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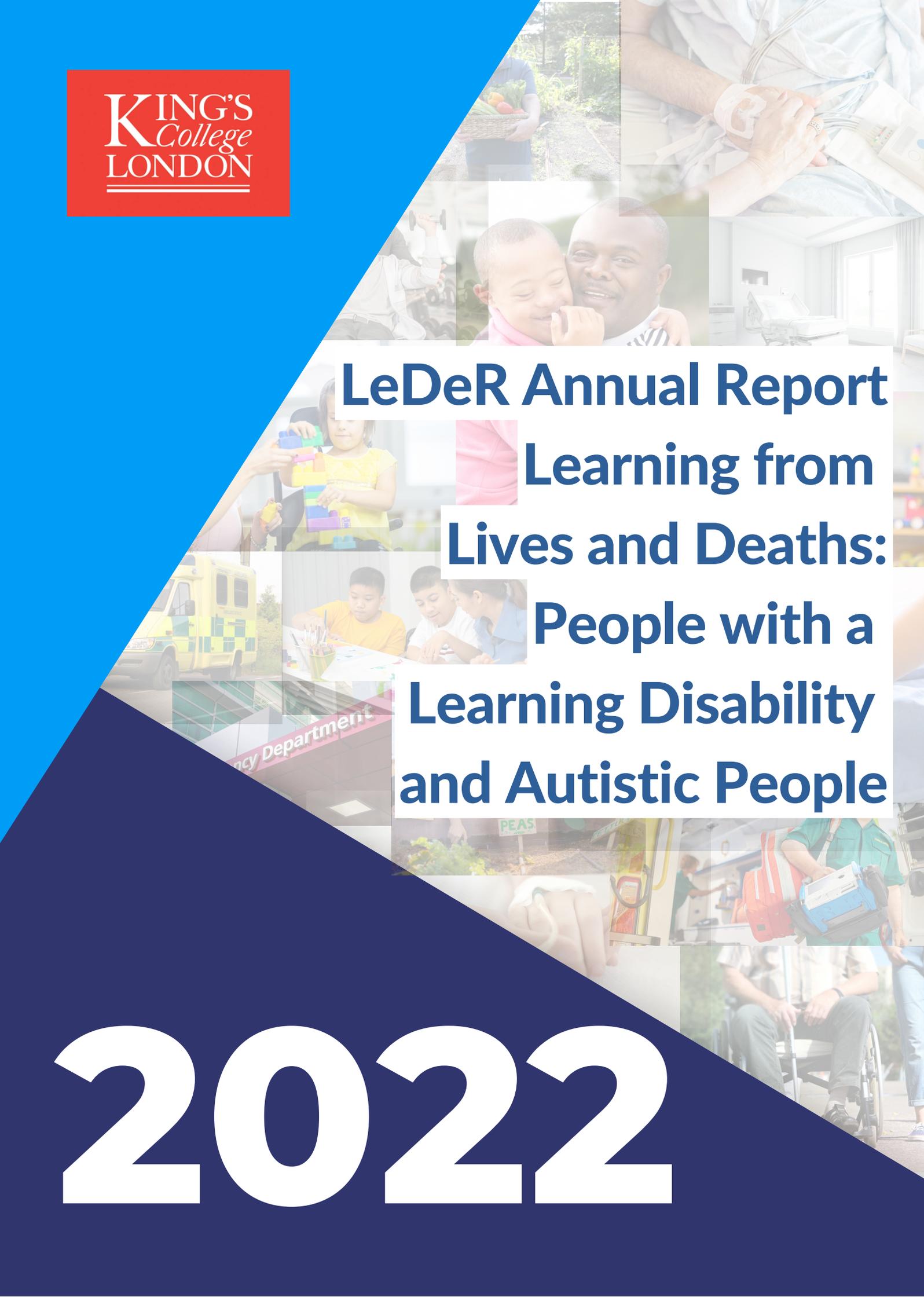
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**KING'S**  
*College*  
**LONDON**



**LeDeR Annual Report**  
**Learning from**  
**Lives and Deaths:**  
**People with a**  
**Learning Disability**  
**and Autistic People**

**2022**

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# LeDeR

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



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

16 De Crespigny Park  
London  
SE5 8AF  
United Kingdom

Website: [www.kcl.ac.uk/research/leder](http://www.kcl.ac.uk/research/leder)

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Learning from Lives and Deaths -  
People with a learning disability and autistic people (LeDeR) report for 2022.  
LeDeR Autism and learning disability partnership,  
King's College London





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 Tonbridge 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 and autistic people, 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 indeed 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 died. 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 the work of Professor Pauline Heslop at the University of Bristol who, alongside her team, had a role in establishing the LeDeR review programme in 2015-2020. We also wish to acknowledge the team at South Central and West Commissioning Support Unit (SCW) that had responsibility for processing and managing the data, without whom this process would not have been possible. We would like to thank 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 also wish to thank our colleague Michal Rosiek at King's College London (KCL) for their technical support with the data extraction and storage.

We are also grateful for the input from our stakeholders (NHS and other organisations), and our advisory board members: John Shaw, Carol Boys, Yvonne Newbold, Sam Potterson, Julian Hallett, and Rhidian Hughes, and chaired by Professor Yona Lunsky of the University of Toronto in Canada.

Please be aware that this report discusses deaths by suicide and may be upsetting and distressing. If you or someone you know is affected by the content of this report, please call Samaritans for free on 116 123 (UK and ROI), email them at [jo@samaritans.org](mailto:jo@samaritans.org), or visit [samaritans.org](https://www.samaritans.org) to find your nearest branch. Other sources of support are listed on the [NHS's help for suicidal thoughts webpage](#). Support is available round the clock, every single day of the year, providing a safe place for anyone struggling to cope, whoever they are, however they feel, whatever life has done to them.

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# Glossary of Abbreviations

CDOP	Child Death Overview Panels.
CI	Confidence interval.
DNAPCR	Do Not Attempt Cardio-Pulmonary Resuscitation.
DoLS	Deprivation of Liberty Safeguards.
DVT	Deep Vein Thrombosis.
GP	General Practitioner.
HR	Hazard ratio.
ICD-10	International Classification of Diseases version 10.
ICS	Integrated Care System.
IMD	Index of Multiple Deprivation.
IQR	Inter-quartile range.
LTC	Long-term condition.
KCL	King's College London.
KStGU	Kingston University and St George's University of London.
LeDeR	Learning from lives and deaths - people with a learning disability and autistic people.
LGBTQIA+	Lesbian, Gay, Bisexual, Transgender, Queer (or questioning), Intersex, Asexual, and more.
MCA	Mental Capacity Act.
MCCD	Medical Certificate of Cause of Death.
MHA	Mental Health Act.
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.

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## Updates to the report

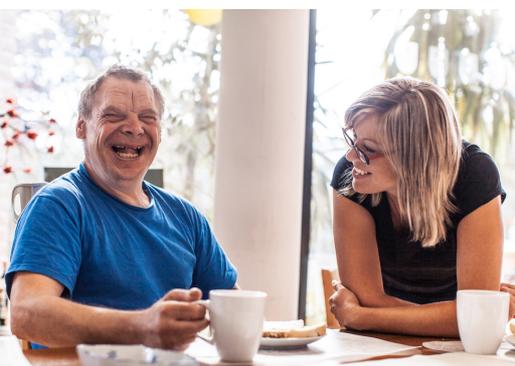
Based on feedback from our stakeholder partners, and from discussions with readers, we have made some changes to the format of the annual report.

Some of these changes include:

- The inclusion of available data of autistic adults without a learning disability.
- The removal of the chapter specifically devoted to COVID-19 deaths. COVID-19 is reported in the analyses where appropriate, throughout the report. Chapter 6 includes a section about COVID-19.
- More input from people with lived experience through a new foreword, videos about the report and direct quotes.
- A greater 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:

- Greater use of video to explain both the LeDeR process, and the foreword of the 2022 report.
- Shorter summaries of only the most important information.
- Dividing the accessible report into smaller, easier to understand sections.



# LeDeR Report 2022



## Introduction and Foreword

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## The Staying Alive and Well Group

Working with people with a learning disability is a central part of LeDeR. 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



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

This year the Staying Alive and Well group produced [6 accessible videos](#) which include further detail from last year’s annual report. The group also made an accessible [video to explain the LeDeR process](#) and shared it with around 200 people who attended an online premier.

The contributions of people with a learning disability are fundamental to our work on the LeDeR project, and, without their contribution, this report would not be possible.

# Foreword from the Staying Alive and Well Group

## Can you spot the difference? We Can't.

Here is the 2022 report. We have decided to call it the "**SPOT THE DIFFERENCE**" report. Why?

We are members of the Staying Alive and Well group. We are a group of people with a learning disability or autism who help with the LeDeR project. We talked with other people with a learning disability when we were writing this introduction. Our job was to make the information in this report easy to understand. [Here is a video we made to explain LeDeR.](#)

For this report, we looked at what happened to 3,648 people with a learning disability who died.

Looking at the numbers for this report was very upsetting for lots of reasons. It was upsetting because each death makes us think of friends and family we have lost. People who were part of our community. People who should be with us now. Seeing the numbers makes us worry because it could be us next. It could be our parents and friends who are grieving. We don't want the Staying Alive and Well group to be sat here in a few years saying 'Well, this is Richard that we are talking about now'.

"It makes me angry knowing I will have to **suffer**, even if it is not necessary, **because someone is not thinking clearly about me.**"

Tim Sally, 42

We are calling this report the "**SPOT THE DIFFERENCE REPORT**" because we are saying the same things year after year after year. We might spot a few differences, but it is not enough. Too many people with a learning disability are dying before their time. Too many people with a learning disability are not getting good care.

When we made last year's report, we had lots of ideas about how things could be made better. You can find much of what we said on page 7.

We have heard about some of the good projects the NHS is doing, and we are happy about that. But it is hard for us to see the changes when we go into hospital. And when we look at the numbers in this report they still sound far too big to us.

So, we sometimes feel like we are banging our heads against a brick wall, like nothing has changed. **Everyone** should be treated equally. Everyone has the right to live and be cared for. People with a learning disability can live well with the right support, but our lives are not valued enough.

"It is sad when someone **does not value my life as important.**"

Sarah Gordy, 46

We do not want to have to repeat ourselves anymore. We have good professionals out there who are doing their best for us. They are fighting our corner but are under a lot of pressure. We need more money in the pot for people with a learning disability.

We need more learning disability training and staff who are learning disability experts. We want the deaths of all people with a learning disability to be reported to LeDeR. This report is upsetting because we know that there are lots more people out there who have died, who we haven't heard about. If we don't hear about them, we can't learn from our mistakes. At the moment, we feel heartbroken because we don't seem to learn from our mistakes. We would like you to try and spot the differences in this report, because we want you to understand how we feel.

"I am talked **about** and not **with**. It feels like you really do not have time for any of this. I am not taken seriously; **it feels like I am a burden.**"

Sonia Reed, 49

If we can get healthcare right for people with a learning disability, we can get it right for everyone. We think things can and will change if more people listen to us and take action.

### Last year our team's ideas were to:

Monitor the health of people with a learning disability more closely by:

- Making sure more people with a learning disability (including people under the age of 50) get full annual health checks, and make it easy for them to get them.
- Sending people for tests and treatments in good time.
- Giving extra attention to people who have diabetes, lung problems, high blood pressure, cancer, epilepsy, and deep vein thrombosis.
- Checking for bowel cancer earlier.

Increase learning disability expertise by:

- Employing more learning disability liaison nurses.
- Training carers so that they know and can recognise when someone's health gets worse so they know what to do about it.
- Training healthcare professionals so they know how to get DNACPR right for people with a learning disability.

Make our services more inclusive by:

- Listening to people with a learning disability, their families, and carers, whilst being sure to take their worries seriously.
- Making sure that people with a learning disability can go for screening by sending invites, making the invites accessible, and making the screening easier to cope with.

Prioritise people with a learning disability during health crises/pandemics by:

- Putting people with a learning disability at the top of the list for vaccinations and boosters. That's all people with a learning disability - including young people, and people with a mild learning disability.
- Counting the people with a learning disability who die in a pandemic. Then quickly publishing the numbers.

Find out more about the health of different groups of people with a learning disability by:

- Finding out more about why some people die younger.
- Finding out more about the people who die too early so we can decide what we need to do about it.
- Making sure that people from ethnic minority backgrounds get extra attention for their health.



Signed: Richard Keagan-Bull, Amanda Cresswell, Andrew Meyer, Lee Scott, Frankie Cutri, Wayne McGregor, Caroline Ogundeji, Maggie Brennan, Sunny Sokhal, Joanne Kennedy, Sonia Reed.

**Members of the Staying Alive and Well Group, 2023**

# Looking Forward

Building on previous reports, LeDeR continues to grow in scope and ambition. The inclusion of data for autistic people during 2022 as a separate group for the first time was a step towards improving information and data collection on the causes of death for autistic people in England. The inclusion of autistic people highlights the commitment of NHS England to strengthening knowledge of the lives and deaths of autistic people to promote increased understanding and allow for better tailoring of resources to improve care. We acknowledge that this is a gradual and continual process, and although the number of deaths of autistic people reported to LeDeR has been relatively small, the information gathered should increasingly impact as awareness and reporting improves in future years. Our preliminary data suggests that suicide and the management of underlying mental health concerns of autistic adults is an important issue to examine in greater detail in future reports, when more data is available.

This year's report identified several encouraging improvements, despite the effects of the COVID-19 pandemic. We have received a higher number of notifications and focused reviews of deaths of people with a learning disability than ever before, suggesting increasing engagement with LeDeR. Far fewer people died of COVID-19 during 2022 compared to 2021 and 2020, although rates are still somewhat higher than in the general population. There are also indications that the age at death is improving for people with a learning disability. Between 2018 and 2022 we see a consistent year-on-year increase in length of life, so that over the past 5 years it has increased by approximately 2.5 years. For the first time, we demonstrate that care packages that meet a person's needs and appropriate use of Deprivation of Liberty safeguards to deliver care are associated with a reduced risk of a premature death. Other improvements include higher rates of referrals to coroners, and slightly improved rates of DNACPR documentation that was correctly followed. Furthermore, with regards to causes of death, although there has been an uptick in people dying of influenza and pneumonia in 2022, rates remained lower than before the COVID-19 pandemic, suggesting improved management and prevention of this avoidable cause of death. With regards to quality of care, reviewers identified fewer concerns about the care of people with a learning disability that died during 2022 than in 2021. These improvements have been driven by NHS England's response to previous findings from the LeDeR report, including ongoing support for annual health checks in primary care, updated guidance from the National Medical Director of NHS England regarding the [DNACPR process](#), and a commitment for more learning disability nurse positions in the [NHS Workforce plan](#). The COVID vaccination program has been successfully rolled out to people with a learning disability whilst making the reasonable adjustments required, and caregivers are being trained on the "[skills for care](#)" platform to better recognise early signs of deterioration. Health inequalities for people with a learning disability from minority ethnic groups have been given the attention it deserves through a new commissioned report by the [NHS Race and Health Observatory](#); it is hoped that this will lead to better access to care.

Despite these improvements, we echo the thoughts of our Staying Alive and Well coproduction team that speaks for people with a learning disability. Like them, we believe that things may not be improving fast enough, and overall care and outcomes all too often still fall below acceptable standards compared to the general population. This is true even with the good and hard work performed by care professionals throughout England, and by improved NHS policy changes. Although there has been a reduction in the proportion of deaths due to avoidable causes, to 42% in 2022 compared to 49% in 2021, this remains much higher than in the general population, and further efforts are required to reduce this. There are other areas where care could be improved. The data for 2022 showed an increase in the proportion of deaths due to conditions of the circulatory system, including ischaemic heart disease. More than 1 in 4 of avoidable deaths were linked to cardiovascular conditions. This suggests a need to improve care pathways to improve the prevention and management of circulatory conditions. We also show a concerning effect on excess deaths of people with a learning disability during heatwaves, which may become more frequent in the future due to global warming. Guidance and adaptations may need to be considered to protect vulnerable individuals during extreme weather.

As awareness of the programme increases, so too should the availability and quality of the data. Whilst notifications of deaths are not mandatory, it has been included in the standard NHS contract from this year. We therefore anticipate more notifications going forward, which will allow us to continue to monitor changes over time and understand the impact of service improvements and highlight areas of concern. These trends can be explored both on a national and regional level, and our related “deep dives”, which investigate selected specific areas relevant to people with a learning disability and autistic people, will hopefully continue to further identify areas for more focused resource targeting and increased awareness. Our recent reports, looking at deaths from constipation, diabetes, pneumonia, and the mental health admissions and use of restraint and restriction for young people, are due to be followed up with further works into other areas identified as priorities for future policy planning. These will be available on our [website](#), and as published works in relevant academic journals. We also hope to continue to increase our communication about these reports, their findings, and the important work of LeDeR in easy read formats, including more videos which will be available alongside this report, with more input from people with lived experience.

As the members of the Staying Alive and Well coproduction team highlighted, we acknowledge there is still more work to be done. We will continue to work with our stakeholders, with people with lived experience, with families, professionals, and interest groups across the country to further strengthen our analyses and interpretation of findings and better serve the needs of people with a learning disability and autistic people across the community. The data this year highlights improvements that have been made, and the good and hard work of carers, clinicians, and through improved policy, but more work still needs to be done. We sincerely hope this report will help to make a difference and improve the health care and outcomes of people with a learning disability and autistic people.

**Thank you for reading the 2022 LeDeR report.**

# The LeDeR process for 2022

## The LeDeR Process Summarised

### Scope of LeDeR

For deaths occurring in 2022, those of people aged 4 and above with a learning disability, and autistic adults aged 18 years and above were in scope of LeDeR. This is what we call an 'eligible death'. It is a requirement within the NHS standard contract for eligible deaths to be reported to LeDeR. There will however be a proportion of deaths of people with a learning disability and autistic people that are not known to services and are therefore not notified; LeDeR is therefore unlikely to receive a complete record of all eligible deaths in England.

Following a notification of a death to LeDeR via the [website](#), the first step is to check that the notification is within the scope of the LeDeR process (the person was aged 18 or over, lived in England and was registered with a general practitioner (GP) practice in England, had a learning disability or had a clinical diagnosis of autism, and had not opted out under the [national data opt-out](#)). Following confirmation that the death is within the scope of LeDeR, a trained LeDeR reviewer will then gather details about the person's life and death from several sources, such as their medical records, the professionals involved in their care, and by speaking with carers, family members, and loved ones. They will then start the initial review process. The target for the review to be completed is within 6 months of starting the review, but there are situations which are more complex, such as those that require a coroner's report, which may be paused while statutory reviews are completed. The LeDeR review process looks at many aspects of the person's life and death, such as their cause of death and where they lived, to create a detailed story about who the person was and why they died.

For some reviews, the initial review will lead to a more comprehensive "focused" review, which looks even more closely at the person's life and circumstances of death. These focused reviews, once completed, are then sent to local governance groups and detail areas of good practice, areas of concern, and wider areas of learning that can be taken from the person's life and death. Certain groups, such as autistic people, people who had been under mental health or criminal justice restrictions at the time of death or in the 5 years before death, and people from ethnic minority backgrounds, will always receive a focused review. The process is outlined in detail on the website <https://leder.nhs.uk/about>.

Scan to find out  
more about  
LeDeR



## A note on the reviews of child deaths for 2022

The deaths of all children aged 0-17 (inclusive), including children with a learning disability and autistic children, must be reviewed through the statutory process mandated in “[Working together to safeguard children](#)”.

The statutory [child death review \(CDR\)](#) and [child death overview panel \(CDOP\)](#) process takes precedent over LeDeR. Local systems are asked only to notify the LeDeR platform of the deaths of children aged 4 – 17 and upload the findings of the child death review process when it is complete, to ensure there is a joined-up approach to learning and service improvement.

A much lower than expected number of records about the deaths of children was notified to LeDeR in 2022. The [National Child Mortality Database \(NCMD\)](#) has confirmed the number of children with a learning disability notified through the statutory process is in line with what would be expected each year and the deaths of children with a learning disability are being reviewed through the child death review process.

NHS England has worked with the NCMD to improve data-sharing arrangements (within the scope of [CAG S251](#)) to reduce the duplication of notification requirements and subsequent analysis across both programmes. The NCMD have been commissioned to produce a thematic review of the deaths of all children with a learning disability and autistic children from 2019 which will provide the most insight to date. This is expected to be published in 2024.

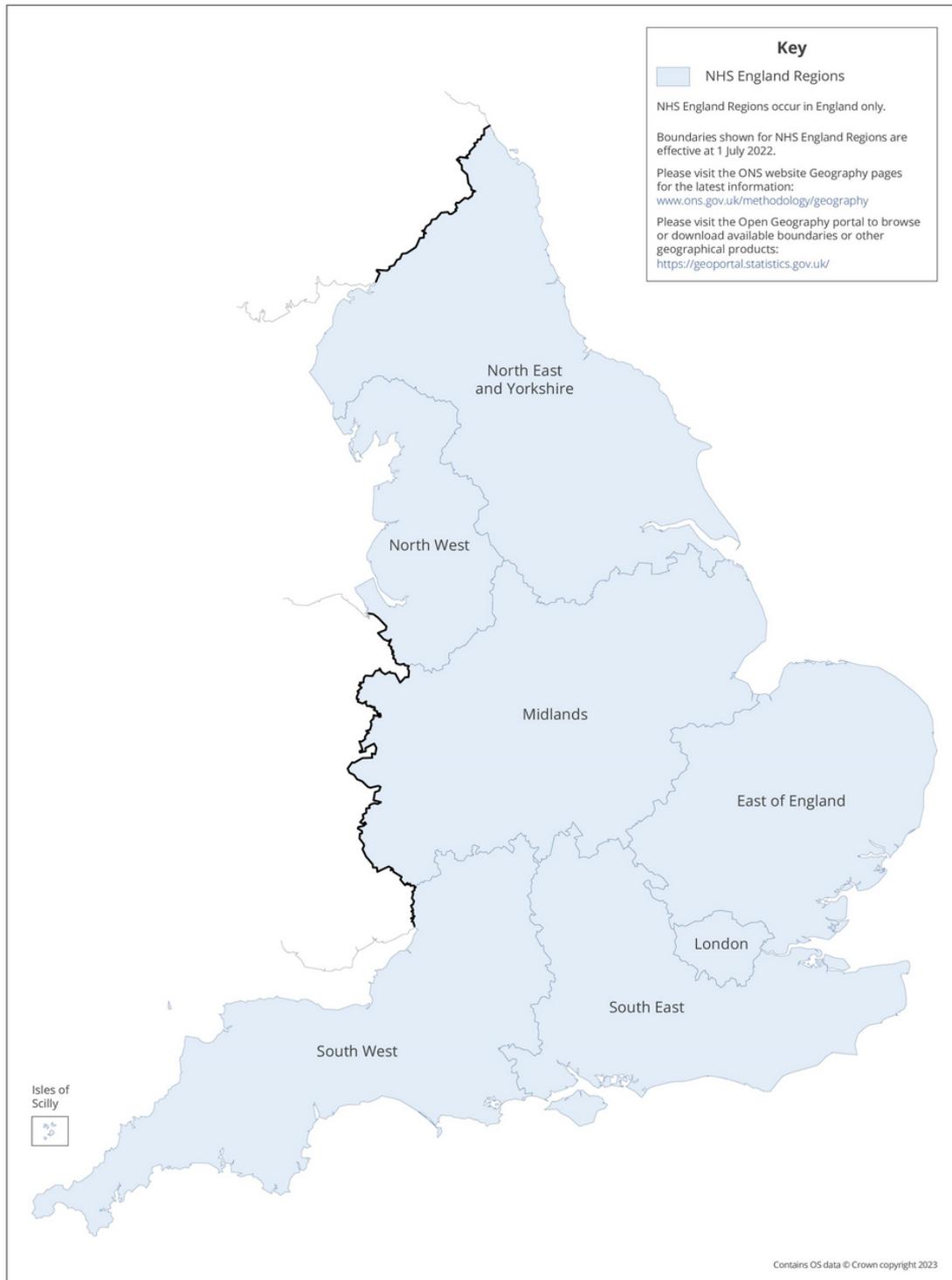
## LeDeR data used in this report

In the annual LeDeR reports, we use data which reflect the different stages of the LeDeR review process. In this report we include all notified deaths of people with a learning disability, people with a clinical diagnosis of autism and autistic people with a learning disability aged 18 years and older, as well as all completed review data (both initial and focused) of people who died and were reviewed by LeDeR in 2022. Our primary focus is on the completed review data, and this forms the majority of our analyses and reporting. In each chapter, we explain from which data set (notification, initial reviews, focused reviews) the analysis is drawn from. Notification data is used for providing an overview of the type and scope of data provided to LeDeR, whilst the review data offers more detailed information about a person's life and death.

In some cases, to provide comparisons over time, we use data from reviews for deaths which occurred in previous years. This will be highlighted when relevant. Figure 1 shows the NHS regions defined in the LeDeR data. Source: [Office For National Statistics \(ONS\) \(2022\)](#).

**Figure 0.1:** Map of NHS regions in the LeDeR data

**England:** NHS England Regions, 2022



## Notification data

Anyone, for instance, a doctor, nurse, social worker, family member, or a friend, can report the death of an autistic person or someone with a learning disability by submitting a notification to LeDeR via the LeDeR website. The notification form includes basic demographic information about the person who died, such as their name, NHS number (if known), address, date of birth, sex, and ethnicity. The person submitting the form is also asked to provide information about the circumstances of the death of the person who died, including where the death occurred, what they thought caused the death, and whether they had any concerns about the care of the person. There are more notifications for 2022 than completed reviews because some reviews have been delayed (e.g. by statutory processes) and have not therefore been able to be completed in time for their completed review data to be included in this report. A video explaining the notification process can be found here at <https://www.youtube.com/watch?v=iVYWqAjahv8&t=153s>.

## Initial review data

If the notification is found to be eligible for a LeDeR review through initial checks (that it is in scope, has not already been reviewed previously, and is of a person who meets the LeDeR review criteria), it is then passed to a trained 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 the person's clinicians. The reviewers aim to build 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 supported by linkage with other available data, such as the [Medical Certificate of Cause of Death \(MCCD\)](#) (also known as a death certificate), data provided by the [Office of National Statistics \(ONS\)](#), and [NHS Digital](#). This helps to create an overall review of this person's life and the reasons for their death.

## Focused review data

Focused reviews explore in more detail the life and death of the person and any examples of good practice and areas where care could be improved. Local areas and regions are also able to choose certain groups of people to conduct focused reviews if they want to focus on a particular topic or subject for improvement, for example, dental care, aspiration pneumonia, or family involvement.

Reviewers then add to data that was already available from the initial review by looking further into the health and social care of the person who died, and the circumstances surrounding their death. More detailed information about the deceased person's medical history, care, treatment, and their social care arrangements are obtained by working closely with the professionals involved in their care and by accessing additional records, such as coroner's reports (when these are available). Judgements are also made about the quality of care a person received and the reviewer suggests explicit learning points, such as identifying issues with the person's care, or highlighting good practices, to be taken from the review. Local governance panels or groups are then able to add actions from this that are to be taken forward.

## General notes for interpretation

Here we present some general notes to help understand the data in this report.

### The protection of personal data

In this report, data for where there are fewer than 5 people (but more than 0) available we have suppressed the true number with “<5”. This is in order to ensure that no individual can be identified from this report or data. In some instances, for example when presenting a cause of death over different age groups, there were more than 5 data available for some groups but not for others. If we presented the numbers for the larger group, then it would be possible to identify individuals from the smaller group. To prevent this, we may have suppressed a full row of data with “\*”. This will be highlighted.

### The use of hyperlinks

This report is primarily designed to be read as a digital document, with hyperlinks to relevant references and external sources highlighted throughout. A references page is included for further reference.

### The use of median

Median is often understood as the “middle number” and is used to give readers the middle number of a range of numbers in this report. We use this primarily for age calculations to determine the average age.

### Rounding of values

In this report we use various rounding of numbers for clarity. In Chapter 1, when describing the overall LeDeR data, we have rounded to 0 decimal place for convenience. In subsequent chapters, we have rounded to 1 decimal place, where required, to provide more detail figures. Finally, when discussing statistics, we have used up to 3 decimal places, again as required, to provide full detailed statistical analysis.

### The inclusion of data on the deaths of autistic people

In January 2022 LeDeR began collecting data on the deaths of autistic adults (aged 18 and over) who did not also have diagnosis of a learning disability (please see Chapter 7 for full details). In this report, the data available for autistic adults was small, with 36 completed reviews. As such, we have taken the following steps:

- The data for autistic adults who do not also have a learning disability has been separated from the rest of the data and has been analysed in Chapter 7. As such, all other chapters do **not** use review data which includes autistic adults who do not also have a learning disability for analysis. For Chapter 1, notifications of autistic adults are only included in the first figure describing sources of notifications to LeDeR.
- In Chapter 7 we have discussed autistic adults alongside autistic adults with a learning disability to provide context to the autistic adults without a learning disability data.
- Data for autistic adults with a learning disability is included in the overall learning disability data sample.

# Chapter 1

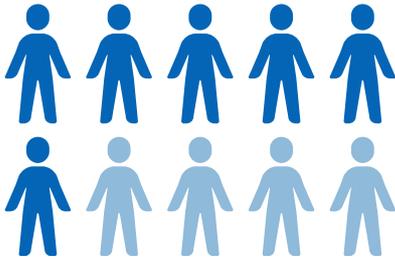


Review of Lives and Deaths for 2022

# KEY FINDINGS OF REVIEW OF LIVES AND DEATHS FOR 2022

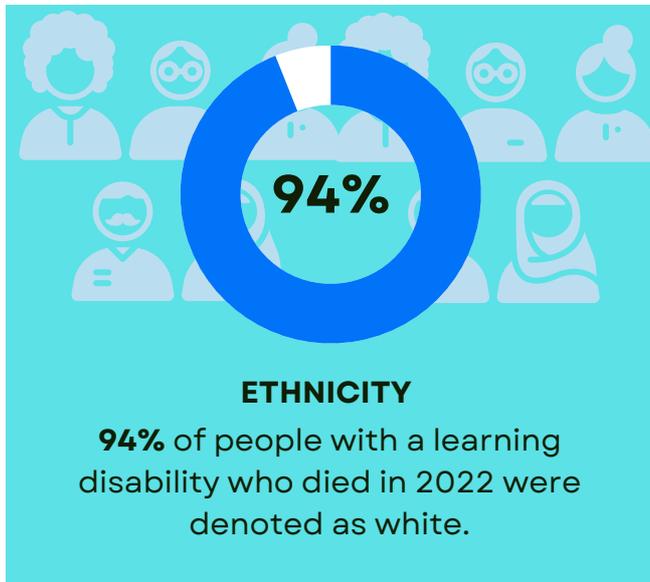
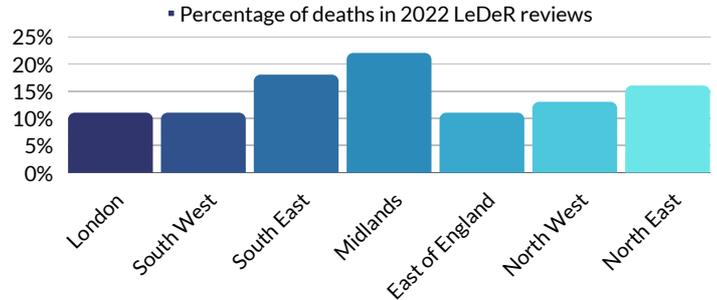
## SEX

**55%** of people with a learning disability who died in 2022 were male.



## REGION

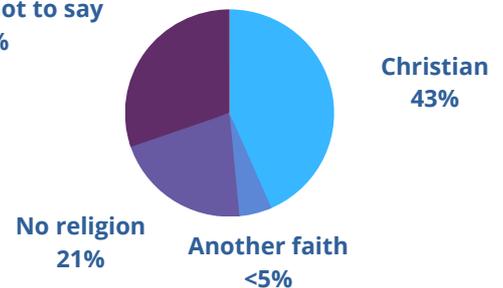
LeDeR reviewed deaths of people with a learning disability from all 7 regions of England.



## RELIGION

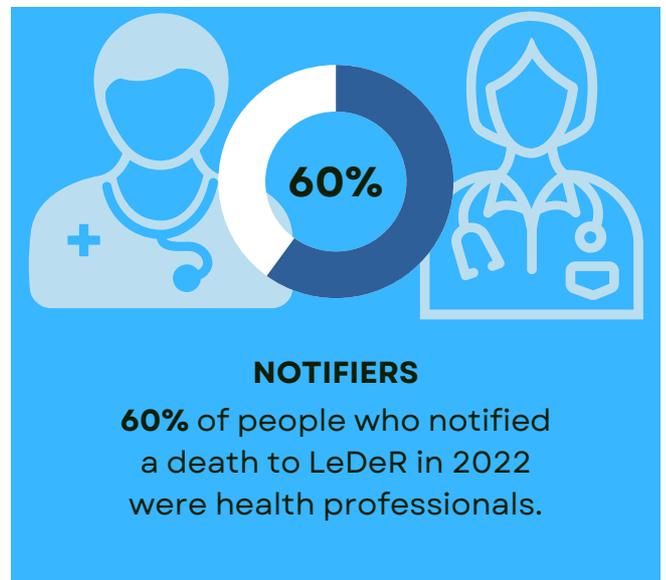
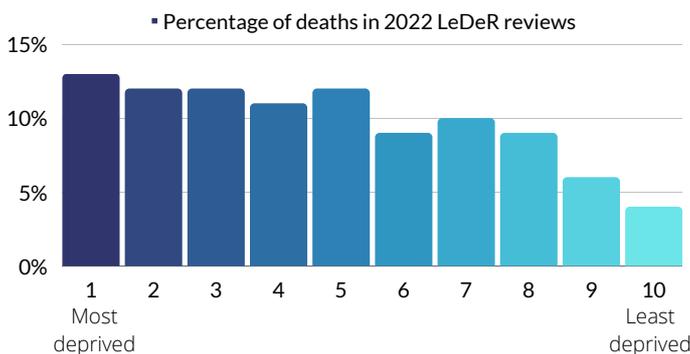
**43%** of people with a learning disability who died in 2022 were denoted as Christian.

Preferred not to say 30%



## DEPRIVATION

**25%** of people with a learning disability who died in 2022 lived in the most deprived neighbourhoods by decile, compared to **10%** in the least deprived.



## Introduction

LeDeR is notified of the death of an adult with a learning disability or an autistic adult through reports from family members, friends or professionals involved in a person’s care (prior to July 2023 LeDeR also received notifications of children with a learning disability). The deaths of autistic adults are discussed in [Chapter 7](#).

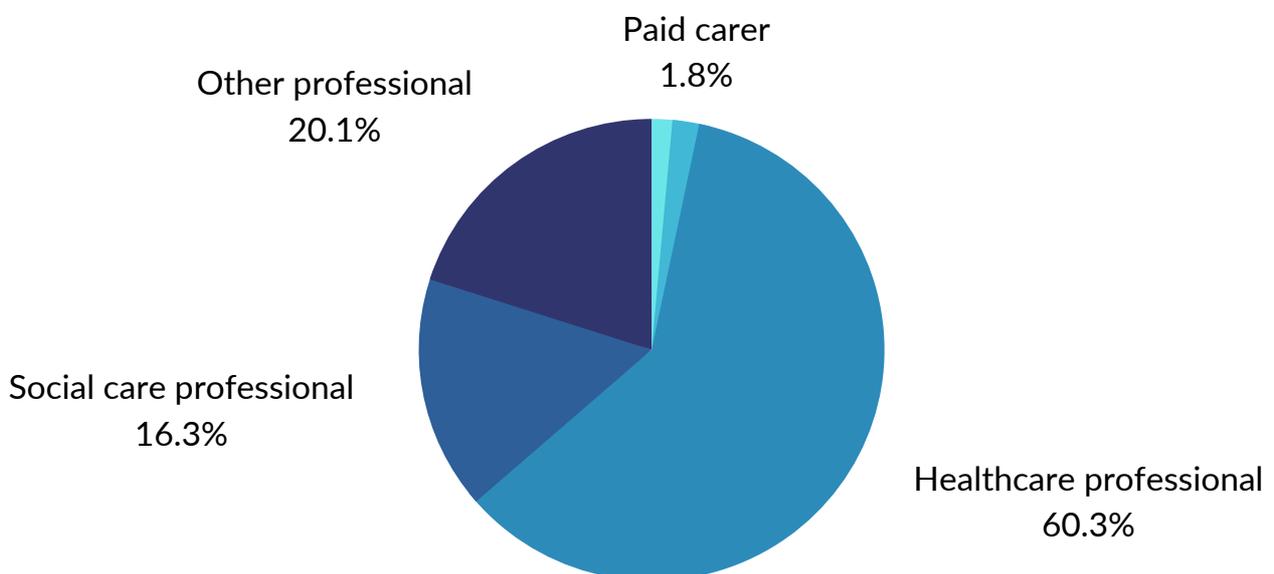
For full details of the LeDeR process from reporting through to reviewing, and the process for child deaths, please see [page 10](#).

## Notifiers to LeDeR

To find out sources of notifications of deaths to LeDeR, we looked at the relationship of the notifier to the person who died for all 5,188 notifications (including duplicate notifications) received by LeDeR in 2022. This includes deaths of people with a learning disability, autistic people with a learning disability and autistic adults. This is shown in Figure 1.1.

The majority of notifications were received from healthcare professionals (60%). A fifth (20%) of notifications were from other professionals, which includes professionals working at the medical examiners’ offices, administrative professionals, professionals involved in reviewing or auditing deaths, safeguarding professionals and other patient-facing and administrative roles not otherwise listed. Approximately 16% were from social care professionals. Only around 1% of notifications were from family members, friends or unpaid carers, and 2% were from paid carers.

**Figure 1.1:** Notifier relationship to the person who died for notifications in 2022.



## Deaths in 2022 notified to LeDeR

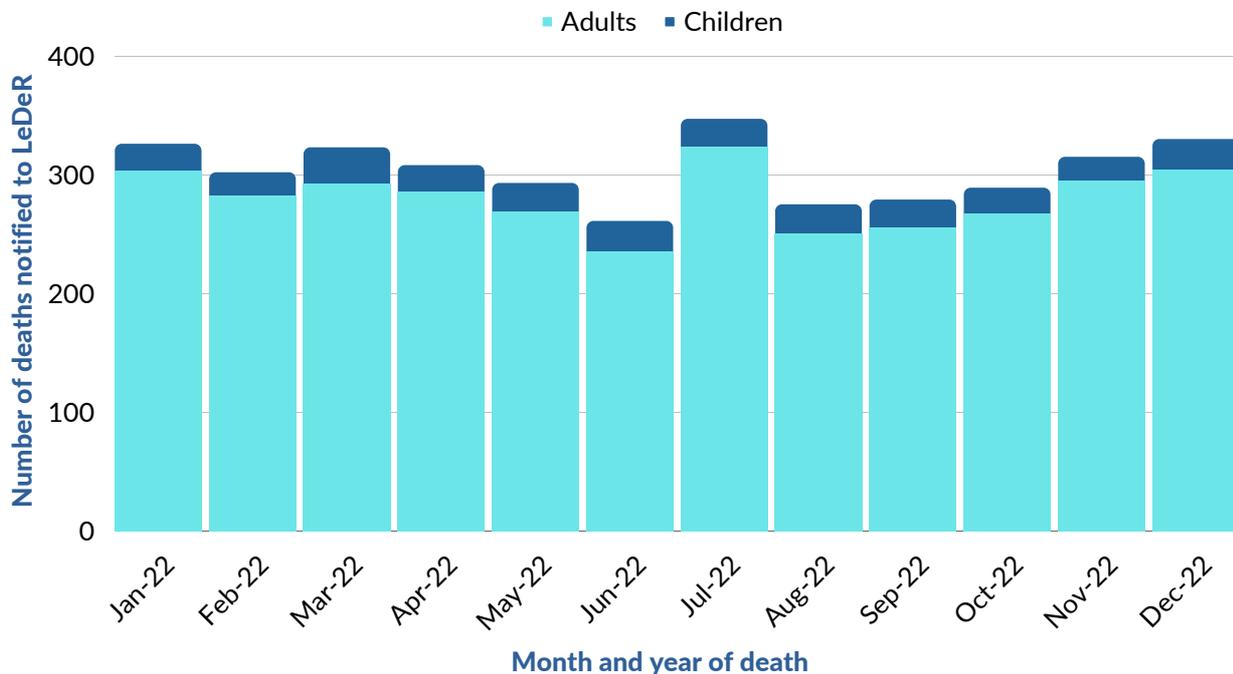
Here, we report the deaths of people with a learning disability, including autistic people with a learning disability. This represents the overall dataset that is used in the analysis of subsequent chapters in this report. Autistic adults without a learning disability are discussed in [Chapter 7](#).

**3,648** unique deaths were notified to LeDeR of people with a learning disability (including autistic people with a learning disability) in the 12 months of 2022 (January 1st to December 31st). This includes 285 notifications of deaths of children aged 4-17 and 3,362 notifications of deaths of adults aged 18 years and older.

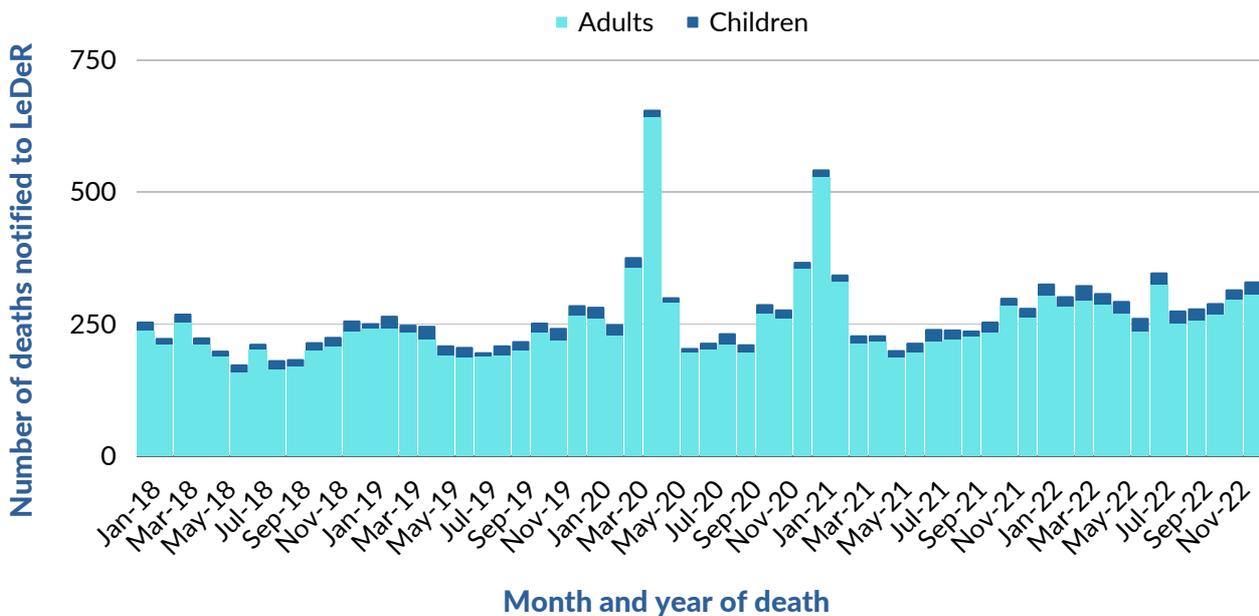
In this report we will use the 2022 data alongside data from 12,398 unique deaths notified to LeDeR that occurred between 2018 and 2021, for a comparison across time.

Below presented in Figure 1.2 is the total number of unique deaths notified by month of death from January 2022 to December 2022. Figure 1.3 presents the total number of unique deaths notified by month of death from January 2018 to December 2022 for comparison across time.

**Figure 1.2:** Total number of deaths notified by month from January 2022 to December 2022.



**Figure 1.3:** Total number of deaths notified by month from January 2018 to December 2022.



There were two noticeable peaks around March 2020 and January 2021, which, as detailed in the [2021 report](#), can be attributed to the COVID-19 pandemic. Seasonal patterns will be explored in more detail in [Chapter 6](#).

## Demographics of the people who died and were notified to LeDeR in 2022

For the remaining analysis of the notifications, we have removed a small number of data duplications, we have also removed any cases that were of autistic people without a learning disability (these 110 cases are covered in [Chapter 7](#)), and removed cases which fell outside of the scope of this report (e.g. date of death not being in 2022).

On the following two pages, we have detailed the demographics of deaths of people with a learning disability that were notified to LeDeR in 2022. This includes autistic people who had a learning disability. Throughout this section when we refer to people with a learning disability we also include autistic people who had a learning disability. Below in Table 1.1 are the demographics of the 3,535 unique notifications of people who died and were notified to LeDeR in 2022.

To protect people from being identified, we have marked all cases where the numbers were below 5 with an \*. Please note, those with “not known” for age and/or the demographic variables reported are excluded.

**Table 1.1:** Overall demographics of the people whose deaths were notified (unique notifications) to LeDeR in 2022.

Reported Sex (registered at birth)	Age group at death (years) 4 to 17	18 to 24	25 to 49	50 to 64	65+	Total (Number, %)
Male	168	72	291	617	689	1,837 (55%)
Female	116	58	253	482	582	1,491 (45%)
Total	284	130	544	1,099	1,271	3,328
Ethnicity*	Age group at death (years) 4 to 17	18 to 24	25 to 49	50 to 64	65+	Total (Number, %)
Asian or Asian British	65	21	44	27	17	174 (5%)
Black, black British, Caribbean or African	*	*	*	*	*	78 (2%)
Mixed or multiple ethnic backgrounds	*	*	*	*	*	29 (<1%)
Other	*	*	*	*	*	27 (<1%)
White	160	78	455	1,001	1,187	2,881 (90%)
Total	262	114	527	1,064	1,222	3,189

\*'Asian or Asian British' includes those of Indian, Pakistani, Bangladeshi, Chinese and any other Asian background. 'Black, black British, Caribbean or African' includes those of African, Caribbean, and any other black, African or Caribbean background. 'Mixed ethnic backgrounds' includes those of white and black Caribbean, white and black African, white and Asian and any other mixed or multiple ethnic background. 'Other' includes those of Arab and any other ethnic background. 'White' includes those of British, Irish, Gypsy or Irish traveller and any other white background.

**Table 1.1** (continued): Overall demographics of the people whose deaths were notified (unique notifications) to LeDeR in 2022.

Region	Age group at death (years) 4 to 17	18 to 24	25 to 49	50 to 64	65+	Total (Number, %)
London	49	19	53	123	154	398 (11%)
South West	22	7	62	116	145	352 (10%)
South East	26	22	81	183	205	517 (15%)
Midlands	66	32	122	245	252	717 (20%)
East of England	33	16	62	129	137	377 (11%)
North West	39	20	90	175	227	551 (16%)
North East and Yorkshire	50	19	118	199	235	621 (18%)
Total	285	135	588	1,170	1,355	3,533

## LeDeR reviews in 2022

This report used data from **2,084** reviews of deaths that occurred in 2022. This does not include the reviews of deaths of children (<18) which are completed as part of CDOP. 1,586 of these were completed as initial reviews and 498 were focused reviews.

8% of reviews were of people from ethnic minority backgrounds, which includes Asian or Asian British, black or black British, Caribbean, or African, mixed or multiple ethnic backgrounds and other ethnic backgrounds.

The review data included in this report were cleaned. This means that reviews with no information available for the key demographics (sex, date of birth and date of death) have been excluded.

## Demographics of adults who died in 2022 and have a completed LeDeR review

The demographics of 2,084 adults who died and received a completed review in 2022 are shown in Table 1.2.

Please note: to protect people from being identified, we have marked all cases below 5 with an asterisk (\*). Please note, those with “not known” for sex, age and/or the demographic variables reported are excluded.

**Table 1.2:** The overall demographics of the adults who died and were reviewed by LeDeR in 2022.

Reported Sex (registered at birth)	Age group at death (years) 18 to 24	25 to 49	50 to 64	65+	Total (Number, %)
Male	45	163	437	494	1,139 (55%)
Female	26	165	336	418	945 (45%)
Total	71	328	773	912	2,084
Ethnicity	Age group at death (years) 18 to 24	25 to 49	50 to 64	65+	Total (Number, %)
Asian or Asian British	13	26	15	12	66 (3%)
Black, black British, Caribbean or African	6	6	23	*	38 (2%)
Mixed or multiple ethnic backgrounds	*	*	*	5	15 (<1%)
Other	*	*	*	*	11 (<1%)
White	44	268	706	862	1,880 (94%)
Total	69	306	751	884	2,010
Unknown	9	52	126	109	296 (15%)
Total	66	313	730	873	1,962

**Table 1.2** (continued) The overall demographics of the adults who died and were reviewed by LeDeR in 2022.

Religion	Age group at death (years) 18 to 24	25 to 49	50 to 64	65+	Total (Number, %)
Buddhist	*	*	*	*	* (<1%)
Christian	19	99	301	423	842 (43%)
Hindu	*	*	*	9	18 (<1%)
Jewish	*	*	5	*	10 (<1%)
Muslim	10	20	8	*	39 (2%)
Sikh	*	*	*	*	* (<1%)
Other	*	*	*	*	42 (2%)
None	16	60	157	186	419 (21%)
Declines to disclose	8	64	101	120	293 (15%)
Unknown	9	52	126	109	296 (15%)
Total	66	313	730	873	1,962
Region	Age group at death (years) 18 to 24	25 to 49	50 to 64	65+	Total (Number, %)
London	10	30	78	107	225 (11%)
South West	*	*	*	*	224 (11%)
South East	15	57	130	156	358 (17%)
Midlands	17	73	184	180	454 (22%)
East of England	7	33	91	90	221 (11%)
North West	9	40	83	135	267 (13%)
North East and Yorkshire	9	52	131	143	335 (16%)
Total	71	328	773	912	2,084

**Table 1.2** (continued) The overall demographics of the adults who died and were reviewed by LeDeR in 2022.

Index of Multiple Deprivation decile	Age group at death (years) 18 to 24	25 to 49	50 to 64	65+	Total (Number, %)
1 (most deprived)	8	51	100	120	279 (13%)
2	9	44	92	106	251 (12%)
3	11	29	92	115	247 (12%)
4	9	39	85	106	239 (12%)
5	7	45	88	105	245 (12%)
6	9	28	70	87	194 (9%)
7	5	25	89	97	216 (10%)
8	*	*	*	*	181 (9%)
9	5	26	54	49	134 (6%)
10 (least deprived)	*	*	*	*	91 (4%)
Total	71	327	771	908	2,077

### Sexuality and gender identity

We looked at sexuality and gender identity for adults with a learning disability including those who have a learning disability who are also autistic. Deaths of adults who identified as LGBTQIA+ were reported, but in small numbers, and as such cannot be detailed here for de-identification reasons.

### Index of Multiple Deprivation

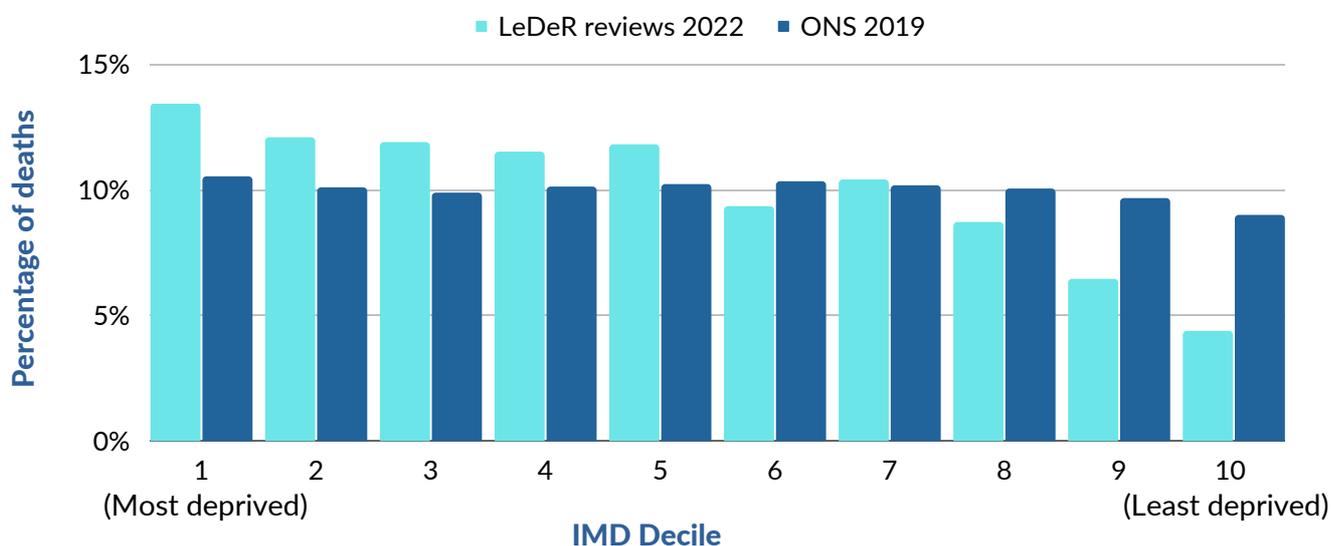
The 2019 Index of Multiple Deprivation (IMD), the latest data available, was used to report the level of deprivation of the home address of the people who died in 2022. According to the ONS, the Indices provide a set of relative measures of deprivation for small areas across England, based on seven different domains, or facets, of deprivation:

- Income deprivation.
- Employment deprivation.
- Education, skills and training deprivation.
- Health deprivation and disability.
- Crime.
- Barriers to housing and services.
- Living environment.

Deprivation is measured in a broad way to encompass a wide range of aspects of an individual's living conditions (please see "[The English Indices of Deprivation, 2019](#)"). Residential postcodes are assigned an IMD decile between 1 and 10. Lower values indicate higher levels of deprivation which is measured by factors such as the average income, employment status, health statistics and crime rates in the area. Further detail can be found [here](#).

Deprivation data were available for 2,077 adults who died in 2022 and had a completed LeDeR review. Figure 1.4 shows the distribution of IMD decile data for 2022, compared to deaths in the general population from 2019, the [latest data available \(ONS, 2020\)](#).

**Figure 1.4:** Percentage of deaths in 2022 with a completed review by Index of Multiple Deprivation Decile, LeDeR review deaths (2022) compared to general population estimates (ONS, 2019).



As can be seen above, around 25% of adults who died in 2022 and had a completed review by LeDeR lived in a neighbourhood with one of the two most deprived deciles. In comparison, around 20% of deaths in the general population in 2019 were of people living in a neighbourhood with one of the two most deprived deciles.

# Chapter 2



## Causes and Circumstances of Death

# KEY FINDINGS ON CAUSES AND CIRCUMSTANCES OF DEATH

## DNACPR

**74%** of people who died in 2022 had a DNACPR in place at the time of death. Reviewers judged this was correctly followed **63%** of the time. This compares with **61%** of the time in 2021.

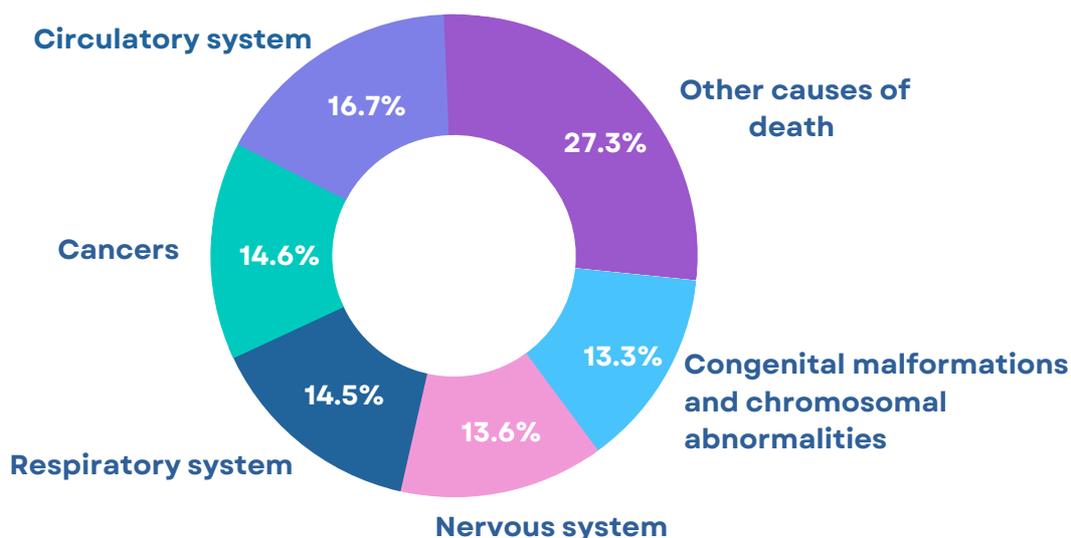


## REFERRALS TO A CORONER

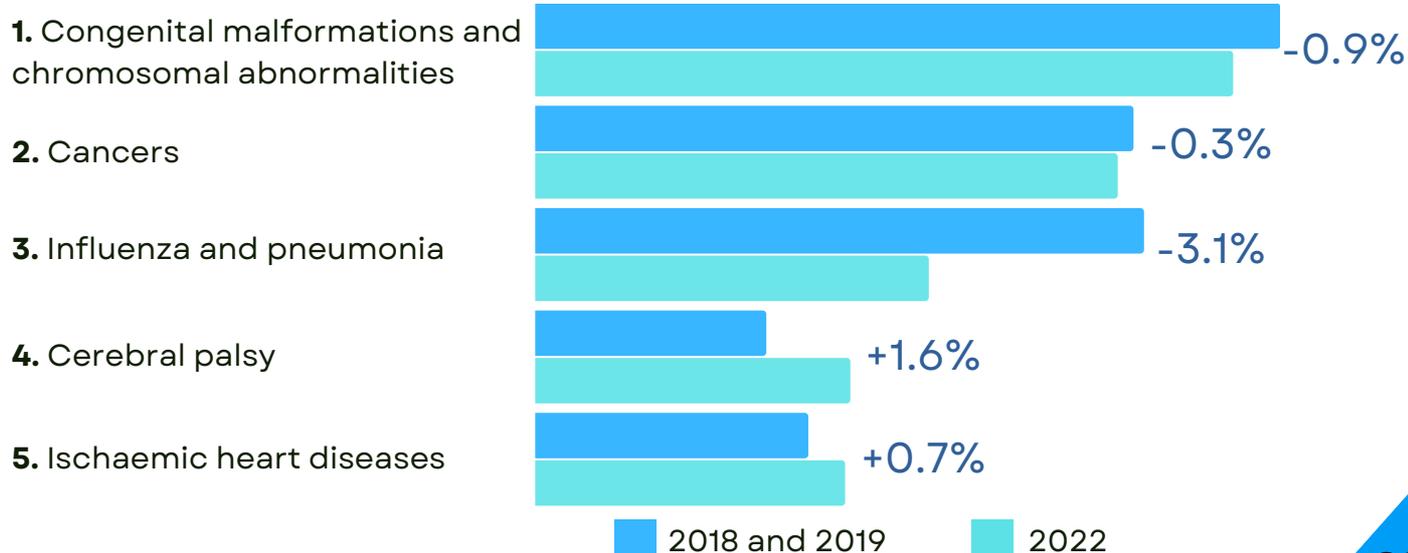
**25%** of deaths that occurred in 2022 were referred to a coroner. This compares to **19%** in 2020 and 2021 and **22%** in 2018 and 2019. **36%** of deaths in the general population were referred to a coroner.



## 5 MOST COMMON CAUSES OF DEATH (ICD-10 CHAPTER)



## 5 MOST COMMON LEADING CAUSES OF DEATH (2022 VS 2018 AND 2019)



## Introduction

In this chapter, we summarise the circumstances and most common causes of death in adults with a learning disability (including autistic adults with a learning disability). Data from 2,084 LeDeR initial reviews and MCCDs for people who died between 2018 and 2022 are used in this chapter. For comparison with 2022, data from 4,844 reviews for deaths that occurred in 2018 and 2019 were combined to allow comparisons with pre-COVID-19 years. Data from 6,391 reviews for deaths that occurred in 2020 and 2021 were grouped as these years were affected by COVID-19.

MCCD data were available for 99% of reviews (2,054 reviews) of deaths which occurred in 2022 (see page 10 for a description of the LeDeR process). MCCD data were available for 95% of reviews for deaths that occurred in 2018 and 2019 and 94% of reviews for deaths that occurred in 2020 and 2021.

## Circumstances of death

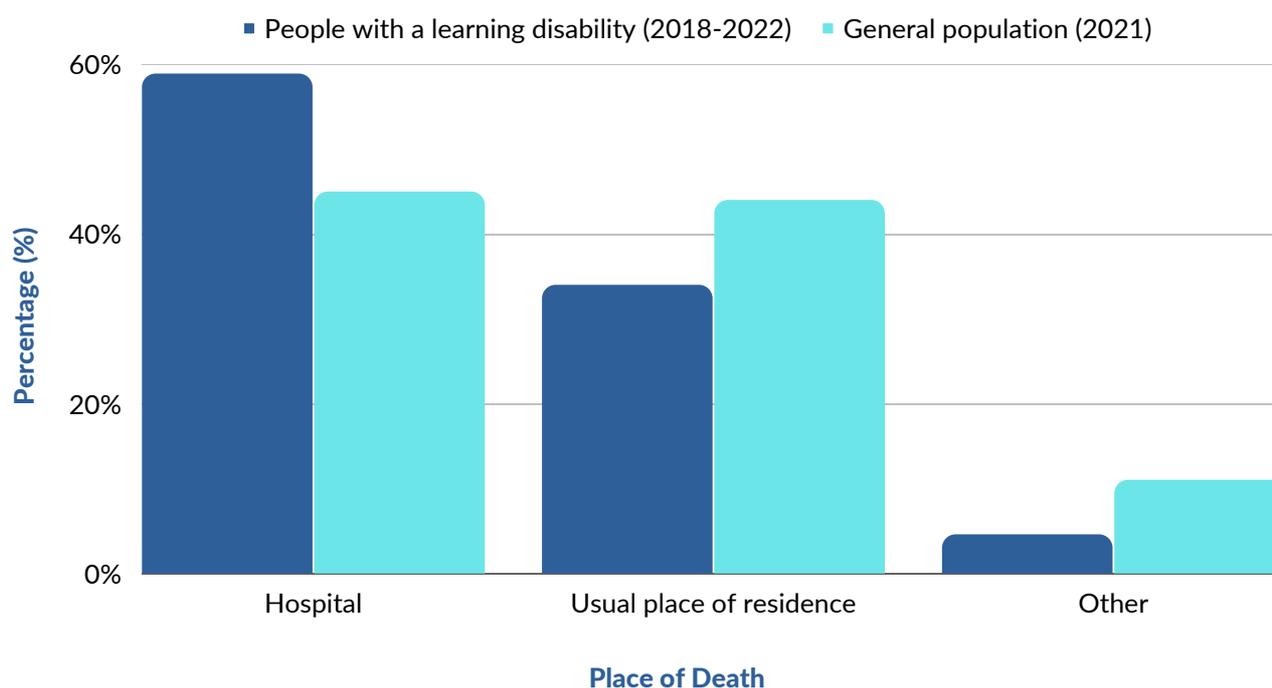
We report where people died, whether their death was reported to a coroner, whether a [Do Not Attempt Cardio-Pulmonary Resuscitation \(DNACPR\)](#) decision was made prior to death and whether procedures around DNACPR were followed correctly.

### Place of death

Of the deaths occurring in 2022 which had an initial review, 57% occurred in hospital. The proportion of people who died in hospital has not changed much between 2018 and 2022. See Appendix Table A2.1 for comparison with previous years.

In comparison to the latest available data from the general population (2021), a greater proportion of people with a learning disability die in hospital (59% of people with a learning disability in 2018-2022 compared to 45% of the general population in 2021) (Figure 2.1). Compared with the general population, a smaller proportion of people with a learning disability died in their usual place of residence ([34% of people with a learning disability compared to 44% of the general population in 2021](#)).

**Figure 2.1:** Place of death for deaths which occurred between 2018 and 2022 and had an initial review compared with the general population (2021).



### Deaths with DNACPR decisions

Of the 2,084 people that died in 2022 and had an initial review, 74% had a DNACPR decision in place at the time of death (see Table 2.1). This compares to 70% in 2018 and 2019 and 72% in 2020 and 2021.

Reviewers judged that DNACPR documentation and processes were correctly completed and followed for 63.3% of the deaths in 2022 where a DNACPR was in place. DNACPR documentation and processes were judged to have been correctly completed and followed for 60.9% of deaths in 2021 where a DNACPR was in place.

In comparison to previous years, there was a lower proportion of deaths where a reviewer was unable to determine whether DNACPR documentation had been correctly completed and followed. There was also a slightly higher proportion of reviews with a DNACPR in place at the time of death that was judged to have been completed and followed correctly. The proportion of reviews with a DNACPR recommendation in place at the time of death that was judged to have been incorrectly completed and followed remained at around 6% (see Table 2.2).

DNACPR documentation can apply to a short period of time (e.g. if someone goes to hospital). DNACPR documentation can also be applied indefinitely (e.g. if someone has a long-term, progressive illness). DNACPRs should be reviewed according to a date that is given on the DNACPR documentation. DNACPR's should also be reviewed if someone's health changes. The reviewers indicated that DNACPR recommendations were reviewed for 47.1% of the deaths in 2022. 30.6% of deaths that occurred in 2022 did not receive a DNACPR recommendation review.

Reviewers reported that there was documented evidence to show a conversation took place with the person or those important to them, to explain DNACPR and ask about wishes and preferences in relation to this for 60.7% of deaths which occurred in 2022. Reviewers were unable to report whether a conversation took place for 33.1% of cases. Reviewers indicated that for 16.1% of deaths that occurred in 2022 where a DNACPR recommendation was in place and a conversation about DNACPR was held, the person with a learning disability was not engaged in the discussion about DNACPR where they had capacity.

Reviewers judged that the person was provided with appropriate accessible communication in 60.0% of the discussions which took place about DNACPR.

**Table 2.1:** Percentage of adults with a learning disability who had a DNACPR decision in place when they died (2018-2022)

DNACPR decision at the time of death	2018 and 2019	2020 and 2021	2022
Yes	69.8%	71.9%	74.2%
No	28.9%	26.4%	25.8%
Not recorded	1.3%	1.7%	0%
Total number	4,844	6,391	2,084

**Table 2.2:** Percentage of adults with a learning disability who died with a DNACPR decision in place at the time of their death, for whom documentation was completed and followed correctly (2021-2022)

DNACPR documentation in place, and was:	2021	2022
Completed and followed correctly	60.9%	63.3%
Completed correctly but was not followed	1.1%	1.2%
Incorrectly completed and followed	6.2%	7.1%
Neither completed nor followed correctly	0.6%	0.8%
Not recorded	31.2%	27.6%
Total number	1,877	1,546

### Deaths reported to a coroner

There is a legal requirement to report a death to a coroner in certain circumstances. These include suspicious deaths, those with an unknown cause, or deaths which have occurred under state detention (e.g. if the person died in prison or whilst held under mental health legislation) (see Appendix 2.2 for a full list of circumstances in which a coroner should be notified). Whether a death is reported to a coroner or not is not an indication of the quality of care a person received.

[The average time it takes to complete a coroner's inquest is 30 weeks.](#) The later date of publication for the 2022 LeDeR report has enabled more deaths which received a coroner's inquest to be included.

25% of deaths of people with a learning disability that occurred in 2022 with a review completed by LeDeR were referred to a coroner. This compares to 22% in 2018 and 2019 and 19% in 2020 and 2021. In 2022, the UK government reported that 36% of all registered deaths were reported to a coroner (see Table 2.3).

In 2022, [a greater number of deaths were scrutinized by medical examiners](#), which aim to encourage more appropriate referrals of deaths to coroners.

**Table 2.3:** Percentage of reviews of deaths that occurred between 2018 and 2022 that were reported to a coroner.

Deaths reported to a coroner	2018 and 2019	2020 and 2021	2022
Adults (aged 18+)	21.8%	19.2%	25.0%

## Causes of death

### Determination of the underlying cause of death

When someone dies, a doctor who was involved in the person's care completes a medical certificate of cause of death (MCCD). This indicates the sequence of conditions which lead to death, including the [underlying cause](#). The World Health Organization (WHO) defines the [underlying cause of death](#) as the disease or injury that initiated the train of events directly leading to death or the circumstances of the accident or violence that produced the fatal injury. Further details can be found here via the [ONS website](#). The underlying cause of death is commonly extracted from the lowest completed line 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 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 ICD-10 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 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, respiratory and circulatory conditions.

Another way in which the ICD-10 codes have been grouped is by [leading cause of death](#) as defined in an internationally recognized list developed by the [WHO](#) and used by the [ONS](#) which focuses on specific prevalent conditions, thereby providing a more epidemiologically meaningful picture of common causes death, and allowing for comparison between populations.

It is important to note that not every condition is assigned to a leading cause of death group. A notable example is aspiration pneumonia, which is a prominent cause of death in people with a learning disability but which is not considered a leading cause of death in the WHO classification. We have included deaths due to COVID-19 as a leading cause.

### **Which conditions are included in each ICD-10 chapter?**

Overleaf in table 2.4 is a summary of some of the conditions and leading causes of death contained within some ICD-10 chapters. You can find more detail by referring to the [ICD-10](#) and [leading cause of death list](#).

**Table 2.4:** ICD-10 chapter and leading cause of death groups.

ICD-10 chapter	Conditions	Leading cause(s) of death
Diseases of the circulatory system	Ischaemic heart diseases, Hypertensive diseases, Cerebrovascular diseases	Ischaemic heart diseases, Hypertensive diseases, Cerebrovascular diseases
Diseases of the respiratory system	Influenza and pneumonia, Chronic lower respiratory diseases, Aspiration pneumonia	Influenza and pneumonia, Chronic lower respiratory infections,
Neoplasms (cancer)	Bowel cancer, Breast cancer, Prostate cancer, Lung cancer	Bowel cancer, Prostate cancer, Lung cancer
Diseases of the nervous system	Cerebral palsy, Epilepsy, Parkinson's disease	Cerebral palsy and other paralytic syndromes, Epilepsy and status epilepticus, Parkinson's disease
Congenital malformations, deformations and chromosomal abnormalities	Down syndrome, Spina bifida, Congenital malformations of the heart	Congenital malformations, deformations and chromosomal abnormalities
Diseases of the digestive system	Paralytic ileus and intestinal obstruction without hernia, Vascular disorders of the intestine, Liver disease, Constipation	Appendicitis, hernia and intestinal obstruction, Cirrhosis and other diseases of the liver
Codes for special purposes	COVID-19	COVID-19 (included as a leading cause of death)
Mental and behavioural disorders	Dementia, Developmental disorder unspecified	Dementia and Alzheimer disease
Diseases of the genitourinary system	Kidney failure	Diseases of the urinary system
Endocrine, nutritional and metabolic diseases	Diabetes, Obesity	Diabetes
External causes of morbidity and mortality	Falls, Inhalation or ingestion of food causing obstruction of the respiratory tract	Accidental falls, Accidental threats to breathing, Suicide and injury/poisoning of undetermined intent
Certain infectious and parasitic diseases	Septicaemia	Septicaemia

## Most common causes of death by ICD-10 chapter

Table 2.5 shows the 10 most common ICD-10 chapter causes of death for people who died from 2018 to 2022 and had an initial review completed by LeDeR before 13th July 2023. See Appendix Tables A2.5-2.8 for breakdowns by age and sex registered at birth.

The most commonly reported underlying causes of death in 2022 were related to the following ICD-10 chapters: diseases of the circulatory system, diseases of the respiratory system, neoplasms, diseases of the nervous system, congenital malformations, deformations and chromosomal abnormalities.

In 2022, Down syndrome was listed in part 1a of the death certificate 9 times, in part 1b 39 times and in part 1c 23 times. Down syndrome was listed in part 2 of the death certificate 210 times in 2022.

Down syndrome should not be provided as the sole cause of death (in part 1a) on a death certificate as Down syndrome itself does not cause death. Down syndrome may have been an important factor in an individual's death. For example, dementia and congenital heart defects are common in some groups of people with Down syndrome and these conditions can cause death. It is important that the complete list of conditions which influenced a person's death are included on the death certificates to ensure that learning can take place.

COVID-19 was the sixth most common ICD-10 chapter cause of death in 2022. There was a lower percentage of deaths caused by COVID-19 for deaths that occurred in 2022 (5.7% of deaths) in comparison to the combined percentage from 2020 and 2021 (21.4% of deaths).

The percentage of deaths caused by COVID-19 was still higher in people with a learning disability in comparison to the general population (5.7% of deaths that occurred in 2022 in people with a learning disability; 3.9% of deaths that occurred in 2022 for the [general population](#)).

Diseases of the circulatory system caused a slightly higher percentage of deaths in 2022 (16.7%) in comparison to the combined percentages from 2020 and 2021 (14.0% of deaths) and 2018 and 2019 (15.8% of deaths). The percentage of deaths caused by diseases of the respiratory system was lower in 2022 (14.6%) in comparison to the combined percentage from 2018 and 2019 (20.7% of deaths), though they remained the second most common cause of death.

**Table 2.5:** The 10 most common ICD-10 chapter causes of death for adults with a learning disability who had a LeDeR reviews (2018 to 2022).

ICD-10 chapter	2018 and 2019	2020 and 2021	2022
	Number, %	Number, %	Number, %
Diseases of the circulatory system	728, 15.8%	843, 14.0%	343, 16.7%
Diseases of the respiratory system	955, 20.7%	785, 13.0%	299, 14.6%
Neoplasms	690, 15.0%	717, 11.9%	298, 14.5%
Diseases of the nervous system	535, 11.6%	629, 10.4%	279, 13.6%
Congenital malformations, deformations and chromosomal abnormalities	655, 14.2%	610, 10.1%	274, 13.3%
Diseases of the digestive system	325, 7.0%	349, 5.8%	144, 7.0%
Codes for special purposes (COVID-19)	-	1,293, 21.4%	118, 5.7%
Mental and behavioural disorders*	222, 4.8%	252, 4.2%	77, 3.7%
Diseases of the genitourinary system	104, 2.3%	153, 2.5%	52, 2.5%
Endocrine, nutritional and metabolic diseases	942.0%	110, 1.8%	44, 2.1%
<b>Total number of deaths</b>	<b>4,614</b>	<b>6,030</b>	<b>2,054</b>

\* Includes dementia and delirium

### Most common circulatory causes of death

The 5 most common circulatory causes of death for people that died between 2018 and 2022 and had an initial review before 13th July 2023 are provided in Table 2.6. This, and the subsequent cause of death Tables are colour coded to easily demonstrate any changes across the years.

The leading circulatory cause of death for 2022 was ischaemic heart diseases, which caused 35.3% of deaths due to circulatory diseases. In 2022, 27.7% of circulatory deaths were caused by cerebrovascular diseases, followed by other forms of heart disease (15.7% of circulatory deaths) and diseases of the veins, lymphatic vessels and lymph nodes, not elsewhere classified (6.7% of circulatory deaths).

There has not been much change in the proportion of deaths caused by different circulatory conditions between 2018 and 2022, though the proportion and number of deaths caused by cerebrovascular conditions may be decreasing and the proportion of circulatory deaths caused by ischaemic heart diseases may be increasing.

**Table 2.6:** The most frequently reported circulatory causes of death for the adults with a learning disability who received a LeDeR review (2018- 2022).

2018 and 2019		2020 and 2021		2022	
Cause of death	Number, % of circulatory deaths	Cause of death	Number, % of circulatory deaths	Cause of death	Number, % of circulatory deaths
Ischaemic heart diseases	241, 33.1%	Ischaemic heart diseases	281, 33.3%	Ischaemic heart diseases	121, 35.3%
Cerebrovascular diseases	226, 31.0%	Cerebrovascular diseases	249, 29.5%	Cerebrovascular diseases	95, 27.7%
Other forms of heart disease	125, 17.2%	Other forms of heart disease	142, 16.8%	Other forms of heart disease	54, 15.7%
Pulmonary heart disease and diseases of pulmonary circulation	44, 6.0%	Diseases of veins, lymphatic vessels and lymph nodes, not elsewhere classified	54, 6.4%	Diseases of veins, lymphatic vessels and lymph nodes, not elsewhere classified	23, 6.7%
Diseases of veins, lymphatic vessels and lymph nodes, not elsewhere classified	39, 5.4%	Pulmonary heart disease and diseases of pulmonary circulation	48, 5.7%	Pulmonary heart disease and diseases of pulmonary circulation	21, 6.1%

### Most common respiratory causes of death

The 5 (or 6 (if including COVID-19) most common respiratory causes of death for people that died between 2018 and 2022 and had an initial review before 13th July 2023 are provided in Table 8.

The leading respiratory cause of death in 2022 was influenza and pneumonia, which caused 37% of deaths due to respiratory diseases. The second most common respiratory cause of death in 2022 was COVID-19, which caused 28% of respiratory deaths. There has been a marked reduction in proportion of respiratory deaths caused by COVID-19 (from 62% in 2020 and 2021; to 28% in 2022). This is likely to be due to the response measures that were implemented to reduce the effect of COVID-19 (e.g. COVID-19 vaccinations). In 2022, chronic lower respiratory diseases caused 14.4% of respiratory deaths, followed by aspiration pneumonia (8.4% of respiratory deaths).

The proportion of deaths attributed to pneumonia that occurred in 2022 is higher (35.3%) than the percentage for 2020 and 2021 (18.9%), but considerably lower than the percentage for 2018 and 2019 (50.9%).

**Table 2.7:** The most frequently reported respiratory causes of death for the adults with a learning disability who received a LeDeR review (2018- 2022).

2018 and 2019		2020 and 2021		2022	
Cause of death	Number, %	Cause of death	Number, %	Cause of death	Number, %
Influenza and pneumonia	535, 53.8%	Covid	2,078, 61.7%	Influenza and pneumonia	154, 36.9%
Most common sub-types: Pneumonia	506, 50.9%			Most common sub-types: Pneumonia	147, 35.3%
Aspiration pneumonia	161, 16.2%	Influenza and pneumonia	400, 19.2%	Covid	118, 28.3%
		Most common sub-types: Pneumonia	393, 18.9%		
Chronic lower resp. diseases	145, 14.6%	Chronic lower resp. diseases	156, 7.5%	Chronic lower resp. diseases	60, 14.4%
Most common sub-types: Other chronic obstructive pulmonary diseases	80, 8.0%	Most common sub-types: Other chronic obstructive pulmonary diseases	81, 3.9%	Most common sub-types: Other chronic obstructive pulmonary diseases	41, 9.8%
Asthma	44, 4.4%	Asthma	40, 1.9%	Asthma	16, 3.8%
Other acute lower resp. infections	59, 5.9%	Aspiration pneumonia	110, 5.3%	Aspiration pneumonia	35, 8.4%
Other resp. diseases mainly affecting the interstitium	29, 2.9%	Other acute lower resp. infections	75, 3.6%	Other acute lower resp. infections	30, 7.2%
-	-	Other resp. diseases mainly affecting the interstitium	18, 0.9%	Other resp. diseases mainly affecting the interstitium	10, 2.4%

## Most common neoplasms (cancers) which cause death

The 10 most common neoplasms (cancers) which were provided as an underlying cause of death between 2018 and 2022 are presented in Table 2.8.

In 2022, the 5 most common were neoplasms of: the digestive organs (35.9% of deaths from cancer), respiratory and intrathoracic organs (11.1% of deaths from cancer), ill-defined, secondary and unspecified sites (9.1% of deaths from cancer), breast (7.4% of deaths from cancer), and lymphoid, haematopoietic and related tissue (7.4% of death from cancer).

Cancer of the bowel accounted for 15.8% of cancer deaths reported to LeDeR in 2022, while cancer of the oesophagus accounted for 5.4% of deaths.

Bowel cancer accounted for a lower percentage of cancer deaths in the UK general population than for people with a learning disability between 2017 and 2019 (bowel cancer: [10% of all cancer deaths](#)). Lung cancer and prostate cancer accounted for a higher percentage of cancer deaths in the UK general population than for people with a learning disability between 2017 and 2019 ([lung cancer: 21% of all cancer deaths](#); [prostate cancer 7% of all cancer deaths](#)) compared with those with a learning disability.

For the UK general population between 2017 and 2019, almost 6 in 10 deaths from bowel cancer (58%) were in people aged 75 and over. Roughly the same proportion of people with a learning disability who died from bowel cancer between 2018 and 2022, were aged above 60. The median age at death for the people reported to LeDeR who died of bowel cancer between 2018 and 2022 was 63.1 years. Bowel cancer screening is offered every two years to everyone over the age of 60. The screening age threshold is in the process of being lowered. By April 2025, all people over the age of 50 will be offered [bowel cancer screening](#).

The median age at death for people with a learning disability who died from breast cancer between 2018 and 2022 was 62.5 years. In the general population between 2017 and 2019, approximately half of deaths (46%) were in [people aged 75 and over](#). Breast cancer screening is offered every three years to all [women aged 50 to 71](#) on the NHS.

There has been little change in the proportion of deaths caused by cancers of the digestive organs between 2018 and 2022, although the percentage of deaths caused by bowel cancer is slightly higher in comparison to previous years. The percentage of deaths that were caused by lung cancer in 2022 (10.1%) was greater than for 2020 and 2021 (7.5%) and 2018 and 2019 (7.0%).

**Table 2.8:** The most frequently reported cancerous causes of death for people with a learning disability who had a LeDeR review (2018-2022).

2018 and 2019		2020 and 2021		2022		General population (2017-2019)
Type of cancer	Number, % of cancer deaths	Type of cancer	Number, % of cancer deaths	Type of cancer	Number, % of cancer deaths	% of cancer deaths
Digestive organs	250, 36.2%	Digestive organs	250, 34.9%	Digestive organs	107, 35.9%	-
Most common sub-types: Bowel Oesophagus Pancreas	99, 14.3% 47, 6.8% 42, 6.1%	Most common sub-types: Bowel Oesophagus Pancreas	90, 12.6% 53, 7.4% 33, 4.6%	Most common sub-types: Bowel Oesophagus Pancreas	47, 15.8% 16, 5.4% 13, 4.4%	10% 5% 6%
Respiratory organs	54, 7.8%	Blood, bone marrow, lymph and lymphatic system	62, 8.6%	Respiratory organs	33, 11.1%	-
Most common sub-types: Bronchus and lung	48, 7.0%	Most common sub-types: Other and unspecified types of non-Hodgkin lymphoma	17, 2.4%	Most common sub-types: Bronchus and lung	30, 10.1%	21%
Ill-defined, secondary and unspecified sites	61, 8.8%	Breast	61, 8.5%	Ill-defined, secondary and unspecified sites	27, 9.1%	-
Blood, bone marrow, lymph and lymphatic system	71, 10.3%	Ill-defined, secondary and unspecified sites	59, 8.2%	Blood, bone marrow, lymph and lymphatic system	22, 7.4%	-
Most common sub-types: Other and unspecified types of non-Hodgkin lymphoma	24, 3.5%			Most common sub-types: Other and unspecified types of non-Hodgkin lymphoma	7, 2.3%	
Breast	51, 7.4%	Respiratory organs	58, 8.1%	Breast	22, 7.4%	7%
		Most common sub-types: Bronchus and lung	54, 7.5%			

**Table 2.8: (continued)** most frequently reported cancerous causes of death for people with a learning disability who had a LeDeR review (2018-2022).

2018 and 2019		2020 and 2021		2022		General population (2017-2019)
Type of cancer	Number, % of cancer deaths	Type of cancer	Number, % of cancer deaths	Type of cancer	Number, % of cancer deaths	% of cancer deaths
Urinary tract	40, 5.8%	Female genital organs Most common sub-types: Cervix and uterus Ovary	54, 7.5%  28, 3.9% 20, 2.8%	Urinary tract	18, 6.0%	-
Female genital organs Most common sub-types: Cervix and uterus Ovary	46, 6.7%  26, 3.8% 17, 2.5%	Urinary tract	51, 7.1%	Female genital organs Most common subtypes: Cervix and uterus Ovary	17, 5.7%  10, 3.4% 6, 2.0%	 2% 2%
Eye, brain and other parts of central nervous system	20, 2.9%	Male genital organs Most common sub-types: Prostate	30, 4.2%  24, 3.3%	Eye, brain and other parts of central nervous system	10, 3.4%	-
Skin	14, 2.0%	Eye, brain and other parts of central nervous system	24, 3.3%	Skin	10, 3.4%	-
Male genital organs Most common sub-types: Prostate	31, 4.5%  26, 3.8%	Skin	12, 1.7%	Male genital organs Most common sub-types: Prostate	9, 3.0%  7, 2.3%	 - 7%

## The overall leading causes of death

Table 2.9 shows the 5 most common leading causes of death for people with a learning disability who died from 2018 to 2022 and had a LeDeR initial review completed before 13th July 2022 (see Appendix Table A2.5.1 and Table A2.5.2 for more detail).

In 2021, COVID-19 was the most common leading cause of death, accounting for 18% of all deaths in people with a learning disability. In 2022, the first leading cause of death was congenital malformations, deformations and chromosomal abnormalities (13.1% of deaths), followed by malignant neoplasms (10.9% of deaths), influenza and pneumonia (7.4% of deaths), cerebral palsy and other paralytic syndromes (5.9% of deaths) and ischaemic heart disease (5.8% of deaths). COVID-19 was the sixth most common leading cause of death in people with a learning disability, accounting for 5.7% of deaths.

Congenital malformation, deformations and chromosomal abnormalities were the first leading cause of death for people with a learning disability in almost every English region in 2022. In London, congenital malformations, deformations and chromosomal abnormalities caused the same number of deaths as malignant neoplasms, and in the North West malignant neoplasms were the joint leading cause of death with influenza and pneumonia. COVID-19 was the leading cause of death in every region in England in 2020 and 2021. Congenital malformations, deformations and chromosomal abnormalities were the leading cause of death in every region in 2018 and 2019.

In 2022, the most common [leading cause of death in the general population](#) was dementia and Alzheimer's disease, which accounted for 11.4% of all deaths. The second most common leading cause of death was ischaemic heart diseases (10.3% of all deaths). The third and fourth most common leading causes of death in the general population were chronic lower respiratory diseases (5.1% of deaths). The fourth most common leading cause of death in the general population was cerebrovascular diseases (5.0% of all deaths). The fifth most common leading cause of death in the general population was malignant neoplasm of the bronchus, trachea and lung (5.0% deaths). COVID-19 was the sixth most common leading cause of death, accounting for 3.9% of all deaths in 2022. In 2021,

COVID-19 was the most common leading cause of death, having caused 11.5% of deaths. The second most common leading cause of death was ischaemic heart diseases (10.3% of all deaths). The third and fourth most common leading causes of death in the general population were chronic lower respiratory diseases (5.1% of deaths). The fourth most common leading cause of death in the general population was cerebrovascular diseases (5.0% of all deaths). The fifth most common leading cause of death in the general population was malignant neoplasm of the bronchus, trachea and lung (5.0% deaths). COVID-19 was the sixth most common leading cause of death, accounting for 3.9% of all deaths in 2022. In 2021, COVID-19 was the most common leading cause of death, having caused 11.5% of deaths.

**Table 2.9:** Most common leading causes of death in the people with a learning disability who died between 2018 and 2022 and received a LeDeR review (all ages).

2018 and 2019		2020 and 2021		2022		General population (2022)	
Leading cause of death	Number, %	Leading cause of death	Number, %	Leading cause of death	Number, %	Leading cause of death	%
Congenital malformations, deformations and chromosomal abnormalities	655, 14.2%	COVID-19	1,293, 21.4%	Congenital malformations, deformations and chromosomal abnormalities	274, 13.3%	Dementia and Alzheimer's disease	11.4%
Influenza and pneumonia	535, 11.6%	Congenital malformations, deformations and chromosomal abnormalities	610, 10.1%	Malignant neoplasms	227, 11.1%	Ischaemic heart diseases	10.3%
Malignant neoplasms	525, 11.4%	Malignant neoplasms	535, 8.9%	Influenza and pneumonia	154, 7.5%	Chronic lower respiratory diseases	5.2%
Ischaemic heart diseases	241, 5.2%	Influenza and pneumonia	400, 6.6%	Cerebral palsy and other paralytic syndromes	123, 6.0%	Cerebrovascular diseases	5.1%
Cerebrovascular diseases	226, 4.9%	Ischaemic heart diseases	281, 4.7%	Ischaemic heart diseases	121, 5.9%	Bronchus and lung cancer	5.0%

### The leading causes of death in adults (18- to 64-year-olds)

In 2022, the most common leading cause of death in 18 to 64-year-olds was congenital malformations, deformations and chromosomal abnormalities, which caused 19.0% of deaths (see Table 2.10 or Appendix Table A2.5.1 and Table A2.5.2 for more detail). The second most common leading cause was malignant neoplasms, which caused 8.7% of deaths.

The leading causes of death for people aged between 50 and 64 in the general population were ischaemic heart diseases (13.9%), followed by malignant neoplasm of the trachea, bronchus and lung (7.1%).

**Table 2.10:** The most common causes of death in the people with a learning disability who died between 2018 and 2022 and received a LeDeR review (18- to 64-year-olds).

2018 and 2019		2020 and 2021		2022	
Leading cause of death	Number, %	Leading cause of death	Number, %	Leading cause of death	Number, %
Congenital malformations, deformations and chromosomal abnormalities	512, 18.9%	COVID-19	669, 19.8%	Congenital malformations, deformations and chromosomal abnormalities	219, 19.0%
Malignant neoplasms	302, 11.1%	Congenital malformations, deformations and chromosomal abnormalities	497, 14.7%	Malignant neoplasms	120, 10.4%
Influenza and pneumonia	281, 10.4%	Malignant neoplasms	295, 8.7%	Cerebral palsy and other paralytic syndromes	94, 8.2%
Cerebral palsy and other paralytic syndromes	169, 6.2%	Cerebral palsy and other paralytic syndromes	214, 6.3%	COVID-19	68, 5.9%
Epilepsy and status epilepticus	146, 5.4%	Influenza and pneumonia	186, 5.5%	Influenza and pneumonia	68, 5.9%

## The 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 2022 and had an initial review conducted before 13th July 2023 are presented in Table 2.11 (see Appendix Table A2.6.1 and Table A2.6.2 for more detail).

Malignant neoplasms (cancers) were the leading cause of death for people aged over 65, accounting for 11.8% of deaths in 2022. The second leading cause of death in 2022 was influenza and pneumonia, which caused 9.5% of deaths. The third leading cause of death in 2022 was ischaemic heart disease, which caused 6.7% of deaths.

The top two causes of death for people aged over 65 in the [general population](#) were dementia and Alzheimer's disease (13.5% of deaths in people aged over 65) and ischaemic heart diseases (10.1% of deaths in people aged over 65).

A larger portion of deaths were found for dementia and Alzheimer's disease (6.6%) and cerebrovascular diseases (5.8%) than in other age groups, which is unsurprising as these conditions are known to be more common in older people. Additionally, chronic lower respiratory diseases (4.8%) and diseases of the urinary system (3.2%) accounted for a larger percentage of deaths for those over 65.

In 2022, the leading cause of death for people aged between 65 and 79 from the general population was ischaemic heart disease, which accounted for 12% of deaths. Malignant neoplasm of the trachea, bronchus and lung was the second most common leading cause of death, which accounted for 8.5% of deaths. Dementia and Alzheimer's disease was the leading cause of death for people aged 80+, which accounted for 18% of deaths, while ischaemic heart disease was the second leading cause of death and accounted for 8.9% of deaths.

For a full breakdown of the leading underlying causes of death by sex at birth, see Appendix Tables A2.7 and A2.8.

**Table 2.11:** The most common causes of death in the people with a learning disability who died between 2018 and 2022 and received a LeDeR review (people aged 65+).

2018 and 2019		2020 and 2021		2022	
Leading cause of death	Number, %	Leading cause of death	Number, %	Leading cause of death	Number, %
Influenza and pneumonia	254, 13.4%	COVID-19	624, 23.5%	Malignant neoplasms	107, 11.8%
Malignant neoplasms	223, 11.7%	Malignant neoplasms	240, 9.0%	Influenza and pneumonia	86, 9.5%
Congenital malformations, deformations and chromosomal abnormalities	143, 7%	Influenza and pneumonia	214, 8.1%	Ischaemic heart diseases	61, 6.7%
Dementia and Alzheimer disease	142, 7%	Dementia and Alzheimer disease	172, 6.5%	Dementia and Alzheimer disease	60, 6.6%
Ischaemic heart diseases	134, 7.1%	Ischaemic heart diseases	148, 5.6%	Congenital malformations, deformations and chromosomal abnormalities	55, 6.1%

## Implications

### Circumstances of death

There are many reasons why a higher proportion of people with a 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 (such as staff in supported living settings feeling unable to manage a death at home), or potential inaccessibility of hospice or palliative care services at home. It may also be that LeDeR is more likely to receive notifications about deaths that have occurred in hospital.

Reviewers judged DNACPR documentation and processes to have been correctly completed and followed in 63.3% of deaths which occurred in 2022 where a DNACPR recommendation was in place. The percentage of deaths in 2022 where reviewers judged that DNACPR documentation and processes were completed and followed correctly was slightly higher than the percentage for 2020 and 2021. Additional work is necessary to understand how procedures around DNACPR can be improved for people with a learning disability.

The proportion of deaths that were referred to a coroner was 14.7% higher in 2022 when compared to 2018 and 2019, likely reflecting an increase in the rate of referral of eligible deaths, although this percentage remains around 10% lower than for the general population.

### **Leading causes of death**

In 2022, the leading cause of death in people with a learning disability was diseases of the circulatory system. There was only a slight increase in deaths caused by diseases of the circulatory system in comparison with previous years. There was little change in the proportion of deaths accounted for by the 5 most common circulatory causes of death, although the proportion of deaths from cerebrovascular diseases may have decreased and the proportion of deaths from ischaemic heart diseases may have increased in comparison in comparison to previous years.

The percentage of deaths caused by COVID-19 in 2022 was 73.4% lower than in 2020 and 2021. However, people with a learning disability are still more likely to die from COVID-19 than the general population. People with a learning disability should continue to be prioritised for vaccination against COVID-19 and closely monitored during future pandemics.

Health outcomes for people with a learning disability should continue to be monitored closely through annual health checks to detect and manage any residual impacts from the COVID-19 pandemic. The percentage of deaths that were caused by bowel and lung cancer has shown slight increases. Work is needed to determine at what median age people with a learning disability get bowel cancer and the threshold for bowel cancer screening in people with a learning disability should be calibrated in line with this.

## Looking forward

### Care and services

- Further work is required to understand how causes of death within the ICD-10 chapter congenital malformations and chromosomal abnormalities are applied in the medical certificate of cause of death, and to establish better guidance on their appropriate use.
- The completion and adherence to DNACPR documentation and processes in people with a learning disability could be further improved by involving people with a learning disability and their families in the decision, and by reducing incorrect recording and following of the documentation.
- People with a learning disability should continue to be prioritised for vaccination to help reduce the continued impact of COVID-19.
- The health of people with a learning disability at risk of developing cardiovascular conditions, bowel cancer and lung cancer should be monitored closely, by identifying high-risk groups for targeted screening, such as smoking history for lung cancer screening. Bowel cancer screening age may need to be adjusted for people with a learning disability.

### Research

- Research should seek to establish the barriers and facilitators associated with compliance with current DNACPR procedures to drive practice improvement.
- Further exploration of the factors associated with place of death, such as access to palliative care at home and in the community, is required to ensure optimal end-of-life care.
- Ways in which the reduction in deaths due to respiratory infections can be maintained should be explored, including optimising pneumococcal and flu vaccinations.

# Chapter 3



Factors Associated with Age at Death

# KEY FINDINGS OF FACTORS ASSOCIATED WITH AGE AT DEATH

## AGE AND ETHNICITY

People from all ethnic minority groups died at a **younger age** in comparison to people of white ethnicity, when adjusting for sex, region of England, deprivation, place of death, and type of accommodation.

% increased risk of dying earlier by ethnic minority group, in comparison with people from white ethnicity backgrounds, when adjusting for other demographic factors



## EPILEPSY AND AGE AT DEATH

**Epilepsy** was the long-term condition that was most **strongly associated with dying at a younger age**. This was followed by deep vein thrombosis, and degenerative conditions.

## CARE AND PREMATURE DEATH

**Appropriate care** was associated with **reductions in premature death**. For instance, care packages that meet a person's needs and have an appropriate use of Deprivation of Liberty safeguards to deliver care are associated with a reduced risk of a premature death.



## AGE AT DEATH

**62.9\* years old** was the median age at death for people with a learning disability in 2022. This is an **increase from 2018**, where the median age at death was 61.8 years. This increase was seen despite the COVID-19 pandemic, showing a continuous improvement between 2018 and 2022.



## TREATMENT AND PREVENTION

The use of **appropriate medical treatment and prevention**, such as the use of vaccines to protect against COVID-19 and pneumococcus and mental health treatments (medications), are associated with **reduction** in the risk of an earlier age at death.



# 62.9 YEARS

\*Calculation based on adult (>18 years old) data only for both 2022 and 2018.

# Factors associated with age at death

## Introduction

This chapter focuses on describing trends in age at death over the last five years, and on examining associations between demographic factors, clinical and social care variables and age at death for adults with a learning disability (age  $\geq 18$  years old) who died in 2022 and had a completed LeDeR review.

## Methods

We report yearly median ages at death (and interquartile ranges) for people with a learning disability (including autistic people with a learning disability) since 2018 who had a LeDeR initial review. In addition, we plot the percentages of people who were in various age groups (<18, 18-24, 25-49, 50-64, 65+) who had LeDeR reviews between 2018 and 2021, in 2022, and for the general population in 2022.

We estimated the associations between demographic, clinical and social care variables and age at death for adults who died in 2022.

The demographic variables were sex, ethnicity, region of England in which the person lived, deprivation, place of death (hospital, usual residence, other), level of learning disability (mild, moderate, severe, profound/multiple) and living arrangements (supported living, residential/nursing home, other).

Long-term condition variables were whether or not the person had cancer, a cardiovascular condition, a degenerative condition, dementia, diabetes, deep vein thrombosis, dysphagia (difficulties with swallowing), epilepsy, hypertension, kidney problems, a mental health condition (anxiety, bipolar affective disorder, depression, psychosis), osteoporosis, a respiratory illness, or a sensory impairment (hearing or vision problems).

Clinical variables included COVID-19 infection, prescription of antipsychotic or antidepressant medication, and COVID-19 or pneumococcal vaccination. Information on medication prescriptions and vaccinations was only available for those people who died and had a focused review (rather than an initial review).

Social and care-related variables included whether the person had an annual health check in the final 12 months of life, whether the care package met their needs, whether there was a [Deprivation of Liberty Safeguards \(DoLS\)](#) in place at the time of their death (no, applied for, or approved), whether they were in an out-of-area placement, and a grading of their quality of care (1-6) as assessed by trained LeDeR reviewers. Quality of care was graded as follows:

- 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 well-being 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 well-being 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).

Information on social and care-related variables were only available for people who died and had a focused review.

### **Statistical analysis**

We used Cox proportional hazards models to investigate the effects of predictor variables on time to death. Such models estimate the effect of predictor variables on age at death using hazard ratios. See note on interpretation for further information about hazard ratios. We fitted univariable models (i.e. one predictor variable for each model) to estimate the unadjusted effects of each of the predictors. We then fitted four groups of models to estimate the adjusted effects of each of the sets of predictors. For these analyses, we first fitted models with variables that came from initial reviews and then, separately, fitted models with variables that came from focused reviews (which also included, i.e. adjusted for, the variables that came from initial reviews such as demographic variables). Therefore, the number of participants in each analysis varied. The first of these groups of models included all the demographic variables. The second included all the long-term condition variables, adjusting for the demographic variables. The third included a series of models with each of the clinical variables, adjusting for demographic and long-term condition variables. The fourth included the social and care-related variables, adjusting for the demographic and long-term condition variables.

## Note on interpretation

It is important to note that some variables are recorded as part of initial reviews and some as part of (more detailed) focused reviews. There were 2082 initial reviews for adults who died in 2022 whose deaths were reported to LeDeR, and 498 focused reviews. These groups constitute our analysis samples.

The results are presented in the form of hazard ratios (HRs), 95% confidence intervals (CIs), and p-values. A hazard ratio can be interpreted as the probability of death in a particular group in the next short interval of time compared with a person in the reference group, with the same levels of any other variables in the model. A hazard ratio of 1 means that there is no evidence of an association between a factor (e.g. sex) and the chance of death in the next short interval of time, adjusting for other variables in the model. A hazard ratio of less than 1 indicates a reduction in the hazard of death. For example, if the hazard ratio were 0.90 for the effect of sex (reference group: male) in a model that also included ethnicity, this can be interpreted as indicating that a person who is female has a 10% lower chance of death in the next short interval of time compared with a person who is male of the same ethnicity. A hazard ratio greater than 1 indicates that the chance of death is higher in a particular group than it is in the reference group. The further the estimated hazard ratio is from 1, the greater the strength of the association. Confidence intervals give an idea of the precision of an estimate. We report 95% confidence intervals. The narrower the 95% confidence interval is, the less uncertainty there is in the estimate. Finally, the p-value demonstrates the strength of statistical evidence. P-values of less than 0.05 are said to demonstrate statistical significance. For example, a p-value of 0.5 suggests that an association between two variables is not statistically significant, and a p-value of 0.005 suggests high statistical significance.

Below we will describe the sample and present the estimates from our analyses. The estimated hazard ratios presented in this chapter are adjusted estimates, meaning that the effects of certain factors have been controlled for. For example, if estimating the effect of sex on the hazard of death and adjusting for ethnicity this means that the effect of ethnicity on the hazard of death has been held constant in the analysis. This is often done to control for confounding, which is when a factor (e.g. ethnicity) is associated with the variables for which an effect is being estimated. Unadjusted tables are viewable in the appendix. A full Table of unadjusted and adjusted estimates can be found in the appendix.

## Findings

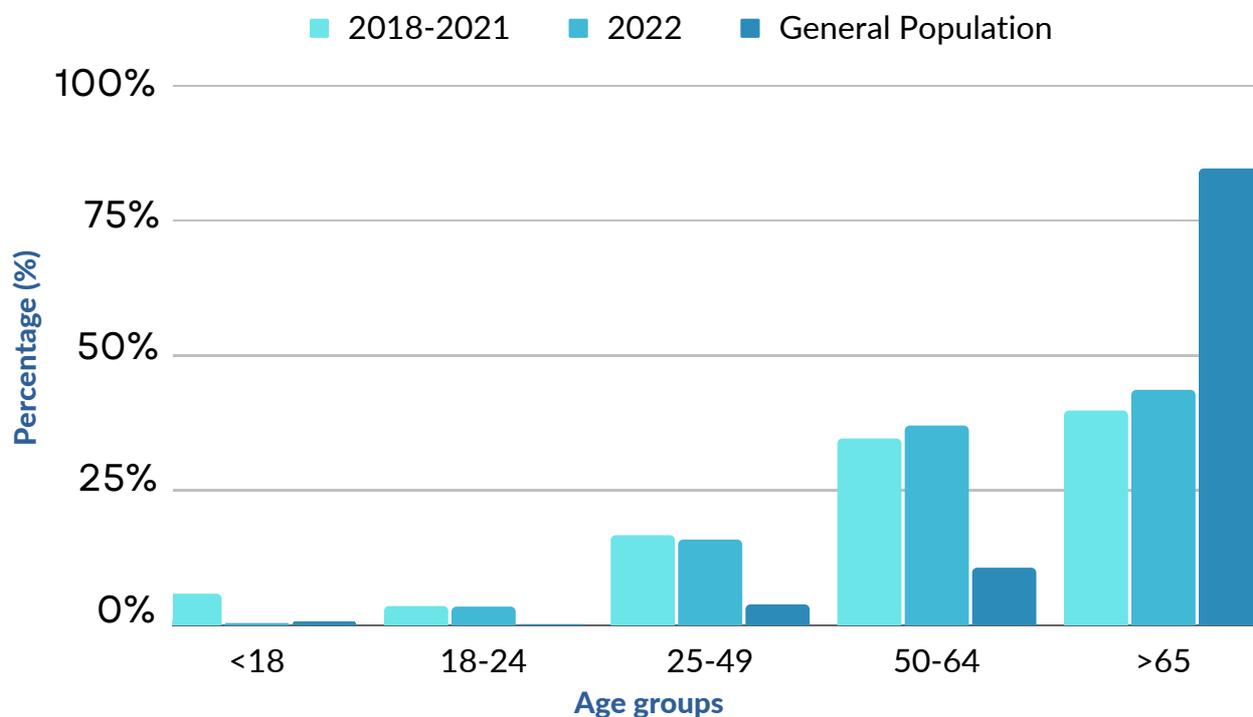
Median age at death by year is shown in Table 3.1. The LeDeR cohorts show that age at death has increased by roughly 2.5 years over the past five years. This is echoed by the change in age group at death when comparing 2018-2021 and 2022, as shown in Figure 3.1. The graph shows lower percentages of people dying in the younger age groups in 2022, albeit with some way to go before the age group distribution matches the general population. The median age at death when divided by sex in 2022 was 62.9 (IQR=53.0 to 72.8) for adult females and 62.9 (IQR=54.2 to 72.0) for adult males. This compares with 86.1 years for females and 82.6 years for males for the general population in England from 2018-2020, [which is the latest data available](#). Note: the ONS data includes all ages whilst LeDeR data for 2022 only includes those over 18 years old

**Table 3.1:** Median age at death by year for people with a learning disability who died between 2018-2022 and had a LeDeR review. Summaries are shown for all those with LeDeR reviews (i.e. adults and children) and for just adults with LeDeR reviews.

Year of death	Age at death (median; interquartile range)	
	All those with LeDeR reviews*	Adults with LeDeR reviews
2018	60.1 (48.2 to 70.3)	61.8 (52.2 to 71.1)
2019	60.0 (45.5 to 70.3)	61.7 (50.8 to 71.1)
2020	61.9 (50.9 to 71.8)	63.0 (53.3 to 72.3)
2021	62.1 (51.6 to 71.8)	62.4 (52.9 to 71.9)
2022	62.7 (53.1 to 72.3)	62.9 (53.6 to 72.4)

\*Note that, for interpretation and completeness, this column includes those under 18 years old; however, for 2022 LeDeR does not have complete data for deaths in this age group.

**Figure 3.1:** Age group at death for people with a learning disability who had a completed review (2018-2021, 2022), and for the general population. [Data on the general population can be found here](#): Note that, for interpretation and completeness, the figure includes those <18 years; however, for 2022 LeDeR does not have complete data for deaths in this age group.



There were 2,084<sup>1</sup> adults who died in 2022 whose age at death was known. The median age at death (excluding under 18's) was 62.9 (IQR 53.6 to 72.4). Just over half the sample were male and the majority were white (90%) (see Table 3.2). The most common long-term conditions recorded were mental health conditions (39%), cardiovascular conditions (38%), epilepsy (37%), sensory impairments (35%), and dysphagia (29%) (see Table 3.3a and Table 3.3b). Of those with data, most had an annual health check (232/498, 47%; only recorded in focused reviews until January 2023, but initial reviews that were completed after this date do include this information in the last 12 months of life and were assessed as having care that met their needs (407/498, 82%) (see Table 3.5). The level of recorded data on prescribed antipsychotics (86; 17%) and/or antidepressants (84; 17%) is lower than the recorded level of mental health conditions (820; 39%) (see Table 3.4).

<sup>1</sup>Note that sample sizes differ per analysis, and are detailed as such. This is due to varying levels of available data. For some criteria, such as age, this is compulsory for analysis in LeDeR, for others, such as cause of death (see Chapter 4), this is not (due to delays with coroner reporting, for example).

**Table 3.2:** Summary of demographic variables for those whose age at death was recorded.

Variable	Level	Total (number, %)
Sex	Male	1,139 (55%)
	Female	945 (45%)
Ethnicity	Asian or Asian British	66 (3%)
	Black, black British, Caribbean, or African	38 (2%)
	Mixed ethnic background	15 (1%)
	White	1880 (90%)
	Other	11 (1%)
	Unknown	74 (4%)
	Region of England	London
South West		224 (11%)
South East		358 (17%)
North Midlands		454 (22%)
East of England		221 (11%)
North West		267 (13%)
North East and Yorkshire		335 (16%)
IMD quintile	High deprivation	529 (25%)
	Moderate-high deprivation	487 (23%)
	Moderate deprivation	433 (21%)
	Low-moderate deprivation	394 (19%)
	Low deprivation	232 (11%)
	Unknown	9 (0%)
Place of death	Hospital	1197 (57%)
	Usual residence	808 (39%)
	Other	76 (4%)
	Missing	<5 (<1%)
Learning disability level*	Mild	236 (11%)
	Moderate	226 (11%)
	Severe	210 (10%)
	Profound-multiple	38 (2%)
	Unknown	1374 (66%)
Living arrangements*	Own or family home	161 (32%)
	Supported living	101 (20%)
	Residential/nursing home	217 (44%)
	Other	19 (4%)

\*Recorded as part of a focused review (498 people had focused reviews); all other information recorded as part of an initial review.

**Table 3.3a:** Summary of long-term condition variables for those whose age at death was recorded.

Variable	Level	Total (number, %)
Cancer	Yes	224 (11%)
	No	1669 (80%)
	Unknown	191 (9%)
Cardiovascular conditions	Yes	798 (38%)
	No	1095 (53%)
	Unknown	191 (9%)
Degenerative conditions	Yes	61 (3%)
	No	1832 (88%)
	Unknown	191 (9%)
Dementia	Yes	380 (18%)
	No	513 (73%)
	Unknown	191 (9%)
Diabetes	Yes	326 (16%)
	No	1567 (75%)
	Unknown	191 (9%)
Deep vein thrombosis	Yes	68 (3%)
	No	1825 (88%)
	Unknown	191 (9%)
Dysphagia	Yes	612 (29%)
	No	1281 (61%)
	Unknown	191 (9%)
Epilepsy	Yes	776 (37%)
	No	1117 (54%)
	Unknown	191 (9%)

\*Recorded as part of a focused review (498 people had focused reviews); all other information recorded as part of an initial review.

**Table 3.3b:** Summary of long-term condition variables for those whose age at death was recorded.

Variable	Level	Total (number, %)
Hypertension	Yes	411 (20%)
	No	1482 (71%)
	Unknown	191 (9%)
Kidney problems	Yes	441 (21%)
	No	1452 (70%)
	Unknown	191 (9%)
Mental health conditions	Yes	820 (39%)
	No	1073 (51%)
	Unknown	191 (9%)
Osteoporosis	Yes	145 (7%)
	No	1748 (84%)
	Unknown	191 (9%)
Respiratory conditions	Yes	279 (13%)
	No	1614 (77%)
	Unknown	191 (9%)
Sensory impairment	Yes	729 (35%)
	No	1164 (56%)
	Unknown	191 (9%)

\*Recorded as part of a focused review (498 people had focused reviews); all other information recorded as part of an initial review.

**Table 3.4:** Summary of clinical variables for those whose age at death was recorded.

Variable	Level	Total (number, %)
COVID-19	Yes	141 (7%)
	No	1650 (79%)
	Unknown	293 (14%)
Total medications* (median, interquartile range, range)		7 (IQR 4 to 11, range 0 to 32)
Prescribed antipsychotic*	Yes	86 (17%)
	No	156 (31%)
	Unknown	256 (51%)
Prescribed antidepressant*	Yes	84 (17%)
	No	131 (26%)
	Unknown	283 (57%)
COVID-19 vaccination*	Yes	409 (82%)
	No	61 (12%)
	Unknown	28 (6%)
Pneumococcal vaccination*	Yes	140 (28%)
	No	201 (40%)
	Unknown	157 (32%)

\*Recorded as part of a focused review (498 people had focused reviews); all other information recorded as part of an initial review.

**Table 3.5:** Summary of social and care-related variables for those whose age at death was recorded.

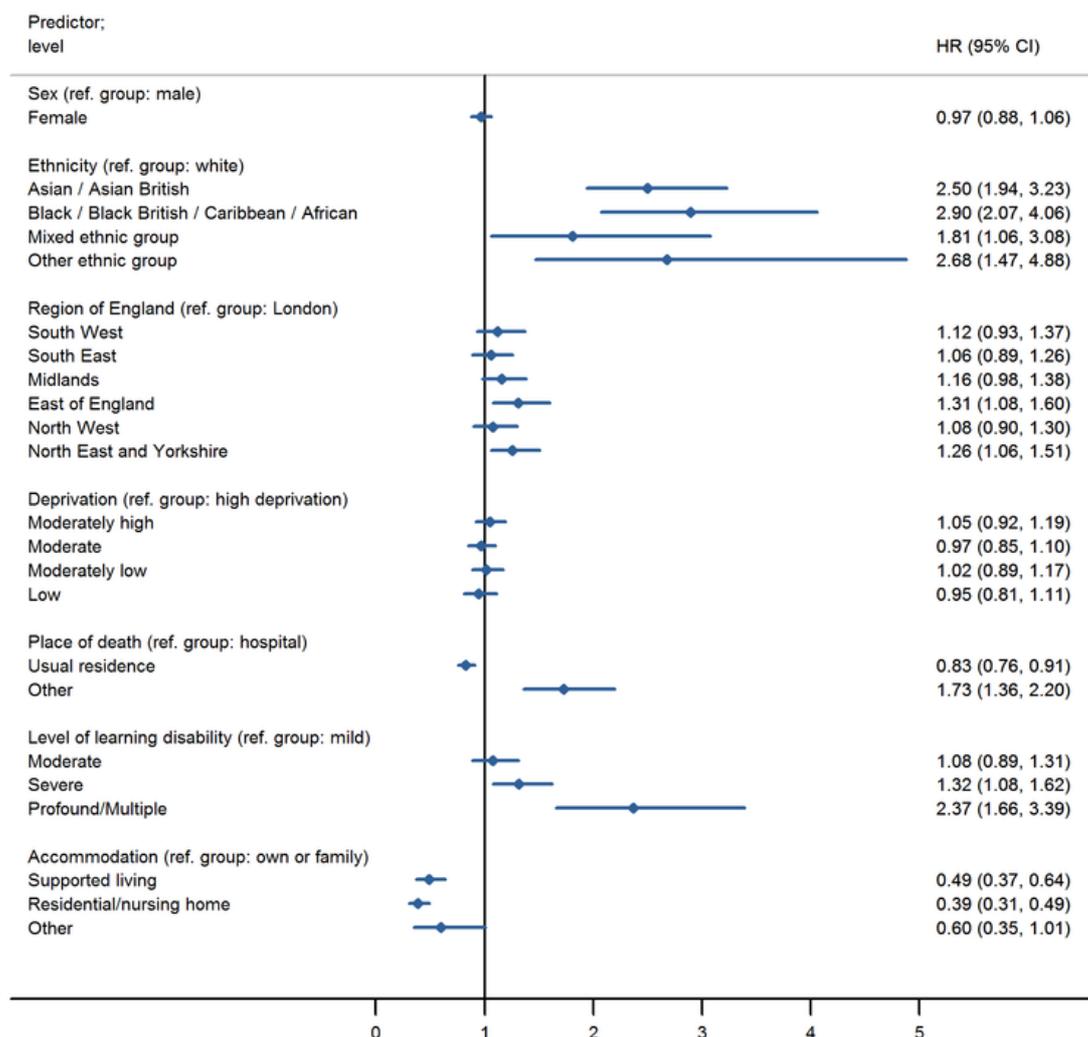
Variable	Level	Total (number, %)
Annual health check* (in past 12 months; number, %)	Yes	232 (47%)
	No	88 (18%)
	Unknown	178 (36%)
Care package met needs*	Yes	407 (82%)
	No	91 (18%)
Deprivation of liberty safeguards* (number, %)	Applied for	37 (7%)
	Approved	126 (25%)
	No	297 (60%)
	Unknown	38 (8%)
Out of area placement*	Yes	49 (10%)
	No	441 (89%)
	Unknown	8 (2%)
Quality of care rating*,**	1	8 (2%)
	2	66 (13%)
	3	101 (20%)
	4	136 (27%)
	5	165 (33%)
	6	22 (4%)

\*Recorded as part of a focused review (498 people had focused reviews); all other information recorded as part of an initial review.

\*\*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).

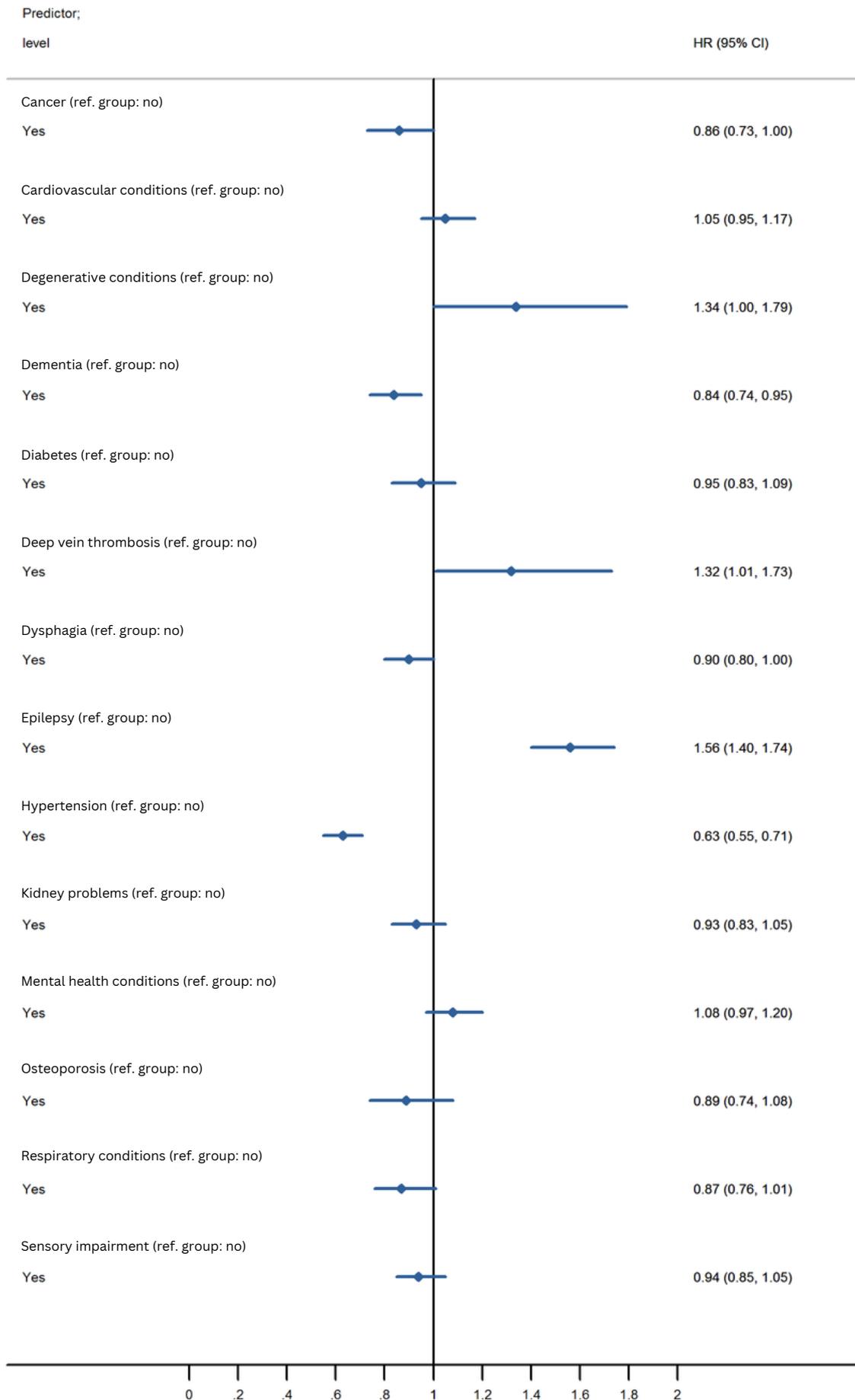
Of the demographic variables, ethnicity was strongly associated with age at death ( $p < 0.001$ ), with the hazard ratio being greater than two for people from ethnic minority backgrounds (black, black British, Caribbean or African and Asian British) compared to those who are white (Figure 3.2). The severity of learning disability is unknown in nearly 66% of cases (Table 3.2). Of the cases where the grading level of disability is known, roughly a third are recorded as having either mild, moderate or severe, with a minority recorded as profound/multiple. Level of learning disability was associated with age at death ( $p < 0.001$ ) with the greatest hazard of death amongst those with a severe or profound/multiple learning disability (Figure 3.3). There was a statistically significant association between place of death and age at death ( $p < 0.001$ ). The hazard was lowest for people who died in their usual residence and greatest for those who died in an 'other' place. There was a weak association between a region of England and age at death ( $p = 0.04$ ), with the greatest hazard of death amongst those in the East and North East and Yorkshire. There was no statistical evidence of an association between either sex or deprivation and age at death.

**Figure 3.2.** Forest plot showing associations (hazard ratios) between demographic predictor variables and age at death. 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.



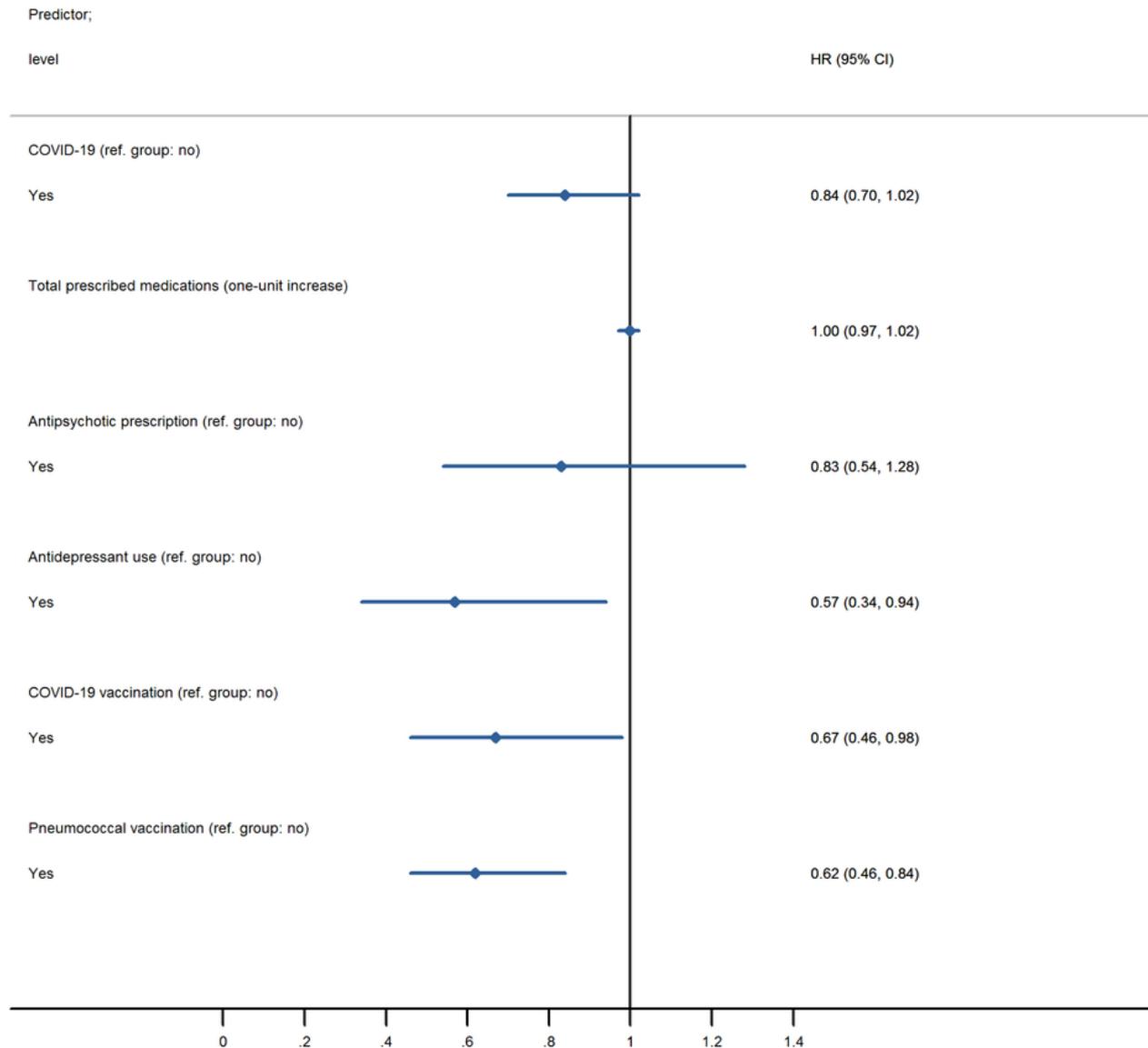
Of the clinical predictor variables, there was strong statistical evidence that epilepsy (HR 1.56, 95% CI 1.40, 1.74,  $p < 0.001$ ) was associated with a greater hazard of death (i.e. younger age at death), after adjusting for sex, ethnicity, region, deprivation, place of death, level of learning disability and type of accommodation (Figure 3.3, overleaf). In addition, there was weaker evidence that having a deep vein thrombosis (DVT) ( $p = 0.04$ ) and degenerative conditions ( $p = 0.05$ ) were associated with a greater hazard of death. High blood pressure (HR 0.63, 95% CI 0.55, 0.71,  $p < 0.001$ ) and dementia (HR 0.84, 95% CI 0.74, 0.95,  $p < 0.01$ ) were found to be associated with a lower hazard of death (i.e. older age at death). There was some evidence that cancer ( $p = 0.06$ ), dysphagia ( $p = 0.05$ ) and respiratory illness ( $p = 0.07$ ) were also associated with lower hazard of death. There was no statistical evidence that cardiovascular conditions, diabetes, kidney problems, mental health conditions, osteoporosis or sensory impairments were associated with the hazard of death.

**Figure 3.3.** Forest plot showing associations (hazard ratios) between long-term condition predictor variables and age at death.



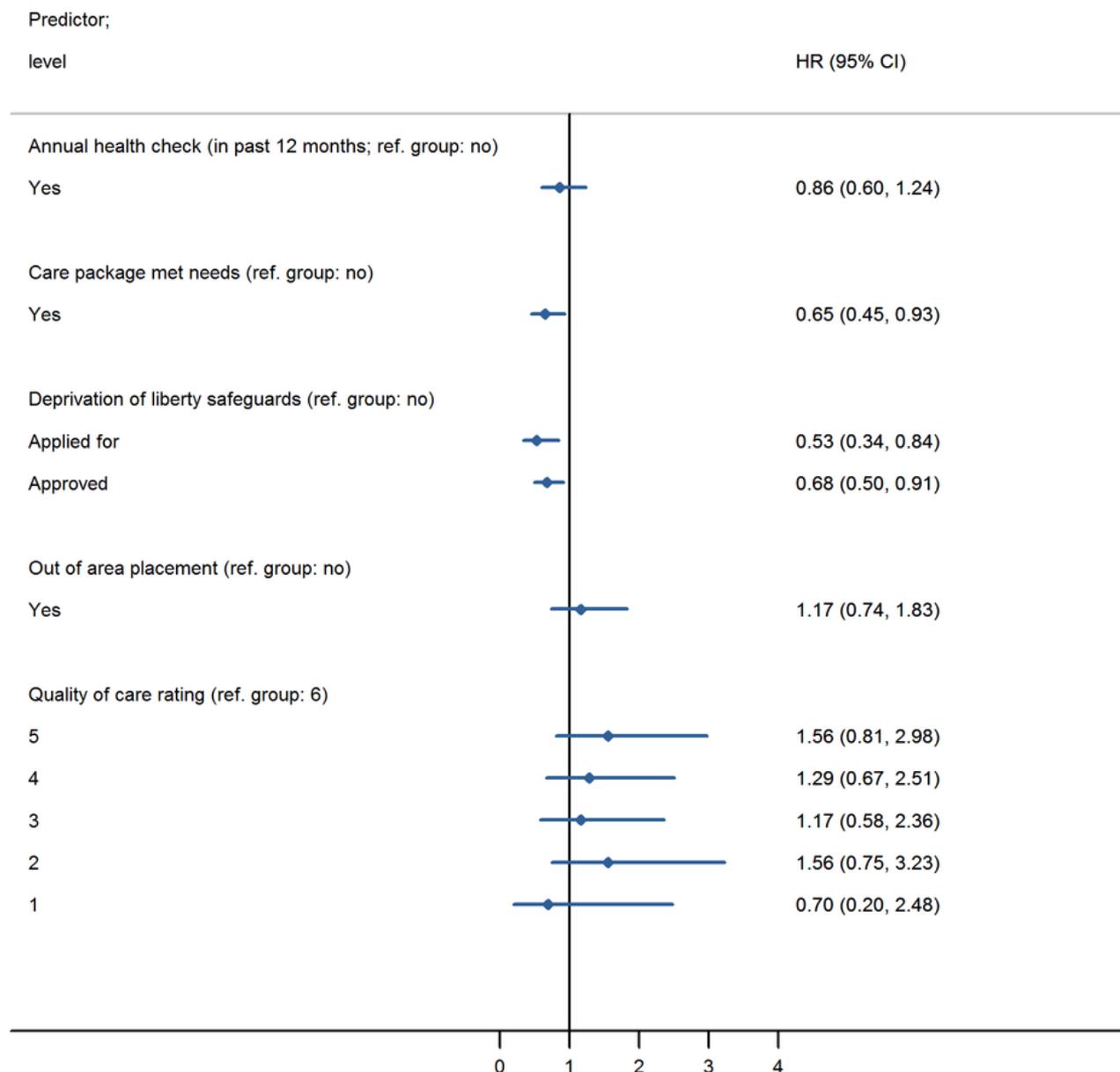
Of the other clinical variables, we found evidence that antidepressant prescription (HR 0.57, 95% CI 0.34, 0.94,  $p=0.03$ ), COVID-19 vaccination (HR 0.67, 95% CI 0.46, 0.98,  $p=0.04$ ), and pneumococcal vaccination (HR 0.62, 95% CI 0.46, 0.84,  $p<0.01$ ) were associated with reduced hazard of death (i.e. older age at death; Figure 3.4). We found little statistical evidence for the effects of COVID-19 infection, total prescribed medications or antipsychotic prescription on the hazard of death.

**Figure 3.4:** Forest plot showing associations (hazard ratios) between clinical predictor variables and age at death.



Of the social and care-related variables, we found that having a care package that met needs was associated with reduced hazard of death (HR 0.65, 95% CI 0.45, 0.93,  $p=0.02$ ) and Deprivation of Liberty Safeguards ( $p<0.01$ , see Figure 11 for estimated hazard ratios) were associated with reduced hazard of death, meaning an older age at death. There was no evidence of associations between annual health checks, out-of-area placement or quality of care rating, and hazard of death. See Figure 3.5.

**Figure 3.5:** Forest plot showing associations (hazard ratios) between social and care predictor variables and age at death.



## Looking forward

We found some evidence, for the first time, of an improvement in length of life for people who had LeDeR reviews. Our findings show that between 2018 and 2022, the median length of life for those who lived to at least 18 years old increased from 61.8 to 62.9 years. This improvement was seen despite the occurrence of the COVID-19 pandemic.

We used statistical modelling to explore factors associated with age at death. Using data from reviews of people who died during 2022, we found that ethnicity was associated with age at death. We found that people from ethnic minority groups were more likely to die at younger ages than those who were white. This finding is similar to that in previous years' reports. There is a need to understand better this inequality and the underlying factors driving the difference. Indeed there is some uncertainty about this finding given the nature of the study cohort.

We found that those who died not in either hospital or their usual place of residence were at increased risk of dying younger. This was also seen in last year's LeDeR report. This suggests that those who die in a variety of places, such as, outside or on vacation, are at increased risk of premature death. Further research as to why this is is required as for both years the data were small in comparison to the number of people who died at either their usual place of residence or in hospital, so the data is therefore limited.

Of the long-term conditions, epilepsy, deep vein thrombosis and degenerative diseases were associated with a greater risk of dying younger. Cancer, hypertension, dysphagia and respiratory diseases were associated with lower risk of dying at a younger age. However, it should be noted that the incidences of these illnesses/disorders are known to increase with age. The associations may reflect this, to some extent.

We found that appropriate care is associated with reductions in the risk of dying. For example, the effects of care packages that met needs and appropriate use of Deprivation of Liberty Safeguards to deliver care were seen to be associated with reduced risk of dying and therefore with older age at death. In addition, we have evidence that appropriate treatment and prevention of illness is associated with a reduction in premature deaths. For example, vaccination for COVID-19 and pneumococcus were found to reduce the risk of dying. With regards to the latter, there remains a need to optimise vaccination programmes, for example, prioritise people with a learning disability and consider age groups targeted for pneumococcal vaccination to include working-age adults with a learning disability.

## Clinical

- For the first time in LeDeR there is some evidence for improvement in the premature deaths for people with a learning disability over time, despite the COVID-19 pandemic.
- Appropriate care was associated with reductions in premature death. This is to say that care packages that meet needs, and appropriate use of DoLS to deliver care, are associated with reduced risk of premature death amongst people with a learning disability.
- Appropriate treatment and prevention is associated with a reduction in premature deaths. Vaccination for COVID and pneumococcus, were especially shown to be so.

## Research

- In keeping with previous LeDeR reports, people from ethnic minority groups died at younger ages compared to white people. Further research is needed to better understand the underlying reasons.
- Due to vaccination for COVID-19 and pneumococcus being shown to be associated with a reduction in premature deaths, further research into how to overcome these barriers for people to get vaccinated, and to optimise the targeting of vaccination programs to vulnerable groups, is suggested.

# Chapter 4

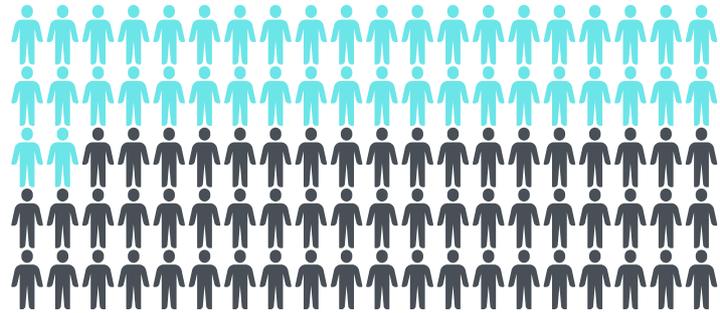


Avoidable Mortality

# KEY FINDINGS OF AVOIDABLE MORTALITY

## AVOIDABLE DEATHS

42% of deaths were deemed "avoidable" for people with a learning disability. This is a reduction from 2021 data, which found 50% of adult deaths were avoidable.



This compares to 22% for the general population.

42% of deaths were deemed avoidable

## Odds ratio of avoidable death for age groups



## AGE AND AVOIDABLE DEATHS\*

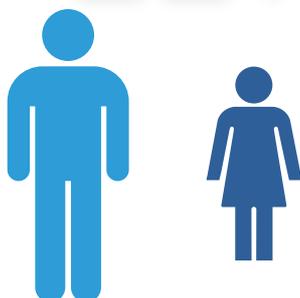
Deaths were more likely to be classified as avoidable with increasing age, peaking in the 25-49 age group before decreasing again for those who died over the age of 65 years.

\*note: deaths of people aged 75+ are defined by the OECD as not being avoidable.

## AVOIDABLE DEATH AND SEX

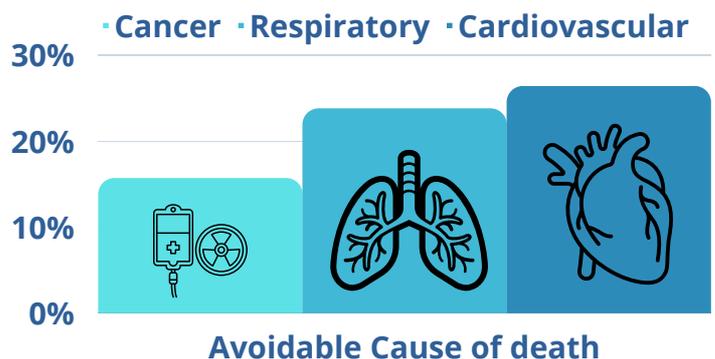
Men were found to be **22% more likely** to die from an avoidable cause of death than women.

+22%



## TOP 3 CAUSES OF AVOIDABLE DEATHS\*\*

26.4% of avoidable deaths were linked to cardiovascular conditions, 23.8% to respiratory conditions (excluding COVID-19), and 15.7% to cancers.



\*\*Unadjusted analyses.

# Avoidable mortality

## Introduction

In this chapter, we explore the factors associated with avoidable deaths by looking at the effects of demographic, clinical, and social and care variables on avoidable deaths for adults with a learning disability who were notified to LeDeR, and who had completed reviews for 2022. Avoidable deaths in this report are defined by applying the [OECD/Eurostat](#) list of preventable and/or treatable causes of death for people who are [less than 75 years old](#). This definition is [also used by the ONS](#) and is reproduced in Appendix 4.3. In essence, avoidable deaths are deaths where, if certain possible and reasonable steps were taken, then the death may not have happened in the way that it did, and it therefore can be classed as having been avoidable. This does not necessarily mean that there were failings of care, but that the person died from a cause of death that, if reasonable circumstances were different, they would likely not have died from. For example, COVID-19 is classified as an avoidable and preventable cause of death as preventative measures, such as vaccination or isolation, exist to limit this risk, whilst hypertension is classified as an avoidable cause of death as it can be tackled with methods to lower its risk, such as exercise and diet.

For this year's report on avoidable mortality, we have data on 2,054 adults (aged 18 and over) with a learning disability who died in 2022 and who had a completed recorded underlying cause of death. 853 (42%; 95% CI 39%, 44%) of these deaths were classified as avoidable. For contrast, in 2021 the percentage of avoidable deaths for adults only was 50% (49% was reported in the 2021 LeDeR report as this included CDOP deaths of people aged over 4 years and under 18 years old). This is notably larger than for England in the general population which, as of 2020, the [latest data available](#), is 22.8% for the entirety of Great Britain. For reference, per 100,000 of the general population, England recorded 256.6 avoidable deaths per 100,000. The most common causes of avoidable deaths overall, for adults aged 18-64; older adults aged 65 and older, and males and females are given in Table 4.1.

For details on how to interpret the data presented below, please see the "note for interpretation" below, and in [Chapter 3](#).

## Statistical analysis

We used logistic regression models to investigate the effects of predictor variables on avoidable causes of death. Such models estimate the effect of predictor variables on avoidable death using odds ratios. See note on interpretation for further information about odds ratios. We fitted univariable models (i.e. one predictor variable for each model) to estimate the unadjusted effects of each of the predictors. We then fitted three groups of models to estimate the adjusted effects of each of the sets of predictors. For these analyses, we first fitted models with variables that came from initial reviews and then, separately, fitted models with variables that came from focused reviews (which also included, i.e. adjusted for, the variables that came from initial reviews such as demographic variables). Therefore, the number of people in each analysis varied. The first of these groups of models included all demographic variables. The second included all long-term condition variables, adjusting for the demographic variables. The third included social and care-related variables, adjusting for the demographic and long-term condition variables. See [Chapter 3](#) for a list of these variables.

### Note for interpretation

The results are reported in the form of odds ratios (ORs), 95% confidence intervals (CIs), and p-values. To interpret this, an odds ratio of 1 suggests that there is no evidence of an association between two factors or events (for example, an ethnic background and an avoidable cause of death). An odds ratio greater than 1 suggests that a particular event (e.g. avoidable death) is more common in a particular group than it is in the reference group. An odds ratio of less than 1 suggests that the event is less likely in a particular group than it is in the reference group. For example, when looking at avoidable deaths amongst people from ethnic minority backgrounds and avoidable deaths, an odds ratio greater than 1 may suggest that people from a particular ethnic minority background (e.g. black, black African, Caribbean or black British ethnicity) are more likely to die from an avoidable death than someone from the reference group (e.g. people from white ethnic backgrounds), whilst an odds ratio of less than 1 may suggest that these people are less likely to die from an avoidable death. The further the estimated odds ratio is from 1, the greater the strength of the association. For further information about the interpretation of confidence intervals and p-values, see [Chapter 3](#). Below we will present the findings from our analyses, both adjusted for various factors and unadjusted (where applicable), as well as the raw percentages of avoidable deaths for various clinical conditions. We will indicate where we are using an unadjusted or adjusted analysis. Full Tables can be found in the appendix.

Overleaf are the unadjusted overall total numbers and percentages of avoidable deaths in 2022 LeDeR data (Table 4.1).

**Table 4.1:** Avoidable causes of death

3 most common occurring causes of avoidable death (overall grouped by ICD-10 disease categories) (number, %)	3 most common occurring specific causes of avoidable death (aged 18-64) (number, %)	3 most common occurring specific causes of avoidable death (aged 65+) (number, %)	3 most common occurring causes of specific avoidable death for males (males) (number, %)	3 most common occurring causes of specific avoidable death for females (females) (number, %)
Cardiovascular "I" codes (225, 26.38%)	COVID-19 (68, 11.91%)	COVID-19 (22, 7.80%),	COVID-19 (52, 10.70%)	COVID-19 (38, 10.35%)
Respiratory excluding COVID-19 "J" codes (203, 23.80%)	Epilepsy (41, 7.18%)	Pneumonia (21, 7.45%)	Pneumonia (41, 8.44%)	Epilepsy (27, 7.36%)
"C or D1-48" (Neoplasms "C or D1-48" codes) (134, 15.71%)	Pneumonia (41, 7.18%)	Bronchopneumonia (17, 6.03%)	Epilepsy (24, 4.94%)	Pneumonia (21, 5.72%)

### Ethnicity and avoidable cause of death

When looking into any potential differences related to ethnicity, data were very limited for people from ethnic minority backgrounds. For specific causes of death, this makes identifying trends for those from ethnic minority backgrounds impossible due to the need to protect the identities of people in our data due to such small sample sizes. When looking at grouped causes of death, the data are still small and results would need to be interpreted with caution as they may not be reflective of the wider population or true figures. In the data for 2022, people from ethnic minority backgrounds were reported in low numbers, which means that it is not always possible to report the full findings due to the risk of identifying individual people. We recognise that in LeDeR we are receiving lower numbers of data from people with a learning disability from ethnic minority backgrounds, and the reasons for this are complex and multifaceted. Efforts to address this are highlighted in the Race and Health Observatory report "[We Deserve Better](#)".

## Long-term conditions (LTCs)

Data were available on 14 major types of long-term conditions for 1,867 people. These are conditions that people had a diagnosis of during their life based on available medical history, rather than the cause of their death. Of the 853 adults who died from an avoidable cause of death, 42% of adults had a history of cardiovascular conditions, 41% a mental health condition, 37% had epilepsy, 33% had a sensory impairment, and 23% had a history of dysphagia. In the analysis adjusted for other factors, the data suggests that adults with cardiovascular conditions, and osteoporosis had significantly higher odds of dying from an avoidable cause. Dementia, dysphagia, and degenerative conditions were found to be associated with reduced odds of an avoidable death. There was no evidence of association between other conditions and odds of avoidable death, adjusting for other factors (see Table 4.2, significant results are highlighted in blue).

These findings differ somewhat from the findings in last year's report. In 2021, adjusted analyses showed that having cancer was associated with a higher chance of avoidable cause of death, which was not observed this year. This change may be related to differences in sample size, and perhaps the impact of the COVID-19 pandemic during 2021. Like last year however, dementia and dysphagia were shown to be significantly associated with reduced odds of avoidable death.

It is notable that degenerative conditions and dementia are all conditions that are typically linked with ageing, and an avoidable cause of death (under the OECD/Eurostat definition) is not possible for people over the age of 75 years of age. Furthermore, dementia and degenerative conditions are not deemed to be avoidable in the OECD definition, which may explain the relationship with lower rates of avoidable deaths.

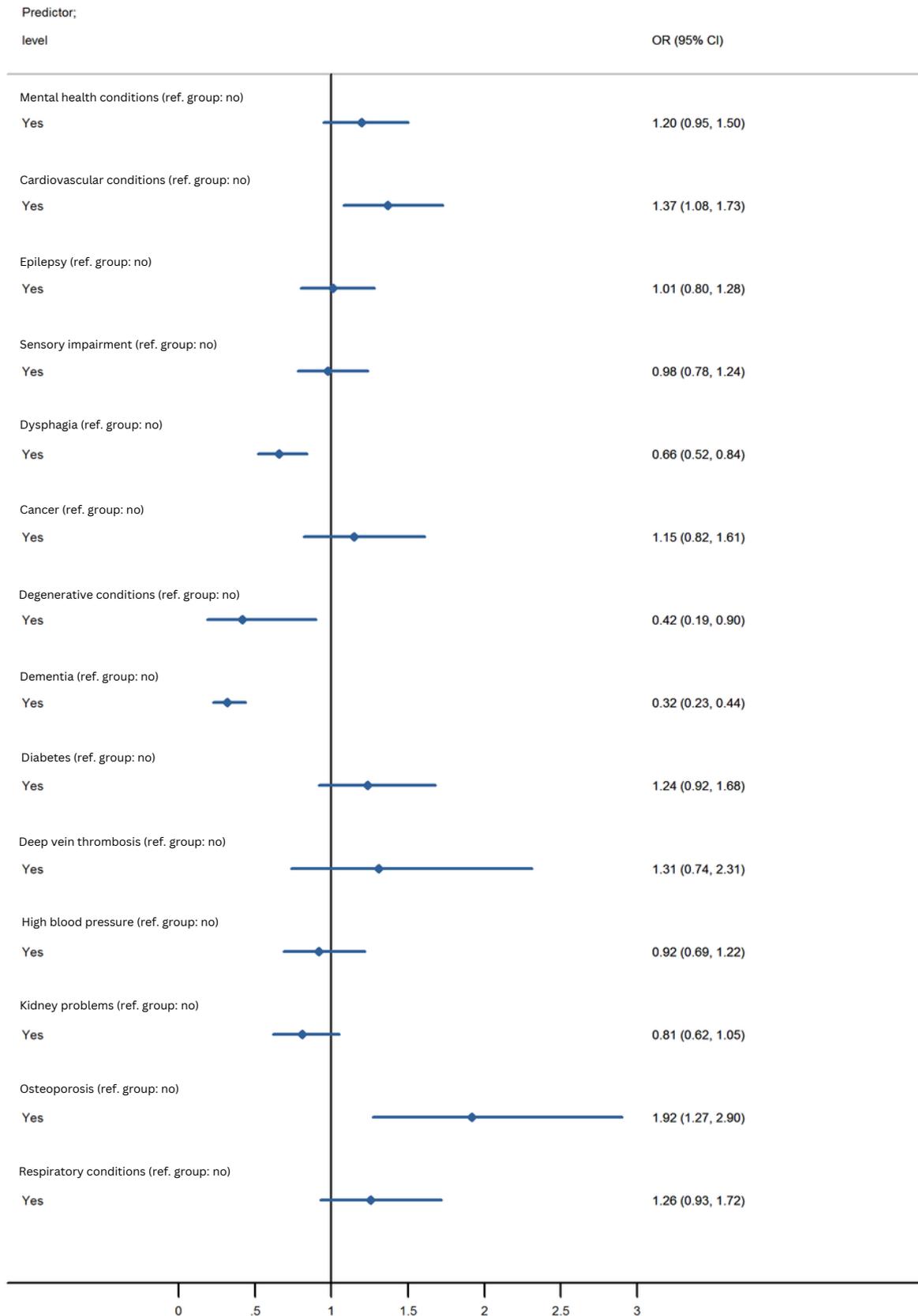
**Table 4.2:** Adults with a learning disability who died with a defined long-term condition in 2022.

Long Term Condition	Number and % of those deaths rated avoidable (number, %)	Adjusted odds ratio*	p-value	95% confidence interval
Mental health conditions	347 (41%)	1.20	0.124	0.95, 1.50
Cardiovascular conditions	354 (42%)	1.37	0.009	1.08, 1.73
Epilepsy	318 (37%)	1.01	0.937	0.80, 1.28
Sensory impairment	282 (33%)	0.98	0.894	0.78, 1.24
Dysphagia	198 (23%)	0.66	0.001	0.52, 0.84
Cancer	95 (11%)	1.15	0.416	0.82, 1.61
Degenerative conditions	13 (2%)	0.42	0.026	0.19, 0.90
Dementia	84 (10%)	0.32	<0.001	0.23, 0.44
Diabetes	149 (17%)	1.24	0.162	0.92, 1.68
DVT	34 (4%)	1.31	0.352	0.74, 2.31
High BP	173 (20%)	0.92	0.545	0.69, 1.22
Kidney problems	166 (19%)	0.81	0.115	0.62, 1.05
Osteoporosis	70 (8%)	1.92	0.002	1.27, 2.90
Respiratory conditions	133 (16%)	1.26	0.138	0.93, 1.72

\*Adjusted for all LTCs, sex, age, ethnicity, region, deprivation and place of death .

Figure 4.1, below, presents the above LTCs in graphical form. As can be seen, cardiovascular conditions and osteoporosis are shown to have higher ORs, suggesting an increased risk of dying from an avoidable death. Dysphagia, dementia, and degenerative diseases all show lower ORs.

**Figure 4.1:** Long-term conditions and avoidable deaths.



## Avoidable Mortality and Demographics

### Ethnicity

The adjusted analyses provided no evidence of an association between ethnicity and avoidable death (p=0.271). The greatest odds of avoidable death were for people from mixed and black, black British, Caribbean or African ethnic backgrounds. However, the numbers of deaths included in the analysis for all ethnic minority backgrounds were very small, resulting in large confidence intervals, meaning that we cannot be certain of their statistical validity. The fact that 94% of the sample were from white ethnic backgrounds made it unlikely that we would find statistical evidence of an association between ethnicity and avoidable death (see Table 4.3).

In the LeDeR data throughout the years, this pattern, although with small total numbers, has previously suggested people from black, black British, Caribbean or African or mixed ethnic backgrounds may be at more risk of death from an avoidable cause. More data is therefore needed to investigate whether this pattern is changing.

**Table 4.3:** Unavoidable and avoidable mortality risks for ethnicity backgrounds.

	Unavoidable death (number, % in relation to total for unavoidable death)	Avoidable deaths (number, % in relation to total for avoidable deaths)	Totals of each identified ethnicity (% overall total)	Adjusted odds ratio*	p-value	95% confidence interval
Asian or Asian British	42 (4%)	23 (3%)	65 (3%)	0.70	0.271	0.40, 1.22
Black, African, Caribbean or black British	18 (2%)	20 (2%)	38 (2%)	1.27		0.64, 2.52
White (our reference population as it is the largest sample)	1086 (94%)	768 (94%)	1,854 (94%)	1 (reference)	reference	-
Mixed ethnic background	7 (1%)	8 (1%)	15 (1%)	1.57	0.271	0.52, 4.70
Other	8 (1%)	<5 (<1%)	<10 (1%)	0.30		0.06, 1.48

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

## Place of death

Of those whose cause of death was avoidable, 484 (57%) died in hospital and 327 (38%) died at their usual residence. For those whose cause of death was not avoidable, 692 (58%) died in hospital and 477 (40%) died at their usual residence. In total, 57% of people died in hospital, 39% at home, and 3% in another location. There was little statistical evidence that place of death was associated with avoidable deaths after accounting for other factors ( $p=0.087$ ). With the place of death being at hospital as the reference category, the adjusted odds ratio for usual residence was 1.02 (95% CI 0.84, 1.24) and the adjusted odds ratio for 'other' was 1.79 (95% CI 1.15, 2.91). These are adjusted for sex, age, ethnicity, region and deprivation. Therefore, the people who died in hospital or usual residence have similar levels of avoidable deaths, however the people who die in an 'other' (in a place that is not their usual residence) place are at higher risk of avoidable death (see Table 4.4).

**Table 4.4:** Unavoidable or avoidable death risk compared to place of death.

Place of Death	Unavoidable death (number, % of overall unavoidable total)	Avoidable death (number, % of overall avoidable total)	Overall total (number, % of overall total)	Adjusted odds ratio*	p-value	95% confidence interval
Hospital	6921(58%)	484 (57%)	1,176 (57%)	1 (reference)	0.087	-
Usual Residence	477 (40%)	327 (38%)	804 (39%)	1.02		0.84, 1.24
Other	31 (3%)	40 (5%)	71 (3%)	1.79		1.07, 3.01
Total	1,200	851	2,051	-		-

\*Adjusted for sex, age, ethnicity, region and deprivation.

## Sex registered at birth

Of people who died from avoidable causes of death, 43% were female. Of the people who died from causes of death that are defined as not avoidable, 47% were female. The adjusted odds ratio for sex was 0.82 (95% CI 0.68, 0.99,  $P=0.036$ ) showing that the odds of avoidable deaths for females were therefore 18% lower than they were for males or, to put it another way, women were 18% less likely to die from an avoidable cause of death compared to men when adjusting for age, ethnicity, region, deprivation and place of death.

## Region

Whilst levels and adjusted odds ratios are slightly higher in some regions than others, once this is adjusted for sex, age, ethnicity, deprivation, and place of death there was no statistical evidence of a regional difference in avoidable deaths ( $p=0.376$ ) (see Table 4.5). Please note that, due to ONS regions being different from those used in LeDeR, we cannot give direct regional comparisons to the general population data. For ONS regional local authority data for the general population, [please see here](#).

**Table 4.5:** Number and proportion of avoidable deaths for people with a learning disability reported to LeDeR by region in England.

Region	Unavoidable death (number, % of overall total for England)	Avoidable death (number, % of overall total for England)	Overall total of deaths (number, % of overall total for England)	Adjusted odds ratio*	P-Value	95% confidence interval
North West	145 (12%)	118 (14%)	263 (13%)	1.04	0.376	0.71, 1.53
Midlands	276 (23%)	174 (20%)	450 (22%)	0.72		0.51, 1.02
London	123 (10%)	97 (11%)	220 (11%)	1		-
South East	206 (17%)	145 (17%)	351 (17%)	0.85		0.59, 1.22
East of England	129 (11%)	91 (11%)	220 (11%)	0.84		0.55, 1.26
North East and Yorkshire	193 (16%)	137 (16%)	330 (16%)	0.83		0.57, 1.21
South West	129 (11%)	91 (11%)	220 (11%)	0.81		0.54, 1.22

\*Adjusted for sex, ethnicity, region, deprivation and place of death.

## Age Group

Deaths were found to be significantly more likely to be classed as being avoidable with increasing age, up to the age of 75. Age was an important predictor in analyses that adjusted for sex, ethnicity, region, deprivation and place of death ( $p<0.001$ ). Similar to the findings for the 2021 data, the highest odds of avoidable deaths were seen in the adult and middle-aged groups (age 25-64 years), compared to younger and older people, with the odds ratios increasing for ages 25-49 years, remaining high for ages 50-64 years, before decreasing for those aged 65+ years. It should be noted that, by the OECD definition, people older than 75 years old are not included in the avoidable deaths calculation. In addition, as shown in Table 4.6, the 50-64-year-old group were roughly three times as likely to have a death classified as avoidable than those in the 18-24-year-old group.

**Table 4.6:** Age group and adjusted odds ratios for avoidable deaths.

Age group	Unavoidable death (number, % of unavoidable deaths)	Avoidable death (number, % of avoidable deaths)	Overall total (number, % of overall deaths)	Adjusted odds ratio*	p-value	95% confidence interval
18-24 years old	47 (4%)	19 (2%)	66 (3%)	1 (reference)	<0.001	-
25-49 years old	157 (13%)	163 (19%)	320 (16%)	3.19		1.70, 5.99
50-64 years old	375 (31%)	389 (46%)	764 (37%)	2.98		1.62, 5.48
65+ years old	622 (52%)	282 (33%)	904 (44%)	1.30		0.71, 2.40

\*Adjusted for sex, ethnicity, region, deprivation and place of death.

### Severity of disability and avoidable mortality

Data on the severity of a person's learning disability was available for 700 people who died in 2022. For the categories of moderate and severe learning disability, the overall percentages of avoidable and unavoidable deaths are comparable and suggest lower odds of dying from an avoidable cause of death the more severe the learning disability is (see Table 4.7). Note that for people with a “profound/multiple” learning disability, there are relatively smaller figures available, so our data must be interpreted for that group with more caution. The reasons for this are likely multifaceted, but may be in part to:

- People with a mild learning disability are less likely to be in supported settings where carers can monitor their health and safety to avoid avoidable deaths.
- People with a mild learning disability may not have as much support with accessing healthcare.
- People with a mild learning disability may be living more independently, which may result in them having less access to support and care than those with a moderate or severe learning disability.

**Table 4.7:** Severity grading of learning disability and odds of avoidable death.

Severity of learning disability	Unavoidable death (number, %)	Avoidable death (number, %)	Overall total (number, %)	Adjusted odds ratio*	p-value	95% confidence interval
Mild	119 (30%)	115 (39%)	234 (33%)	1 (reference)	0.001	-
Moderate	128 (32%)	96 (32%)	224 (32%)	0.73		0.49, 1.10
Severe	128 (32%)	77 (26%)	205 (29%)	0.48		0.31, 0.74
Profound/ Multiple	28 (7%)	9 (3%)	37 (5%)	0.25		0.10, 0.60

\*Adjusted for sex, ethnicity, region, deprivation and place of death.

## Deprivation

Deprivation ratings ([for information about the IMD data used, see Chapter 1](#)) were available for 2,045 deaths in the data. The findings suggest no evidence of an overall effect of deprivation on odds of avoidable cause of death ( $p=0.823$ ), with all odds ratios close to 1. Therefore, deprivation does not seem to be correlated with avoidable causes of death in this sample (see Table 4.8).

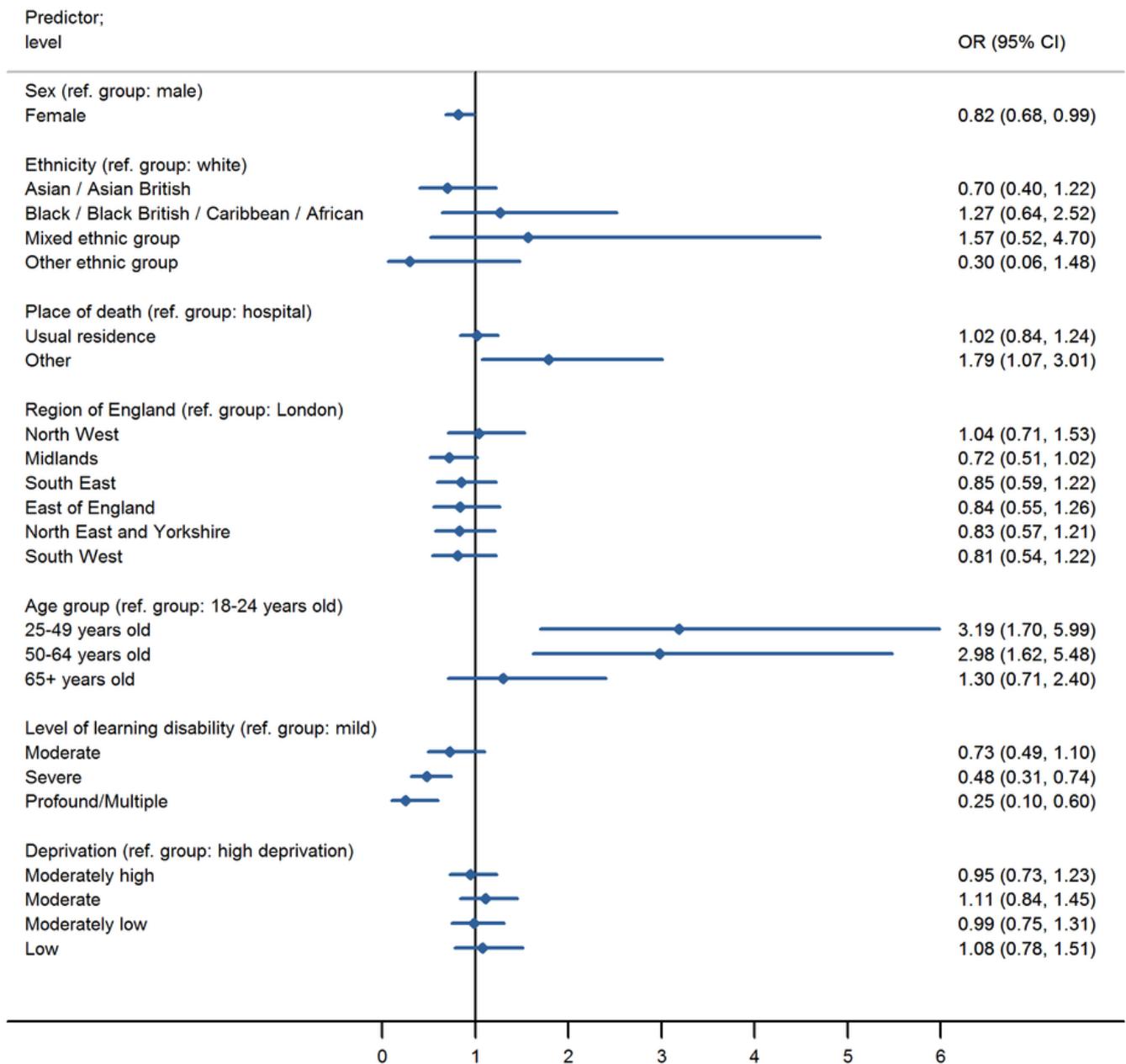
**Table 4.8:** IMD quintile and avoidable deaths.

IMD quintile	Unavoidable Death (number, % of unavoidable deaths)	Avoidable death (number, % of avoidable deaths)	Overall total (number, % overall)	Adjusted odds ratio*	p-value	95% confidence interval
High Deprivation	308 (26%)	216 (25%)	546 (26%)	1 (reference)	0.823	-
Mod-High deprivation	286 (24%)	193 (23%)	479 (23%)	0.95		0.73, 1.23
Moderate deprivation	244 (20%)	185 (22%)	429 (21%)	1.11		0.84, 1.45
Low-Moderate deprivation	230 (19%)	155 (18%)	385 (19%)	0.99		0.75, 1.31
Low deprivation	128 (11%)	100 (12%)	228 (11%)	1.08		0.78, 1.51

\*Adjusted for sex, ethnicity, region, deprivation and place of death.

Figure 4.2 below presents all the above demographic information in forest plot graphical form, in relation to each demographic factor and its respective HR and CI. As can be seen, age and place of death (other) present with higher HR's than other factors.

**Figure 4.2:** Demographics and avoidable death.



## Social and care variables

There was no statistical evidence of an association between quality of care ratings and avoidable cause of death ( $p=0.492$ ), adjusting for sex, age, ethnicity, region, deprivation place of death, long-term conditions, and other social and care variables (see Table 4.9). Of the 243 people who were classed as having avoidable causes of death, 30% had ratings of 5 (Good care -it met expected good practice). This was similar to those who were classed as having unavoidable causes of death (36%). Ratings of 6 (excellent care) and ratings of 1 (care fell short of expected good practice and contributed to the cause of death) were both relatively infrequent: 4% of those who were classed as having died from avoidable and 5% unavoidable causes of death received a rating of 6, and around 1% of those with avoidable or unavoidable causes of death received a rating of 1.

**Table 4.9:** Quality of care ratings and avoidable deaths.

Quality of Care rating	Unavoidable cause of death (number, %)	Avoidable cause of death (number, %)	Total number and respective % of rating	Adjusted odds ratio*	p-value	95% confidence interval
1	<5 (1%)	<5 (1%)	6 (1%)	-	0.492	-
2	28 (11%)	37 (15%)	65 (13%)	0.81		0.17, 3.93
3	41 (17%)	59 (24%)	100 (20%)	1.45		0.31, 6.72
4	73 (30%)	61 (25%)	134 (27%)	0.70		0.17, 2.99
5	88 (36%)	74 (30%)	162 (33%)	0.77		0.18, 3.26
6	12 (5%)	10 (4%)	22 (4%)	1 (reference)	base	-
Total	246	243	489			

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).

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

## Place of Usual Residence

The analysis gave no evidence that place of usual residence was associated with avoidable cause of death ( $p=0.147$ ), adjusting for sex, age, ethnicity, region, deprivation and place of death (see Table 4.10). The analysis suggested that the odds of dying from an avoidable cause of death were very similar for people who live in their own or family home and those who live in places in the “other” category. The results suggest that, for both a supported living environment and for a residential/nursing home, the odds of dying from an avoidable cause of death were somewhat lower but this was not shown to be statistically significant.

**Table 4.10:** Place of usual residence and avoidable deaths.

Place of Usual Residence	Unavoidable Cause of death (number, % of unavoidable deaths)	Avoidable cause of death (number, % of avoidable deaths)	Total (number and respective % of overall deaths)	Adjusted odds ratio*	p-value	95% confidence interval
Own or family home	158 (66%)	82 (34%)	240 (33%)	1 (reference)	-	-
Supported living arrangement	100 (65%)	54 (35%)	154 (21%)	0.80	0.147	0.44, 1.45
Residential/ Nursing home	212 (69%)	96 (31%)	308 (42%)	0.57		0.34, 0.96
“Other”	19 (63%)	11 (37%)	30 (4%)	1.08		0.35, 3.35

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

## Did the care package meet the needs of the person?

Of the 489 who had data available for a care package and whether or not their needs were met, 243 died due to an avoidable cause of death, of which 194 (80%) were rated as having a care package that met their needs. This contrasts with 246 of those who died from an unavoidable cause of death, of which 207 (84%) of those 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 at the time of death.

## Annual Health Checks

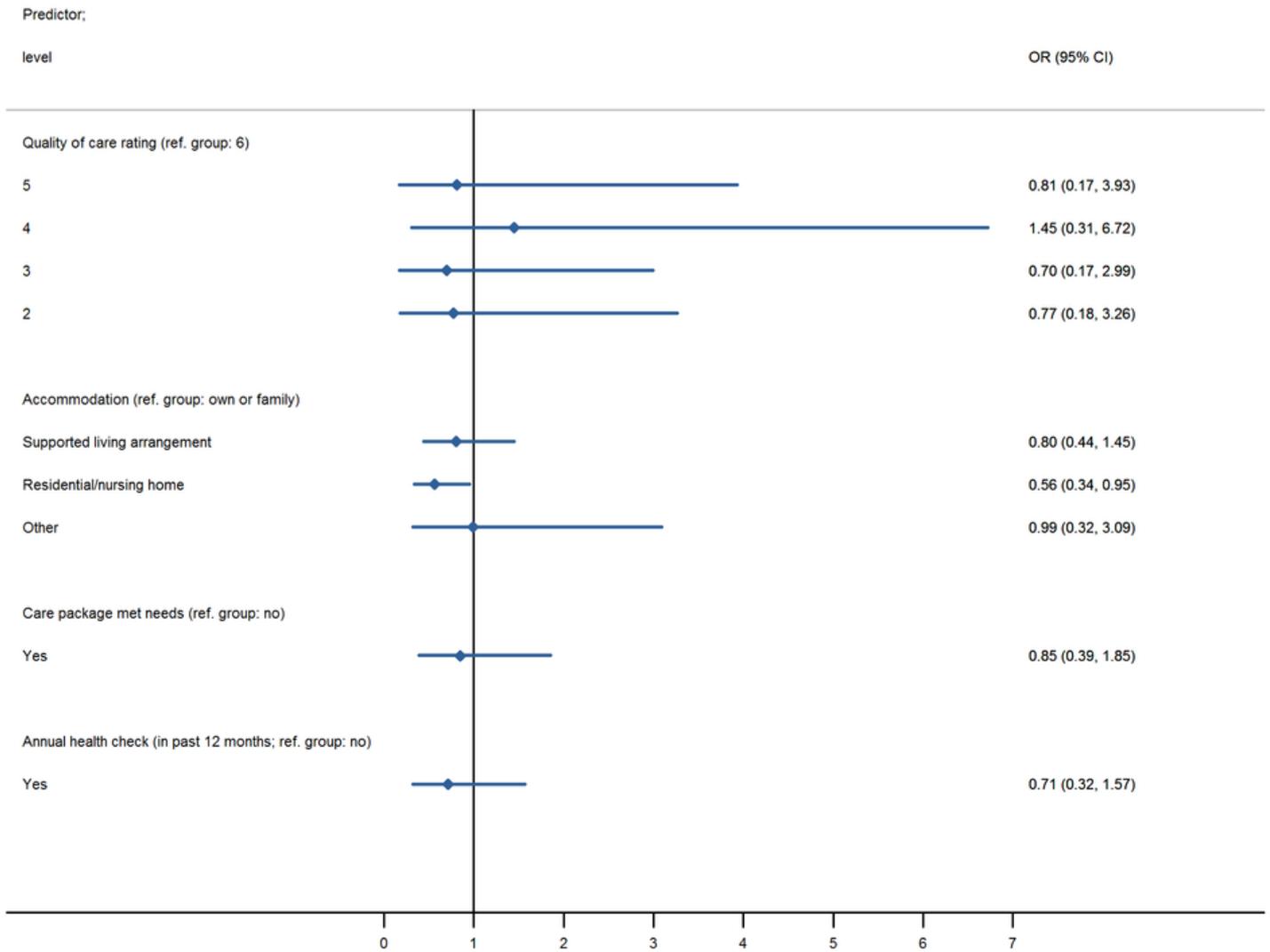
315 people were found by LeDeR reviewers to have data for whether or not they had an annual health check in the 12 months preceding their deaths. Of those, 72% were found to have had an annual health check (see Table 4.11). When comparing those who died from an avoidable death compared to those who died from an unavoidable death, the proportions who received an annual health check were very similar. The results therefore suggest there is little difference in the likelihood of avoidable death between people who had an annual health check in the 12 months before their death and people who did not. However, it must be noted that annual health checks have been shown to result in the identification of undiagnosed problems, and likely have an effect on outcomes over a longer period of time. Even though this year's data has not shown a difference in the likelihood of avoidable death between those who received one and those who did not before their death, it does not account for all of the benefits of an annual health check. The LeDeR data on annual health checks is limited to the year prior to death and needs to be considered over a longer period of time. We are not able to investigate the effect on avoidable deaths of having regular health checks over longer periods of time in this data as this information is not collected beyond 12 months which means that, in this data, we cannot determine if the provision of annual health checks throughout life contribute to a reduction in avoidable deaths or not. [NIHR is in the process of reviewing effectiveness evidence in relation to annual health checks for people with a learning disability.](#)

**Table 4.11:** Annual health checks and avoidable deaths.

Annual Health Check in the past 12 months	Unavoidable (number, % of unavoidable deaths)	Avoidable (number, % of avoidable deaths)	Total (number, % of overall deaths)	Adjusted odds ratio*	p-value	95% confidence interval
No	43 (28%)	44 (27%)	87 (28%)	1 (reference)	-	-
Yes	108 (72%)	120 (73%)	228 (72%)	0.71	0.401	0.32, 1.57
Total	151	164	315			

Figure 4.3 below presents the above social and care quality information in graphical form.

**Figure 4.3:** Social and care quality and avoidable deaths.



## Summary

42% of adults with a learning disability who died in 2022 and received a LeDeR review died from an avoidable cause of death in 2022. This is a lower percentage than last year, which found 49% of people died from an avoidable cause of death. There are several potential reasons for this, including the decrease in COVID-19 deaths in 2022. COVID-19 is classed as an avoidable cause of death, and due to factors such as vaccinations, overall deaths due to COVID-19 have decreased in 2022 in comparison. However, this figure is still significantly higher than for the general population of Great Britain, which in 2020 (the latest data available) [reported 22.8% of deaths for the general population were avoidable \(22.5% were reported as avoidable in 2019 in comparison\)](#). While the percentage of deaths attributable to COVID-19 has decreased by around 13%, this decrease is greater than the 7% decrease in avoidable deaths, suggesting that other factors are having an impact on the higher levels of avoidable deaths in people with learning disability compared to the general population. Overall, our data suggests that twice as many people with a learning disability died from an avoidable cause of death than in the general population during 2022.

Altogether, the factors that were found to be significantly associated with avoidable deaths in the LeDeR 2022 data when other factors were accounted for were:

- Age - the highest odds of dying from an avoidable cause of death were for the 24-49 age group.
- Sex - being male resulted in a 22% more likely risk of dying from an avoidable cause of death than being female.
- The severity of learning disability - lower odds of avoidable death were seen with greater severity grading of learning disability.

For long-term conditions that were associated with a greater risk of dying from an avoidable death, the most significant were:

- Cardiovascular conditions.
- Osteoporosis.

Long-term conditions that were shown to not be significantly associated with dying from an avoidable death were:

- Dysphagia.
- Degenerative conditions.
- Dementia.

## Looking forward

### Interpretation and suggestions for improvement for further research

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

1. Prevention and better management of avoidable and long-term conditions in adults, particularly the age group 25-49.
2. Improving management of specific long-term and recurrent conditions, particularly cardiovascular conditions and osteoporosis.
3. Addressing reasons for the increased risk of dying from an avoidable death in males compared to females.

Comparisons with the data between this and previous years suggest that the impact of the COVID-19 pandemic, both the illness itself but also its overall impact on healthcare, has had a significant effect on the avoidable mortality for adults with a learning disability. It remains to be seen whether this finding will change over time.

### Research

- Continue to identify methods to increase data collection of more marginalised groups amongst people with a learning disability, particularly regarding ethnicity, to be able to draw better conclusions and comparisons with other groups.
- Improve data collection on COVID-19 (and other) vaccination status in the LeDeR data, to enable greater investigation into vaccination status and avoidable deaths.
- Further investigate the long-term impact of COVID-19 on avoidable mortality. Is the current data showing a decrease in avoidable mortality due to the decrease in COVID-19 deaths, or are other factors impacting this figure?
- Further research is required to establish the long-term effectiveness and impact of the learning disability annual health check.

### Care and Services

- Avoidable deaths appear to increase around the age of 50, so earlier interventions for preventable and avoidable causes of death may be necessary. These may include earlier screening ages, continued prioritisation for and awareness of vaccinations, and ongoing provision of annual health checks.
- Improve prevention and care pathways of specific LTCs such as cardiovascular and osteoporosis.

# Chapter 5



Quality of Care

# KEY FINDINGS ABOUT QUALITY OF CARE

## DATA

The findings in this chapter are based on 563 focused reviews of deaths in 2021 and 503 focused reviews of deaths in 2022. We looked at what reviewers said about the quality of care of the person with a learning disability who died.

## CARE PACKAGE

**8 out of 10** of reviewers indicated that the **care package provided met the needs of the individual** in deaths in 2022.



## PROBLEMS WITH CARE

**Organisation systems and processes** were the most commonly reported area of problems with care.



## CONCERNS ABOUT QUALITY OF CARE ARE REDUCING

Concerns with care were expressed in **39%** of deaths which occurred in 2021 and **25%** deaths in 2022



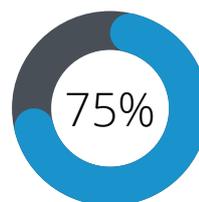
## EVIDENCE OF GOOD PRACTICE



9 out of 10 reviews included evidence of good practice.

## REASONABLE ADJUSTMENTS

Personalised reasonable adjustments were highlighted as crucial tools to support people.



## THE MENTAL CAPACITY ACT

The Mental Capacity Act was correctly followed in three-quarters of deaths in 2022 where it was deemed relevant.

# Quality of Care

## Introduction

A number of questions in the LeDeR review provide indications of the quality of care that a person received. Data from those questions are presented in this chapter. 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 completing the review. Reviewers are not limited to reporting the care received immediately prior to death or to evaluating any one organisation's input. Thus, the data here take a person-centred approach and broadly reflect most aspects of the care that a person with a learning disability who has died had received. This chapter includes data about people with a learning disability and people with a learning disability who were autistic.

## Methods

### Data source

Data in this chapter are taken from LeDeR-focused reviews. This is to ensure consistency with the LeDeR 2021 annual report and because most questions concerning quality of care are included only in these more detailed reviews.

Focused reviews account for approximately one-third of all reviews. Focused reviews are undertaken where:

- The reviewer finds areas of concern or significant learning points following the initial review.
- The person is from an ethnic minority background.
- The person had been under mental health or criminal justice restrictions at the time of death or within the 5 years prior to death.
- The person was autistic with no diagnosis of learning disability (data from these reviews are not reported in this chapter, see [Chapter 7](#) for more details).
- Where the family have asked for a focused review to be carried out.

The findings from focused reviews are therefore not representative of all the deaths that are notified to LeDeR. For the same reason, it is not possible to make direct comparisons between data presented here and quality of care data gathered before 2021 due to changes to the LeDeR review format.

Many of the quality of care indicators presented here are simple questions that have a selection of pre-defined responses (e.g. Yes/No answers; quality of care rating from 1 to 6). In this case, results are tabulated or presented graphically. Findings from reviews of deaths occurring in 2021 are presented alongside reviews of deaths occurring in 2022.

We also include findings from two questions that ask the reviewer to describe areas of positive practice and concerns or issues with the care that people received. The reviewers typically provide short comments as responses to these questions. We summarised the responses to these questions using a structured form of analysis. We first categorised the positive practice or concern with care according to the setting, where this was evident from the comment. The settings were:

- Primary and community care (including hospital outpatient services).
- Hospital in-patient care.
- Social care.
- End-of-life care.

We then grouped the responses by the broad theme to create a matrix. The themes were pre-defined according to categories within the LeDeR review. The themes are:

- Equality and disability.
- Statutory duties.
- Quality of care.
- Care coordination.
- Information sharing and documentation.
- Skills, knowledge and competency.

We have summarised the responses in a short narrative. We have included a number of quotes reflecting both concerns with care and positive practice to both reinforce the learning that can be taken from the reviews to convey a small part of people's experience. We took a random sample comprising over half of the comments from all reviews of deaths occurring in 2021 and 2022 as the data source for this analysis. Reviewer comments were read independently by members of the LeDeR academic team, who then worked collaboratively to describe major themes in each category and to produce text that faithfully reported the data.

## Results

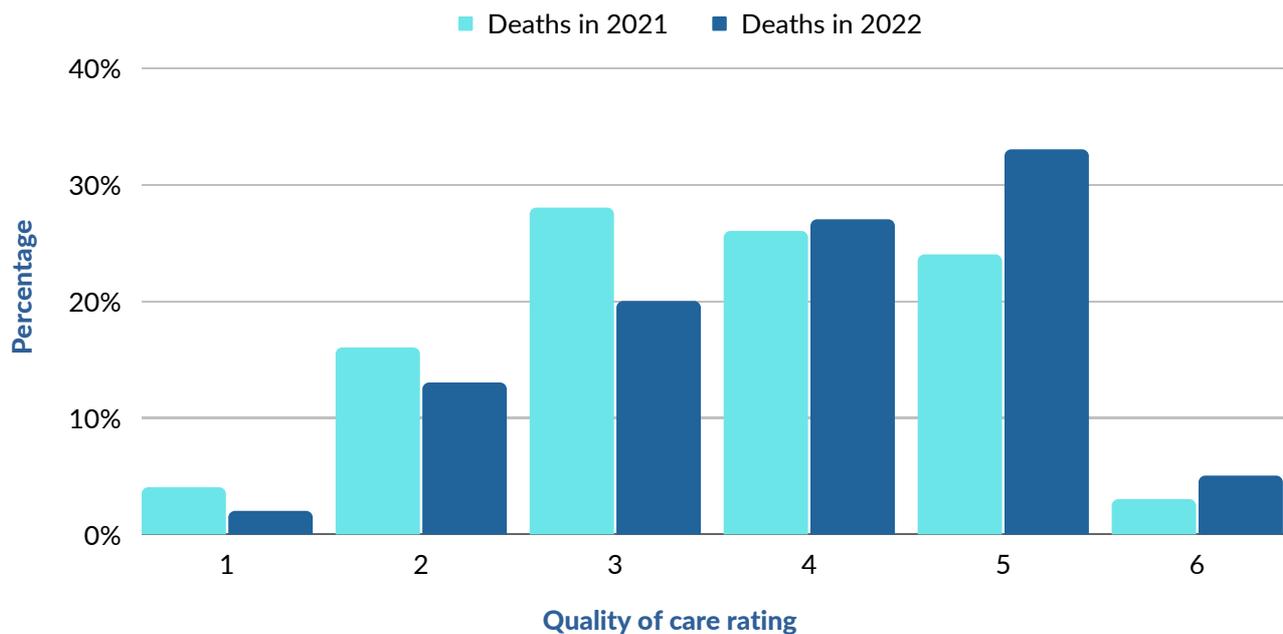
The findings of 1,067 focused reviews completed are reported in this chapter. This includes 563 focused reviews of deaths that occurred in 2021 and 504 focused reviews of deaths that occurred in 2022. All reviews looked at the lives and deaths of people with a learning disability who were aged 18 years or older when they died. A very small number of reviews did not have complete data and this is reported in the Tables.

## Overall quality of care

Reviewers are asked to rate the overall quality of care that a person received according to a six-point scale. The rating is a global judgement of the health and social care that was received and is not limited to the final period of illness or care provided in a single setting. The six-point scale is as follows:

- 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 well-being 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 well-being).
- 5 = Good care (met expected good practice).
- 6 = Excellent care (exceeded good practice).

**Figure 5.1:** Overall quality of care rating .



The vast majority of overall quality of care ratings were between 2 and 5 on the six-point scale. Only a very small proportion of people received care that was rated either as “falling short of expected good practice such that it contributed to the cause of death”, or as having been “excellent”.

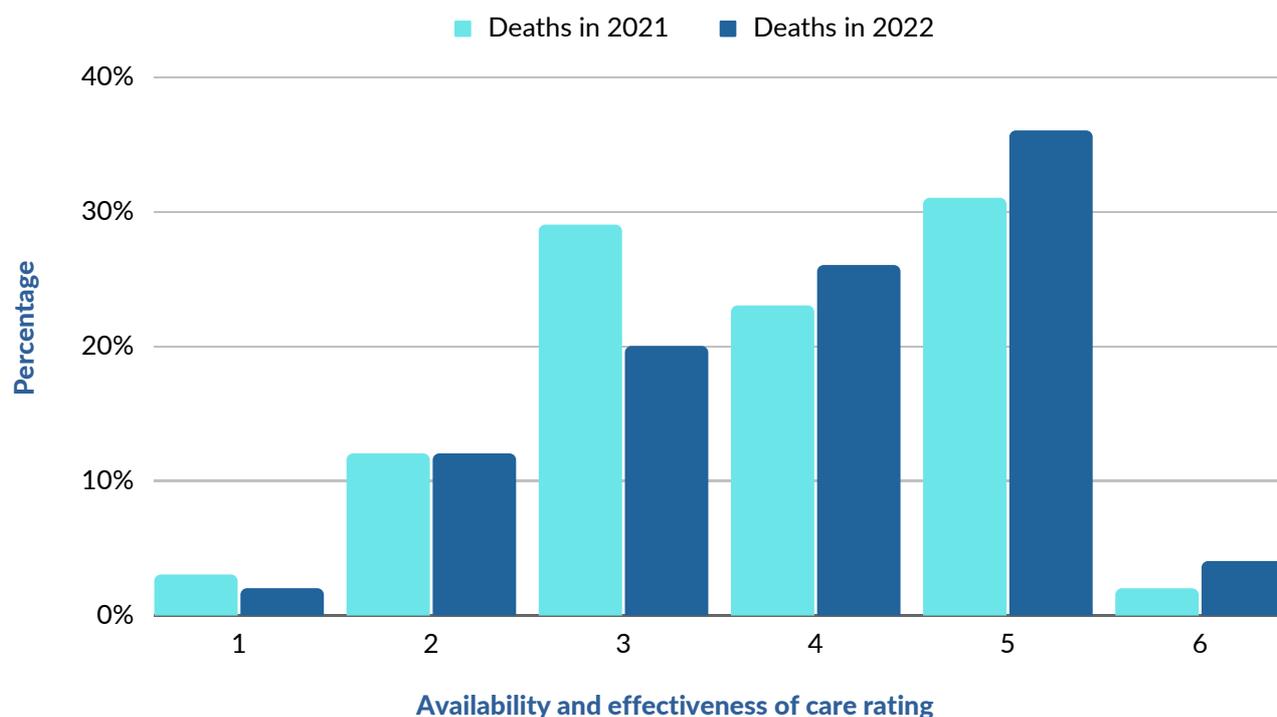
There appears to be a trend for higher ratings of overall quality of care in reviews of deaths occurring in 2022 compared with reviews of deaths occurring in 2021, with fewer people receiving the lowest ratings of quality of care. The proportion of reviews where the care contributed, or had the potential to contribute, to the cause of death (grading 1 or 2) was 19.7% in deaths occurring in 2021 and 14.7% in deaths occurring in 2022. See Table A5.1 in the Appendix for more detailed information.

### Availability and effectiveness of care

Reviewers also rate the availability and effectiveness of care on a scale between 1 and 6:

- 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 well-being 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.

**Figure 5.2:** Availability and effectiveness of care rating.



Again, the majority of reviews are allocated a grade of between 2 and 5, with very few reviewers judging the availability and effectiveness of services as either: “fell far short of the expected standard which contributed to the cause of death”, or was “excellent”. In keeping with the results of overall quality of care, there is a trend for higher ratings of availability and effectiveness of care in deaths that occurred in 2022 compared with those occurring in 2021. The proportion of reviews receiving the lowest ratings for availability and effectiveness of care has fallen and the proportion receiving higher ratings has increased. See Appendix 5.2 for full data.

### Identification of good practice

Reviewers are asked to indicate whether any good practice was identified in the care the person received. The response is selected from a number of available options. We have taken good practice to have been identified when any of the good practice options was selected and assumed that no good practice was identified when the box was left blank.

**Table 5.1:** Proportion of reviews with evidence of good practice.

Good practice identified by reviewer	Deaths occurring in 2021, (number, valid %)	Deaths occurring in 2022, (number, valid %)
Yes	452 (80.3%)	488 (96.8%)
No	111 (19.7%)	16 (3.2%)
Total (valid)	563 (563)	504 (504)

Good practice was identified in a greater proportion of reviews of deaths occurring in 2022 compared with deaths occurring in 2021. Almost all reviews now have some evidence of good practice in the care of the individual who died.

### Concerns about the death

The reviewer is asked if anyone has expressed concerns about the death. This may include anyone who participated in the review and the person who notified the death.

**Table 5.2:** Proportion of reviews where concern had been expressed about the death.

Concern expressed about the death	Deaths occurring in 2021, (number, valid %)	Deaths occurring in 2022, (number, valid %)
Yes, concerns	218 (38.8%)	127 (25.2%)
No / I don't know	344 (61.2%)	377 (74.8%)
Unrecorded	1	0
Total (valid)	563 (562)	504 (504)

### Review of care package

Reviewers are asked to judge whether the care package that a person receives met the needs of an individual. There has been an increase in the proportion of reviews in which the care package was judged to meet the needs of the individual to just over 8 in 10 deaths occurring in 2022.

**Table 5.3:** Proportion of reviews where the care package met the needs of the individual.

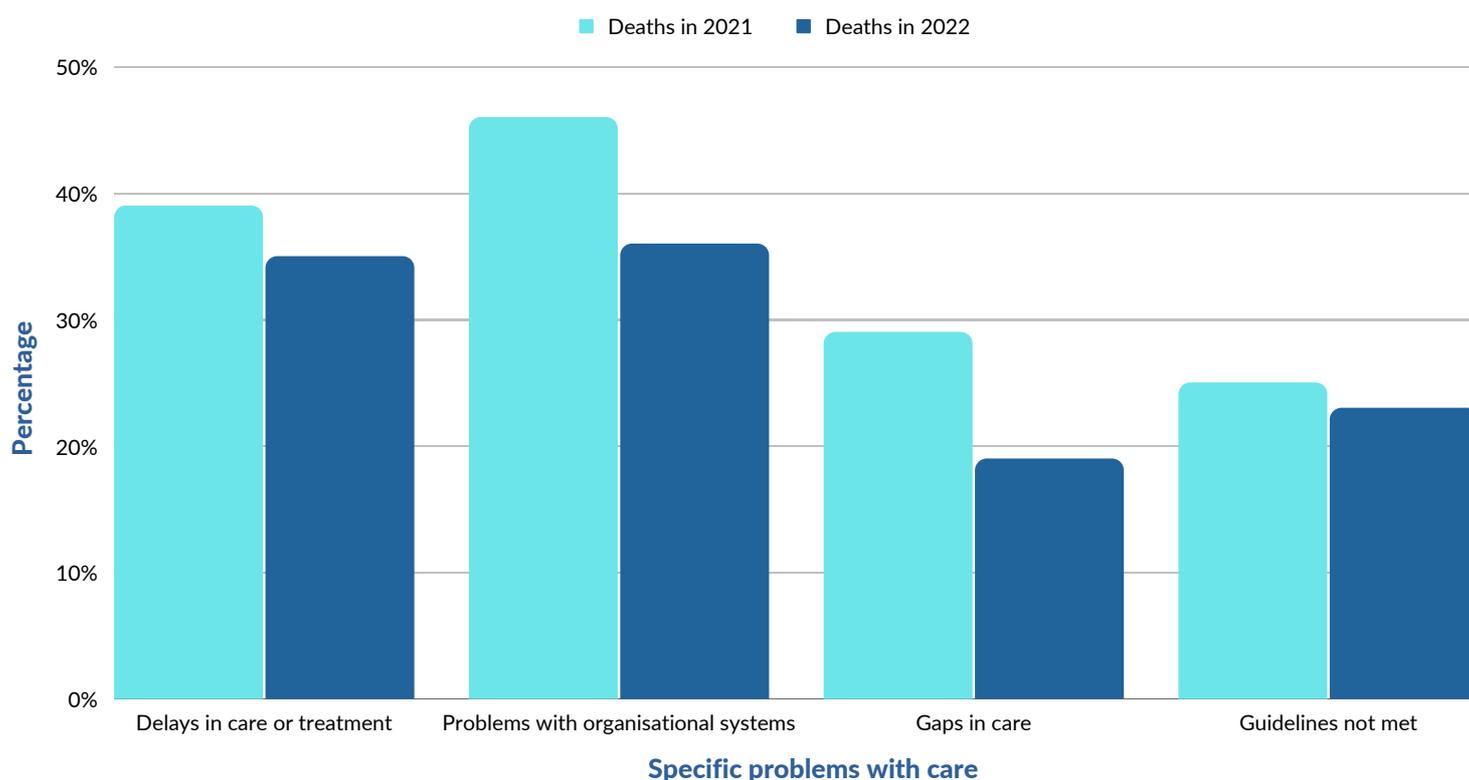
Care package meets needs	Deaths occurring in 2021, (number, valid %)	Deaths occurring in 2022, (number, valid %)
Yes	424 (74.4%)	412 (81.7%)
No	138 (24.6%)	92 (18.3%)
Unrecorded	1	0
Total (valid)	563 (562)	504 (504)

## Specific areas of problems with care

The LeDeR review asks about specific areas of care where there may have been problems. These are:

- Delays in care or treatment.
- Problems with organisational systems and processes (including the coordination of care).
- Gaps in service provision.
- Recommended diagnostic and treatment guidelines not being met.

**Figure 5.3:** Specific areas of problems with care.

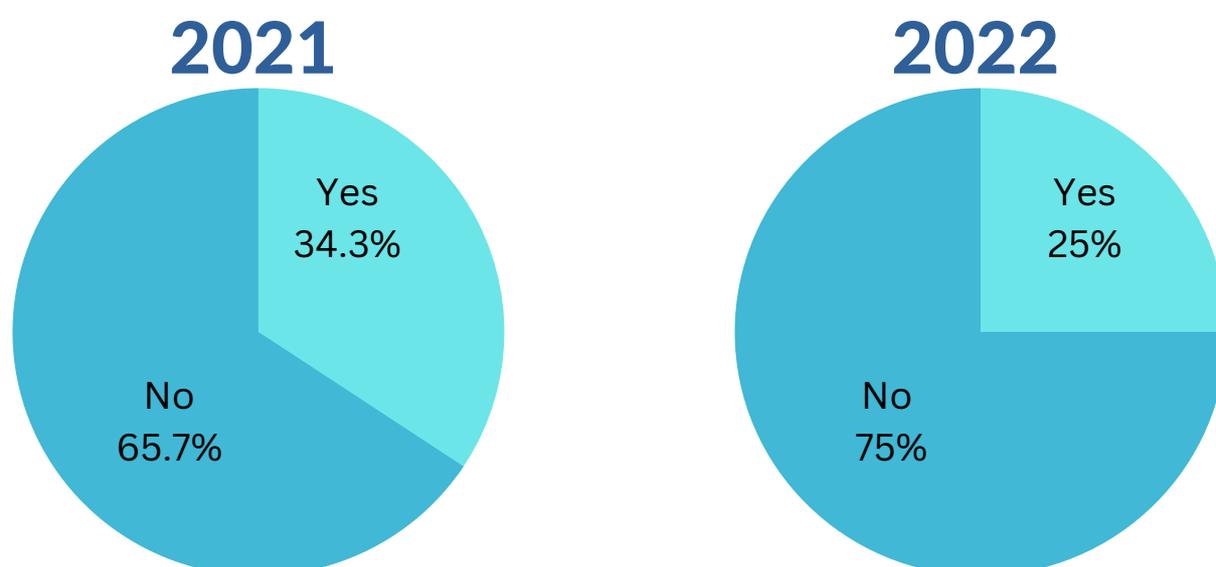


The most commonly reported problems were with organisational systems and processes. Overall, 42.1% of reviews of deaths in 2021 and 2022 were reported to have shown problems with organisational systems and processes. The least reported problem across reviews of deaths occurring in 2021 and 2022 was gaps in care, which were considered to have been present in 24.3% of cases. There appears to be improvement across these domains over the past two years. See Table A5.3 in the appendix for full data.

## Reasonable adjustments

The qualitative data analysis in the LeDeR 2021 report highlighted some areas of concern. One of these was in the provision of reasonable adjustments in hospital care and in primary care settings. The reviewer is asked whether any reasonable adjustments should have been made but were not, or if anyone mentioned any reasonable adjustments that should have been provided but were not. The data below show that reasonable adjustments were not made where they should have been in roughly one-third of deaths occurring in 2021, and in one-quarter of deaths occurring in 2022. See Appendix 5.4 for full data. NHS England defines “reasonable adjustments” as “to make it as easy for disabled people to use health services as it is for people who are not disabled” and has provided a definition and [guide to reasonable adjustments here](#).

**Figure 5.4:** Proportion of reviews in which reasonable adjustments to care should have been made but were not.

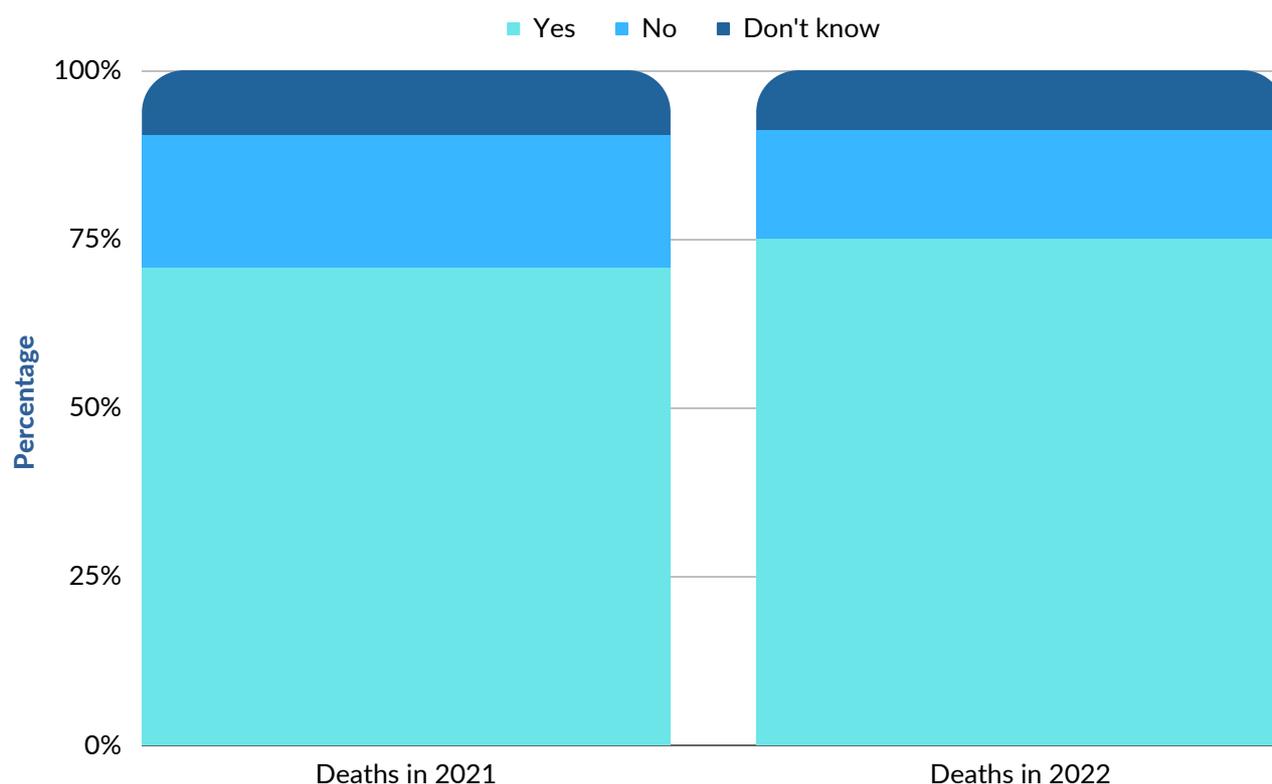


## Adherence to the Mental Capacity Act (MCA)

Also arising from the qualitative work in the LeDeR 2021 report were concerns about the application of the [Mental Capacity Act \(MCA\)](#) in cases where it should have been used.

The reviewer is asked whether the person needed a mental capacity assessment. Most people who died and received a focused review required a mental capacity assessment (78.5% of people who died in 2021 and 75.8% of those who died in 2022). Of those who required a mental capacity assessment (and excluding those who did not require a mental capacity assessment), the MCA was followed in 70.7% (deaths occurring in 2021) and 74.9% (deaths occurring in 2022) (Figure 18 and Appendix 5.5 and 5.6).

**Figure 5.5:** Proportion of reviews where the person required a mental capacity assessment and the MCA was followed.



## Issues with care and positive practice

Free text responses to questions about concerns with care and areas of positive practice and issues identified in reviews of deaths occurring in 2021 and 2022 were analysed as described above. The data presented here are intended to capture the main topics that were reported by reviewers; the section is not intended to be representative of all LeDeR reviews, and we must also remember that the qualitative data are taken only from focused reviews.

Relatively less data were available regarding positive practice compared with concerns with care. This may be because the reviewers found fewer notable examples of positive practice, or because they tended to highlight and focus on the areas where improvements are needed. There was insufficient data in some areas to report summarised findings and this was particularly the case in end-of-life care, although a number of issues and areas of good practice are likely to be common to all settings. As some of the quotes demonstrate, concerns or positive practice examples often cut across several of the themes.

Please note that some of the quotes in the following section have been chosen to highlight problems with care. If, in the course of the LeDeR review, any issues are raised that might result in any other person being put in danger, there is a duty under the [Care Act \(2014\)](#) to report this to the relevant safeguarding authority. For the LeDeR policy regarding safeguarding issues that may arise in the review process, please see [here](#).

## Equality and disability

### Areas of concern

In **primary and community care**, a lack of reasonable adjustments was a recurring theme. This included a lack of accessible communication and information which, in some cases, could limit individuals' access to healthcare:

*"[Name] received text messages from the GP which [their] mother states [they] would be unable to read"*

Primary and community care settings sometimes had inadequate equipment to cater to people with additional needs; a lack of hoisting facilities or of wheelchair scales was mentioned in reviews:

*"The GP surgery could not accommodate [Name] having a full examination due to not having a hoist or high low bed"*

Similarly in **hospital in-patient care**, a lack of reasonable adjustments was highlighted including fixed visiting times that prevented families or carers from staying with the person. Some reviewers mentioned that specific supports such as involvement of an advocate or a learning disability nurse, or specific information resources, were not utilised during the admission:

*"The acute learning disability team did not see [Name] as they had not been aware of their admission... they did not have a learning disability patient tracking alert at the hospital [although they] were known to community teams"*

**Across care settings**, cultural needs not being met were highlighted as one area of concern, including cases where language barriers affected the care that was provided.

*"[Name's] language was seen as a barrier...it is frequently recorded that they were unable to understand due to not speaking English"*

In **end-of-life care**, assumptions about a person's abilities and again a lack of reasonable adjustments was reported:

*"The person was recorded as not able to participate in discussion about end of life care due to learning disability"*

## Positive practice

As well as the concerns with lack of reasonable adjustments in some cases mentioned above, there were many reports of reasonable adjustments being implemented across the different settings of **primary and community care, hospital in-patient care, and social care**. The reasonable adjustments offered were diverse and personalised, and included; longer appointment times, adjustments to the sensory environment, acclimatisation visits to clinical spaces or home visits if preferred, delivering information in adapted formats, and welcoming family and carers to support the person:

*“The use of visual resources supported [Name] in successfully having their procedure”*

*“[Name] had a needle phobia and would not accept a blood test. [They] were referred to the home phlebotomy service...with support from staff [they] accepted [their] bloods being taken”*

*“[Name’s] mother was allowed to stay in the hospital and help with their personal care and eating and drinking, allowing [Name’s] particular needs and preferences to be catered for as much as possible”*

## Statutory duties

### Areas of concern

As in the LeDeR 2021 report, the main area of concern within the statutory duties category was lack of adherence to the MCA and its principles. In **primary and community care**, there were examples of lack of use of the MCA affecting several types of decision, including sometimes complex decisions around screening and preventative healthcare and treatment for long-term conditions.

*“[Name] was clinically vulnerable to infections but was frightened of needles...[they] did not have a flu jab for over ten years...[with] no evidence that a capacity assessment was carried out”*

In **hospital in-patient care**, issues related to Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) were raised as concerns in several cases. This included DNACPR decisions being made without consultation with the family or key professionals, decisions being made inappropriately on the grounds of a learning disability diagnosis “rather than any clinical condition”, and DNACPR orders and Advance Care Plans not being followed:

*“The DNACPR process was not followed resulting in [Name] receiving CPR due to lack of wrist band and incorrect information”*

Some reviewers flagged a lack of use of the MCA and of best interest decisions in cases in hospitals where these procedures were warranted. This also extended to **social care**, where decisions around accommodation and care placements did not always follow correct procedures.

### Positive practice

In contrast to those examples above in which the MCA was neglected, and where DNACPR processes were not followed, the positive practice data in this category was dominated by effective use of both of these mechanisms. In **primary care**, the MCA promoted thoughtful decision making:

*“[Name’s] brother was very much involved in best interest decisions and received timely communication from healthcare professionals”*

This was replicated in **hospital in-patient care** where there were accounts that “mental capacity assessments and consent procedures were completed fully for all procedures.” Hospital ethics committees were used in cases where there were conflicting views.

Good practice in applying the MCA was also achieved in **social care**:

*“The care home and social services department had detailed documentation of capacity assessments and had undertaken best interest decision making”*

## Quality of care

### Areas of concern

In **primary and community care**, a lack of, or delay in, investigation of health conditions was noted in some reviews which could have had serious implications:

*“the underlying cause of anaemia was never investigated and may have identified the malignancy earlier...there was an assumption that [Name] would not tolerate invasive procedures”*

*“Despite 33 GP consultations in the last year of [Name’s] life, they were not diagnosed with metastatic cancer until halfway through the year...”*

There was concern that people with a learning disability could automatically be discharged from care if they missed one appointment, with little consideration of the reasons for why they might have not attended.

Diagnostic overshadowing, where an underlying cause of a problem was inadequately investigated, was reported:

*“[Name’s] demeanour changed dramatically when they started experiencing difficulties with their bowels...the causes of these changes remained unknown and [they] were treated for the behaviour”*

There was also a theme of the inappropriate, or potentially inappropriate long-term use of medication, and medication reviews not being completed.

*“[Name] had been prescribed anti-psychotic medication for many years with no reason or diagnosis given. [There was] no evidence of this medication being reviewed”*

In **hospital in-patient care**, there could be delays in diagnosis and treatment:

*“[The] fracture diagnosis was made 12 days after the admission and 9 days after the X-ray was performed”*

*“[Name] was not given antibiotics until day 5 of admission despite the need being documented on day 1”*

There were also examples of inadequate care in hospitals in specific areas, including patients having multiple falls, missing pain relief, and having poor pressure-care.

In **social care**, there were some systems delays that caused delays in the provision of appropriate care to people living in the community:

*“[Name] was assessed as needing support...but a care package was not approved until 6 months later, and that care did not start because there was no agency to provide it”*

## Positive practice

In **primary care and community care**, there were many specific reports of high-quality care delivered by a range of professionals and encompassing physical and mental health conditions. For example, there was evidence of the use of advocacy and support and of “medication review in line with [\[Stopping over medication of people with a learning disability, autism or both\] STOMP](#)”. Treatment in **hospital in-patient care** could be “timely” and “very responsive, taking into account [Name’s] learning disability”:

*“[Name received] comprehensive medical care for their cancer throughout, from initial concerns until they reached palliative care”*

In **end-of-life care**, there were examples of responsive and person-centred care that respected wishes for preferred place of death and cultural wishes:

*“[Name’s] mother was full of praise regarding personalised and responsive care at the hospice...[There was] rapid response regarding pain and seizure relief and mother was given time to think through [Name] progressing towards the end of [their] life”*

## Care coordination

### Areas of concern

In **primary and community care**, the learning disability annual health check was sometimes reported to be “limited” and “brief” and a “missed opportunity” for promoting health and exploring long-term health conditions. There was a concern that not all annual health checks resulted in the development of health action plans or clinically indicated actions being undertaken.

Referrals to specialists were sometimes not made when the reviewer considered they would have been beneficial:

*“[Name’s] bleeding was not referred to a haematologist despite their platelet count being reported as below the normal range on a number of occasions”*

A further issue concerned the care of people with several complex health conditions where there could be a lack of joined-up thinking:

*“There was a lack of holistic oversight to ensure good communication between specialisms and a cohesive way of understanding [Name’s] health”*

In **hospital in-patient care**, issues were evident with discharge processes, such as discharge planning meetings not being held and care home staff not receiving discharge reports. In some cases, this was considered to have led to “failed discharge and readmission”:

*“[Name] was discharged from the hospital without [themselves] or [their] care provider being given clear information about what to do following [their] diagnosis...they were still awaiting confirmation of next steps when [they] were readmitted and died”*

In **social care**, delayed or missing reviews of care packages and a lack of future planning became especially problematic when people’s needs changed:

*“[Name’s] package of care was not reviewed despite concerns being raised that the care provider was struggling to meet their increasing needs. This resulted in [Name] experiencing abuse and neglect”*

*“Care took no account of the predictability of [Name’s] increasing frailty...[their] sister described [Name] as having a rich and full life, but [their] final years were full of fear”*

Further issues were raised with delays in obtaining funding for appropriate care placements.

In **end-of-life care**, issues arose when people did not receive end-of-life care planning or were not referred to palliative care teams at an appropriate stage in their illness.

### **Positive practice**

In contrast to the issues reported with annual health checks in **primary and community care**, there were examples of “high-quality learning disability health checks” and comprehensive health action plans. There were numerous examples of preventative care activities taking place.

Good communication between health professionals was at the heart of well co-ordinated care. This could be facilitated by having a team or a professional “taking a lead” on care.

In **hospital in-patient care**, the use of hospital passports was highlighted as a means of ensuring people’s needs were met during their admission. The varied activities of learning disability liaison nurses were important in ensuring the quality of care during the admission:

*“The learning disability liaison nurse made a thorough and well-documented appraisal of [Name’s] needs during admission, liaised effectively with family, and raised concerns and a safeguarding when concerns remained. They also convened a multi-disciplinary team meeting to discuss and address issues. They advocated for [Name] effectively and robustly during their admission”*

In **social care**, “good working relationships” and “open and accessible lines of communication” across agencies facilitated access to care and treatment. In contrast to the lack of future planning described above, there were examples where the changing needs of the person were proactively considered and attended to:

*“Regular reviews with [Name] and his father encouraged planning for the future. When [Name] could no longer attend the day centre due to deterioration in health, the staff made regular phone calls and home visits”*

The benefit of consistent care staff who knew people over time was emphasised as they were closely attuned to changes in presentation and how to manage these appropriately. In **end-of-life care**, multi-disciplinary team and “collaborative” approaches were especially helpful in allowing the person a death that was in keeping with their wishes:

*“The palliative care team were responsive to all of [Name’s] needs at the right time, and the GP, district nursing team, and learning disability team all worked together to provide a fantastic service which represents the ‘gold standard’ of palliative care”*

## **Information sharing, including family involvement and documentation**

### **Areas of concern**

**Across settings** there were issues with a lack of communication and involvement of the person’s family when significant decisions were made about their care:

*“Communication with the family was perceived as poor...a DNACPR was completed but not discussed with the family despite them being in regular contact to check on [Name] and they were not informed of [Name’s] positive COVID test for two days”*

There were also sometimes deficits in information sharing between **staff working in different parts of the health system, for example, sharing hospital passports between primary and secondary care**. Poor communication between NHS teams and paid carers also impacted care at points of care transition:

*“Care staff reported they could have been more supported with caring for [Name] after their surgery if specialist staff had interacted with them to ensure [Name] was receiving the right care”*

In the absence of direct communication, family members sometimes had to relay information between the hospital and community care staff.

In **primary and community care**, there was an issue with some patients not being recorded on the GP learning disability register which could result in people “not being flagged and having reasonable adjustments.” It was also noted that there were inconsistencies in the recording of health conditions between different record systems which could lead to people missing support:

*“Dementia was diagnosed in the hospital but not reflected in GP or social care notes and [Name] was not signposted or referred for support”*

### **Positive practice**

A number of accounts in **primary and community care** attested to strong and trusting relationships formed between health professionals and families:

*“The learning disability team formed an excellent relationship with [Name’s] family...they offered guidance, support, and help during [Name’s] treatment and up to the end of [their] life”*

There were several examples of family involvement in **hospital in-patient care** of relatives with a learning disability, with families feeling “involved in discussions” with “regular updates”:

*“Medical and nursing staff spent a lot of time discussing things with [Name’s] family... a doctor who spoke the same language explained the situation and an Iman was called to provide spiritual guidance”*

Similar examples of good practice were seen in social care and in end-of-life care:

*“[Name’s] mother felt included and valued as a partner in care planning and received excellent communication about end-of-life care”*

## Skills, knowledge and competency

### Areas of concern

In **secondary care**, there were reports of a lack of understanding of learning disability and of the requirements of patients by staff working in the acute hospital which impacted care:

*“[Name’s] brother reported a lack of understanding by hospital staff of [Name’s] baseline functioning and their communication and care needs”*

In **social care**, as highlighted in last year’s LeDeR report, there was sometimes poor knowledge and skills for health monitoring, particularly in recognising signs of potentially serious illnesses and clinical deterioration:

*“Staff in the care home and agency nurses were unfamiliar with signs of sepsis and signs of deterioration of this vulnerable person”*

There were some reports that specialist “advice was not always followed” including advice from the learning disability liaison nurse (secondary care) or from NHS 111 (social care).

### Positive practice

In **primary and community care** and hospital in-patient care there were numerous examples of professionals who were singled out for praise by reviewers and family members:

*“A student nurse provided support and care to relative over and above what would normally be expected”*

*“The residential home manager noted how helpful and responsive the GP practice was. The GP knew [Name] well. Additionally, [they] received weekly phone calls from the GP practice even throughout the pandemic”*

Praise was also extended to social care staff:

*“Exceptional care provided by the care manager and [their] team throughout [Name’s] life (as described by [their] father...they were attentive to [Name’s] needs and knew them so well that they could identify, from their behaviour, whether they were in pain or if this was a manifestation of their mental illness”*

In **social care**, efforts had been made to provide appropriate training to staff to meet the care needs of people, including those with particular medical conditions:

*“All of [Name’s] carers were trained in seizure and tracheostomy interventions and followed protocols to ensure safe interventions...so as to optimise the meeting of [Name’s] health needs”*

## Summary

The quantitative and qualitative data presented in this chapter reflect a number of aspects of the care received by the person who died.

Although spanning deaths occurring over only two years (2021 and 2022), all of the quality of care indicators analysed here show improvement over time. This is hopefully the beginning of a trend that will become more apparent as future years’ review data are incorporated into the LeDeR dataset. It may be that the improvements observed reflect a return to usual levels of care following the major disruption to health services caused by the COVID-19 pandemic and resulting lockdown restrictions. It is also likely that improvements in quality of care result from increased awareness and better management of people with a learning disability; LeDeR and other improvement initiatives across the care pathway may have contributed to this.

The structured qualitative analysis highlights several areas of good practice and areas where care needs to be improved. As with last year’s report, correct use of the MCA and implementation of reasonable adjustments featured heavily. The importance of involving families in the care of the individual was highlighted, as was the need for good and timely communication within the health service and between agencies. The positive impact that individual staff can make to the care of someone with a learning disability was highlighted and is testament to the commitment found across care providers to enable the best possible care.

## Looking forward

### Research

- Further in-depth investigation of the LeDeR dataset could be undertaken to investigate specific areas of problems with care and to suggest areas for improvement, for example, where are delays in care most likely to occur and how can they be minimised?
- The implementation of the [Reasonable Adjustments Flag](#) should be monitored, and research conducted to consider how it is used to guide adaptations to care, and whether this can be improved.

### Care and services

- How can staff in primary care be supported to make the best use of existing guidance and resources to maintain the learning disability register, and are there better IT solutions to ensure registers remain up to date?
- What resources are needed for training or support to ensure all clinical staff consistently apply the MCA correctly?
- How can we ensure that people with a learning disability who have multiple long-term conditions receive an individualised management plan and what mechanisms can be used to best co-ordinate care for people who are involved with different health professionals?

# Chapter 6



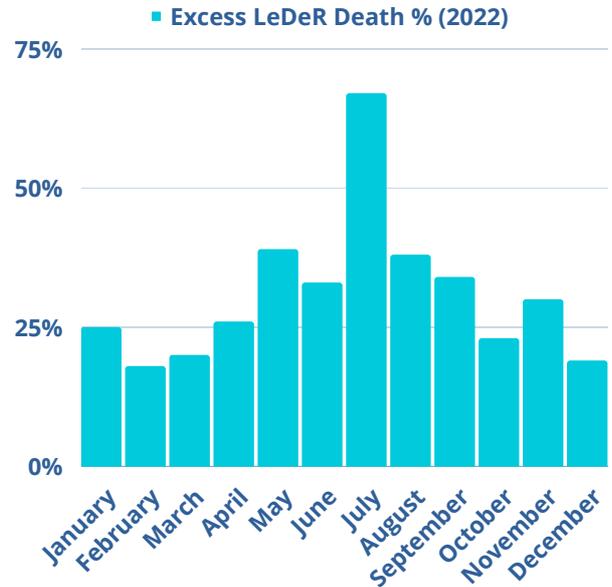
COVID-19, Excess Deaths, COVID-19,  
and Climate Change in England

# KEY FINDINGS OF EXCESS DEATHS, COVID-19, AND CLIMATE CHANGE

## EXCESS DEATHS

Deaths notified to LeDeR of occurring in July 2022 appear to be **greater than expected for every month of 2022** when compared to notifications from 2018 and 2019. July 2022 demonstrated the greatest excess.

This may be due to better reporting of deaths, as well as the impact of the pandemic and the heatwave.

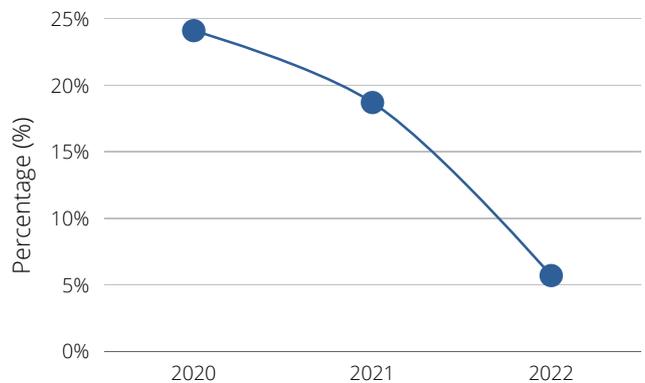


## COVID-19

COVID-19 has **decreased** from 24% of all causes of death in 2020 to 19% in 2021 and **6%** in 2022 for adults with a learning disability. It has gone from the most common cause of death to the 6th most common.



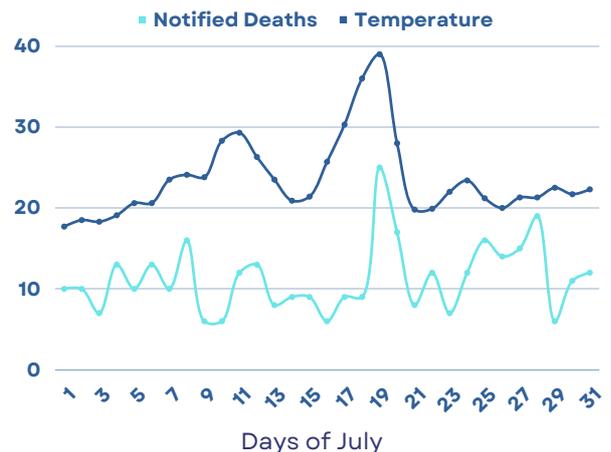
## DEATHS DUE TO COVID-19 ARE FALLING YEAR ON YEAR



## THERE WAS A SPIKE IN NOTIFICATIONS OF DEATHS AROUND THE JULY 2022 HEATWAVE PEAK

July 2022 recorded the highest number of notifications of deaths in 2022, **13% of which occurred on the 19th and 20th of July.**

The 19th of July saw a record high temperature of 40.3°C in England. This spike in deaths was not due to COVID-19 or flu, and appears to be linked to the extreme heat.



# Excess Deaths, COVID-19, and Climate Change in England

## Introduction

In this chapter, we will look into three topics that appear to have had an impact on the LeDeR mortality data for 2022. These are the overall excess in deaths noted in 2022 in both LeDeR and the general ONS data compared to previous years, the impact of COVID-19, and the impact of the summer heatwaves of 2022 which saw England record its highest ever temperature. Whilst these may or may not be directly related to each other, all have had an impact on the lives and deaths of people with a learning disability in England during 2022. Below we have presented a deeper analysis of these three topics and summarised what these may mean for the care of people with a learning disability. The data available in LeDeR 2022 offers important insights for the possible areas to focus on in future work, and, in combination with further evidence from studies outside of LeDeR data, important considerations for both present and future care for people with a learning disability in England.

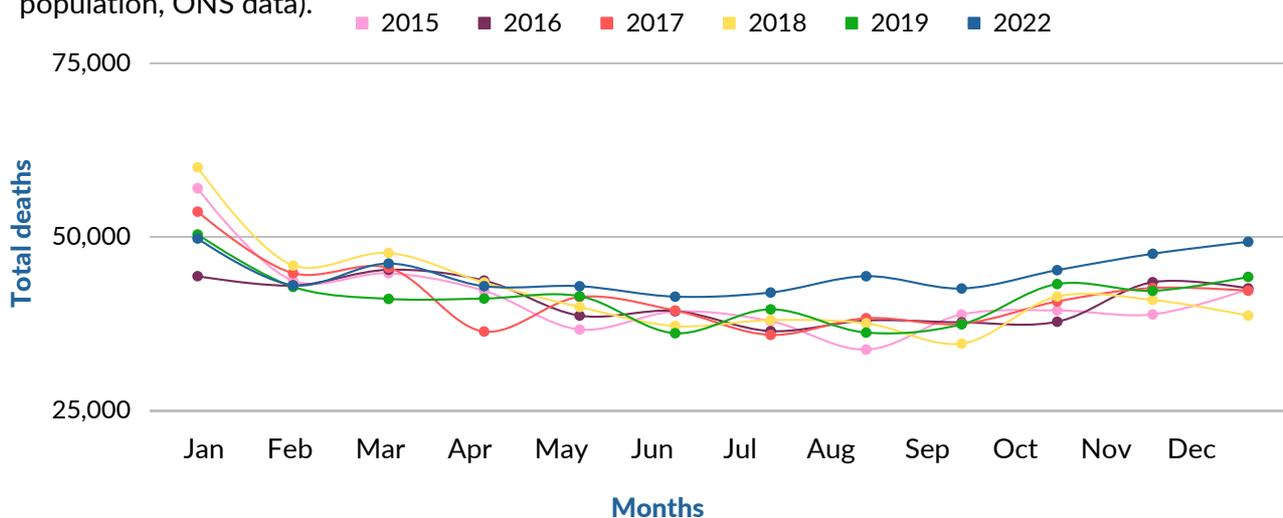
## Part 1: Excess Deaths in 2022

“Excess deaths” is a term used by the [ONS](#) to refer to the number of deaths above the five-year average. For 2022, the ONS used as a baseline rate the average of the yearly number of deaths from 2015 to 2019 (pre-pandemic). It has been widely reported in the national media that excess deaths for 2022 were shown to be [9% higher than for 2019 for the general population](#). This increase has been demonstrated to not be solely down to COVID-19 which, as discussed earlier, has been decreasing as a cause of death in England throughout 2022. As discussed in Chapter 2 and 4 of this report, COVID-19 deaths have also been shown to be decreasing throughout the year for people with a learning disability, due to preventative measures such as vaccination.

According to data available from the ONS about the general population, 2022 saw excess deaths across England of nearly 40,000 deaths in total, which became more noticeable from April 2022 onwards, remaining above expected and above average throughout the rest of the year. By using ONS data for the total deaths per month in England for 2015, 2016, 2017, 2018, and 2019 as a comparison, we can see that 2022 remains noticeably above the prior years’ averages, from April 2022 onwards (see Figure 6.1).

There has been an increase in the notifications of deaths of people with a learning disability in 2022 in comparison to previous years. There are potentially several reasons for this, which may also include increased awareness and publicity of LeDeR, and as such this is worth looking into further. Considering the recorded and published excess deaths notable in the general population, we have therefore drawn some comparisons with the data available in LeDeR this year, in contrast to the data from 2018 and 2019, as was done in last year’s report. Please note that for this calculation, all unique notifications are counted, including those of people who died under the age of 18 years.

**Figure 6.1:** Comparison of deaths in England from 2015-2022, excluding 2020 and 2021 (general population, ONS data).



Based on notification averages from 2018 and 2019, in total, there was an excess of 29.96% (95%CI, 37.64%, 22.28%<sup>2</sup>) deaths notified to LeDeR in 2022. In 2022, it is notable that for every month except for January, deaths were in excess of what would be expected based on the averages for 2018/2019, with July 2022 showing the greatest monthly excess at +67%. The median excess per month in 2022 was 28.08%. Possible explanations for the July excess deaths are presented in this chapter’s following section. Table 6.1 demonstrates the percentage of excess deaths in England per month for 2022 for the general population, and for the deaths reported to LeDeR. However, since LeDeR notification is not mandatory it is difficult to distinguish whether an increase in the number of notifications is down to a larger number of deaths, and therefore more notifications as a result, or rather due to an increase in awareness of the requirement to report deaths to LeDeR. It is conceivable that it is a complex combination of both.

**Table 6.1:** ONS calculated excess deaths in 2022 compared with calculated LeDeR excess notification deaths in 2022 (%).

Month	ONS Calculated Excess %	LeDeR Calculated Excess %
January	-10%	25%
February	-7%	18%
March	3%	20%
April	5%	26%
May	16%	39%
June	9%	33%
July	10%	67%
August	16%	38%
September	11%	34%
October	10%	23%
November	9%	30%
December	14%	19%

<sup>2</sup>Please see chapter 3 for explanations of CI’s and median descriptions.

## Excess death by region, age group and sex

For each region of England, excess deaths in both LeDeR data and ONS data were notable compared to the expected calculated deaths using data from 2018 and 2019. As can be seen in Table 6.2, the greatest increase in excess deaths for LeDeR data was seen in the North West, with the lowest in the South East. Note: the ONS regions are categorised differently to the NHS England regions used in LeDeR, and thus the LeDeR data for the Midlands and East of England cannot be directly compared to the data for the general population. The additional ONS regions of Yorkshire and Humber, East Midlands, and West Midlands are presented alongside LeDeR NHS regions for comparison. As can be seen, all ONS defined regions and all NHS regions reported an excess in deaths in 2022.

**Table 6.2:** The mean excess percentage of deaths for ONS NHS reported and defined regions, and LeDeR reporting regions. ONS specific regions are highlighted in green, NHS specific regions are highlighted in blue.

Region Name	London	South West	South East	Midlands	East Midlands	West Midlands	East of England	North West	North East	Yorkshire and Humber
Mean* Excess % deaths for ONS 2022	3%	9%	7%	n/a	8%	7%	7%	8%	6%	8%
Mean Excess % deaths for LeDeR 2022	30%	38%	14%	29%	n/a	n/a	21%	44%	37%	n/a

\* mean presented to match ONS data.

As can be seen, the findings show a potentially larger excess evident for LeDeR data in contrast to the ONS general population data. Similarly, excess deaths were observed in all age groups in the general population and in LeDeR mortality data (Table 6.3).

**Table 6.3:** Age group and notified deaths in the LeDeR 2022 data and the ONS data for 2022.

Age Group (years)	4-17	18-24	25-49	50-64	65+	Total overall average
Excess % deaths for ONS 2022	n/a	4%	5%	8%	7%	6%
Excess % deaths for LeDeR 2022	34%	29%	29%	27%	33%	26%

There were more excess deaths reported for females than males in the LeDeR notification data for 2022, when compared to 2018-2019 expected levels. This is different to the ONS data, which shows slightly more excess deaths for males than females for 2022.

**Table 6.4:** Excess deaths in LeDeR 2022 compared to the general population (ONS data) by sex.

	LeDeR 2022 Data	General population (ONS)
Male	23%	7%
Female	30%	5%

Due to limited sample sizes, calculating excess deaths for ethnicity in the LeDeR data would not be appropriate because, as discussed in [Chapter 1](#), the numbers are likely unrepresentative. In addition, the ONS does not provide excess death calculations with ethnicity breakdowns, so it would not be possible to compare LeDeR excess death data by ethnicity with data from the general population.

## Summary of Excess Deaths for 2022

As stated earlier, calculating excess deaths based on LeDeR notification data is subject to assumptions about the consistency of reporting rates over time. We can not be certain about the causes of excess deaths in the LeDeR data in this report. However, what these figures can tell us is that in 2022 we received notifications of deaths in excess of what would have been expected based on 2018 and 2019 (pre-pandemic years). This was consistent across regions, age, sex, and month of death. As COVID-19 does not seem to be the sole cause of any increase, there are likely to be other contributing factors, including increased rates of reporting.

As seen in the ONS data, excess deaths in the general population were around 9% greater than what would have been expected, even when factoring in COVID-19. This became more apparent from April 2022 onwards and was also demonstrated across regions, age, and sex. The reasons for this are [currently debatable](#), with suggestions such as a lingering effect from COVID-19 (particularly on cardiovascular conditions), the impact of an [NHS backlog accumulated during the COVID-19 pandemic](#) (resulting in some delayed treatment times and referrals), climate-related events (as discussed below), and current [NHS staff shortages](#). Regardless, both ONS data and LeDeR data suggest a significant excess in deaths compared to what would be expected based on previous years.

Further data, deliverable in future LeDeR reports, may provide more evidence as to the causes of excess mortality seen in the 2022 data, and as to whether these are attributable to an expected increase in awareness of the need to report to LeDeR or whether there have been more excess deaths amongst people with a learning disability than the general population.

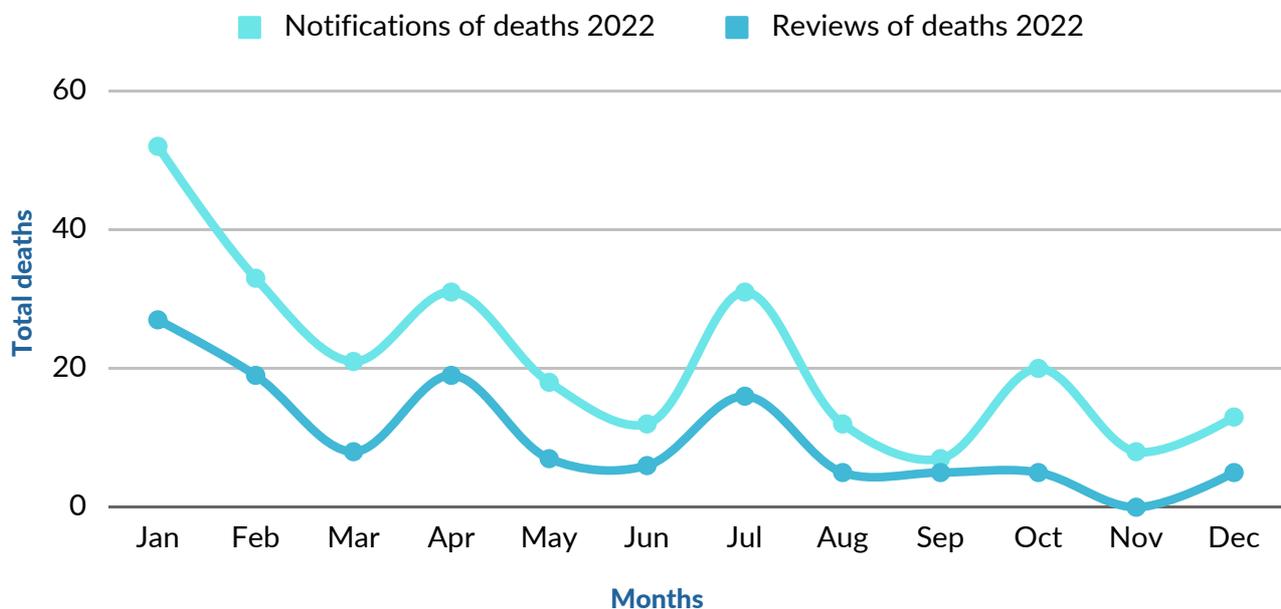
## Part 2: COVID-19 Deaths in 2022

For unique notifications, there were 258 records of COVID-19 as yes, or probable, for the cause of death (note that notifications are not completed reviews, so the cause of death is not confirmed at this stage of the review process and only assumed by the notifier). Of these, 226 had demographic data; the median age at death was 62 years old), 50% were male, 85% were recorded as being of white ethnicity, 43% were female, and in 7% of cases sex was unknown by the notifier at the time of notification. In terms of the regional distribution of deaths, this was similar to that of all notified deaths in relation to the expected population.

As reported in [Chapter 2](#), compared to 2020 and 2021, deaths from COVID-19 are no longer the most common cause of death, dropping to the 7th most frequent cause of death in 2022. This represents a decrease from 24.1% of all causes of death in 2020 and 18.7% in 2021 to 5.7% in 2022.

Both notified and completed reviews (both initial and focused combined) of deaths from COVID-19 by month are presented below in Figure 6.2. As can be seen, COVID-19 deaths were greatest in January, peaking again in April and July, and once again in October. Overall, death notifications to LeDeR with COVID-19 as the underlying cause were on a downward trend throughout the year.

**Figure 6.2:** LeDeR data for notification and reviews of COVID-19 deaths in 2022.



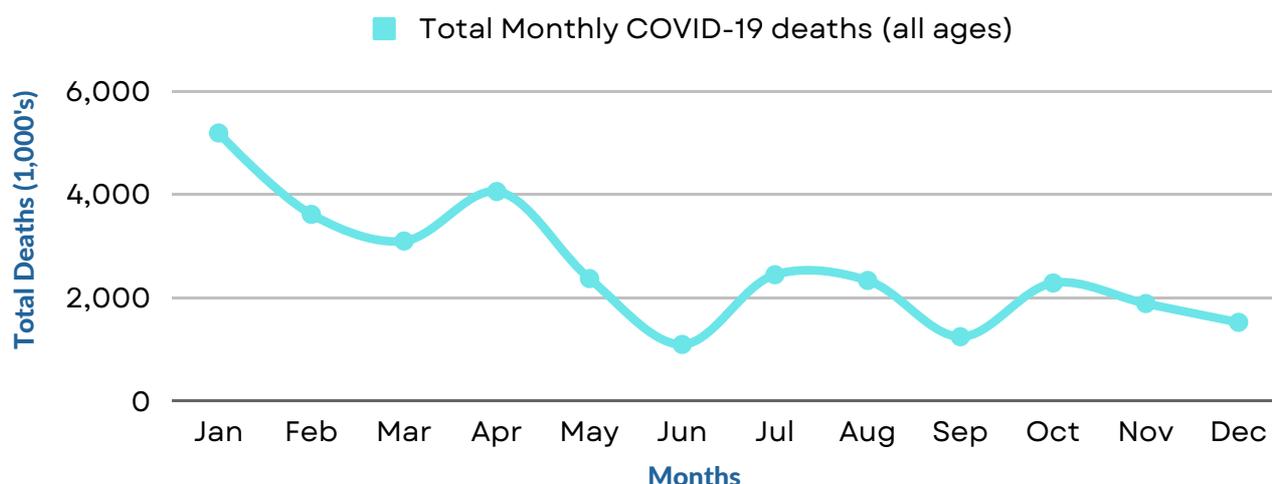
Of the 2,084 completed review deaths of people with a learning disability, or autistic people with a diagnosis of a learning disability, 63 had COVID-19, in line 1a of their MCCD (the most proximal cause of death), and 188 had COVID-19 listed as their underlying<sup>3</sup> cause of death, resulting in 251 combined recording of deaths from COVID-19.

<sup>3</sup>See Chapter 2 for definitions of underlying death and MCCD explanation.

Of those, the median age at death was 62.5, 58% were male and 42% were female, 90% were of white ethnicity, and London was the highest reporting region with 23% of deaths there being reported as from COVID-19.

The COVID-19 data evident in LeDeR 2022 demonstrates a similar pattern to that of the general population. As can be seen in Figure 6.3 below, ONS data for the general population shows that COVID-19 deaths in England overall fell throughout 2022. There are notable spikes, particularly in January, April, July, and October, and these are also observed in the LeDeR data.

**Figure 6.3:** ONS data for all COVID-19 deaths in England (all ages) over 2022.



### Vaccination rates

Data concerning COVID-19 vaccination was often not available in the LeDeR review data due to it only being collected in focused reviews (vaccination status was therefore recorded in only 21% of the data). Studies have shown that [people with a learning disability are at an increased risk of dying from COVID-19, and that effective vaccination is one of the most impactful ways to reduce this risk](#). In addition, [ONS data](#) suggest that COVID-19 vaccines have a high efficacy for decreasing the risk of dying from COVID-19, with a 58.7% reduction after the first dose, 88.6% for a second dose and 93.2% for a third dose. [Increased protection is also seen for boosters](#).

### Trends in COVID-19 Deaths

Recent studies have explored the decrease in deaths due to COVID-19 in England. A [review of deaths from 2020-2022 across population groups](#) noted that people with a learning disability were shown to be amongst the most at-risk groups in the first and second waves of the pandemic before the COVID-19 vaccinations existed but there were notable decreases in the number of these deaths following vaccination campaigns. Subsequent waves of COVID-19 (in terms of peaks of deaths) therefore showed that those who were not vaccinated, or those who were immunocompromised or in other high-risk groups, had smaller decreases in COVID-19 deaths than those who were vaccinated.

COVID-19 deaths are still a significant cause of death for people with a learning disability and persist in the 10 most common causes of death in the LeDeR data for 2022. It remains important to consider how this (avoidable) cause of death can be reduced further<sup>4</sup>. Indeed, [recent data from the UK Government COVID-19 dashboard for 2023](#) suggests that COVID-19 hospitalisation is again increasing in 2023 as this report is being written, with the potential for new variants to emerge and infect more people. Encouraging uptake of the booster vaccine and vaccination in those who are not yet vaccinated can help to reduce avoidable mortality due to COVID-19 and should remain a priority for health services.

## Summary of COVID-19 deaths for 2022

As stated earlier, COVID-19 deaths for 2022 have decreased for people with a learning disability compared to previous years, as has also been noted in the wider general population data. This is likely in part due to the COVID-19 vaccinations. COVID-19 waves are still occurring, and it is important to maintain booster vaccines and to continue to practice COVID-19 awareness when caring for vulnerable people. Further data is needed to determine whether this decrease in deaths due to COVID-19 is a continuing trend.

<sup>4</sup>Please see chapter 4 for definition of avoidable mortality.

## Part 3: Heat Periods and Seasonal Patterns of Deaths in 2022

Close analysis of deaths by month highlights an unexpected spike in the notifications of deaths in July 2022. Of particular note is that the notifications of date of deaths during July were the highest overall total of deaths of any month in 2022. Deaths in July have typically been lower than at other points in the year in previous years' data, with the highest number of deaths occurring in the winter months. This seasonal pattern during winter months could be attributed to increased mortality as a result of flu and the onset of colder weather.

Table 6.5 shows the total notifications of deaths per month for 2022 (excluding under 18's, and deaths of autistic people without a learning disability).

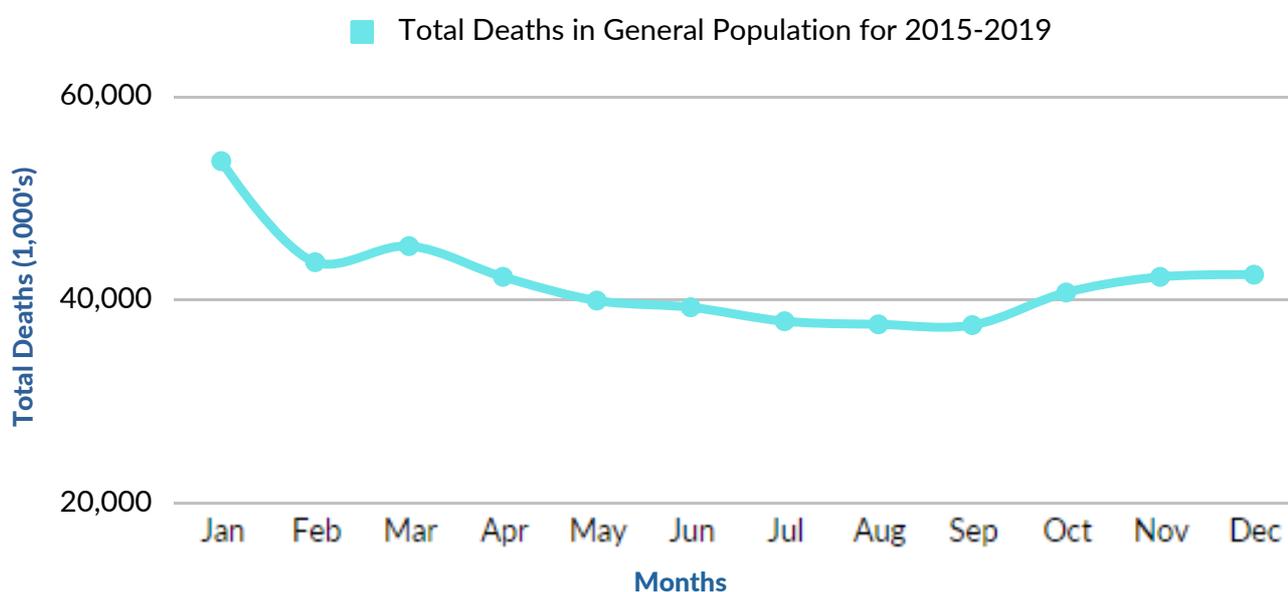
**Table 6.5:** Total of reported notified deaths by month in 2022.

Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
303	282	292	286	269	235	323	250	255	267	295	305

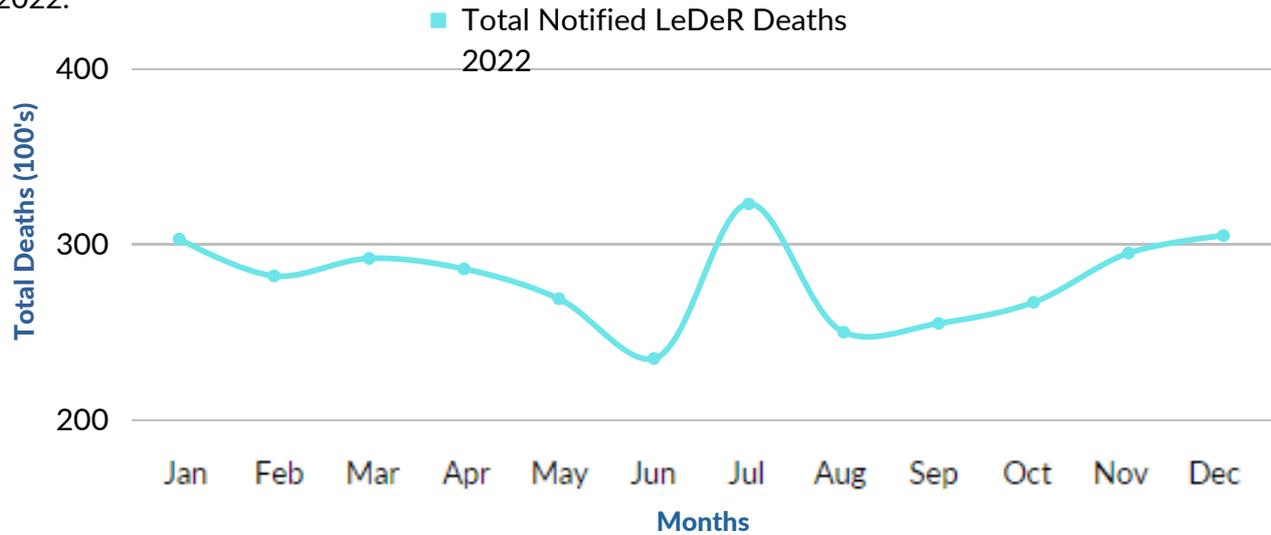
A more detailed exploration showed that there were 25 notified deaths on the 19th of July and 17 on the 20th of July, a combined total of 42 deaths, meaning that 13% of all deaths in July were within those 48 hours.

Figure 6.4 demonstrates the median recorded deaths in 2015, 2016, 2017, 2018, 2019 and 2022 (2020 and 2021 excluded due to the impact of COVID-19) for the general population ONS data. As can be seen, deaths generally follow a pattern with fewer deaths in the summer months, including July, and more in the winter. Seasonal deaths to LeDeR however follow a different pattern during 2022, demonstrated further in Figure 6.5.

**Figure 6.4:** Median recorded death for 2015-2019 and 2022 for the general population.

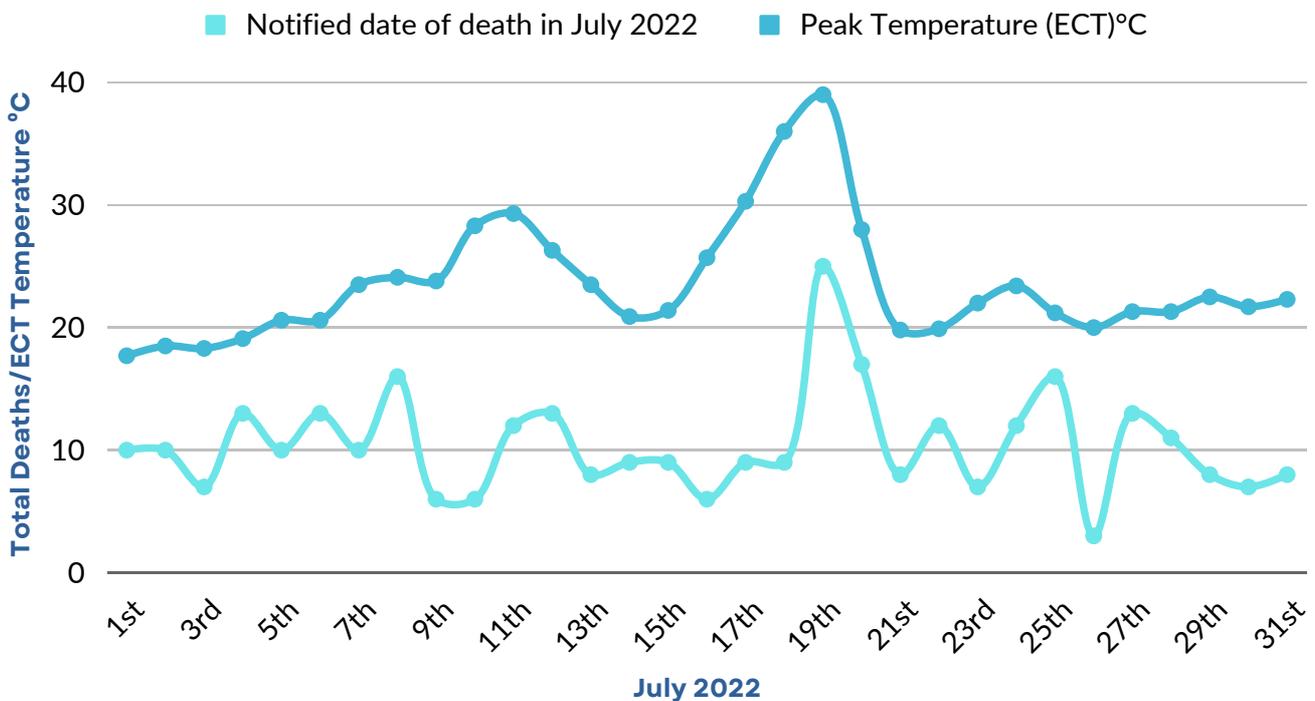


**Figure 6.5:** The total number deaths notified by date of death from January 1st to December 31st 2022.

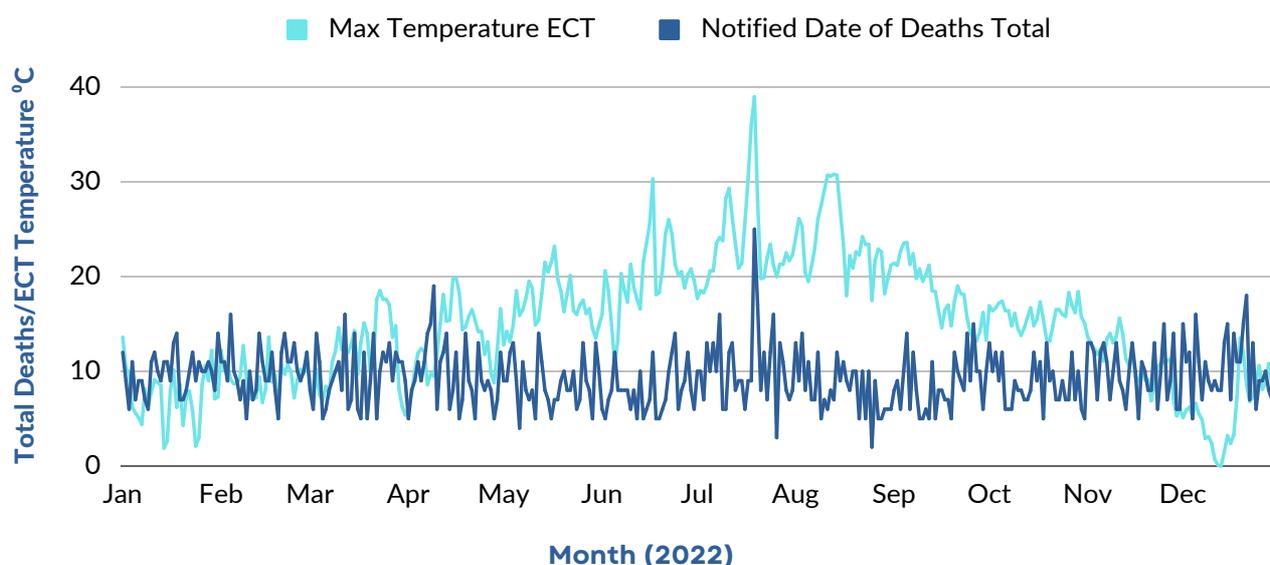


A possible explanation for the spike in notified deaths in July 2022 is that England experienced an extreme heat period which culminated in a record all-time high [Central England temperature](#) of 40.3°C on 19th of July. When the recorded peak temperature is mapped against the notification of deaths for July, the spike in deaths appears to be associated with a spike in temperature (see Figure 6.6). This becomes even more apparent when a comparison across the year is made and the significance of the extreme temperature on the 19th and 20th of July can be seen in contrast to other temperatures throughout the year (see Figure 6.7).

**Figure 6.6:** The total number of notified deaths in July 2022.



**Figure 6.7:** The total notifications of death per day against recorded peak temperature for 2022. NB: Days <5 are rounded to 5, other than 0.



As notifications are not completed reviews<sup>5</sup> there are limited demographic data available about the people who died. However, the median age at death from notification data for the 19th and 20th of July was 61 years, with a range (rounded for de-identification) between 20 and 90 years. 14 were recorded as female and 25 were recorded as male, and 21 (50%) were recorded as dying in their usual place of residence. 90% were recorded as being from white ethnic backgrounds. The remaining 10% were recorded as being either from an ethnic minority background or no ethnicity data was recorded.

### Review data for 2022 spikes in death

When looking at completed review data (both initial and focused) we also noticed a spike in the number of deaths for the July heatwave period, with 28 completed reviews concerning deaths occurring on 19th and 20th of July 2022. The demographics of the people whose lives and deaths had been reviewed showed that the median age at death was 61 years with a range between 22 and 85 years. 16 deaths were recorded as male and 12 as female, and almost all were recorded as white. The top 3 causes of death on line 1a of the MCCD (by broad group, please see chapter 2 for further details of MCCD data) for deaths occurring on the peak heatwave days of 19th and 20th July were:

1. Respiratory-related conditions (excluding COVID-19) (n=7).
2. Cancers (n=6).
3. Cardiovascular conditions (n<5).

The top 3 grouped underlying causes of death on the MCCD were recorded as:

1. Cancers (7).
2. Cardiovascular conditions (6).
3. Congenital malformations, deformations and chromosomal abnormalities (<5).

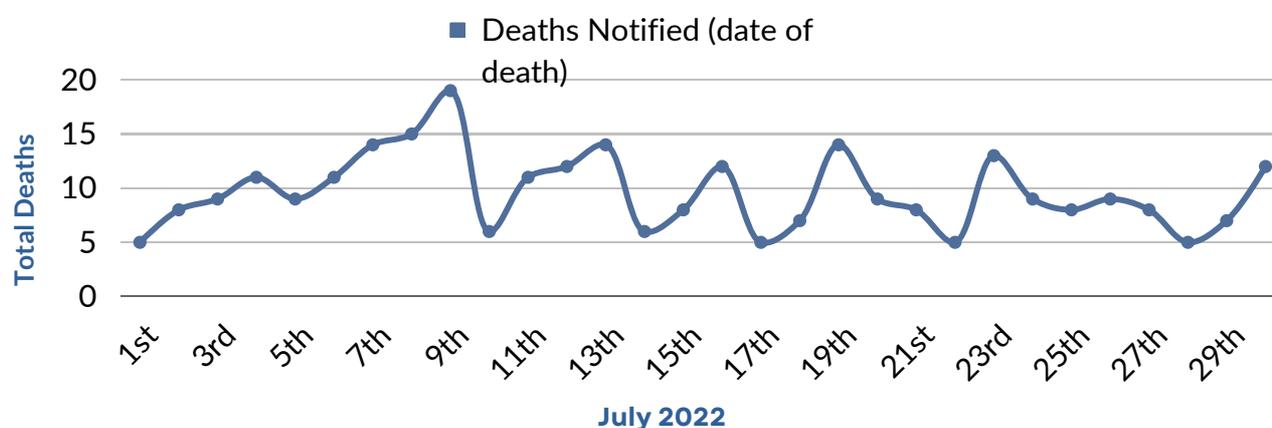
<sup>5</sup> Please see 10 for details of the LeDeR process and the time required to complete a LeDeR review.

COVID-19 accounted for less than 5 deaths in this two-day period, and so can be excluded as the cause of the spike. When compared with other dates in the year, these causes of death themselves are not particularly unusual, other than being in greater numbers. In addition, the overall demographics do not stand out as unusual either, with the average age at death, ethnicity, and sex of those who died being comparable to other months throughout the year. For the place of death, 13 (46%) were in acute settings (including Assessment and Treatment Units (ATU) and community hospitals) whilst 15 (54%) were at the person's home (including residential and nursing homes). This differs from the overall annual place of death averages (57% acute settings and 38% home for the general LeDeR data), however, it is important to remember that these are relatively small sample sizes, which limits the conclusions that can be drawn.

### Further seasonal spikes in deaths in 2022

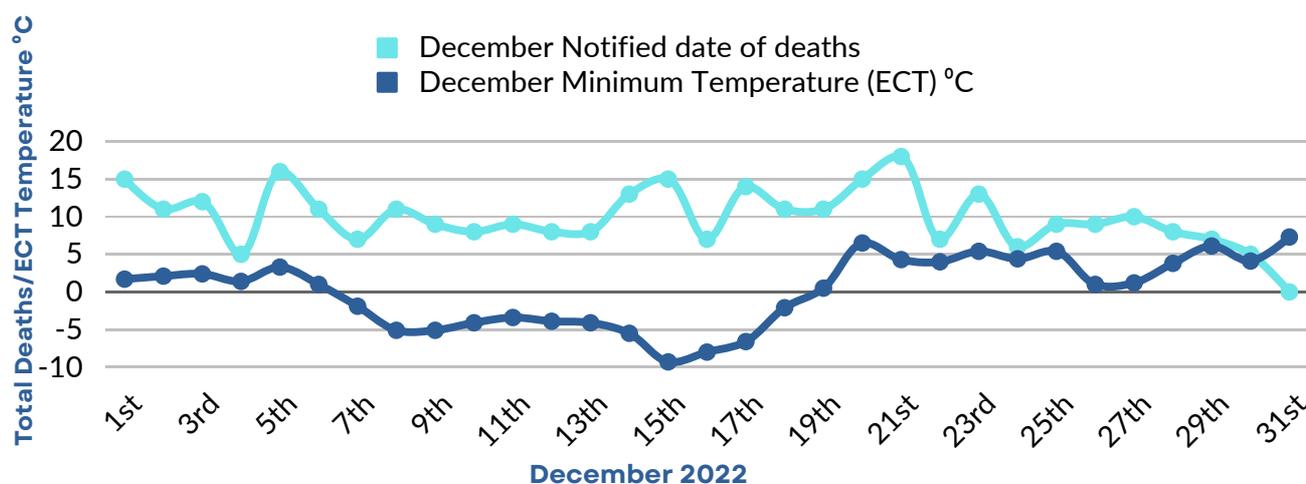
Starting with the people who died in April, an examination of the grouped cause of death from the completed reviews shows that 15 of the recorded 36 deaths of that period were related to respiratory illnesses. The median age at death was 66.5, which is slightly higher than the average across the year. [ONS data show that](#), for weeks 13 to 14 of 2022 (the first two weeks of April), there was a noted increase in healthcare contact related to seasonal flu across England. This corresponds with LeDeR data and is part of an increase in flu-related deaths, which appears to explain the notable spike in deaths during early April (see Figure 6.8).

**Figure 6.8:** The notification of deaths in LeDeR data for April 2022.



The small spikes in early and mid-late December correlate with a drop in temperature in December, however this is not unusual. The average number of daily deaths in December was shown to be higher than in the average summer months, averaging around 10 deaths a day. The median age at death throughout December was 64 years, with grouped respiratory conditions making up 66 of the 117 recorded deaths. Increased chance of death is a known risk in the general population with the winter months temperature dips and increase in seasonal illnesses, and is a pattern also documented and seen in previous [research in countries around the world](#), and within our own historical LeDeR data for people with a learning disability (see Figure 6.9 overleaf).

**Figure 6.9:** The notifications of deaths in LeDeR data for December 2022 against England Central Temperature minimum daily temperatures ( $^{\circ}\text{C}$ ).



## Summary of seasonal variations

Whilst some seasonal spikes in deaths are to be expected, due to factors such as [annual influenza waves](#), and expected [cold snaps in winter](#), unexpected or unpredictable spikes due to adverse external events are at risk of becoming more frequent. The spikes in deaths of people with a learning disability in July 2022 were not attributable to COVID-19, or to any epidemic or disease outbreak. They were instead likely correlating with environmental factors, in particular the extreme hot weather seen in July 2022. This is in line with other published evidence which has found an increase in mortality associated with [exceptionally hot weather events](#).

The ONS has produced a [report](#), in association with the UK Health Security Agency, which examined the excess deaths seen in the general population data from the period of the heat waves from June 1st to August 31st 2022. The report noted that between the 10th and 25th of July 2022, deaths were at an excess of 10.4% above average across the general population in the UK. In addition, average deaths were higher on the days of excess heat, or “heat-period” days, than on non-heat period days. Furthermore, the ONS found that “each heat-period peak, most notably that on 19th of July 2022, was followed by a fall in deaths to below the average over the following days; this suggests a short-term mortality displacement, where deaths among vulnerable individuals are ‘brought forward’ to within the heat-periods.” ([ONS, 2022, pg 3](#)). Whilst the LeDeR data sample is comparatively small, this can also be seen within LeDeR data, with a rapid decrease in deaths reported on the 21st of July as the heatwave subsided. However, our data also showed above-average deaths continuing through to the 28th of July, even as temperatures returned to cooler levels.

As more extreme weather events appear to be becoming more frequent, the importance of living arrangements and care plans that acknowledge cooling and heating tools is integral to the care of people with a learning disability. The use of tools such as air conditioning, heat pumps, fans, window shutters, and heating equipment are not simply tools of convenience, [but can save lives](#). NHS England has [published guidance](#) on the importance of managing heat for those who are vulnerable and living in supported accommodation. Considerations for how people with a learning disability living in other situations, such as in private rented accommodation, are supported to ensure they have adequate access to both cooling and heating tools is required, as is the need to ensure that families and carers can access support for temperature control.

The consequences of a changing climate are wide-ranging and are having [demonstratable impacts on numerous aspects of our daily lives](#). In relation to [healthcare](#), extreme weather events, of both [heat](#) and [cold](#), have been shown to have a [significant impact](#) on the [health and well-being of those affected](#), particularly [vulnerable people](#). If current climate trends [continue in the UK](#), our data on the impact of extreme weather may, unfortunately, become more robust. For our data for 2022, it is likely that a correlation between the July heatwaves and an increase in deaths in adults with a learning disability is apparent, as was also noted in the wider general population in national mortality trends.

## Looking forward

The data used in this report, alongside academic research and ONS statistical findings, suggests that due to extreme weather events being likely to continue for the short to medium term, healthcare provision should continue to incorporate concerns regarding climate change into their policy and planning. LeDeR data shows that people with a learning disability may be at particular risk from climate change impacts, particularly those of extreme weather events. Considerations for how to ensure adequate hydration, particularly for those who may have difficulty self-regulating their fluid levels, how to ensure access to temperature control such as air conditioning or fans, and in the winter in colder months how to enable access to adequate heating and insulation, should therefore be incorporated into residential and hospital care settings and care plans wherever possible.

The impact of external events on the health and well-being of people with a learning disability is complex and, to a degree, uncertain. The impact of the COVID-19 pandemic continues to be felt, and although deaths due to COVID-19 have been declining, we identified ongoing high levels of excess deaths throughout 2022. Although this may partially be due to improved reporting of deaths to LeDeR, data from the general population suggests other factors related to the impact of the pandemic may also be relevant to the excess deaths of people with a learning disability. Whilst it is difficult to discern this from the LeDeR data, it is an important area of further research to consider. All these issues pose specific challenges to people with a learning disability and complex care needs, and all require consideration.

## Research

- Continue to monitor data on the deaths of people with a learning disability in relation to levels of excess deaths, including within marginalised populations, such as people from ethnic minority backgrounds.
- Continue to assess the impact of extreme weather events on the mortality of people with a learning disability.
- Investigate ways to better prepare people's homes for the impact of heat waves and cold snaps.
- Continue to monitor COVID-19 deaths, including the potential impact of new variants, and assess vaccination records for people with a learning disability against mortality from COVID-19.

## Clinical

- Ensure care plans for people with a learning disability include mitigations and advice for dealing with hot and cold weather. Provide this information in accessible ways.
- Investigate ways to improve to the collection of data on marginalised and vulnerable people.
- Support flu vaccination for people with a learning disability to reduce seasonal flu-related and respiratory deaths.
- Support COVID-19 vaccination for people with a learning disability to reduce seasonal COVID-19 related and respiratory deaths.

# Chapter 7



Review of Deaths of Autistic  
Adults for 2022

Please be aware that this chapter discusses deaths by suicide and may be upsetting and distressing. If you or someone you know is affected by the content of this chapter, please call Samaritans for free on 116 123 (UK and ROI), email them at [jo@samaritans.org](mailto:jo@samaritans.org), or visit [samaritans.org](https://www.samaritans.org) to find your nearest branch. Other sources of support are listed on the [NHS's help for suicidal thoughts webpage](#). Support is available round the clock, every single day of the year, providing a safe place for anyone struggling to cope, whoever they are, however they feel, whatever life has done to them.

# KEY FINDINGS ABOUT AUTISTIC ADULTS WITHOUT A LEARNING DISABILITY IN 2022

## DATA FOR 2022

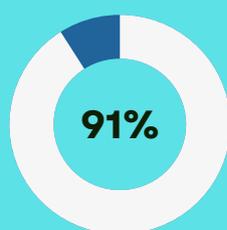
2022 was the first year LeDeR reviewed deaths of autistic adults without a learning disability. The amount of reviews was **small**, with **36 completed reviews**. These reviews are not representative of all autistic adults without a learning disability, and only limited conclusions can be made. Increased reporting is needed to be able to better determine areas for improvement in the care of autistic adults without a learning disability.

# 36 reviews

## THE MOST FREQUENT CAUSES OF DEATH

Underlying cause of death for autistic adults without a learning disability (grouped ICD-10 codes)	Totals in the data
Suicide, misadventure* or accidental death**	11
Respiratory conditions	8
Cardiovascular and stroke related	<5
Cancer	<5
Other	8

Note: \* includes drug and alcohol related deaths that were not thought by the coroner to be intentional.  
\*\* includes falls.

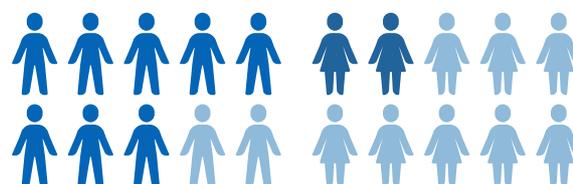


## ETHNICITY

91% of autistic adults without a learning disability were denoted as white.

## SEX

81% of autistic adults without a learning disability who died in 2022 were male, 19% were female\*.



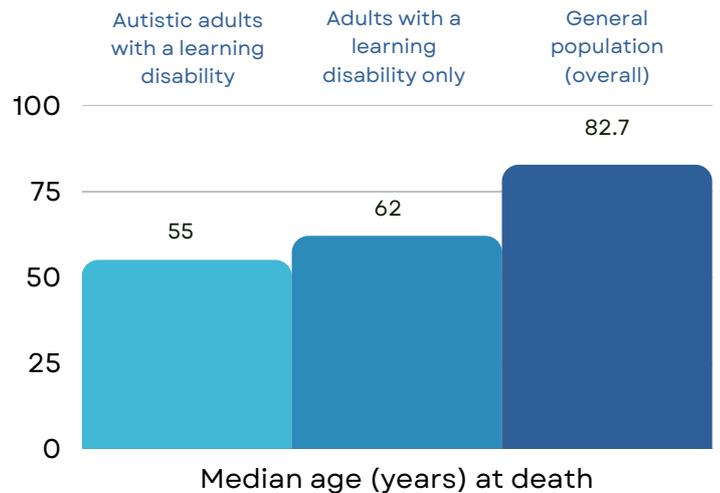
\*a small number (<5) identified as neither male or female, or transgender, but could not be reported in order to ensure de-identified data.

# KEY FINDINGS ABOUT AUTISTIC ADULTS WITH A LEARNING DISABILITY

## AGE AT DEATH

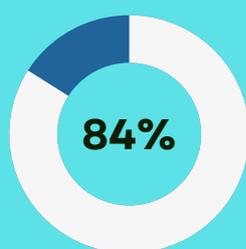
The median age at death for the 178 autistic adults with a learning disability was **55 years**. The median age at death for the general population in 2018-2020 was **82.6 years for males and 86.1 for females**.

# 55 Years



## THE 5 MOST FREQUENT CAUSES OF DEATH (EXCLUDING “OTHER”)

Underlying cause of death for autistic adults with a learning disability (grouped ICD-10 codes)	Totals in the data
Respiratory conditions	66
Cardiovascular conditions	27
Cancer	22
COVID-19	17
Stroke, Cerebral Haemorrhage or Embolism	8

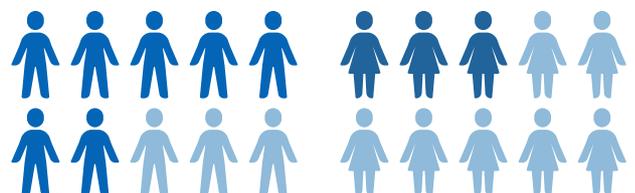


## ETHNICITY

84% of autistic adults with a learning disability and died in 2022 were denoted as white.

## SEX

68% of autistic adults with a learning disability who died in 2022 were male, 30% were female\*.



\*a small number (<5) did not have information regarding their sex available in the data.

## Introduction

For the first time, the LeDeR annual report includes reports of deaths of autistic adults without a learning disability. This is in addition to autistic people with a learning disability who have been included in all LeDeR reports. Data for autistic people with a learning disability have been reported in this year's and in previous reports. Following extensive consultation, NHS England published a revised LeDeR policy in 2021 which presented an opportunity to include the deaths of autistic people without a learning disability. The LeDeR 2021 policy followed the creation of the [national autism programme in 2020, itself built on the NHS Long Term Plan \(2019\)](#). The initial work of that programme identified the lack of data available about the health inequalities faced by people who are autistic ([Autistic People's Healthcare Information Strategy for England, 2022](#)). In response to both the consultation and in recognition of a need for more data, the policy was updated and LeDeR began to collect data on the deaths of adults (over 18 years old) without a learning disability with a clinical diagnosis of autism from January 2022. These data will be included in the annual LeDeR reports, as well as associated LeDeR projects, to support the NHS and its partners in endeavours to improve services for autistic people. By using these data, we hope to produce a better picture of the health needs of autistic people in England, enabling ICBs to take action to improve services for people and reduce premature and avoidable mortality, which has been shown to be [higher for autistic people than in the general population](#).

For 2022, LeDeR received 110 notifications of deaths of autistic adults without a learning disability, and 264 notifications of deaths of autistic adults with a learning disability. From these, we received **36** completed reviews of autistic adults without a learning disability and **178** completed reviews of autistic adults with a learning disability. Please see [Chapter 1](#) for more information about the overall data we received this year and the foreword for details of the difference between notifications and the types of reviews in the LeDeR data.

2022 was the first year of collecting data about the deaths of autistic adults without a learning disability in England, therefore the number of completed reviews that could be included in this report is relatively small. This could be because there is less awareness around the inclusion of autistic adults in LeDeR, and because all reviews of autistic adults are focused reviews which take longer to complete than initial reviews. Some reviews may have been subject to police investigations and/or coronial processes, which further can impact on the pace of LeDeR review completion. It is important to be aware that this is a limited sample of the overall population of autistic adults, and it will not be representative of all deaths of autistic adults in England in 2022. These findings cannot be generalised more widely. These figures are true of the data that was available this year and will likely change in the future as we anticipate that notifications will increase with greater awareness of the inclusion of autistic adults in LeDeR.

In this chapter, we will first report the data for autistic adults without a learning disability who died in 2022 who were notified to LeDeR and who had a completed review by our cut-off date of 13th July 2023<sup>6</sup>. We will then report on the data for the completed reviews of deaths of autistic adults with a learning disability from the same period. Finally, we will present the findings of a brief thematic analysis of emerging trends in the reviews for autistic adults in 2022. For autistic adults with a learning disability, this thematic analysis will be incorporated into [Chapter 5](#) along with the wider learning disability data. Please note, to avoid small numbers which may place people at risk of identification, we will redact figures below 5 where necessary.

## Deaths of autistic adults without a learning disability

Below is the breakdown of the data for the **36** completed reviews of autistic adults without a learning disability.

### Sex registered at birth

29 (81%) were denoted as male and 7 (19%) were denoted as female. Please note, a small number (<5) were reported who did not identify as male or female (e.g. non-binary or other), or had a gender identity that was different to their sex registered at birth. However, to protect identification, we have reported the sex only as defined in the medical records at birth.

### Age

The median age at death was 53 years. Due to small numbers, we cannot report median age at death by sex.

### Ethnicity

The reported ethnicities were: 31 (86%) white, and 5 (14%) preferred not to say, or “other”. In this analysis we are unable to report the number of deaths of autistic adults who are from an ethnic minority due to small numbers.

### Causes of death of autistic adults without a learning disability

The causes of death are only available for completed reviews (please see foreword for details of the LeDeR process and data checks). For this chapter, to avoid small numbers, we will only report the 5 most common grouped causes of death (with redacted figures of <5 where necessary).

The completed review data of grouped causes of death for autistic adults without a learning disability in the 2022 LeDeR data are presented overleaf in Table 7.1.

<sup>6</sup>There was an original draw down date of 1st of July 2023 for when we were to receive the data for this report, however this was extended to the 13th of July 2023 to provide reviewers sufficient time to complete their reviews.

**Table 7.1:** Grouped underlying cause of death for autistic adults without a learning disability.

Grouped underlying cause of death for autistic adults without a learning disability	Totals
Suicide, misadventure, or accidental Death <sup>7</sup>	11
Respiratory conditions	8
Cardiovascular and stroke	<5
Cancer	<5
Other <sup>8</sup>	8

### DNACPR of autistic adults without a learning disability

Of the 36 reviewed deaths, 18 people had a DNACPR in place at their time of death. Documentation and processes were judged to have been correctly completed and followed in 15 of these reviews. Information about DNACPR decisions in adults with a learning disability is found in [Chapter 2](#).

### Emergent themes in the reviews of autistic adults without a learning disability

The quality-of-care ratings of the 36 autistic adults who died in 2022 and received a LeDeR focused review were analysed to provide an overview of the health and social care received by these people (see [Chapter 5](#) for more information on the quality-of-care ratings). Due to the small numbers, the ratings cannot be taken to represent the experiences of all autistic people treated within the NHS, but could provide preliminary information on where improvements may be required.

Reviewers comments about issues and positive practice in the reviews of 36 autistic adults without a learning disability were read by one of the LeDeR research team and grouped into emergent themes. A second member of the research team read the comments separately to check the reliability of the emergent themes. Several quotes are presented alongside the emergent themes to provide a sense of the data. Analysis of the quality of care received by people with a learning disability (including autistic people with a learning disability) is [provided in Chapter 5](#).

<sup>7</sup>In this report we have grouped suicide, misadventure, and accidental death due to the method of reporting on the MCCD by coroners. This may be in relation to changes in the standard of proof used by coroners to determine whether a death is a suicide or not. [Please see the ONS website here for more detail](#). Please also see Appendix A7.1.

<sup>8</sup>“other” refers to conditions that are not in the 5 most common. These can be singular instances, or a small number of occurrences. When added together however, they become a large number, but are not representative of one distinct condition, so are removed for ease of understanding the data.

10 of the 36 reviews for autistic adults without a learning disability were rated as receiving overall care quality at grade 3 or below (i.e. generally indicative of poor care). The emergent themes in the issues identified by reviewers for reviews that received a care quality rating at grade 3 or below were:

- A lack of high-quality training, awareness, or understanding of the specific needs of autistic people.
- A lack of adequate support services being provided, specifically tailored towards the needs of the person, or a lack of support to access services.
- Overlooking the potential impact of a relationship status change for autistic adults.
- A lack of crisis escalation plans, or a lack of an awareness of the increased risk of suicide in autistic adults.
- A lack of communication between different professionals and agencies providing support.
- Overshadowing of the impact of autism by other co-occurring mental health conditions.

Quotes that reflect the themes in issues with care:

“[name] was significantly failed by services in relation to assessment of [their] health needs in both community and hospital settings.... [name]’s mental health issues were not identified at an early stage and was viewed as largely behavioural...”

“[name]’s autism was rarely taken into account as to the reasons for non-attendance or self-discharging...little evidence of adjustments that may have positively enabled this person to access services, for example, only group therapy was offered, [name] could not cope with group sessions, but no one to one therapy was offered...”

“Organisation systems and processes did not allow for reasonable adjustments.”

“Mental health services did not support [name] effectively due to not accepting [their] diagnosis of autism...”

26 of the 36 reviews for autistic adults without a learning disability were rated as receiving overall care quality at grade 4 or above. The emergent themes in the positive practice identified by reviewers for reviews that received a care quality rating at grade 4 or above were:

- An awareness of autism and efforts to make reasonable adjustments.
- Timely communication between agencies providing care.
- Plans in place for crisis and escalation supports where appropriate, including assessments of suicide risk.
- Supports are both offered and explained, tailored to the needs of the individual, and reasonable adjustments are made to help service users access these services and supports.

Quotes that reflect the emergent themes:

“[name]’s wishes and preferences were listened to and [their] care package was person centred.”

“[name] had a thorough assessment of [their] risk of suicide and how to keep [them] safe at each appointment. [They] were also referred to talking therapies.”

“[name] was well cared for by carers who .... took time to understand [their] needs.”

In summary, good and excellent care was shown to be placing the person central to their care, offering supports that were suitable and beneficial to them, and providing individualised reasonable adjustments for autistic people to access services. In addition, good care was found to be that which considered and understood the specific needs of the autistic person, whilst poorer care was found to be less responsive and understanding of autism and what specific needs an autistic person may require that are different from a service user without autism. Throughout the reviews, comments on the awareness, or lack of, of the specific needs of autistic people, and how these may differ from the needs of people without autism, were seen in both evidence of good, and less good, practice.

## Deaths of autistic adults with a learning disability

LeDeR has always collected data of autistic adults with a learning disability. There are often notable differences in the amount of care and support that is needed and provided amongst autistic people with a learning disability and autistic people without ([Building the Right Support Action Plan, 2022](#)). Autism is a [spectrum condition](#), as such some autistic people require more support than others, and some require no support at all. Given these differences, a comparison between autistic people with and without a learning disability may not be informative. It is also important to note that it may be possible that the prevalence of autism in adults with a learning disability is underreported in this dataset. The diagnosis of autism for adults with a learning disability cannot always be easily determined, which may explain some of the lower reporting than may be expected in this dataset. Overall, [NHS England however estimates that approximately 20-30% of people with a learning disability are likely also autistic](#). In our data this year around 2% of the total completed reviews were for autistic people with a learning disability. Below we will detail the demographics of the 178 autistic adults with a learning disability who died in 2022 and who were notified to LeDeR and had a completed review by July 2023.

### Age

The median age at death for autistic adults with a learning disability who had a completed a LeDeR review was 55 years. For those who were registered at birth as female it was 56 years, and for those who were male it was 55 years. We do not have full data on autistic people with a learning disability in previous years as this was information was not collected. However, we do have data for 103 people with a learning disability who also were autistic who died in 2021; the overall median age at death was 53 years. [This compares to 82.6 years for males and 86.7 for females in the overall general population \(which includes deaths from both adults and children\)](#). For both 2022 and 2021 this is a younger age at death than for people with a learning disability who were not diagnosed as autistic, but, as numbers are relatively small this finding will need to be confirmed in future reports.

### Sex registered at birth

For completed reviews of autistic adults with a learning disability, 68% (121) registered at birth as male, and 30% (54) were female. Data was not provided for <5 people.

### Ethnicity

For completed reviews of autistic adults with a learning disability the ethnicity breakdown was: 149 white, 11 Asian or Asian British, 8 who preferred not to say, 5 black or black British, Caribbean or African, and, to de-identify the data, a group of 5 people who were identified as mixed ethnicity, other ethnicity, or not known.

### Cause of death for autistic adults with a learning disability

To avoid small numbers, we will only report the 5 most common grouped causes of death, excluding the “other” grouping (see Table 7.2). For autistic adults with a learning disability, these were: 66 (37%) respiratory, 27 (15%) cardiovascular, 22 (12%) cancer, 17 (9%) COVID-19, 8 (4%) stroke, cerebral hemorrhage, or embolism. For contrast with autistic people without a learning disability, <5 were reported as dying by suicide. In the context of the wider report, this was also noted for adults with a learning disability who were not autistic, where <5 deaths by suicide were reported.

**Table 7.2:** Grouped underlying cause of death for autistic adults with a learning disability.

Grouped underlying cause of death for autistic adults with a learning disability	Total
Respiratory conditions	66
Cardiovascular conditions	27
Cancer	22
COVID-19	17
Stroke, cerebral haemorrhage or embolism	8

### DNACPR for autistic adults with a learning disability

112 autistic adults with a learning disability had a DNACPR in place, <5 were incorrectly completed and followed, and <5 were correctly completed but not followed. In 32 cases the reviewer was unable to determine whether the correct processes had been followed.

## Summary of the data

The data we have presented here comes from a small number of reviews. It is not possible to generalise to the wider population of autistic adults. Nevertheless, taking the data we have with these caveats, we can see emerging patterns that suggest different results to the LeDeR findings for people with a learning disability. These differences are important to note and warrant further monitoring and consideration. The demographic profile of the reported deaths for autistic adults with and without a learning disability differs from that of the overall LeDeR reviews of people with a learning disability only, where the overall median age at death is 62.9 years. Whilst we must be cautious that this may be due to an under-reporting of the deaths of autistic adults to LeDeR, we do know from studies that more males than females are diagnosed with autism and that an autism diagnosis is less likely to have been made in older adults ([Russell et al., 2022](#)). Because of the demographics of people who have received a diagnosis of autism, the average age at death of adults who were included in this sample could be skewed to a younger age than perhaps would be reflective of the age of autistic people in the wider population ([O’Nions et al., 2023](#)). However, the current data we have available in LeDeR 2022 suggests a younger average age at death in comparison to the wider LeDeR population, for both autistic adults with and without a learning disability. Further data are needed in order to determine whether or not this is reflective of the wider population, or simply due to this limited sample size.

A further notable finding is the deaths by suicide, misadventure, or accident in autistic adults without a learning disability in this sample, which warrants further investigation. It is also notable that death by suicide is not as apparent in the sample of autistic adults with a learning disability. Suicide has also been shown to be a far less frequent cause of death for adults with a learning disability (who do not have a diagnosis of autism), having been reported fewer than 5 times to LeDeR in 2022. The data we have available in this report is consistent with other work that suggests that deaths by suicide are more common in autistic people without a learning disability than in the general population ([Hirvikoski et al., 2020](#); [Newell et al., 2023](#)). However, it may also be the case that these deaths by suicide are more likely than other causes of death to have been notified to LeDeR as part of the coronial process. [Deaths by suicide are routinely investigated by a coroner](#) and therefore may be more likely to be reported to LeDeR than other causes of death that were not investigated by a coroner. As detailed earlier, this sample size is small, and findings should be interpreted cautiously. It is difficult to infer how common deaths by suicide are from this sample size alone. That being said, the number of deaths by suicide is an important theme emerging in this data, and one that should be explored in more detail in future reports to inform policy in the care and support of autistic adults.

## Looking forward

The number of completed reviews of deaths of autistic adults without a learning disability this year is limited, but this is perhaps to be expected as the inclusion of autistic adults' deaths in LeDeR only started in 2022. As awareness grows around the need to collect data on autistic people's deaths to better target services, identify areas where care can be improved, and guide policy, the number of deaths of autistic adults that are reported to LeDeR is likely to increase. NHS England is working with partners, such as the National Autistic Society and Autistica, to deliver a campaign to raise awareness of the fact that the deaths of autistic adults can be notified to LeDeR.

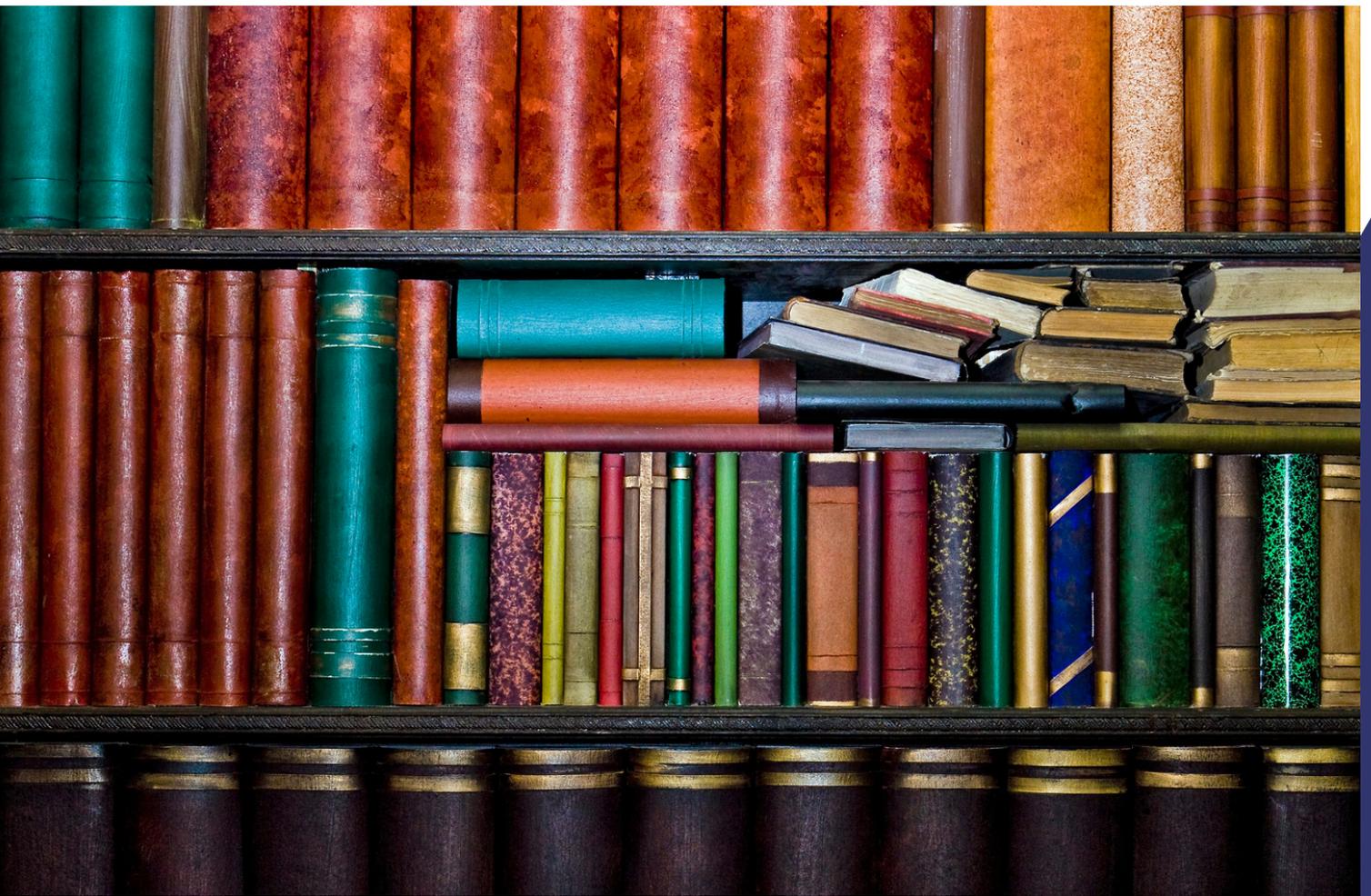
### Care and Services

- For autistic adults with a learning disability, there are specific needs and considerations that need to be considered that differ from those of autistic adults without a learning disability. Awareness of this, and factoring in the specific needs of the person in any care plan, should continue to be a priority.

### Research

- The limited analysis possibly suggests a high rate of deaths by suicide for autistic adults without a learning disability in this dataset. This is concerning and requires ongoing attention through further data collection. Preliminary emergent thematic analysis suggests that to address this, services need to ensure a good understanding by staff of the needs of autistic people to identify those at risk, ensure adequate provision of support tailored to the needs of the person, and provide personalised crisis plans. This includes the provision of reasonable adjustments for autistic adults who access care and person-centred care plans. Autistic adults with a learning disability have distinct needs compared with autistic adults without a learning disability. Autism is not a learning disability, and appropriate awareness training and reasonable adjustments to acknowledge this need to be considered in all care plans.
- The lower average age at death for autistic adults with and without a learning disability should be investigated further with larger sample sizes. This may be achieved in future LeDeR reports.
- Continued efforts are needed to increase data from more marginalised members of society, such as people from ethnic minorities, members of the LGBTQIA+ population, people in the criminal justice system, and people who are homeless.

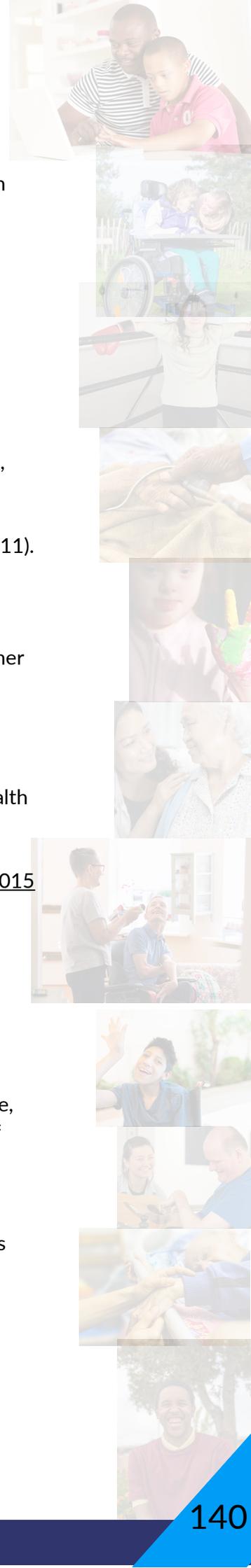
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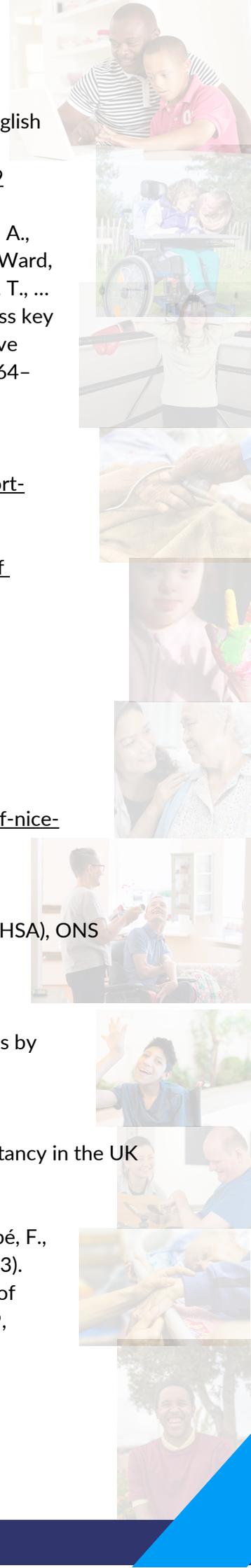
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