower facilities despite it being flagged on repeated occasions".

"Blanket bans" on visitors due to the COVID-19 pandemic were viewed as unhelpful. Several reviewers mentioned that hospital staff had not made use of initiatives that are designed to improve care for people with learning disability who are admitted to hospital, including the hospital passport and learning disability liaison services.

Positive practice

Positive practice in this domain in **primary and community care** included "comprehensive" annual health checks that were followed by completed health action plans. Multidisciplinary team working, including between different agencies, was seen as important and the actions of individual clinicians in providing good and personalised care was noted.

In **hospital in-patient care**, the input of learning disability liaison nurses throughout the hospital stay was highly valued. There was evidence that hospital passports had been used effectively and that these were associated with reasonable adjustments being implemented.

"Acute Learning Disability Nurse Specialist actively involved in her care and treatment. This included being present when she received physiotherapy and arranging regular contact via video calls to the care home and her family. This included a special call to celebrate her birthday and decorating her hospital bed. She also informed the community team of her admission to hospital and established the best interest meeting to discuss nutritional options".

A smaller amount of data related to **social care** and **end-of-life care**. This highlighted the benefit of health action plans and the successful provision of person-centred care, particularly as an individual's needs changed.

"[Name's] care provider was very flexible and adaptable as his health deteriorated. They made adjustments for him so that he could remain in his home as he needed to be fed via a PEG tube and when he needed to be on oxygen therapy".

Statutory duties

Areas of concern

In **primary and community care** the main concern in the responses was lack of adherence to the Mental Capacity Act (MCA), in that the Act was sometimes not clearly discussed when decisions were made, or that its principles were not followed.

"mental capacity for decision making was not clearly and consistently recorded".

Similar issues were flagged in **hospital in-patient care** with a number of reviewers commenting on the Mental Capacity Act "not being referred to," or being poorly understood and implemented. Also within this category were comments related to the hospital Structured Judgement Review (SJR; a local mortality review) not being completed accurately or on time.

"The SJR concluded that good care was given, and yet there were a range of issues identified as not being addressed"

Positive practice

Conversely, the positive practice in this domain included regular assessments of mental capacity in **primary and community care** and **hospital in-patient care** and 'best interests' processes that included family, carers, independent advocates, and the person themselves, to the extent that was possible.

"Capacity assessments carried out regularly to determine ability to make decisions and although [name] did not have capacity, they were involved in the decision-making process and decisions made ensured the least restrictive option".

At end-of-life care, 'ReSPECT' (Recommended Summary Plan for Emergency Care and Treatment) documents were highlighted as having been completed as a marker of positive practice.

Quality of care

Areas of concern

Quality of care concerns in **primary and community care** centred around missed or late diagnosis of potentially treatable disorders, including lack of investigation when potential problems were identified. At times, there was a lack of monitoring and review of established conditions.

"[Name's] family were concerned about changes in their presentation from 2017 onwards ... repeated requests for a dementia assessment went unheeded"

"[Name] was prescribed antipsychotic medication long term without adequate review [and] physical health was not monitored in line with guidance".

Delays in receiving appropriate care were noted in **hospital in-patient care**, including delays in investigations, onward referrals, and treatment. During the LeDeR review process, some families reported a lack of “compassionate” hospital care and hospital teams that “lacked knowledge on how to care for a disabled person”.

Delays were also raised in **social care**, particularly in escalating medical problems and seeking advice from health services. In part this may have been due to availability of basic monitoring equipment (“the supported living provider did not have access to a pulse oximeter”) and staff who appeared not to have enough training.

Positive practice

There were numerous examples of positive practice in the quality of care domain for all care settings. Individual staff members from across professions were frequently singled-out for praise and for their effectiveness, “strong advocacy,” “fierce support,” and “going above and beyond.”

There were many reports of good practice in **primary and community care** and **hospital in-patient care** that spanned several distinct conditions or interventions. Common to these were proactive care and support and consistency of staff. Some families reported “excellent” experiences of care to LeDeR reviewers.

A number of areas of positive practice related to quality of care were noted in **social care** settings. These included support packages that were comprehensive and promoted people's independence. Good practice included "consistency of carers" who were able to develop an understanding of people's strengths and support needs.

“[Name's] care package supported her to live in her own flat and enjoy life to the full”.

“The supportive living environment [Name] resided in enabled her to flourish and finally be happy”.

A further aspect of positive practice that was highlighted was the ability of some **social care** providers to be “flexible and adaptable” in responding to a person’s changing health needs.

Positive care at the **end-of-life** often included person-centred actions, multi-disciplinary team involvement, and the involvement of hospice services.

Care coordination including pathway and transition

Areas of concern

In primary and community care, themes in this domain were a lack of multi-disciplinary team working, disputes between clinical teams, and lack of clear pathways for people with long-term health conditions where input traversed primary care, hospital care, and multiple specialities.

In hospital in-patient care, a theme was “poor discharge processes” with reports of people having been discharged too quickly without appropriate investigation or without effective discharge planning and liaison with those who were providing community support.

"[Name] was discharged without further investigation of ongoing pain and no collateral history taken from family or carers".

Care co-ordination and pathway issues in **social care** included disjointed care caused by changes in social worker or in support provider which were perceived as being disruptive for individuals. Some families believed that appropriate services for people with "complex needs" did not exist.

Positive practice

Multi-disciplinary care, team working, and "collaboration" were positive practice themes across all care settings. There were many examples of good communication between professionals which was linked to effective decision-making, timely interventions, and improved outcomes.

The presence of an assigned professional who could "take the lead in co-ordinating professional involvement and liaising with [Name's] family" was recognised as a means of promoting a "joined up approach to care."

Information sharing and documentation

Areas of concern

Within this domain, gaps in general practice and hospital records were concerns.

In **primary and community care** this related to missing diagnosis of learning disability and some who were seemingly not included on the learning disability register. In **hospital in-patient care**, gaps in documentation related to the Mental Capacity Act, best interest decisions, Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) decisions, and accuracy of next-of-kin details.

There were some concerns that learning disability had been recorded as a cause of death on the death certificate, against national guidance.

There was an overlap between this domain and the preceding domain, with concerns related to poor communication between professionals and agencies. One particular point highlighted was potential issues with information sharing at points of care transition where sometimes "information did not transfer" with the person.

Positive practice

Again, positive practice in this domain was mainly expressed as multiple examples of good communication which included a person's wider network. Families reported positive experiences of being involved in care.

Examples of good practice in documentation included addition of extra information to the GP care record and recording of discussions with families and supporters of the person with learning disability.

"There was evidence that the [care] home ensured the family were involved and consulted throughout [Name's] journey, despite the family being resident outside the UK."

Skills, knowledge and competency

There was proportionately less evidence falling into this category.

Areas of concern

In **primary and community care** and **hospital in-patient care** there were some reports of a general lack of learning disability awareness amongst staff and a lack of experience working with this group.

A theme related to **social care** was a lack of understanding of physical health problems in people with learning disability and, in particular, a lack of recognition of deterioration in physical health and when and how to seek medical support which could lead to "delayed escalation" of care.

Positive practice

There were not enough examples of positive practice in this domain to draw themes from or summarise the data.

Summary of issues and positive practice

One message to emerge from these data is the need for continued work to ensure that healthcare services make reasonable adjustments for people with a learning disability. A number of initiatives have been introduced over the past few years to improve healthcare for people with a learning disability, including the annual health check, health action plans, hospital passports, and learning disability awareness training. Although there were many examples in which these initiatives had been associated with positive practice, implementation was not universal. These practice initiatives are supported by legislation such as the Equalities Act and the Mental Capacity Act but there were reports of these principles not being applied consistently. The learning disability liaison nurse role in acute hospital settings was valued as a bridge between the principles and the provision of good care.

It was notable that the actions and approach of individual staff from across disciplines in the health and social care sector were singled out for praise, suggesting a real willingness and commitment to providing the best care possible. This was set against systems which were, at times, perceived as being inflexible.

Perhaps unsurprisingly, many of the systems issues relate to communication and transfer of information between different teams and at points of transition or transfer of care.

Multi-disciplinary team working was evident and believed to be of great importance. However, it did not always occur optimally. For example, it was reported that discharge from an acute hospital was not always discussed with families and community services, leaving them unprepared and potentially leading to readmission. Similar to the value of the learning disability liaison nurse role, an allocated community professional who could oversee an individual's care and span services was seen as important in connecting what was often described as a complex web of care.

Concerns were noted with supported or residential living facilities responding to health problems in people with a learning disability, particularly in acute situations. This may be related to a lack of training in recognising deteriorating health, or to the presence of diagnostic overshadowing, in which problems are incorrectly attributed to the learning disability rather than a potentially-treatable cause.

Future quality of care dataset

The LeDeR 2021 annual report is atypical in that the reviews span both earlier versions and the newer review approach which was introduced midway through the reporting period. As discussed above, the new focused review (conducted on selected cases) contains the quality of care indicators, limiting direct comparisons between this and previous years' data.

Future LeDeR annual reports will include data from reviews of autistic adults (without a learning disability) who have died, giving much needed understanding of current practice and how it might be improved.

Moving forward

Research

- Additional focused reviews over subsequent years will contribute to a rich dataset of comparable longitudinal data. This will allow the effect of the COVID-19 pandemic and related service changes on the quality of care of people with a learning disability to be investigated.

- New initiatives that aim to improve the quality of care for people with a learning disability and autistic people from countries beyond the United Kingdom should be explored for implementation, if shown to be effective.

Care and Services

- The reviewers believed that the learning disability liaison nurse role brought benefits for people with learning disability who are admitted to hospital. How can acute trusts most effectively implement models of providing learning disability liaison care?

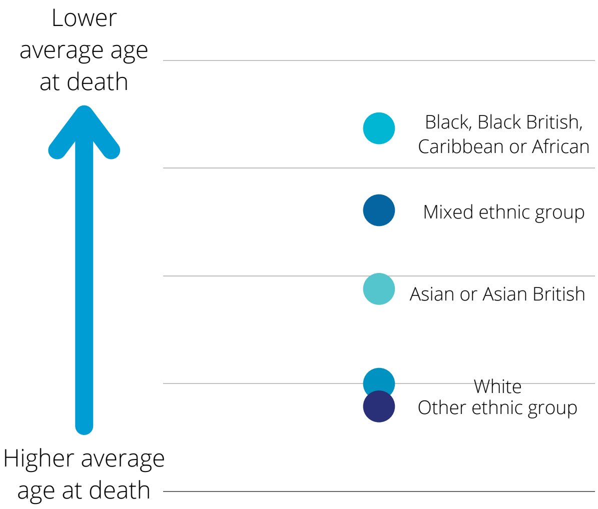
- Up-to-date annual health checks and health action plans were associated with positive practice. How can professionals and services make the annual health check most accessible and maximise the proportion of eligible individuals who receive one?

- Prompt identification and response to worsening physical health is important. What additional strategies are needed for carers to be able to recognise and respond appropriately to deteriorating physical health of people with a learning disability?

Chapter 4

Factors Associated with Age at death

KEY TAKEAWAY OF FACTORS ASSOCIATED WITH AGE AT DEATH



People of Black, Black British, Caribbean or African, mixed ethnic group and Asian or Asian British ethnicity died at a younger age in comparison to those of white ethnicity.

Epilepsy was the most common long-term health condition associated with an earlier age at death.

People who died in a place other than their usual place of residence or hospital showed a small increase in the likelihood of dying earlier.

Factors associated with age at death

Background and rationale

Previous LeDeR annual reports have investigated various factors that may influence a person's age at death, ranging from demographics to number of long-term health conditions (LTCs). There has also been some modelling of the likelihood of people with a learning disability dying at younger age. Factors that were found to be significantly associated with dying before 50 years of age in adjusted analyses included being of Asian or Asian British ethnicity, and having severe and profound learning disability, and not having an annual health check (LeDeR annual report, 2020).

In this chapter, we will revisit this topic, looking at factors related to age at death in deaths during 2021 and taking a more comprehensive approach to factors that might be associated with age at death, by including clinical factors such as long-term conditions, and by using survival analysis. Specifically, we are using a type of survival analysis called Cox proportional hazards models to investigate the effects of factors that could be related to survival. In this case, age at death is the time to event and thus allows for a lifetime approach. The results of the analyses are expressed as hazard ratios (HR). A HR of more than one means an increased risk by the end of the time period, whilst a value below 1 means reduced risk.

Similar caveats as in other chapters apply to interpreting the data, with respect to 2021 being an “unusual” year due to the pandemic, number of deaths with complete clinical data, as well as the relatively small number of people from ethnic groups other than white.

Analysis

We modelled the data (using survival analysis) to look at how factors relating to demographics, long-term health conditions, social and care factors contribute to when a person died using data about adults (18 years or over) who died in 2021. The demographic factors were sex, ethnicity, the region of England in which the person lived, and the place of death (hospital, usual residence, other). LTCs as coded by the coding team included having cancer, a cardiovascular condition, a degenerative condition, dementia, diabetes, deep-vein thrombosis (DVT), epilepsy, hypertension, kidney problems, a mental health condition (anxiety, bipolar, depression, psychosis etc), osteoporosis, a respiratory condition, a sensory impairment (hearing or vision problems), or dysphagia.

Social and care factors included whether the person had an annual health check in the 12 months preceding their death, whether the care package was judged to meet their needs, whether there was a

Deprivation of Liberty order (DoL) in place (no, applied for, approved), whether they were in an out-of-area placement, and a grading of their quality of care (1-6) as assessed by LeDeR reviewers (see Chapter 3 for details).

We used Cox proportional hazards models to investigate the effects of predictor variables on time to death. We fitted separate models with each of the predictor variables to estimate the unadjusted effects of each of these. We then fitted three models to estimate the adjusted effects of each of the sets of predictors. The first of these models included all the demographic variables.

The second included all the clinical variables together with the demographic variables. The third included the social and care variables together with the demographic variables.

Dataset

There were 2,584 adults who died in 2021 with completed reviews whose age at death was known and thus included in this analysis. In adjusted analyses that took account of long-term health conditions, approximately 42% of cases with data were included. The other features of the deaths included in our analysis are described in Appendix 4.1.

Findings

Sex and geographical region of death were not significantly associated with time to death (age).

Ethnicity was a significant predictor of death at a younger age. The data suggest that being of Black, Black British, Caribbean or African ethnicity was associated with the highest risk (hazard ratio (HR) 3.37; 95% confidence interval (CI) 2.49, 4.57), meaning that deaths from people from these ethnic groups were at younger age compared to the white population. Similarly, being of Asian or Asian British, mixed ethnic group and other ethnic group was also associated with earlier death. The findings are broadly consistent with previous LeDeR reports which have shown a significant association between age at death and ethnicity; here we show that this association remains even when adjusted for additional factors such as long-term health conditions (see Appendices 4.2) . However, see below for further discussion of the potential limitations of the analysis.

Compared to those who died in hospital, people who died at their usual residence died at an older age (HR 0.83; 95% CI 0.76, 0.91), whilst those who died in a location categorised as “other” tended to die at younger age (HR 1.36; 95% CI 1.08, 1.71).

Figure 4.1 demonstrates the associations between demographic factors and time to death (age). This type of graph is called a forest plot and shows the reference group for each factor – e.g. the hazard ratio (HR) for sex describes the effect for females relative to males.

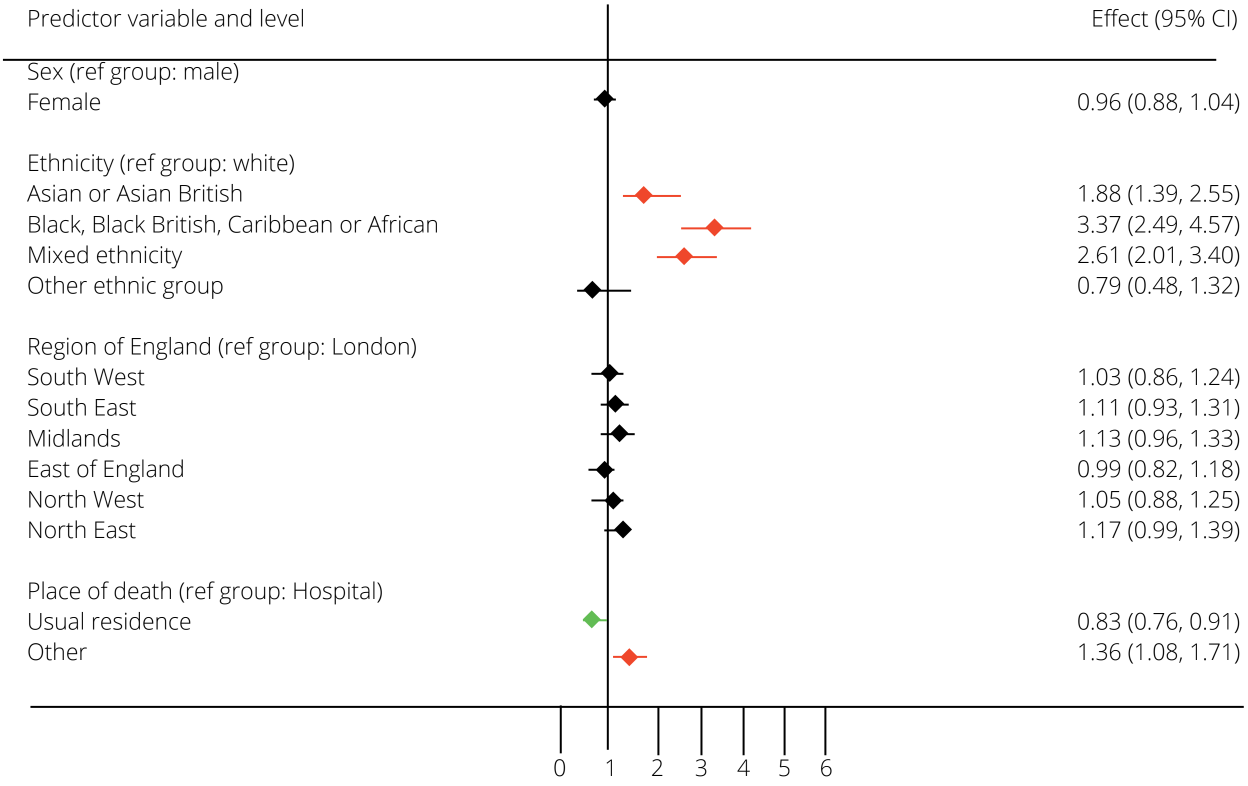
The vertical line indicates where the hazard ratio suggests no difference between the groups / conditions being compared. Horizontal lines for each diamond (the HR) are the 95% confidence intervals (CI) around the estimated HR.

If the horizontal line crosses the vertical line, then the HR for age at death is not statistically significant for that factor. If the CI stops to the left of the vertical line, then the factor is associated with increased age at death and would be a better outcome and indicated in green on the plot. If the CI starts to the right of the vertical line, then the factor is associated with younger age at death, therefore a worse outcome and indicated in red on the plot.

Long-term health conditions

Data on long-term health conditions were available for approximately 1,100 deaths. The most common long-term health conditions were epilepsy (355, 33% of those with data on long-term health conditions), cardiovascular conditions, sensory impairment, mental

Figure 4.1: the associations between demographic factors and time to death (age). The graph shows the reference group for each factor – e.g. the hazard ratio (HR) for sex describes the effect for females relative to males.



health conditions and dysphagia (see Appendix 4.1).

Some long-term health conditions were associated with higher hazard of earlier death than others. The greatest hazard was associated with having epilepsy compared to not having epilepsy (HR 1.47; 95% CI 1.28, 1.69).

There was evidence to suggest that the hazard of death may be greater for those with DVT (38, 4% of those with data on long-term health conditions) than those without (HR 1.37; 95% CI 0.98, 1.91) though numbers were small, and therefore CIs are wide. Some conditions such as cardiovascular conditions, hypertension, kidney problems, and mental health conditions were associated with older age of death. The data are presented in Figure 4.2.

Social and care factors

Recording of data for social and care factors were variable (see Appendix 4.1). Of those for whom data were available for health checks (28%), most (75%) had health checks in the last twelve months of their life and 87% were considered by reviewers to have received care that met their needs.

As all CIs cross the hazard ratio of 1, none of the social and care factors were associated with time to death (see Figure 4.3, page 62).

Figure 4.2: Forest plot showing estimated effects of long-term health conditions on age at death. Effects are hazard ratios with 95% confidence intervals.

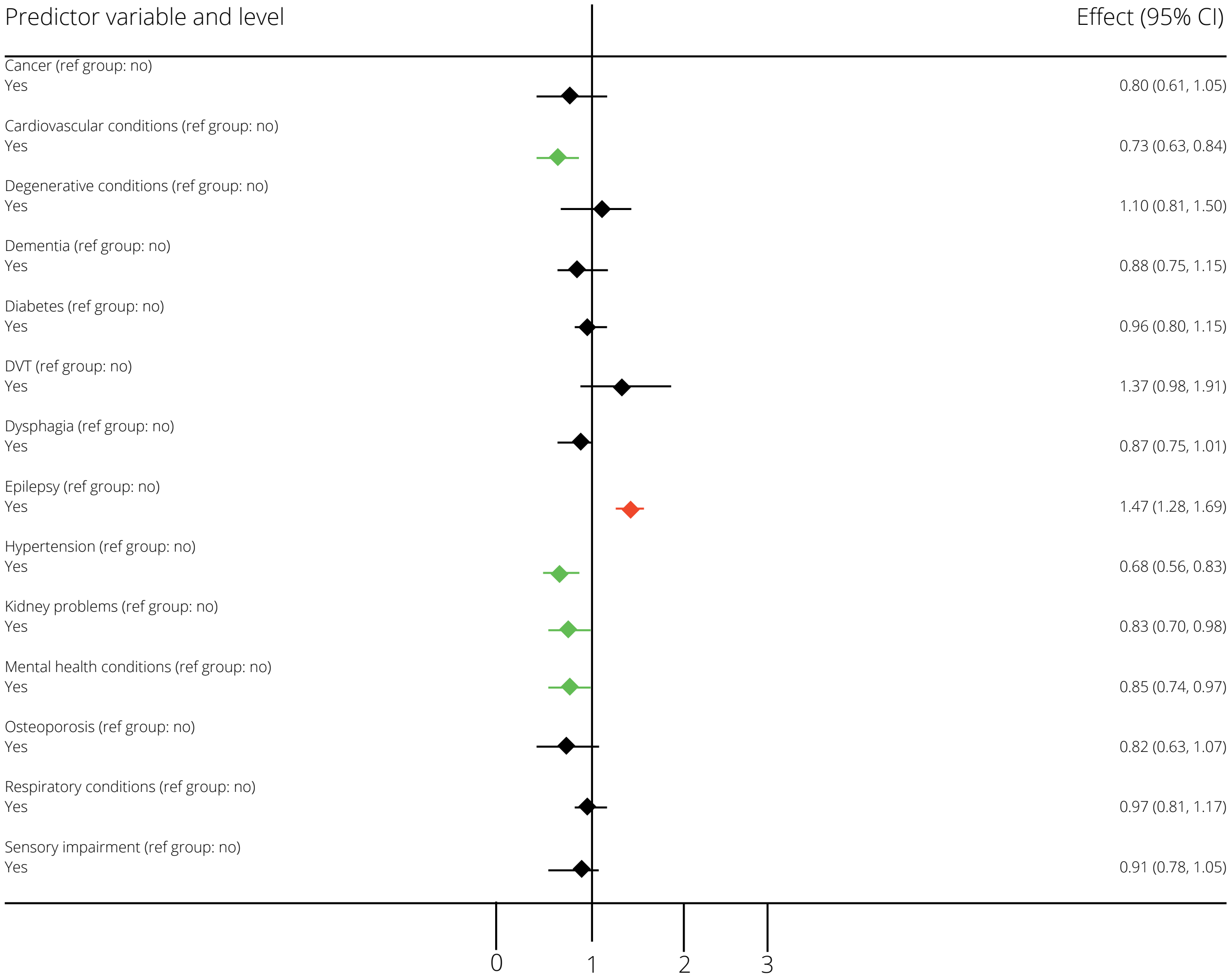
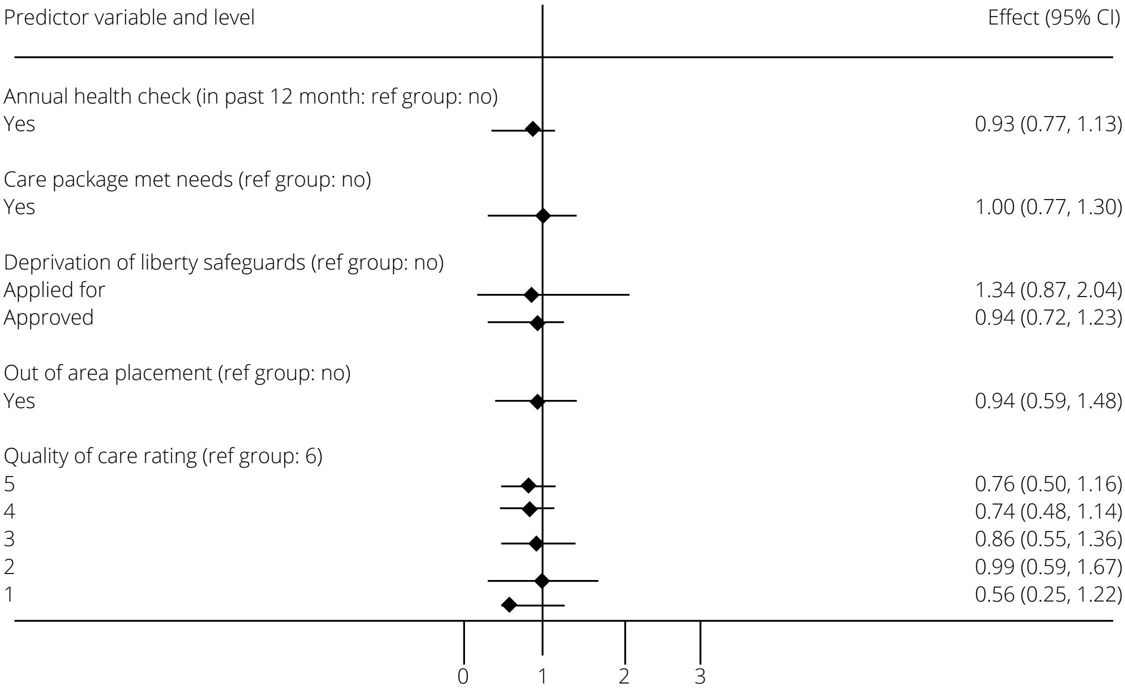


Figure 4.3: Forest plot showing estimated effects of social and care variables on age at death. Effects are hazard ratios with 95% confidence intervals.



Interpretation, areas for improvement and further research

We used a statistical modelling approach to explore the factors associated with age at death. Using data from reviews of people who died during 2021, we found that ethnicity may be associated with age at death, with people from certain ethnic backgrounds (mixed ethnic group, Black, Black British, Caribbean or African, Asian or Asian British) dying at younger ages, even when other factors are taken into account.

However, the numbers of people who have died in some of these groups that we included in the analysis were quite small. Furthermore, the underlying population structure may impact on the numbers of people dying at certain ages, with a smaller proportion of people from ethnic minority groups amongst older adults with a learning disability in this data sample.

The data provide areas for further research and consideration. Whilst the data here are limited in scope due to being only of people who have died and should be interpreted with caution due to unavailable data and small sample sizes, it does suggest important areas of focus for future research and deep dives.

Most notably, ethnicity and its relation to early death merits further investigation. LeDeR data from previous years could be combined to increase sample sizes and epidemiological research using other large representative datasets with longitudinal data will help to determine differences in age at death and some of the underlying causes, as well as the impact of the underlying population structure.

Regarding place of death, those who did not die in either hospital or their usual place of living demonstrated a small increase in likelihood of early death.

This category is broad, and can include a variety of situations such as temporary housing etc., but may indicate that these individuals are at increased risk, potentially due to poorer access to care or breaks in continuity of care.

We also found that having a diagnosis of epilepsy and DVT are associated with younger age at death. This suggests that improvements in treatment of these conditions may help to delay age at death. Several other health conditions were associated with older age at death, including cardiovascular conditions, dementia, and hypertension. The reason for this may be that these conditions are related to aging, and therefore more common in those that die at advanced age. When interpreting these findings, it is important to note that the sample size for some of the long-term health conditions was relatively small.

Several other conditions were not associated with age at death, or had only a small effect, such as diabetes, respiratory conditions and mental health conditions. It is possible that some of these conditions are relatively well monitored and managed in most people, and therefore less likely to be associated with age at death. In support of this is that many of these conditions are subject to specific NHS initiatives, such as the requirement to undertake annual blood tests for patients being prescribed certain types of medication for mental health conditions.

However, this analysis was subject to sample size limitations, and further limited by potential under-reporting of long-term health conditions. It may therefore have underestimated the effect of some conditions. Furthermore, as the analysis only includes people who have died, additional research would be required to replicate the findings with larger, longitudinal datasets.

Moving forward

Research

- Further research is required regarding ethnicity and its relation to premature deaths. This may require using alternative datasets that will allow for taking account of the population structure.

- Improving data collection or utilising other sources of data to increase the breadth of data collected, for example prescriptions and other treatments, and long term conditions, should be explored.

Care and Services

- How can NHS and its partners best target interventions to improve the health of people from minority ethnic groups?

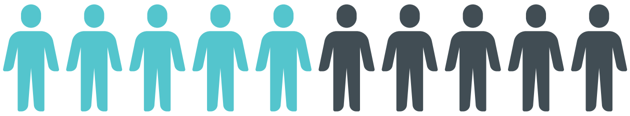
- How can the NHS improve the identification and management of LTC's that are associated with younger age at death (DVT, epilepsy)?

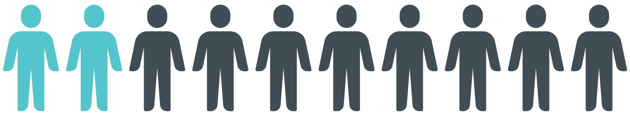
Chapter 5

Avoidable Mortality

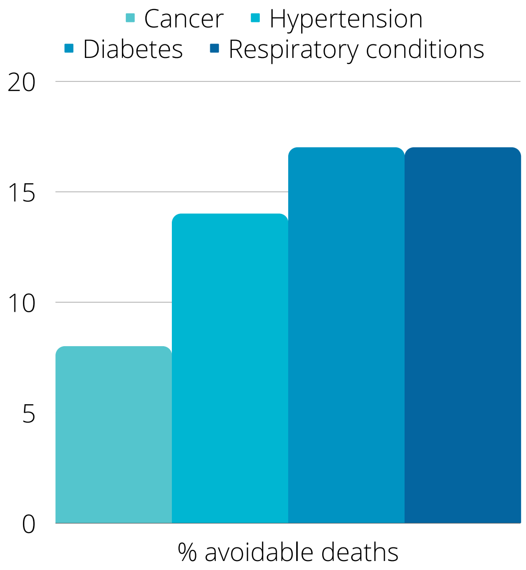
KEY TAKEAWAY OF AVOIDABLE MORTALITY

Geographical regional differences in avoidable deaths were noted, with the highest rates in the North West (54% of deaths) and the lowest in the South West (42% of deaths).

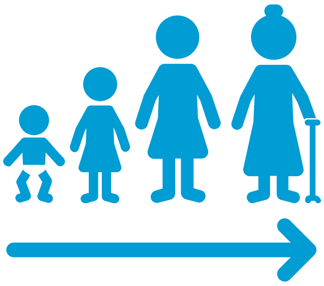




49% of deaths were rated as "avoidable" for people with a learning disability. This compares to 22% for the general population*.



8% of avoidable deaths were linked to cancer, 14% to hypertension, 17% to diabetes and 17% to respiratory conditions.



Deaths were more likely to be rated as avoidable with increasing age, peaking at the middle aged groups before decreasing for 65+.

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*ONS data for 2020.

Avoidable mortality

Background and rationale

In Chapter 4 we discussed deaths of people with a learning disability in relation to age. Here we explore the factors associated with avoidable deaths by investigating the effects of demographic, clinical, social and care variables on avoidable deaths for people who died in 2021. Avoidable deaths are defined by applying the Organisation for Economic Cooperation and Development (OECD)/ Eurostat list of preventable and treatable causes of death using the underlying cause of death recorded on death certificates, for people who died at younger than 75 years old. This definition is also used by the ONS[22].

For this, we have data on 2,392 people who died in 2021 who had a recorded underlying cause of death. 1,170 (49%) of these were classified as avoidable, which compares to 22% of deaths for the overall general population (in 2020, the latest data available from the ONS)[23].

Note for interpretation

It is important to note that approximately 42% of the sample had information on clinical variables as these were only recorded and inputted if they were applicable to the individual record so have, on occasion, resulted in small numbers. Data for these clinical variables were more likely to be recorded amongst those whose death was classified as avoidable compared to those whose death was classified as unavoidable.

The data presented in the tables and graphs in this chapter are the adjusted data, with a summary of the variables viewable in Appendix 5.1 and full detail of the analysis available in Appendix 5.2.

Avoidable mortality and demographics

Ethnicity

Based on adjusted analyses, only mixed ethnicity was associated with higher odds ratio (OR) for avoidable deaths (OR 2.55, 95% CI 1.45, 4.51). However, the numbers of deaths included in the analysis for some ethnic groups were very small, resulting in large confidence intervals. The results need to be interpreted with caution.

Table 5.1 (page 66) shows the odds for avoidable deaths by ethnicity.

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[22] www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/methodologies/avoidablemortalityinenglandandwalesqmi

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

Table 5.1: Avoidable deaths by ethnicity for deaths in 2021.

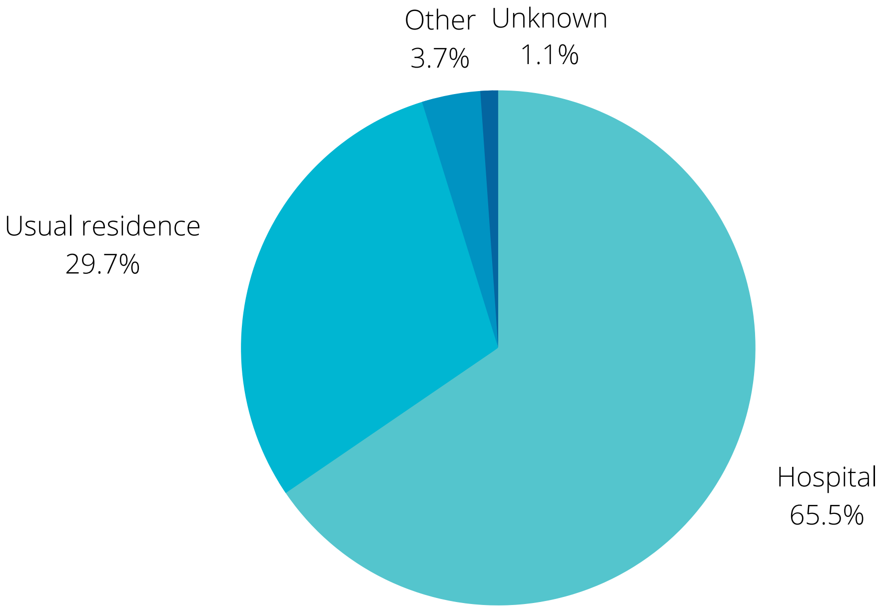
Ethnicity	**Unavoidable death (n % in relation to total)**	**Avoidable death (n. % in relation to total)**	**Totals of each identified ethnicity**	**Adjusted odds ratio***	**Confidence interval**
Asian or Asian British	20 (2%)	20 (2%)	40 (2%)	1.15	0.59, 2.23
Black, Black British, Caribbean or African	18 (2%)	27 (3%)	45 (2%)	1.66	0.86, 3.22
White	1020 (94%)	960 (90%)	1980 (92%)	1	-
Mixed ethnic group	22 (2%)	45 (4%)	67 (3%)	2.55	1.45, 4.51
Other	6 (1%)	11 (1%)	17 (1%)	2.51	0.84, 7.48

*Adjusted for sex, age, region and place of death.

Place of death

Of those whose cause of death was avoidable, 65.5% died in hospital and 29.7% died at their usual residence. For those whose cause of death was not avoidable, 58% died in hospital and 37% died at their usual residence. Place of death remained a significant predictor of avoidable deaths after accounting for other factors (see Appendix 5.2.1).

Figure 5.1: Place of death for avoidable deaths in 2021



Region

In unadjusted analyses, there was weak evidence that region was associated with avoidable deaths, with the Midlands and North West showing the biggest differences in avoidable compared to unavoidable death (53% of deaths were avoidable in the Midlands and the North West compared to 48% in London; see Table 5.2 page 67). When other factors were included in the model for the adjusted analyses, the regional effect remained similar, with the greatest odds of avoidable deaths being in the North West and Midlands.

Table 5.2: Avoidable deaths by region for deaths in 2021

Region	Unavoidable deaths (n, %)	Avoidable deaths (n, %)	Overall total (n, %)	Odds ratio (adjusted)*	Confidence interval
North West	148 (47%)	167 (53%)	315 (13%)	1.45	0.99, 2.13
Midlands	220 (47%)	251 (53%)	471 (20%)	1.47	1.03, 2.10
London	118 (52%)	109 (48%)	227 (9%)	1	-
South East	215 (52%)	199 (48%)	414 (17%)	1.22	0.85, 1.76
East of England	153 (52%)	144 (48%)	297 (12%)	1.35	0.92, 2.00
North East	214 (53%)	190 (47%)	404 (17%)	1.16	0.81, 1.68
South West	153 (58%)	110 (42%)	263 (11%)	0.95	0.63, 1.42

*adjusted for ethnicity, sex, age and place of death.

Sex and age group at death

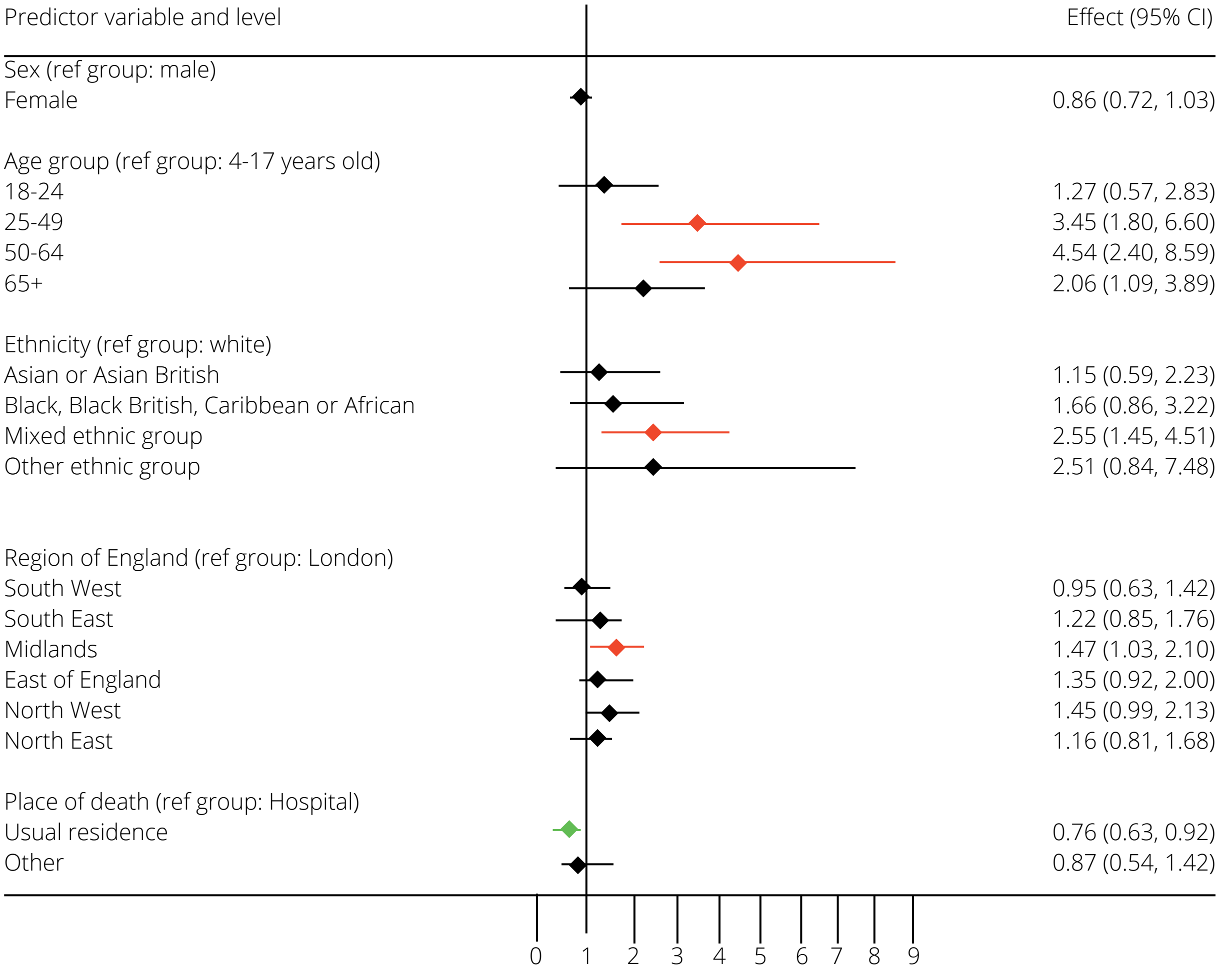
Although there were more avoidable deaths in men (58%) compared to women (41%), this result was not statistically significant when adjusted for other factors.

Deaths were more likely to be assessed as being avoidable with increasing age, which remained an important predictor after taking account of other factors in the adjusted analysis. The highest risk for avoidable deaths were seen in “middle aged” groups (age 25 – 64), compared to children and young people, with the odds ratios increasing by age group, before decreasing for those aged 65+. As shown in Table 5.3, the 50-64 age group were nearly five times as likely of having a death classified as avoidable.

Table 5.3: Avoidable and unavoidable deaths by age group at death in 2021

Age group	Unavoidable death (n, %)	Avoidable death (n, %)	Adjusted odds ratio	Confidence interval
4 - 17	59 (5%)	23, (2%)	1	-
18-24	48 (4%)	29 (2%)	1.27	0.57, 2.83
25 - 49	179 (15%)	218 (19%)	3.45	1.80, 6.60
50 - 64	343 (28%)	510 (44%)	4.54	2.40, 8.59
65+	590 (48%)	390 (33%)	2.06	1.09. 3.89

Figure 5.2: Forest plot showing overall adjusted odds ratios and confidence intervals for predictors of avoidable death.



Overall graphical presentation of adjusted odds of death

Above is a graphical presentation of the data in table 5.3 (page 67), using a forest plot. As discussed previously, age showed the highest odds for avoidable deaths. Sex and place of death show no significant difference, while the effect of ethnicity and region varied but overall, was not statistically significant (see Appendix 5.2.1).

Long-term health conditions

When looking at individual LTCs, 8% of avoidable deaths were related to cancer, 17% to diabetes, 14% to hypertension, and 17% to respiratory conditions, whilst for all other long term conditions deaths were more likely to be rated as unavoidable. In the analysis adjusted for other factors, the data suggests that people with cancer had higher odds to die from an avoidable cause, and although those with respiratory conditions during life also had increased odds for avoidable death, but this was somewhat diminished in adjusted analyses (Table 5.4, page 69).

Dementia and dysphagia were less likely to be associated with an avoidable death. All other conditions were not associated with significantly different odds for avoidable deaths when the analysis was adjusted for other factors.

Table 5.4: Avoidable mortality for each long-term health condition.

LTC	% of these deaths rated avoidable	Adjusted odds ratio*	Confidence interval	p-value
Cancer	8%	2.04	1.12, 3.71	0.02
Respiratory conditions	17%	1.43	0.97, 2.12	0.07
Hypertension	14%	1.38	0.90, 2.13	0.14
Diabetes	17%	1.01	068, 1.50	0.96
DVT	4%	1.05	0.51, 2.15	0.90
Mental health conditions	33%	1.11	0.83, 1.49	0.47
Cardiovascular conditions	31%	0.99	0.73, 1.33	0.94
Epilepsy	33%	1.06	0.79, 1.43	0.69
Sensory impairment	23%	0.96	0.70, 1.32	0.80
Kidney problems	16%	0.76	0.53, 1.09	0.14
Dementia	16%	0.55	0.39, 0.78	<0.01
Osteoporosis	4%	0.63	0.35, 1.12	0.12
Dysphagia	16%	0.49	0.35, 0.69	<0.001
Degenerative conditions	3%	0.57	0.28, 1.18	0.13

*adjusted for ethnicity, sex, age, region, place of death and LTCs

Social and care variables

For quality-of-care ratings (table 5.5), of the 397 who were rated as having avoidable causes of death, 42% had ratings of 5 (Good care (it met expected good practice)). This was similar to those who rated as having unavoidable causes of death. Ratings of 6 (excellent care) were relatively infrequent: 5% of those who were rated as having died from avoidable causes of death, and 5% of those with unavoidable causes of death. Likewise, ratings of 1 did occur, but were extremely infrequent, representing less than 1% of ratings.

Table 5.5: Avoidable mortality for quality of care ratings.

Quality of care rating	**Unavoidable cause of death (n (%))**	**Avoidable cause of death (n (%))**	**Total n and respective % of rating**
1	4 (1%)	1 (0%)	5 (1%)
2	18 (6%)	22 (6%)	40 (6%)
3	62 (22%)	73 (18%)	135 (20%)
4	66 (23%)	113 (28%)	179 (26
5	119 (42%	168 (42%)	287 (42%)
6	13 (5%)	20 (5%)	33 (5%)

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

Of those who died due to an avoidable cause of death, 82% were rated as having a care package that met their needs. This contrasts with 86% of those who had a death classified as unavoidable having a care package that met their needs. In essence, the vast majority of both avoidable and unavoidable deaths were rated as having suitable care packages for their needs.

None of the effects of social and care factors was statistically significant in adjusted analyses (see Appendices 5.2), including deprivation of liberty safeguard procedure application or approval.

Interpretation, suggestions for improvement and further research

As avoidable deaths are defined by underlying causes of death, a relationship with some long-term health conditions is expected. For instance, hypertension is an avoidable cause of death, and if it was mentioned as underlying cause of death in the death certificate and recorded as long-term concern, then there will likely be a relationship with avoidable death.

However, some long-term health conditions were not significantly associated with avoidable causes of death, such as epilepsy, kidney problems and diabetes, despite their inclusion in the classification of avoidable deaths. This suggests that to reduce avoidable deaths, efforts may need to be focused in specific areas.

These areas are:
1. Adults in mid-life, particularly the age group 50-64, and people from certain ethnic minority groups
2. Addressing regional disparities
3. Improving management of specific long-term and recurrent conditions, including hypertension, cancer and respiratory conditions.

However, in order to make more specific recommendations, further research should be conducted with additional analyses making use of the LeDeR dataset over time.

We note that due to the recent switch to a new format for collecting LeDeR data, there will be limited data on clinical factors such as long-term health conditions. This will limit the ability to track changes associated with management of these conditions in future analyses.

Consideration needs to be given as to how clinical data can be incorporated in future research using LeDeR data.

Moving forward

Research

- Identify methods to increase data collection of more marginalised groups, particularly in relation to ethnicity, so as to be able to draw more informed conclusions and comparisons with other groups.

- With the new system in place for data collection, there are more limited data on clinical factors such as long-term health conditions. Ways to improve clinical data collection in future datasets should be considered.

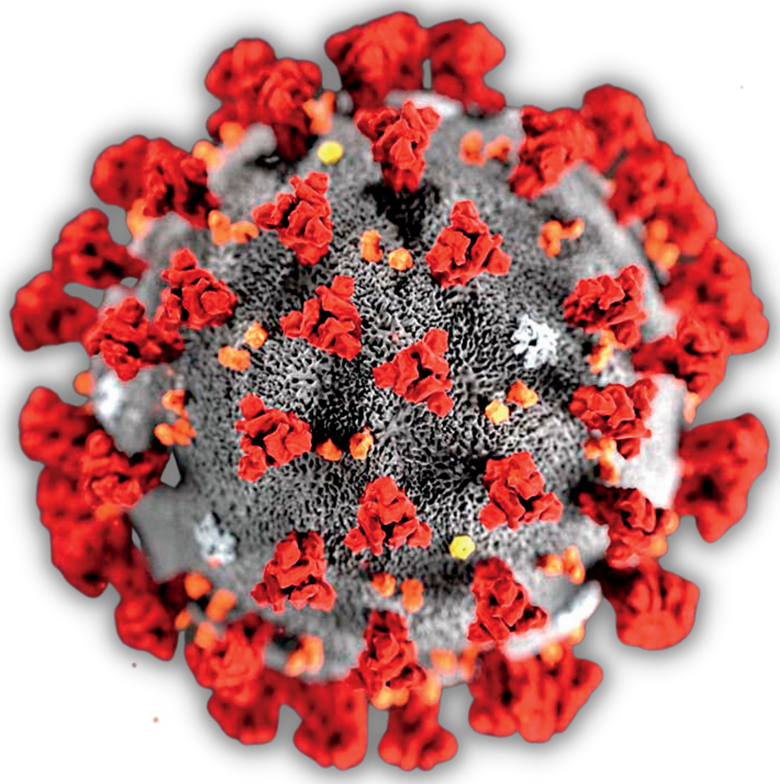
Care and Services

- Avoidable deaths appear to increase towards middle age, so earlier interventions may be necessary.

- How can prevention and care pathways of specific LTC's, such as cancer and respiratory conditions (and possibly hypertension) which are associated with higher risk of avoidable deaths, be improved?

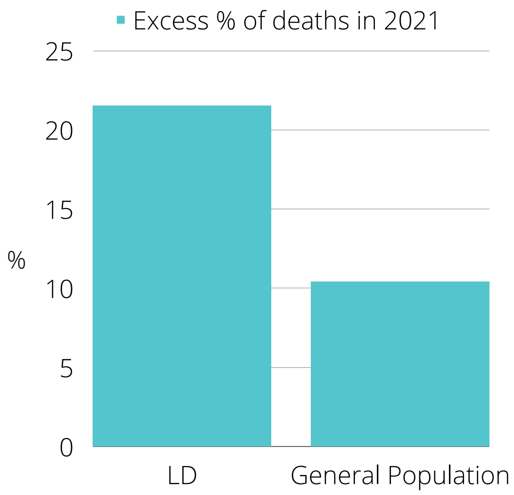
- How can local systems better understand the regional differences in avoidable mortality?

Chapter 6



COVID-19

KEY TAKEAWAY OF COVID-19



During 2021 the rate of excess deaths was more than two times higher for people with a learning disability compared to the general population.

COVID-19 was the leading cause of death for people with a learning disability in 2021.

9x

Those who were unvaccinated were 9 times more likely to die of COVID-19 than another cause compared to those who were vaccinated.

28% of those who were unvaccinated died from COVID-19 compared to 3.4% of those who were vaccinated.

As in the general population, there were no excess deaths for children with a learning disability in 2021. Deaths of children actually decreased by about 3% in comparison to 2018-2019.

COVID-19

In this chapter, we examine deaths due to COVID-19. The COVID-19 pandemic has been a feature of our lives for the past 2 years, therefore, for a complete picture of how this may have affected mortality in people with a learning disability, we have used data from the LeDeR dataset from 2018 to 2021. This allowed us to compare changes in the numbers of death notifications during 2020 and 2021 with the two years before the pandemic.

The LeDeR report from 2020 showed an increase in deaths due to COVID-19 during the first wave of the pandemic[24]. Since then, several reports confirmed that people with a learning disability have an increased risk for poor outcomes if they developed COVID-19, which is particularly high for those with Down syndrome[25]. There have also been evidence of inequalities in access to treatment such as respiratory support and admission to intensive care units for people with a learning disability who have been admitted to hospital with COVID-19[26].

Methodological considerations

Most of this chapter is based on deaths notified to LeDeR, unless otherwise stated; the methodology section in Appendix 6.1 has further details.

Where possible, we make comparisons with deaths in the general population as reported by the ONS in their most recent reports for 2020[27] and 2021[28]. Deaths reported to be due to COVID-19 within the notification dataset are restricted to those reported as “confirmed” cases. For the analyses where adjustments are made for long-term health conditions using reviewed deaths, we used data from death certificates and denoted the death being due to COVID-19 if the underlying cause was recorded as COVID-19.

Findings

As reported in Chapter 1, the largest increases in deaths were during March and April 2020. Deaths increased again during December 2020, and remained high during January and February 2021. Figure 6.1 (page 76) summarises the deaths reported by month during 2018 - 2021, with the addition of the proportion of deaths that were due to COVID-19. This shows that the number of deaths for people with a learning disability increased early during the initial stages of the pandemic, in keeping with what we now know about their increased vulnerability. It also shows that much of the increase in deaths during these “peak months” appear to be due to COVID-19.

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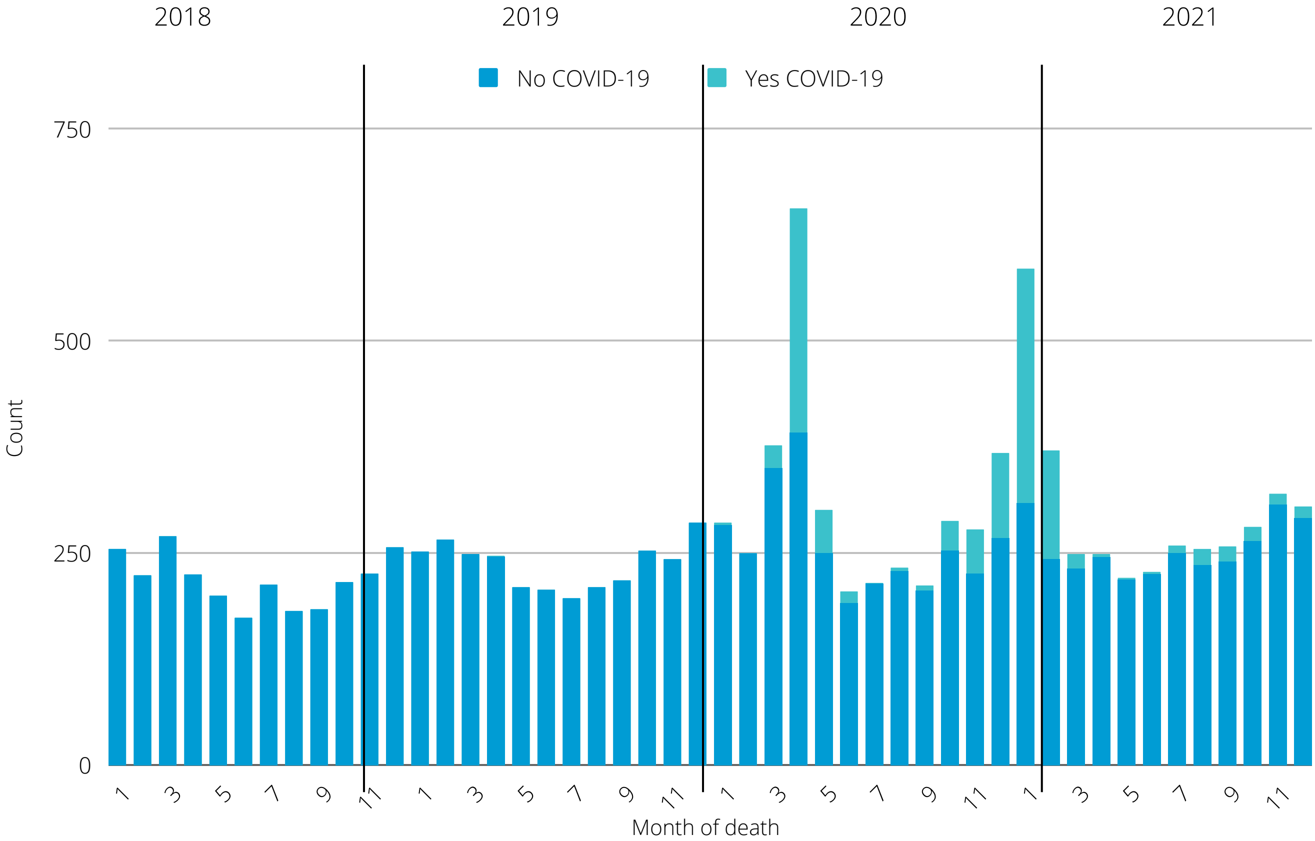
[24] https://www.england.nhs.uk/publication/university-of-bristol-leder-annual-report/
[25] https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00049-3/fulltext
[26] https://bmjopen.bmj.com/content/11/10/e052482.abstract
[27] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/excessdeathsinenglandandwales2020final
[28] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/excessdeathsinenglandandwales/march2020todecember2021

Figure 6.1: Number of deaths in 2018, 2019, 2020 and 2021 by month and by COVID-19 status.



Excess deaths (more deaths than we would expect)

We estimated an average number of expected deaths by month based on notification data collected by LeDeR for 2018 and 2019, and then calculated the percentage of deaths in excess of that during the pandemic for 2020 and 2021. This was based on similar methods reported by ONS[29] and therefore allowed for comparison with the general population - see Appendix 6.2 for further details, as well as for the potential limitations to the analysis.

The excess percentage of deaths for people with a learning disability by month compared to those from the general population are plotted in figure 6.2 (page 77). In total, during 2020 there was an excess of 34.3% (95% CI 32.5% - 36.2%) of deaths for people with a learning disability, while during 2021 it was 21.5% (95% CI 19.9% - 23.1%). This compared with 14.5% (95% CI 14.43% - 14.62%) and 10.4% (95% CI 10.35% - 10.52%) for the general population, respectively. During both 2020 and 2021, the proportion of excess deaths were more than double for people with a learning disability compared to the general population.

The data shows an excess of deaths for people with a learning disability early on during the pandemic, with approximately 45% more deaths in March 2020 compared to March 2018 and 2019, and 178.7% for April 2020. The comparable rates of excess deaths for the general population in England during these months were 3.6% for March 2020 and 101.6% for April 2020.

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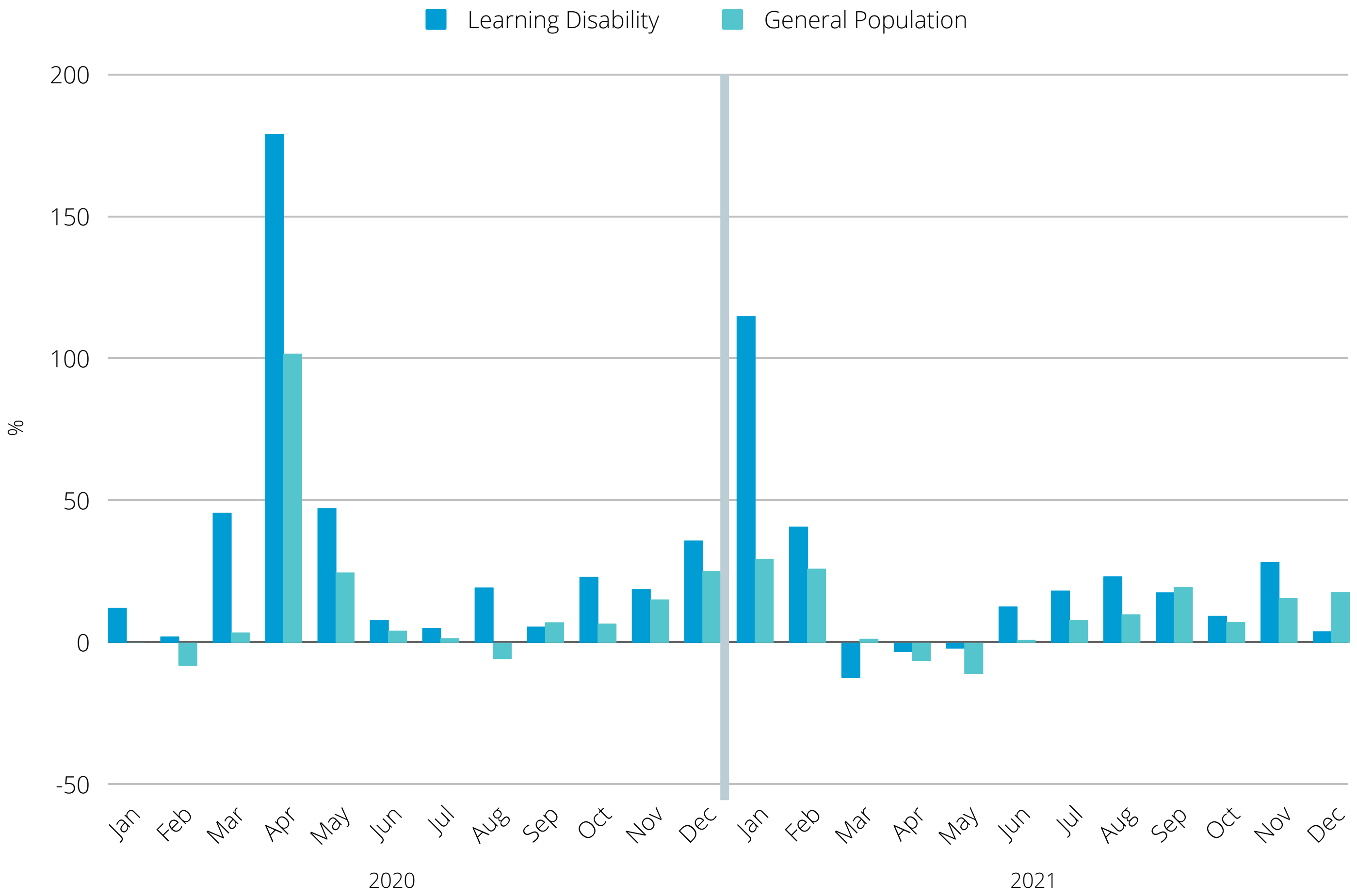
[29] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/excessdeathsinenglandandwales/march2020todecember2021

Figure 6.2: % of excess deaths for people with a learning disability by month compared to the general population (2020 – 2021)



Excess deaths by sex

There was an excess of 34.6% (95% CI 32.3% - 37.0%) of deaths during 2020 for males with a learning disability, compared to 33.9% (95% CI 31.2% - 36.7%) for females. The equivalent figures for 2021 were 18.9% (95% CI 17.03% - 20.98%) and 24.9% (95% CI 22.41% - 27.46%) respectively. This compared to an excess deaths rate of 17.7% for males and 10.8% for females in the general population in England, based on ONS data from March 2020 to December 2021. Deaths for people with a learning disability during 2020 and 2021 did not show the same excess for deaths of males compared to females as in the general population, with the excess death rate being fairly similar in people with a learning disability regardless of sex.

Excess deaths by ethnicity

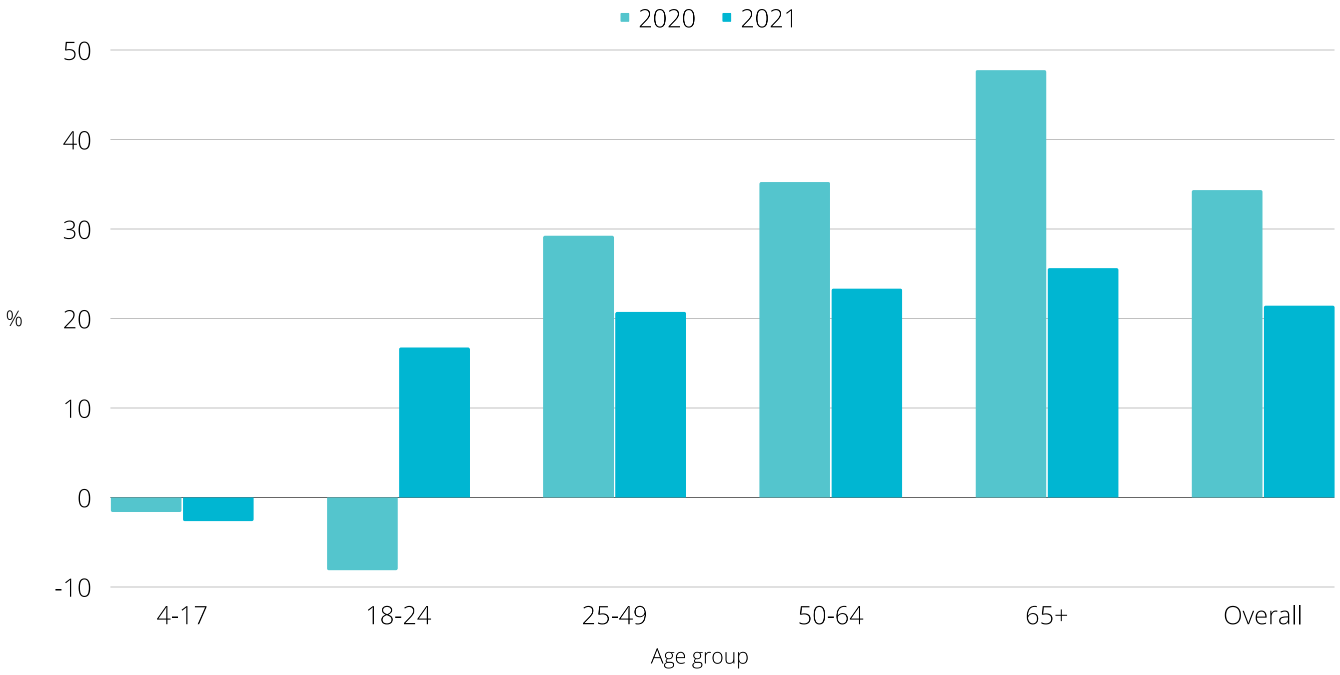
Deaths for people with a learning disability from minority ethnic groups varied too much (likely due to low numbers) between 2018 and 2019 to reliably calculate an expected death rate. For example, between 2018 and 2019, deaths for people with mixed ethnicity notified to the LeDeR programme increased by 37.5% in 2019, while deaths for people with Asian or Asian British ethnicity decreased by the same percentage over the same period. We therefore combined all the minority ethnic groups and compared them to the white population with regards to excess deaths during 2020 and 2021.

This showed that during 2020, there were 31.3% of (95% CI 29.4% – 33.2%) excess deaths in people with a learning disability of white ethnicity, while those from minority ethnic groups had a considerably higher excess death rate of 58.2% (95% CI 51.4% – 64.6%). For 2021, the difference in excess death rates were smaller – 17.5% (95% CI 15.63% – 19.06%) for deaths of people with a learning disability of white ethnicity, compared to 20.7% (95% CI 15.63% – 26.56%) for those from minority ethnic groups.

Excess deaths by age group

Deaths for children with a learning disability (aged 4 – 17) did not show an excess during 2020 (approximately 2% fewer than for 2018-2019) or 2021 (3% less than 2018-2019) (figure 6.3). In comparison, ONS reported a reduction in the number of expected deaths for children from the general population during this period that varied from -20% for females aged 4 – 9 years of age, to -0.7% for males aged 15-19[30]. For young adults with a learning disability aged 18-24, there was a small reduction in deaths during 2020 (approximately -8.6%) compared to 2018-2019, but during 2021 there was an excess death rate of 16.7% in this age group. As in the general population, the highest rates of excess deaths were for older adults aged 65 and older – during 2020, the excess death rate in this group was 47.7% compared to 2018-2019, and reduced to 25.6% during 2021. Overall, the excess death rate for adults with a learning disability aged 18 and older was 37.4% (95% CI 35.5% - 39.3%) for 2020 and 23.5% (95% CI 21.85% - 28.20%) for 2021, compared to 2018/2019.

Figure 6.3 Excess deaths by age group and year (deaths occurring in 2020 and 2021).



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[30] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/excessdeathsinenglandandwales/march2020todecember2021

Excess deaths by region

There was considerable variation in excess deaths by region, and by year (2020 compared to 2021), as plotted in figure 6.4. During 2020, the highest excess death rates compared to 2018/2019 were for London (50.7%), and the South West of England (44.1%), while the lowest rate was in the South East of England (23.6%). However, during 2021, London region had the lowest excess death rate (6.5%), while the highest death rate was recorded in the East of England (35.2%). This may reflect both the spread of the virus through different regions at different times, and factors such as demographic structure and vaccination roll-out.

Figure. 6.4: % of excess deaths by region and year (deaths occurring in 2020 and 2021).

Predictors of having COVID-19 as cause of death recorded on death certificates

In order to determine the factors that were associated with dying due to COVID-19 as recorded on death certificates, we used data from initial reviews during 2021 that had been linked with death certificates.

We firstly conducted unadjusted analyses, which identified statistically significant relationships with COVID-19 as underlying cause of death for place of death, season, region, age, and ethnicity. Most long-term health conditions except for cardiovascular conditions were not strongly associated with COVID-19 deaths (table A6.1, appendix).

We then conducted a regression analysis, with COVID-19 as underlying cause of death compared to other causes of death combined (see appendix 6.2 for methods and for regression table). We included the following factors - age, sex, region, place of death (hospital, usual residence, other), ethnicity, season of death, as well as long-term health conditions (Cancer, cardiovascular conditions, degenerative conditions, dementia, diabetes, DVT, epilepsy, hypertension, kidney problems, mental health conditions, osteoporosis, respiratory conditions, sensory impairment and dysphagia).

The regression analysis showed that if all factors are considered, region was marginally (p=0.06) associated with COVID-19 deaths, with people who died in the East of England being more likely to have died with COVID-19 as underlying cause of death (OR 2.99; 95% CI 1.19 - 7.51).

Older age also remained a significant predictor, as did place of death (those in hospital were more likely to die of COVID-19 than those who died at home), and season (more deaths with COVID-19 in winter).

Ethnicity was not associated with having COVID-19 as underlying cause of death in the adjusted analysis, suggesting that the other factors explained the unadjusted association between ethnicity and having COVID-19 as cause of death. Of all the long-term health conditions, those with cancer and cardiovascular conditions were less likely to have COVID-19 recorded as underlying cause of death, while those with dementia were more likely to have COVID-19 recorded as cause of death.

Impact of COVID-19 vaccination on deaths of people with a learning disability

There were limited data on vaccination status – of all of the deaths during 2021, only 304 (11.1%) had data on vaccination status. Restricting the analyses to these cases, Figure 6.5 shows the proportion that have been vaccinated increased from January 2021 to December 2021 in keeping with the vaccine roll-out during 2021. By May 2021, the majority for which vaccination data was available, had been reported to have been fully vaccinated (i.e. had had two vaccinations). Overall, 154 (50.7%) of the deaths of people with a learning disability who had vaccination status recorded were unvaccinated, and 150 (49.3%) were fully vaccinated.

To examine whether the deaths of people who were unvaccinated were more likely to be due to COVID-19, we compared the underlying causes of death recorded in the death certificates by vaccination status (Table 6.1, page 82).

This showed that of those who were unvaccinated, 28% died of COVID-19, while only 3.5% of deaths of people who were vaccinated were due to COVID-19. The odds ratio of the death being due to COVID if unvaccinated compared to being vaccinated was 8.12 (95% CI 3.31 – 19.94); in other words, people who were unvaccinated were more than 8 times more likely to die of COVID-19 rather than another cause, compared to people who were vaccinated.

Figure 6.5: Number of deaths occurring in 2021 by month and by COVID-19 vaccination status.

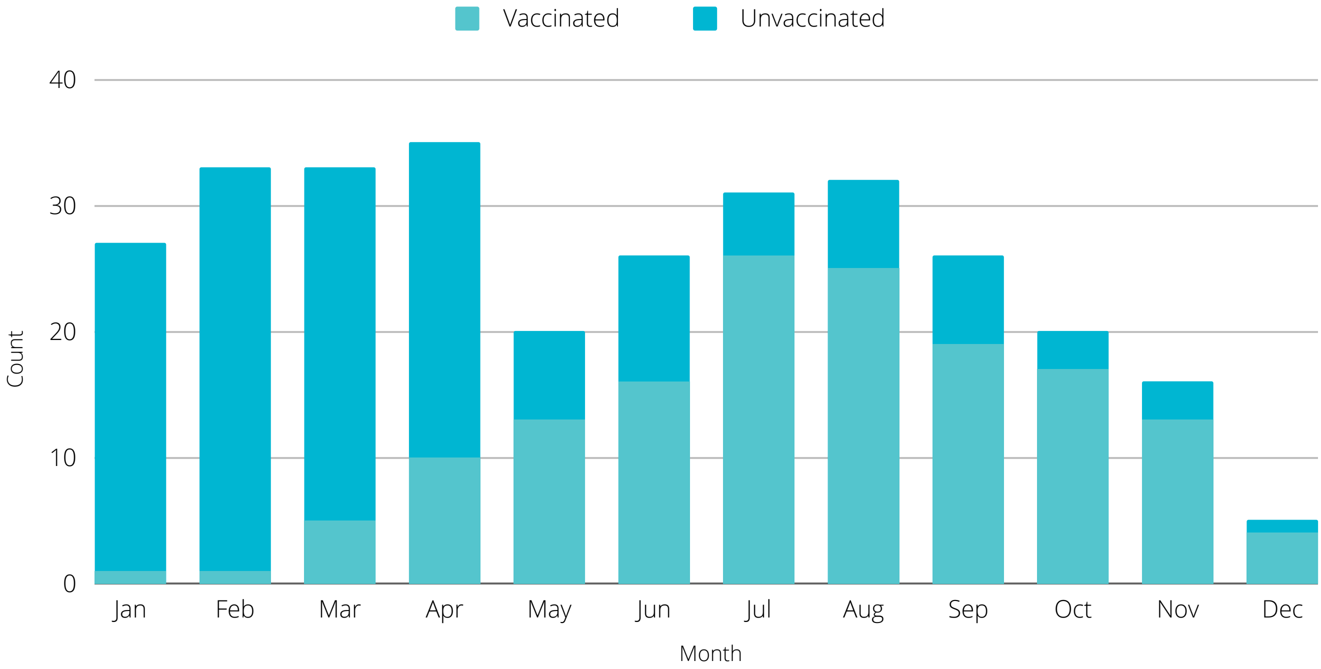


Table 6.1 COVID-19 vaccination status by COVID-19 deaths as recorded on death certificate.

Underlying cause of death as recorded in death certifcate	Count and Percentage	Unvaccinated	Fully Vaccinated	Total
COVID-19	Count	42	5	47
	%	28.2%	3.5%	16.04%
Other Causes	Count	107	139	246
	%	71.8%	96.5%	83.95%
Total	Count	149	144	293
	%	100.00%	100.00%	100.00%

Summary and implications

There has been an excess of deaths for people with a learning disability in 2020 and 2021 of 34.3% and 21.5%, which was higher than for the general population (14.5% and 10.4% respectively). There are some indications that the excess deaths increased earlier than in the general population and was particularly high during the first wave of the pandemic in the spring of 2020. Most of the increase in deaths during 2020 and 2021 seemed to be related to COVID-19 diagnoses. This has important implications for safeguarding people with learning disability during future pandemics and new waves of COVID-19 infection.

As in the general population, there was no excess deaths for children with learning disability based on LeDeR data, and the highest rates of excess deaths was for older adults. Although similar to the trends in the general population, data on children with a learning disability may need to be viewed as preliminary due to the delays in completion of the review process, as mentioned previously.

During 2021, as the COVID-19 pandemic progressed through different regions and groups, there was also an excess of deaths of younger adults with a learning disability. There were some regional differences in excess deaths during different stages of the pandemic, but ultimately all regions were affected.

During 2020, people from ethnic minority groups showed higher rates of excess deaths, but this reduced during 2021. Ethnicity was not associated with being more likely to have COVID-19 as underlying cause of death when we took account of other factors, including long-term health conditions.

Although we had limited data on vaccination status, we found that being unvaccinated was strongly associated with deaths due to COVID-19 during 2021. This has implications for the ongoing prioritisation of vaccination of people with a learning disability, including younger adults.

Moving Forward

Research

- Further research is required to explore the extent to which conditions other than COVID-19 contribute to excess deaths as more data become available.
- Urgent work is required to better understand why some people with a learning disability remain unvaccinated despite being a high risk group for COVID-19 to identify the barriers preventing people from being vaccinated, as well as to identify solutions.

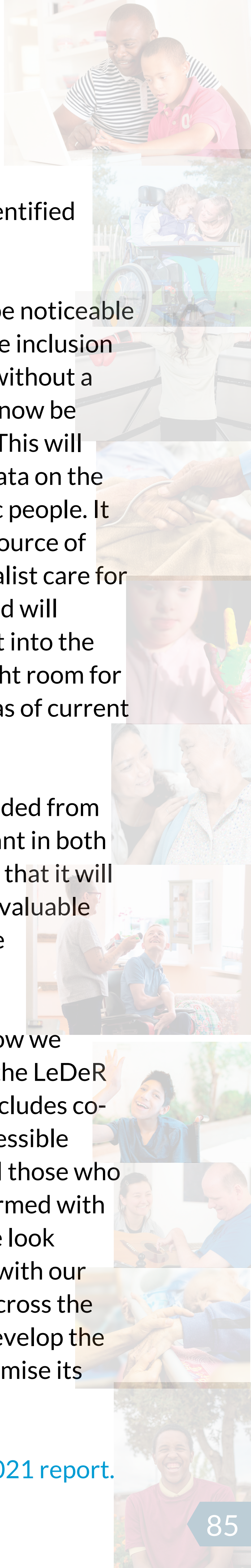
Care and services

- People with a learning disability should be protected against future pandemics and further waves of COVID-19 e.g. by enabling rapid implementation of methods to reduce transmission.
- Our findings suggest people with a learning disability should continue to be prioritised for vaccinations and booster vaccinations, including young adults.
- What mechanisms can be implemented to improve uptake of vaccinations for people with a learning disability?
- How can excess deaths for vulnerable groups be monitored closely during pandemics so that prompt action can be taken if it remains high or increases?
- Future reports will aim to see how the pandemic has impacted autistic people.

Chapter 7

Looking Forward

Looking Forward



2021 was a year of transitions and change in the LeDeR programme, with the introduction midway of a new reporting interface and review template and a new major academic partnership led by KCL. Alongside this has been the continuing COVID-19 pandemic, the full impact of which is gradually becoming apparent and which will continue to be explored in future reports. In recognition of the importance of the LeDeR programme to date, NHSE has renewed its investment and commitment to the programme. The LeDeR programme continues to grow in scope, including the addition of reviews of deaths of autistic adults, and new elements to ensure that learning is translated to practical improvements in the lives and care of people with a learning disability.

In future years we seek to enhance on these reports further, engaging with stakeholders and looking into more areas of particular interest to people with a learning disability. As the LeDeR dataset grows, so will the opportunities for longitudinal analysis across years and the capacity for further statistical analysis. This will allow us to chronicle change over time, understand where initiatives have been effective, and target areas where more needs to be done. There will also be more exploration of regional trends and patterns to work with local providers, commissioners and quality improvement specialists to implement tailored local solutions to identified issues.

One major change that will be noticeable in the immediate future is the inclusion of deaths of autistic adults (without a learning disability), who will now be eligible for a LeDeR review. This will provide specially focussed data on the mortality and care of autistic people. It will also act as a significant source of information regarding specialist care for autistic people in England and will provide much needed insight into the current situation and highlight room for improvement, as well as areas of current success.

We anticipate the data provided from this expansion to be significant in both number and detail, and hope that it will serve as a much needed and valuable source of information for the community.

Finally, we are developing how we communicate the results of the LeDeR data in these reports. This includes co-producing documents in accessible formats and ensuring that all those who are interested can keep informed with the latest developments. We look forward to continuing work with our partners and stakeholders across the community to continue to develop the LeDeR programme and maximise its benefit in years to come.

Thank you for reading the 2021 report.

End