



The Learning Disability Mortality Review
(LeDeR) Programme



University of
BRISTOL

Annual Report

2018

University of
Bristol Norah
Fry Centre
for Disability
Studies



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England

The Learning Disabilities Mortality Review (LeDeR) Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP), on behalf of NHS England.

This is the third annual report of the English Learning Disabilities Mortality Review (LeDeR) programme. It presents information about the deaths of people with learning disabilities aged 4 years and over notified to the programme from 1st July 2016 – 31st December 2018. A particular focus is on deaths for which a review was completed during the last calendar year (1st January – 31st December 2018).

For ease of reading, data tables are not included here but are available from leder-team@bristol.ac.uk on request.

Separate collated findings about the priority themes for the programme (young people aged 18-24 years and people from Black, Asian and Minority Ethnic (BAME¹) groups) will be available from NHS England.

This annual report contains information about recommendations and intended actions that reviewers have made and shared in their reports (see Chapter 7 and Appendix 1). A separate report is being prepared by NHS England that provides an overview of the actions taken following mortality reviews and in response to the recommendations made in our annual report 2016/2017 (see Appendix 2).

The report has been prepared by Professor Pauline Heslop (Programme Lead) with Rachel Calkin and Dr Avon Huxor, in conjunction with the current LeDeR team at the University of Bristol: Chris Allen, Lindsey Allen, Melanie Avis, Alison Burnett, Nick Cook, Ann Farr, Kamila Gielnik, Amanda Gray, Dave Hanford, Karen Mepsted, Joanna Richards, Elena Vergara, Rebecca Williams and Andy Wistow.

Our thanks also to past members of the team who have helped with our work.

Acknowledgements

We would like to acknowledge the contribution of the many people with learning disabilities, family members, reviewers, local area contacts and local steering group members who have notified deaths that led or contributed to the reviews of deaths of people with learning disabilities and worked to put service improvements in place.

We would also like to thank the priority themed review panel members who have shared their insights about deaths of young people with learning disabilities and those from BAME communities.

Our grateful thanks too to those who have joined consultation events and helped us develop our recommendations.

Art work credit

We are grateful to Artists First, a collective of artists with learning disabilities in Bristol for providing the art work for this report. Full details about the work of Artists First, and further examples of their work can be found on their website at:

www.artistsfirst.org.uk.

Thank you to Amanda Harman for the photographs of the art work

www.amandaharman.co.uk.

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This report was published in May 2019.

¹ The number of deaths of people from different Black, Asian and Minority ethnic groups is too small for analysis by individual ethnicities. They have therefore been merged into a single group, although we recognise there may be significant differences between them. Black Asian and Minority Ethnic (BAME) group refers to anyone who is not of a white British ethnicity.

Some of the people who have died

This report is about people who have died. They were people who were loved and cherished, and whose deaths have been heartbreaking for their family and those who loved them.

Sometimes when we read reports such as this, we can forget that there are people at the heart of it. In the mass of data provided, there is a danger that people can become numbers, and numbers are impersonal.

We are therefore starting this report by sharing who some of the people whose deaths have been reviewed by the LeDeR programme were. All details have been anonymised, but the stories are those as told by families or paid carers to reviewers. We would like to thank the many families who have given us permission to use their stories.

Matt, died aged 29 from pneumonia

Matt was described as a 'cheeky and happy' person' who loved life. He was good at making himself understood using eye contact and facial expressions. He had a lovely smile that was evident in all the photos of him around his home. Matt enjoyed being around people and being out and about. He liked bowling, feeding the ducks and shopping. He went on holidays, including one time when he swam with dolphins. His favourite song 'I'm too sexy for my shirt' was played at his funeral.

May, died aged 65 from heart failure

May loved to knit, to go on bus trips and do simple jigsaws. She enjoyed listening to music especially Abba and Steps and attended a weekly disco at which she loved to dance. She liked to have manicures and her nails painted with bright coloured polish.

Zane, died aged 65 from pneumonia

Zane was described as playful and mischievous; he liked to play practical jokes. Sometimes he could be stubborn. Zane liked a cup of tea as well as a pint of Guinness. He loved rock music and previously had drumming lessons; he would often be outside using the waste bins as drums.

Tayler, died aged 59 from bowel obstruction

Tayler was a very sociable person who attended an art group at the day centre. He was very structured in his routines; each activity was done on a certain day and there was no deviation from this. A year before his death Tayler had an assessment for Universal Credit and was taken off his benefits. He didn't understand the impact and ran out of money. His sister believes that he spent the last six months of his life worrying about his financial situation and felt that he was very anxious and troubled by this.

Roy, died aged 75 from aspiration pneumonia

Roy used to live with one of his sisters, who recalled that she used to have a really good laugh with him he had a great sense of humour. Roy used to walk into town and back home again and was well known in the local area. He loved wearing hats, and his family would bring him a cap back whenever they went away.

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Executive Summary

'Nobody will learn if you don't have these reviews. Nobody will learn and they need to learn to know, to be able to make changes' (family member)

Key recommendations

| | Recommendation |
|----|---|
| 1 | Consider designating national leads within NHS England and local authority social care to continue active centralised oversight of the LeDeR programme. |
| 2 | NHS England to support Clinical Commissioning Groups to ensure the timely completion of mortality reviews to the recognised standard. |
| 3 | There should be a clear national statement that describes, and references to relevant legislation, the differences in terminology between education, health and social care so that 'learning disability' has a common understanding across each of the sectors and between children's and adults' services. |
| 4 | Clinical Commissioning Groups and local LeDeR steering groups to use local population demographic data to compare trends within the population of people with learning disabilities. They should be able to evidence whether the number of deaths of people from Black, Asian and Minority Ethnic groups notified to LeDeR are representative of that area and use the findings to take appropriate action |
| 5 | The Department of Health and Social Care and NHS England to support national mortality review programmes to work with 'Ask, Listen, Do' and jointly develop and share guidelines that provide a routine opportunity for any family to raise any concerns about their relative's death. |
| 6 | The Department of Health and Social Care, working with a range of agencies and people with learning disabilities and their families, to prioritise programmes of work to address key themes emerging from the LeDeR programme as potentially avoidable causes of death. The recommended priorities for 2019 include: i) recognising deteriorating health or early signs of illness in people with learning disabilities and ii) minimising the risks of pneumonia and aspiration pneumonia. |
| 7 | Guidance continues to be needed on care-coordination and information sharing in relation to people with learning disabilities, at individual and strategic levels. |
| 8 | Shortfalls in adherence to the statutory guidance in the Special Educational Needs and Disability Code of Practice in relation to identifying and sharing information about people with learning disabilities approaching transition, transition planning and care coordination must be addressed. |
| 9 | The Royal College of Paediatrics and Child Health to be asked to identify and publish case examples of best practice and effective, active transition planning and implementation for people with learning disabilities as they move from children's to adults' health services. |
| 10 | The Department of Health and Social Care, working with a range of agencies and the Royal Colleges to issue guidance for doctors that 'learning disabilities' should never be an acceptable rationale for a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order, or to be described as the underlying or only cause of death on Part I of the Medical Certificate Cause of Death. |
| 11 | Medical Examiners to be asked to raise and discuss with clinicians any instances of unconscious bias they or families identify e.g. in recording 'learning disabilities' as the rationale for DNACPR orders or where it is described as the cause of death. |
| 12 | The Care Quality Commission to be asked to identify and review DNACPR orders and Treatment Escalation Personal Plans relating to people with learning disabilities at inspection visits. Any issues identified should be raised with the provider for action and resolution. |

This is the third annual report of the English Learning Disabilities Mortality Review (LeDeR) programme.

It presents information about the deaths of people with learning disabilities aged 4 years and over notified to the LeDeR programme from 1st July 2016-31st December 2018, with a particular focus on deaths reviewed and completed during 2018.

The process for undertaking reviews is now established across England, although some variation in local delivery and accountability is an aspect of the programme that needs strengthening.

Deaths notified to the programme

From 1st July 2016-31st December 2018, 4,302 'in scope' deaths have been notified to the programme. In 2018, this was approximately 86% of the estimated number of deaths of people with learning disabilities in England each year.

By 31st December 2018, the review process had been completed for a quarter (25%) of these deaths. One in 10 (10%) included a multi-agency review.

Reviews were in progress for a third (37%) of the notified deaths by the end of December 2018. However, 38% of the deaths were still waiting to be allocated to a reviewer, indicating continuing and significant problems with the timeliness with which reviews of deaths take place.

The people whose deaths were notified

The proportion of deaths notified from people from Black, Asian and Minority Ethnic (BAME) groups was lower, at 10%, than that from the population in England as a whole (14%). However, children and young people from BAME groups were over-represented in deaths of people with learning disabilities. Of the deaths of children (aged 4-17 years), 42% were from BAME groups (n=95);

of 18-24 year olds the proportion was 26% (n=34), and of adults aged 25 years and over it was 7% (n=239).

A quarter (25%) of people from BAME groups had profound and multiple learning disabilities, twice the proportion (11%) of white British ethnicity.

Almost all (93% of 590 people) had at least one long-term health condition in addition to having learning disabilities.

Age at death

The median age at death for people with learning disabilities (aged 4 years and over) who died from 1st April 2017-31st December 2018 was 59 years. For males it was 60 years; for females 59 years. In our 2016/2017 annual report we reported a median age at death of 58 years.

Our updated data suggests a disparity in the age at death for people with learning disabilities (aged 4 years and over) and the general population (all ages) to be 23 years for males and 27 years for females. In our 2016/2017 annual report we reported the disparity to be 23 years for males and 29 years for females.

Month of death

There was a rise in deaths through autumn and early winter. Over a third (37%) of people who died from aspiration pneumonia did so between October – December.

Place of death

The proportion of people with learning disabilities dying in hospital was 62%; in the general population it is 46%. In our 2016/2017 annual report we reported the proportion of deaths in hospital of people with learning disabilities to be 64%.

Deaths reported to a coroner

Deaths of people with learning disabilities were reported to a coroner less frequently (31%) than people in the general population (43%). Once reported to a coroner, people with learning disabilities were more likely to have a post-mortem or inquest than the general population².

Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) order

Reviewers felt that the majority (79%) of DNACPR orders were appropriate, and correctly completed and followed.

However, 19 reviews reported that the term 'learning disabilities' or 'Down's syndrome' was given as the rationale for the DNACPR order.

Antipsychotic medication

A fifth (19%) of adults with learning disabilities were usually prescribed antipsychotic medication at the time of their death. Of these, 20 people were taking two different types, 6 were taking three different types, and 1 person was taking four different types of antipsychotic medication.

Cause of death

Concerns have been raised about the accuracy of the coding of the underlying causes of death in people with learning disabilities, nationally and internationally. Our data reinforces these concerns.

In people with learning disabilities, the most frequent causes of death by ICD-10 chapter were diseases of the respiratory system (19%), congenital malformations and chromosomal abnormalities (16%) and diseases of the circulatory system (16%).

Fifteen people with learning disabilities had their underlying cause of death erroneously coded as '*developmental disorder of scholastic skills, unspecified*' – a commonly used code for 'learning disabilities'. Six of these had been discussed with a coroner - suggesting that a lack of training and knowledge and potential for 'diagnostic overshadowing' extends across primary and secondary care and into the coronial service.

The medical conditions most frequently cited anywhere in Part I of the Medical Certificate of Cause of Death were: pneumonia (25%), aspiration pneumonia (16%), sepsis (7%), dementia (syndrome) (6%), ischaemic heart disease (6%) and epilepsy (5%).

Pneumonia, aspiration pneumonia and epilepsy were causes of death more frequently reported in people with severe or profound and multiple learning disabilities.

People with learning disabilities who had experienced gaps in service provision that may have contributed to their death more frequently died from sepsis compared to others.

Best practice

A third (33%) of reviews reported one or more examples of best practice. These were frequently in relation to:

- Strong, effective inter-agency working.
- Person-centred care.
- End-of-life care.

Many involved the provision of 'reasonable adjustments'³.

Indicators of poor-quality care

Based on the evidence they have from the review of

² The reference for general population data is on p.2

³ See Footnote on p.36

the death, reviewers are asked to report on aspects of the quality of care provided.

One in ten reviews (11%) noted that concerns had been raised about the person's death. These were commonly in relation to:

- Delays in diagnosing and treating illness.
- The quality of health and social care received by the person.

Delays in the person's care or treatment that adversely affected their health were reported in 12% of reviews. The delays were of various types including:

- Delays in diagnosing and treating illness.
- Delayed discharge from hospital.
- Delayed recognition of approaching end-of-life.

Problems with organisational systems and processes were reported in 13% of reviews. Again, the problems were wide-ranging, including:

- The coordination of care.
- Information sharing.
- Transition planning for those moving from children's to adults' services.
- Policies for specialist referral.
- Staff resources and skills.

Gaps in service provision that may have contributed to the death of a person were reported in 7% of reviews. Such gaps included:

- Postural care and epilepsy expertise.
- Access to cancer screening.
- Lack of 'joined up' working and holistic assessments and support.

Overall assessment of the quality of care provided

Almost a half (48%) of deaths reviewed in 2018

received care that the reviewer felt met or exceeded good practice. This is slightly more than the 44% we reported in our last annual report.

Seventy-one adults with learning disabilities (8%) were reported to have received care that fell so far short of good practice that it significantly impacted on their well-being or directly contributed to their cause of death.

The reasons varied but included:

- Problems with clinical care.
- Problems with medication or equipment.
- Not summoning medical attention in a timely manner.
- A lack of coordination of a person's care and treatment.
- Poor quality end-of-life care.

Multi-agency review

Multi-agency panels reviewed 112 deaths.

Overall, most panels (68%) concluded that the death was not potentially avoidable; 19% felt that the death was potentially avoidable. The panel could not reach a unanimous decision on 8%; the question was unanswered 5%.

Recommendations made by local reviewers

A wide variety of recommendations were made by local reviewers, most commonly in relation to:

- System level issues (e.g. the development of clinical care pathways; adjustment of standard operating procedures).
- Staff training.
- Care coordination and communication.
- DNACPR orders.
- Recognising signs of deterioration.



Chapter 1: Introduction

'It might seem an odd thing to start with the deaths, but I think unless we can unpick what went on, what went wrong, then we're never going to be able to prevent it happening in the future' (family member)

Introduction to the LeDeR programme

2015

1st June – establishment of LeDeR programme in response to significant ongoing concerns about the likelihood of premature deaths of people with learning disabilities.

Team based at the University of Bristol responsible for developing and rolling out a review process for deaths of people with learning disabilities that takes a holistic perspective of their health and social care needs and how these needs were met.

2016

Pilot sites established and trial review process. NHS England National Operational Steering Group established. Each NHS region appointed an NHS England Regional Coordinator to guide the roll out of the LeDeR programme across their geographical region.

First annual report published October 2016, describing the ‘set up’ activities for the programme.

2017

April – introduction of the national Learning from Deaths framework in England which states that deaths of people with learning disabilities should be reviewed using LeDeR methodology.

LeDeR Steering Groups established to cover all Clinical Commissioning Groups (CCGs) (apart from Bristol, North Somerset and South Gloucestershire which was restructuring at the time).

2018

Second annual report published May 2018. See Appendix 2 for the recommendations made and the response from the Department of Health and Social Care (DHSC) and NHS England.

Handover of quality assurance of completed reviews from University of Bristol to NHS England.

Train the trainer model, and e-learning introduced for training reviewers and local area contacts.

Handover of quality assurance of completed reviews from University of Bristol to NHS England.

Development of links and establishment of interface between LeDeR and other mortality review programmes and initiatives (e.g. reviews of deaths in acute hospitals; child death review process; medical examiners) to avoid duplication.

2019

NHS Long Term Plan⁴ supports the continuation of the LeDeR programme.

⁴ <https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/>

Those covered by the LeDeR programme

The LeDeR programme reports on deaths of people with learning disabilities⁵ aged 4 years and over⁶. The definition of 'learning disabilities' is that of 'Valuing People' (2001)⁷ and includes the presence of:

'A significantly reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently, which started before adulthood, with a lasting effect on development.'

The review process

The LeDeR review process is described on the LeDeR website at: www.bristol.ac.uk/sps/leder. A summary of the process is in Appendix 3. All deaths of people with learning disabilities aged 4 years and over in England are notified centrally and reviewed locally.

Involvement of people with learning disabilities and families

The agreed methodology of the LeDeR review process recommends that all families should have the opportunity to be involved in the review of their relative's death from the outset. Over three-quarters (81%) of families were invited to contribute to the review of their relative's death in 2018. If a family member is not able to be identified, someone who knows the person well is invited to contribute to the review.

Outside of the review process, some people with learning disabilities and their families have been involved as steering and advisory group members, priority theme review panel members, and *ad hoc* consultation groups.

Delivery of the LeDeR programme

The LeDeR methodology is now established throughout England. NHS Sustainable Improvement reviewed it in spring/summer 2018 and requested no significant developments. In response to requests, some amendments to the initial review documentation have been made; most recently (January 2019) some review questions became mandatory.

In September 2018 we extended training for reviewers and local area contacts via e-learning. The team at the University of Bristol are responsible for maintaining the e-learning platform; NHS England regional coordinators deliver training.

During early 2018 the team at the University of Bristol prepared to hand over the quality assurance of completed reviews to NHS England. Local area contacts took over this responsibility in October 2018.

The University of Bristol team remains responsible for taking notifications of deaths, supporting the LeDeR review system and e-learning platform, holding independent panels for priority themes, collating and analysing completed reviews and communicating overall findings.

Local steering groups ensure that local reviews of deaths take place and the recommendations from reviews result in a local action plan. The structure and constitution of some groups differs from that set out in guidance; this has resulted in some variation in approach, local delivery and accountability and is an aspect of the programme that needs strengthening.

⁵ The terms 'learning disability' and 'learning disabilities' are used interchangeably in this report.

⁶ Prior to the age of 4 years it can be difficult to identify if a child has learning disabilities unless they have a specific syndrome associated with learning disabilities.

⁷ Department of Health (2001) Valuing People: A New Strategy for Learning Disability for the 21st Century. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf



Chapter 2: Deaths notified to the LeDeR programme

‘When my daughter died, there wasn’t a review process in place at all. But I think had it been there... it would have given us the confidence that the learning that we had from that experience could be captured and could prevent other people having relatives die in similar circumstances’ (family member)

Deaths notified to the programme

From 1st July 2016 - 31st December 2018, 4,302 ‘in-scope’⁸ deaths were notified to the LeDeR programme. The majority of these (2,926) were notified in 2018.

There is no accurate record of the total number of people with learning disabilities in England, nor of the number of deaths each year. Estimates from Public Health England suggest the approximate number of deaths of people with learning disabilities of all ages each year to be more than 3,400. It should be noted, however, that this is unlikely to be evenly distributed across England due to historic patterns of institutional provision.

Approximately 86% of the number of estimated number of deaths were notified to the LeDeR programme in 2018.

Notification of deaths in the South East region was greater than the estimated number of deaths in that region; notifications from all other regions were less than estimated (Table 1, Figure 1) yielding an estimated 14% shortfall overall.

A summary table of the distribution of notifications to estimated number of deaths in 2018 by Clinical Commissioning Group is available on request from leder-team@bristol.ac.uk.

Table 1: Number of in-scope notifications of deaths of people with learning disabilities aged 4 years and over, by NHS England region

| | 1 st July 2016 – 31 st Dec 2016 | 1 st Jan 2017 – 31 st Dec 2017 | 1 st Jan 2018 – 31 st Dec 2018 | Estimated number of deaths in 2018 ⁹ | Percentage of notifications to estimated number of deaths in 2018 | Total deaths notified 1 st July 2016 – 31 st Dec 2018 |
|-----------------|---|--|--|---|---|---|
| North | 56 | 565 | 813 | 1,071 | 76% | 1,434 |
| Midlands & East | * | 268 | 948 | 1,079 | 88% | 1,217 |
| South East | 27 | 134 | 587 | 483 | 122% | 748 |
| South West | 14 | 126 | 254 | 361 | 70% | 394 |
| London | * | 181 | 324 | 419 | 77% | 509 |
| Total | 102 | 1,274 | 2,926 | 3,413 | 86% | 4,302 |

*Number of deaths is fewer than 10

Figure 1: Percent of actual number of notifications to estimated number of deaths in 2018, by NHS region

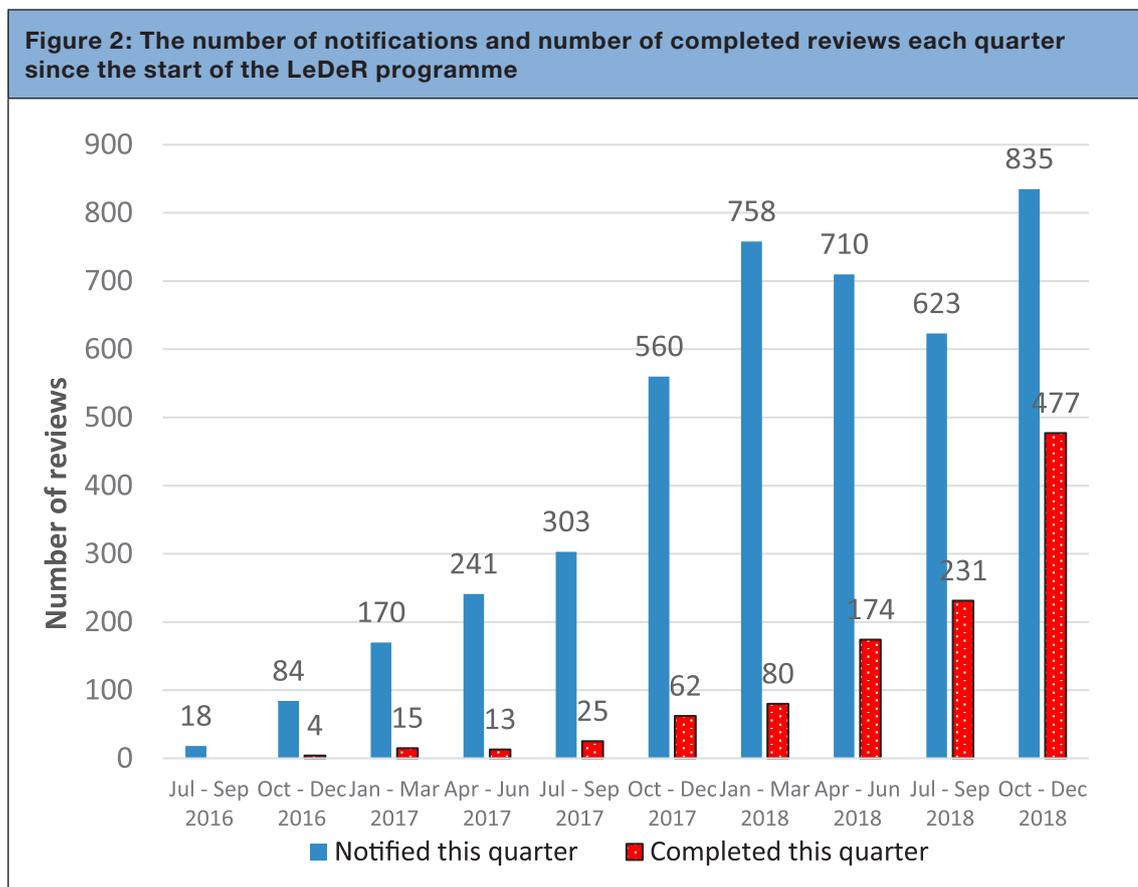


⁸ ‘In scope’ deaths are those of people with learning disabilities aged 4 years and over registered with a GP/living in an area where the LeDeR programme had started reviewing deaths.

⁹ Estimates were calculated by Professor Gyles Glover of Public Health England in September 2018. Estimates are for deaths of people with learning disabilities of all ages (including 0-4 years).

Progress in completing reviews

Figure 2 shows the number of notifications and number of completed reviews each quarter since the start of the LeDeR programme.



Almost two-fifths (38%, n=1,636) of deaths notified to the LeDeR programme were still waiting to be allocated to a reviewer¹⁰ at the end of December 2018 (Figure 3). Key explanations given for this in our last annual report were that trained reviewers did not have sufficient time away from their other duties to be able to complete a review, and that the process is not formally mandated. These appear to be ongoing issues.

The Midlands and the East had the highest proportion of deaths notified that were still awaiting allocation to a reviewer (49%); London had the least (16%) (Appendix 4).

¹⁰ Deaths are notified to the LeDeR team at the University of Bristol where they are logged. The IT system informs the relevant local area contact, who identifies a local reviewer to review the death.

Deaths that have been reviewed

Of the 4,302 deaths notified to the LeDeR programme between 1st July 2016 and 31st December 2018, a quarter (25%, 1,081) had been reviewed by 31st December 2018.

London had completed the greatest proportion of completed reviews (34%); the Midlands and the East the least (19%) (Figure 4).

Initial reviews and multi-agency reviews

Of the 1,081 completed reviews, 90% (n=969) had received an initial review only. About one in ten, (10%, n=112) received a full multi-agency review¹¹.

Figure 3: Progress of reviews of deaths notified 1st July 2016 – 31st December 2018

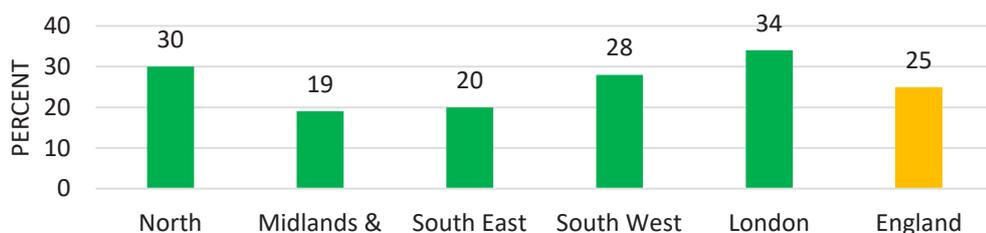
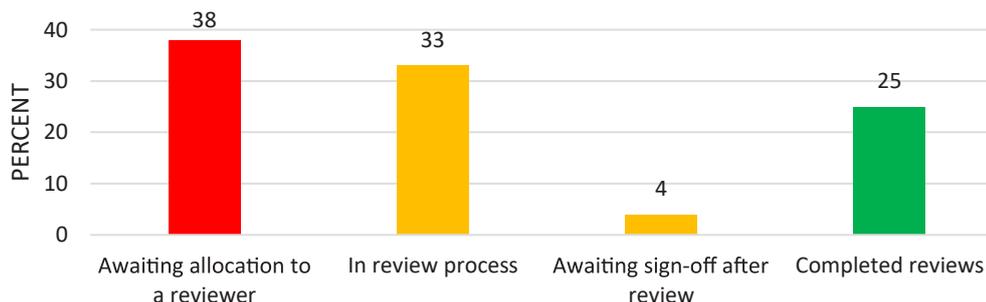


Figure 4: Progress of reviews of deaths notified 1st July 2016 – 31st December 2018



¹¹ See Appendix 3 for the criteria for a multi-agency review.



Chapter 3: The people whose deaths were notified to the LeDeR programme

'They were real people who were loved and cared for; if somebody just reads clinical case notes they've got no real sense of who that person was and what was important to them in their lives' (family member)

In this and succeeding chapters we focus on the 4,302 people with learning disabilities whose deaths were notified to the LeDeR programme between 1st July 2016 and 31st December 2018. Where accurate information was not available at the time the death was notified¹², we only consider the 962 deaths that were reviewed in 2018.

Deaths of children with learning disabilities are reviewed by the statutory Child Death Review programme and completed reviews into deaths of children with learning disabilities aged 4 -17 years are shared with the LeDeR programme. We have analysed the information separately for children and summarised this in Chapter 6.

The LeDeR programme also has a specific focus on the deaths of two priority themes: deaths of young people aged 18-24 years, and deaths of people from Black, Asian and Minority Ethnic (BAME) groups.

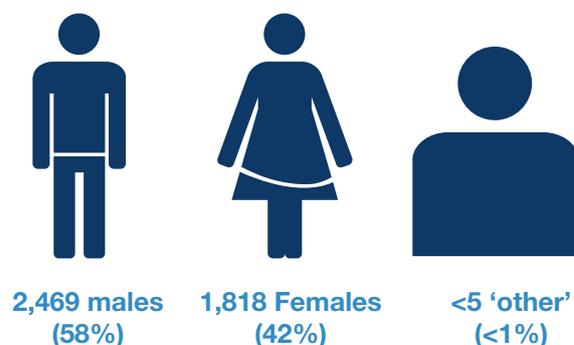
These two groups were selected as priority themes in recognition of concerns about the transition from children’s services to adult services, and the continuation of inequalities in health and social care for people with learning disabilities from BAME groups.

For more information about the methodology of priority theme reviews see Appendix 3.

Information about the two priority theme groups is presented throughout the report. A summary of the collated information is available on request at **leder-team@bristol.ac.uk**.

Gender

The person’s gender was reported for 4,290 deaths notified. Of these, over half (58%) were males.



The proportion of males is similar to that of people with learning disabilities aged 4-17 years (58% male), aged 18-24 years (61% male), and from BAME groups (58% male).

Ethnicity

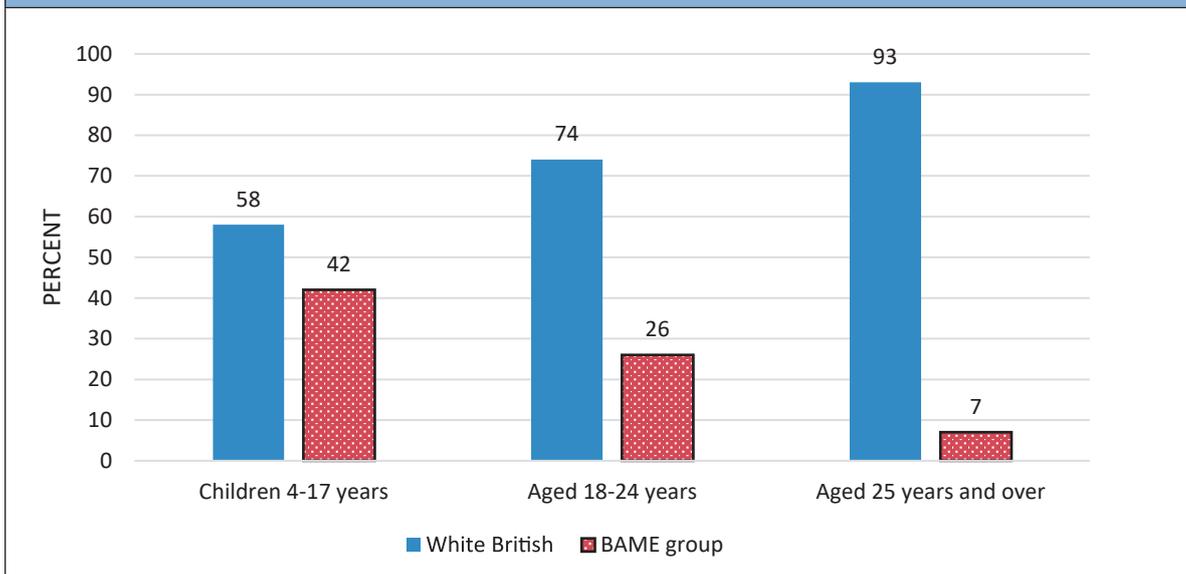
The person’s ethnicity was reported for 3,815 deaths. The majority (90%) were of white British ethnicity, 4% were Asian, and 6% were from other ethnicities. The proportion aged 4 years and over whose ethnic group was described as ‘white British’ was higher at 90% than the 86% recorded for England and Wales as a whole¹³.

Children and young people from BAME groups were over-represented in deaths of people with learning disabilities. Of the deaths of children (aged 4-17 years), 42% (n=95) were from BAME groups; of 18-24 year olds the proportion was 26% (n=34), and of adults aged 25 years and over it was 7% (n=239) (Figure 5).

¹² At the point of notification of a death, some of the key demographic information may be missing; the reviewer would complete any missing information during the review process. We have excluded missing data from the information below.

¹³ <https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/articles/ethnicityandnationalidentityinenglandandwales/2012-12-11>

Figure 5: Proportion of children young people and adults with learning disabilities by ethnicity



Level of learning disabilities

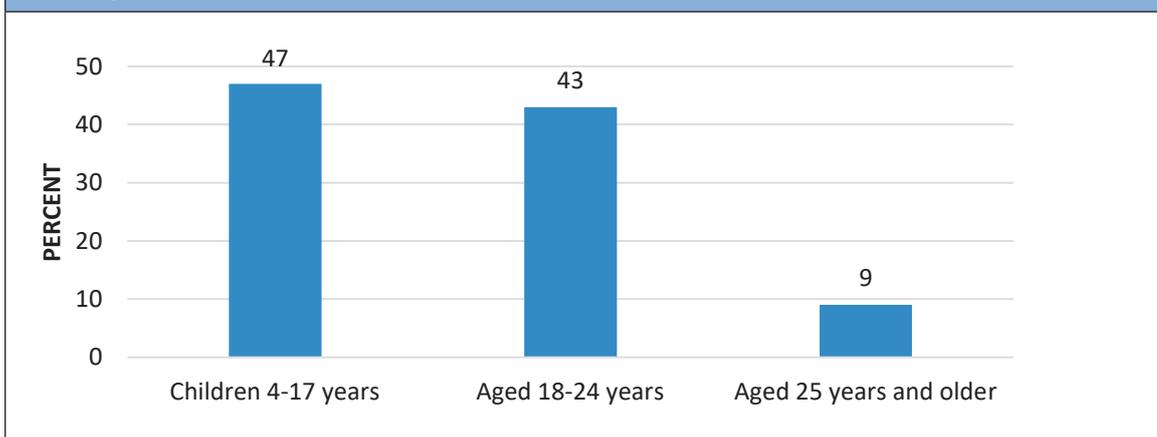
The level of a person’s learning disabilities was only reported for 1,719 people. A quarter (27%) were known to have had mild learning disabilities; 34% moderate learning disabilities; 27% severe learning disabilities; and 12% profound or multiple learning disabilities.

The level of a person’s learning disabilities differed by age at death. More people who died at a younger age had profound and multiple learning disabilities. Many people with profound and multiple learning disabilities

would have complex medical conditions that may make an earlier death likely or might have genetic conditions that are life limiting. Of the 209 people with profound and multiple learning disabilities, almost half (47%) were children, 43% were young people aged 18-24, and just 9% were adults aged 25 years and over (Figure 6).

A quarter (25%) of the 369 people from BAME groups (for whom information about the level of their learning disabilities was available) had profound and multiple learning disabilities, compared with 12% of people of white British ethnicity.

Figure 6: Proportion of children young people and adults with profound and multiple learning disabilities



Multimorbidity

The NICE Guideline 56¹⁴ about clinical assessment and management of multimorbidity defines multimorbidity as the presence of two or more **long-term** health conditions, which can include:

- Defined physical and mental health conditions such as diabetes or schizophrenia.
- Ongoing conditions such as learning disability.
- Symptom complexes such as frailty or chronic pain.
- Sensory impairment such as sight or hearing loss.
- Alcohol and substance misuse.

Of 590 people with learning disabilities whose deaths were reviewed and hand-coded¹⁵ by LeDeR in 2018, 550 had at least one long-term health condition (in addition to having learning disabilities). The mean number of long-term health conditions (in addition to having learning disabilities) was 2.9.

The five most common long-term health conditions reported were:

- Epilepsy (39%, n=227).
- Dysphagia (38%, n=222).
- Cardiovascular problems (28%, n=162).
- Dementia (25%, n=147).
- Mental illness (23%, n=134).

The most common combinations of long-term health problems were:

- Epilepsy and dysphagia (18%, n=104).
- Dysphagia and dementia (13%, n=79).
- Dysphagia and cardiovascular (12%, n=72).
- Epilepsy and dementia (11%, n=67).

There was no association between the presence of multimorbidity and median age at death (Table 2).

| Table 2: Median age at death for people with learning disabilities with additional long-term health conditions | | | |
|---|----------|----------|----------------------------|
| Number of long-term health conditions (in addition to having learning disabilities) | % | N | Median age at death |
| Males | | | |
| One | 14 | 47 | 61 |
| Two | 20 | 67 | 59 |
| Three or more | 58 | 194 | 61 |
| Females | | | |
| One | 17 | 44 | 58 |
| Two | 23 | 58 | 61 |
| Three or more | 55 | 140 | 63 |
| All | | | |
| One | 15 | 91 | 59 |
| Two | 21 | 125 | 59 |
| Three or more | 57 | 334 | 62 |

There was an association between the level of a person's learning disabilities and the number of long-term conditions they had. People with mild learning disabilities had an average (mean) number of 3.3 additional long-term conditions; for people with moderate learning disabilities it was 3.0; for severe learning disabilities it was 3.0; and for profound and multiple learning disabilities it was 2.5.

There was also an association between ethnicity and the number of long-term conditions. People of white British ethnicity had an average (mean) of 3.0 long-term health conditions; people from BAME groups had an average (mean) of 2.2 long-term conditions.

¹⁴ <https://www.nice.org.uk/guidance/ng56>

¹⁵ Hand-coding refers to a system of a coder checking through the completed review form and identifying and classifying any long-term conditions that are mentioned.



Chapter 4: The deaths of people with learning disabilities

'I welcome the review because I think it's been too long that people's deaths have been attributed to learning disability - very often it's about attitudes ...towards whether their health is as important as someone without a learning disability' (family member)

Age at death

Here we report on the age at death of people with learning disabilities who died from 1st April 2017 onwards¹⁶. It is important to remember that comparisons with the general population are indicative but not directly comparable: deaths of people with learning disabilities are notified from the age of 4 years, while general population data also includes information about children aged 0-3 years.

In addition, as we have already mentioned, more people who died at a younger age had profound and multiple learning disabilities, and some of these would have complex medical conditions or genetic conditions that may make an earlier death likely.

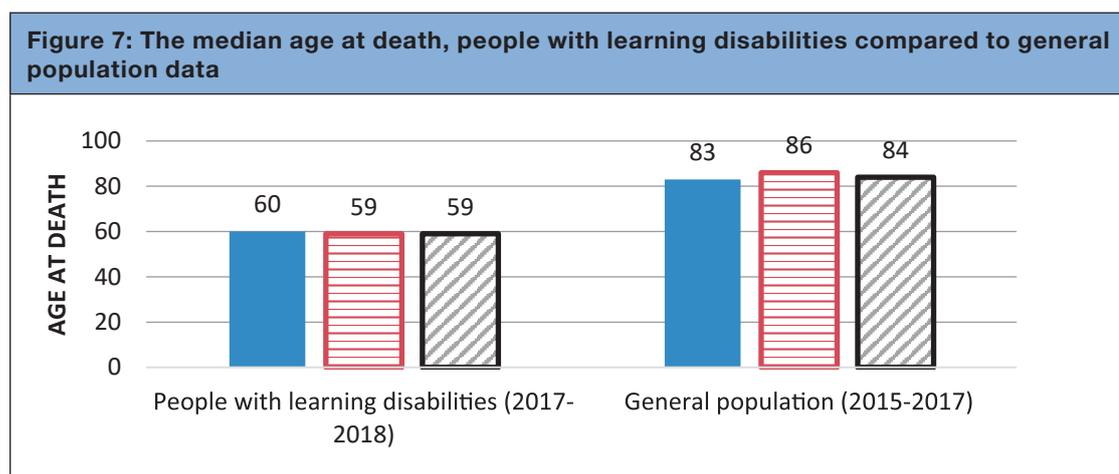
The median age at death¹⁷

The median age at death for 3,860 people with learning disabilities (aged 4 years and over) was 59 years. For males it was 60 years (min 4 years; max 98 years); for females it was 59 years (min 4 years; max 98 years) (Figure 7).

In the general population of England from 2015-2017, the median age at death (for people of all ages, including 0-4 years) was 83 years for males and 86 years for females (Office for National Statistics, 2018¹⁸).

Our updated data suggests that the disparity between the age at death for people with learning disabilities (age 4 years and over) and the general population (all ages) is 23 years for males and 27 years for females.

In our 2016/2017 annual report we reported the disparity to be 23 years for males and 29 years for females.



¹⁶ From 2016 to 31st March 2017 the LeDeR programme only reviewed the deaths of people aged 74 or less. The upper age limit was then removed to align the LeDeR programme with the Learning from Deaths national framework. Here, we only report on deaths from 1st April 2017 onwards, in order to aid comparisons with national data and ensure consistent interpretation of the data.

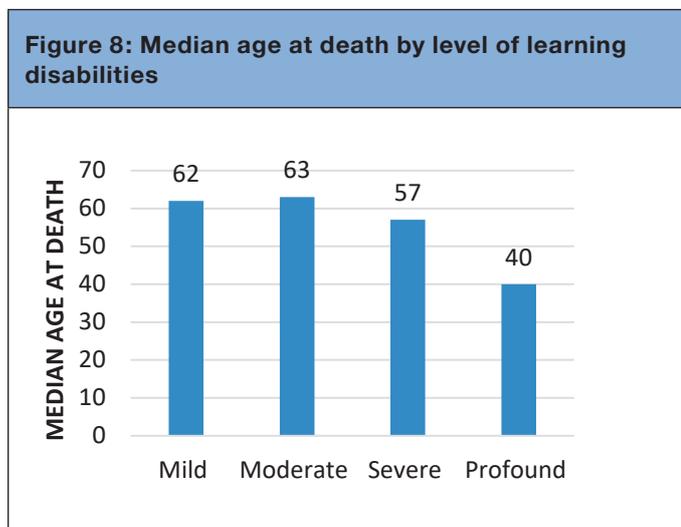
¹⁷ The median age at death is the age at which exactly half the deaths were deaths of people above that age and half were deaths below that age.

¹⁸ <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/datasets/averageageatdeathbysexuk>

Who is most at risk of dying early?

People with profound/multiple learning disabilities

The median age at death for people with mild learning disabilities was 62 years; for moderate learning disabilities was 63 years; for severe learning disabilities 57 years; and for profound and multiple learning disabilities 40 years (Figure 8).



There was a considerable difference in the median age at death for people of white British and BAME groups. The median age at death for people of BAME groups was 35 years (min 4; max 88), compared to 61 years (min 4; max 98 years) for people of white British ethnicity (Figure 9).

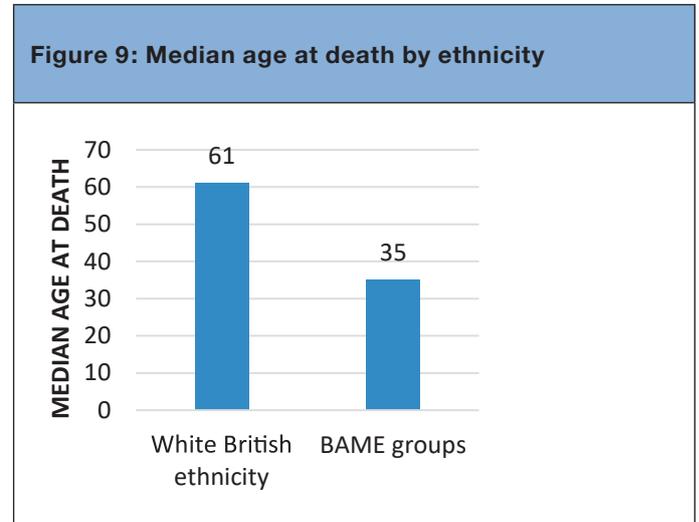


Table 3: Median age at death by ethnicity and level of learning disabilities for children and adults

| Child/Adult | Number | Level of learning disabilities | Ethnic group | Median age at death |
|-------------|--------|--------------------------------|---------------|---------------------|
| Child | 11 | Mild/moderate | White British | 10 |
| Child | * | Mild/moderate | BAME | * |
| Child | 26 | Severe/profound and multiple | White British | 14 |
| Child | 16 | Severe/profound and multiple | BAME | 11 |
| Adult | 840 | Mild/moderate | White British | 64 |
| Adult | 71 | Mild/moderate | BAME | 56 |
| Adult | 479 | Severe/profound and multiple | White British | 57 |
| Adult | 57 | Severe/profound and multiple | BAME | 36 |
| All (851) | 851 | Mild/moderate | White British | 63 |
| All (75) | 75 | Mild/moderate | BAME | 55 |
| All (505) | 505 | Severe/profound and multiple | White British | 56 |
| All (73) | 73 | Severe/profound and multiple | BAME | 33 |

* number of deaths is fewer than 10

When considering age at death, ethnicity and level of learning disabilities together, it is apparent that children and adults from BAME groups have a lower median age at death than their peers (Table 3). Some numbers are small so should be interpreted cautiously.

We have considered children separately because of the mandatory reporting of deaths of children¹⁹. What we must bear in mind is whether the under-reporting of deaths of people from BAME groups more significantly affects people with mild or moderate learning disabilities. If so, this would be likely to have lowered the median age at death.

Month of death

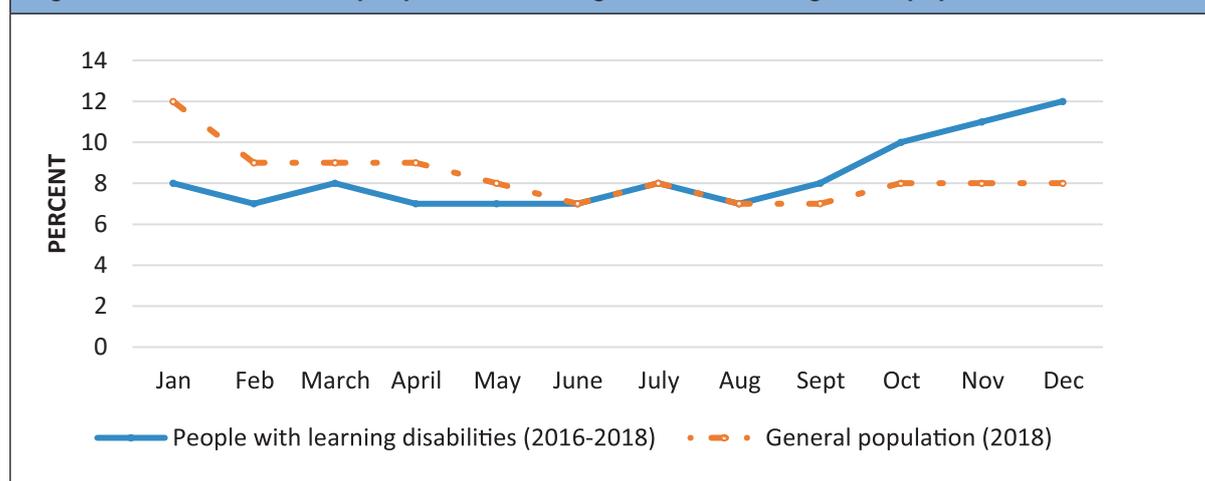
Of 4,302 deaths notified to the LeDeR programme, a similar proportion of deaths occurred each month, apart from a rise through autumn and early winter months (Figure 10), earlier than the peak winter deaths in the general population.

Some caution is required in interpreting this data, as without mandatory reporting of all deaths to LeDeR, it may in part, reflect trends in reporting deaths to the LeDeR programme.

Comparing those who died between January-September, and those who died between October-December, there was no significant difference according to age group, gender, ethnicity or level of learning disabilities.

A significantly greater proportion of people who died from aspiration pneumonia did so between October – December (37%, n=116) than did those without aspiration pneumonia (31%, n=498).

Figure 10: Month of death: people with learning disabilities and general population



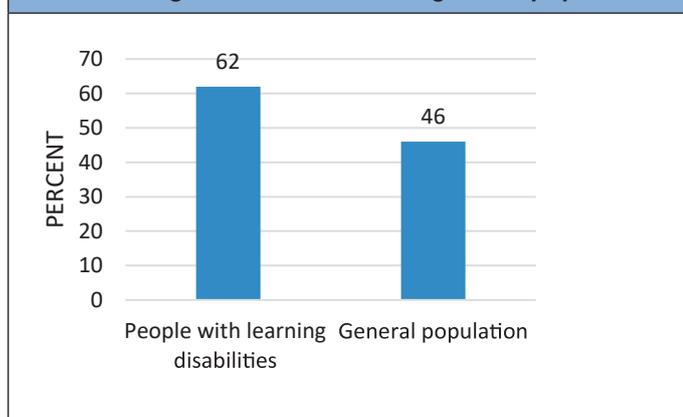
¹⁹ <https://www.gov.uk/government/publications/child-death-review-statutory-and-operational-guidance-england>

Place of death

Of the 4,147 deaths of people with learning disabilities with the place of death reported, 62% died in hospital. The corresponding proportion for people in the general population is 46%²⁰ (Figure 11).

There was no difference in age group, gender, ethnicity or level of learning disabilities as to whether a person died in hospital or not.

Figure 11: Proportion of deaths in hospital for people with learning disabilities and the general population



Deaths of people in contact with specialist services

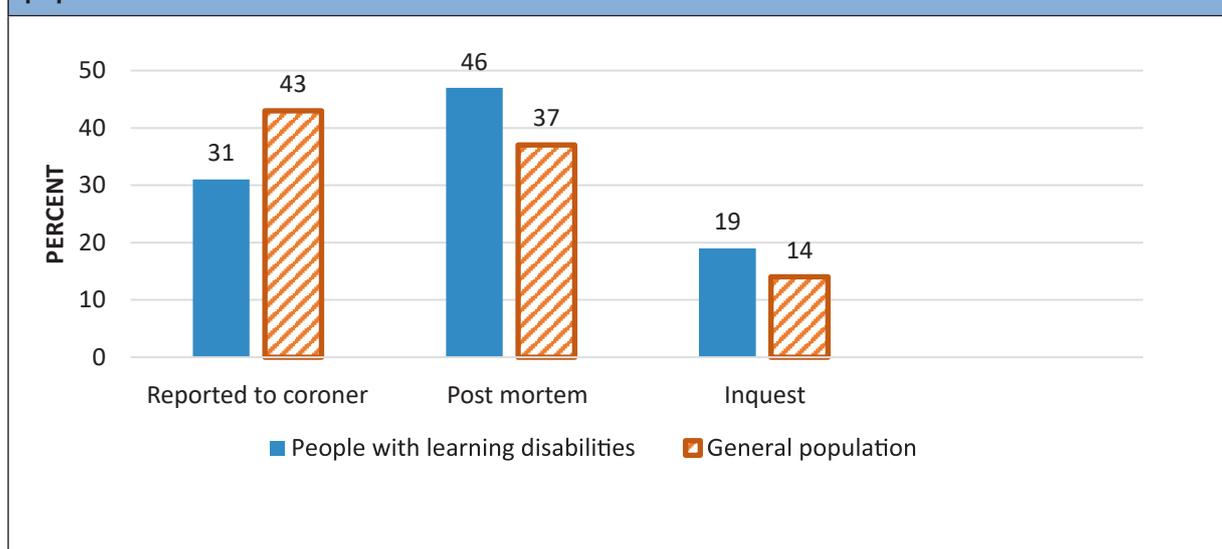
Fewer than five people had been in an inpatient of an Assessment and Treatment Unit (learning disabilities) or a specialist hospital (mental health) in the past but had been discharged more than five years prior to their death. Fewer than five people died whilst a current inpatient or within 30 days of discharge from a specialist hospital or an Assessment and Treatment Unit. To protect anonymity, further analysis of these deaths is not presented here.

Deaths reported to a coroner

Of the 962 deaths reviewed in 2018, a smaller proportion of deaths of people with learning disabilities was reported to a coroner (31%) than in the general population (43%)²¹ (Figure 12).

Whether the death had been reported to a coroner was related to a person's age: children more frequently had their death reported (43%), and those aged 18-24 the least (23%).

Figure 12: Proportion of deaths of people with learning disabilities reviewed in 2018 that were reported to a coroner, and of these, post mortems and inquests ordered, compared with general population data



²⁰ http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death

²¹ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data_file/760123/Coroners_Statistics_Bulletin_2017.pdf

There was no relation between whether or not the death was reported to a coroner according to the person's ethnicity, or the level of their learning disabilities.

Of the 302 deaths of people with learning disabilities reported to a coroner, people with learning disabilities were more likely to have a post-mortem (46%) or an inquest (19%) than people in the general population (37% and 14% respectively) (Coroners Statistics Bulletin 2017 – see Footnote 21).

End-of-life care plan

Of 588 deaths reviewed in 2018 for which coded data was available about end-of-life care, almost half (46%) indicated that the person had an end-of-life care plan.

Children and young people were least frequently reported to have an end-of-life plan (35% of 4-17 year olds; 25% of 18-24 year olds) rising to 50% of those aged 50-64 years and 48% of those aged 65 and over.

People of white British ethnicity more frequently had an end-of-life plan (46%) than people from BAME groups (40%).

Deaths with a Do Not Attempt Cardio-pulmonary Resuscitation (DNACPR) Order²² or a decision to allow a natural death

Of 897 deaths reviewed in 2018 for whom data was available about DNACPR orders, 69% had such an order. Reviewers felt that the majority of these (79%) were appropriate, correctly completed and followed.



The DNACPR was in place within the community setting. When Josie was admitted to hospital there is clear evidence that this was revisited and discussed again with the family (reviewer).

There were no instances reported of cardio-pulmonary resuscitation (CPR) inappropriately being denied; there were some reports of CPR being attempted although a decision not to attempt CPR had previously been documented, mostly relating to an ambulance service not having up-to-date information or care home staff being unsure as to whether to proceed or not.

The majority of concerns raised in reviews were in relation to DNACPR orders were about the inappropriate inclusion of 'learning disabilities' or a related condition as a reason for DNACPR²³.

Nineteen reviews reported that the term 'learning disabilities' or 'Down's syndrome' was erroneously given as the rationale for the DNACPR order.

Children and young people were least frequently reported to have a DNACPR order (46% of 4-17 year olds; 50% of 18-24 year olds) rising steadily to 74% of those aged 65 and over. People of white British ethnicity were no more frequently reported to have a DNACPR order than people from BAME groups.



The DNACPR included reasons not to resuscitate which related to judgements on the individuals' quality of life: '*Down's syndrome, learning difficulties, cognitive decline*'. Clear guidance has been shared by the safety and quality team to ensure medical reasons not to resuscitate are clearly documented (reviewer).

²² Cardio-pulmonary resuscitation is when a person receives chest compressions and artificial breaths to help pump blood around their body when their heart has stopped. A decision not to attempt cardio-pulmonary resuscitation is made and recorded in advance when it would not be in the best interests of the person because they are near the end of their life or the procedure would be unlikely to be successful.

²³ Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing explicitly states that decisions about DNACPR must not be based on assumptions related to the person's age, disability or the professional's subjective view of a person's quality of life.

Deaths of people taking antipsychotic medication

There is a higher rate of prescribing psychotropic²⁴ medicines among people with learning disabilities than the general population although they may not have the health conditions for which the medicines are prescribed^{25,26}. Antipsychotics are one type of psychotropic medication used to treat a number of conditions, including, bipolar disorder, schizophrenia and psychosis; sometimes they are prescribed to help manage behaviour. The focus here is on antipsychotic medication only.

Information about medication was available for 550 adults (aged 18 and over) with learning disabilities whose deaths were reviewed in 2018. A fifth (19%, n=102) were usually prescribed antipsychotic medication (Table 4).

| Type of antipsychotic medication | % | Number |
|----------------------------------|----|--------|
| Risperidone | 37 | 38 |
| Olanzapine | 22 | 22 |
| Promazine ²⁷ | 18 | 18 |
| Haloperidol | 16 | 16 |
| Chlorpromazine | 11 | 11 |
| Quetiapine | 10 | 10 |
| Levomepromazine | * | * |
| Other | 14 | 14 |

*number or proportion equates to fewer than 10

Most (73%) of those who were taking anti-psychotic medications were only taking one type²⁸, but 27% were taking more than one type, including 20 people taking two different types, 6 taking three types and 1 person taking four types.

There was an increase in the proportion of adults taking antipsychotics with age: 90% of those taking antipsychotics were aged 50 or over. There was no significant difference according to gender, ethnicity, the level of learning disabilities, or the geographical region of the country in which a person lived.

The overall number of people taking antipsychotic medication was small, so the data need to be interpreted with caution. However, we found no significant difference in whether a person was taking antipsychotic medication in general, or specific antipsychotic medications, when considering causes of death from pneumonia, aspiration pneumonia, sepsis, or epilepsy, or according to whether they had Down's syndrome or dementia.

²⁴ Psychotropic medication is any drug that affects mental processes and behaviour. They include antipsychotics, hypnotics, antidepressants, and anti-anxiety drugs.

²⁵ See: <https://www.gov.uk/government/publications/psychotropic-drugs-and-people-with-learning-disabilities-or-autism/psychotropic-drugs-and-people-with-learning-disabilities-or-autism-results>

²⁶ See STOMP (Stopping Overprescribing of Psychotropic Medication) at: <https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>

²⁷ Although promazine is an antipsychotic it is usually prescribed to treat severely agitated or restless behaviour.

²⁸ In line with published prescribing guidelines such as those developed by NICE, most people with a psychotic illness only receive one antipsychotic at a time.

Causes of death²⁹

Concerns have been raised about the accuracy of coding causes of death for people with learning disabilities, nationally and internationally. These are the under-reporting that a person had learning disabilities when it was relevant to the cause of death, and erroneously listing a learning disability or an associated condition as an underlying cause of death³⁰.

In England and Wales, completed Medical Certificates of Cause of Death (MCCD) are coded according to the International Classification of Diseases (version 10) (ICD-10). In order to ensure we have accurate coding for the deaths of people with learning disabilities, we received the official Office for National Statistics (ONS) ICD-10 codes via NHS Digital for the causes of death of people with learning disabilities whose deaths had been notified to LeDeR.

Here we present cause of death data for the 1,938 deaths for which we have a verified ICD-10 code for causes of death³¹.

Underlying cause of death by category

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

Table 5 indicates, by ICD-10 chapter, the most common underlying causes of death in people with learning disabilities (within the LeDeR 2016-18 data) compared with 2017 data for the general population. In addition, we have separated out data for children aged 4-17 years, young people aged 18-24 years and by ethnicity.

Columns 1 and 2 show that people in the general population more frequently died from cancer and diseases of the circulatory system than people with learning disabilities. People with learning disabilities more frequently died from congenital malformations/ chromosomal abnormalities and diseases of the nervous system (e.g. epilepsy) than people in the general population.

Columns 3-6 present the most frequent causes of death for people with learning disabilities aged 4-17 years and 18-24 years within the LeDeR data, compared to data for the general population. Caution must be used here in that the number of children (n=97) and young people (n=69) with learning disabilities for whom we currently have a verified ICD-10 code for the causes of death is small.

Columns 7 and 8 compare the causes of death by ethnicity, which are broadly similar.

²⁹ Medical certificates of cause of death (MCCD) are divided into two sections, Parts I and II. Part I contains the immediate cause of death, tracking the sequence of causes back to any underlying cause or causes. Part II of the MCCD is used to list other significant conditions, diseases or injuries that contributed to the death, but were not part of the direct sequence. Guidance for doctors completing MCCD in England and Wales is available at: <https://www.gov.uk/government/publications/guidance-notes-for-completing-a-medical-certificate-of-cause-of-death>

³⁰ For a summary of concerns see: <https://onlinelibrary.wiley.com/doi/full/10.1111/jar.12448>

³¹ It takes some time for the Office for National Statistics to receive MCCDs and for these to be coded and the codes verified. Codes for the most recent deaths are therefore not yet available.

Table 5: Underlying cause of death by ICD-10 chapter, for people with learning disabilities whose deaths have been notified to the LeDeR programme and for whom a verified ICD-10 code has been provided, and data for the general population

| | Column 1 | Column 2 | Column 3 | Column 4 | Column 5 | Column 6 | Column 7 | Column 8 |
|---|---|-------------------------------|---------------------------------------|--|-------------------------------------|--|----------------------------------|---|
| | Gen pop'n ³² n=529,605 % | LD aged 4yrs+ n=1,938 % | Children with LD 4-17yrs n=97 % | Children gen pop'n 5-14yrs n=549 % | Aged 18-24 yrs with LD n=69 % | Aged 15-24 yrs gen pop'n n=1,978 % | LD aged 4yrs+ BAME n=153 % | LD aged 4yrs+ white British n=1,566 % |
| Neoplasm (cancer) | 28 | 14 | * | 30 | * | 11 | 9 | 15 |
| Diseases of the circulatory system | 25 | 16 | 10 | 5 | * | 7 | 14 | 16 |
| Diseases of the respiratory system | 14 | 19 | 11 | 9 | 23 | 4 | 18 | 19 |
| Mental and behavioural disorders | 10 | 4 | * | <1 | * | <1 | * | 5 |
| Nervous system | 6 | 14 | 21 | 10 | 26 | 7 | 20 | 12 |
| Diseases of the digestive system | 5 | 6 | * | 2 | * | 2 | 8 | 6 |
| External causes of death | 4 | 2 | * | 21 | * | 38 | * | 2 |
| Endocrine, nutritional and metabolic diseases | 2 | 2 | 14 | 5 | * | 7 | 8 | 2 |
| Infections | 1 | 2 | * | 5 | * | 1 | * | 2 |
| Congenital malformations/ chromosomal abnormalities | <1 | 16 | 17 | 8 | * | 3 | 11 | 17 |
| Other underlying causes of death | 6 | 5 | * | 5 | * | 20 | * | 4 |

*Proportions equate to fewer than 10 deaths

³² From: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables>

In summary:

- A smaller proportion of children (aged 3-17 years) died from respiratory disorders than adults (aged 18 and over). This may be due to the protective influence of the influenza and pneumovax vaccinations in children, but the data to support or refute this assertion is not available.
- A greater proportion of children (aged 0-17 years) in the general population died from cancer and external causes (e.g. accidents and injuries) compared to children with learning disabilities (aged 4-17 years).
- A greater proportion of young people aged 18-24 years with learning disabilities died from disorders of the nervous system (e.g. epilepsy), respiratory system, and congenital malformations and chromosomal abnormalities, compared to young people (aged 15-24 years) in the general population.
- A greater proportion of young people (aged 15-24 years) in the general population died from external causes (e.g. accidents and injuries) and cancer compared to young people with learning disabilities (aged 18-24 years).

Although the underlying cause of death is commonly reported in national statistics, its usefulness is diminished when considering the cause of death of people with learning disabilities.

First, a large minority of these deaths (16%) are ascribed to 'congenital malformations and chromosomal abnormalities' most commonly Down's syndrome, usually in association with Alzheimer's disease. In our view, coding Down's syndrome as an underlying cause of death in this way is neither helpful nor accurate; rather, it should be coded on Part II of the MCCD.³³

Secondly, of people with Down's syndrome identified in Part I or Part II on their MCCD, 62 had their death coded as 'dementia, unclassified' (ICD-10 code F01-03) and 38 had their death coded as 'Alzheimer's disease' (ICD-10 G300). Dementia is a syndrome, a group of symptoms that does not have a definitive diagnosis; it is not a disease, although it tends to be an umbrella term that Alzheimer's disease can fall under. We suspect that there has been some conflating of dementia and Alzheimer's disease in the codes for causes of death.

Thirdly, within the category of 'mental and behavioural disorders' are codes for 'learning disabilities'. Again, the use of these codes for an underlying cause of death is inaccurate. The national guidance for doctors completing MCCDs states to avoid physical and mental conditions that are not fatal in themselves, and that having learning disabilities is rarely a sufficient medical explanation of the death.³⁴

Within this category, 15 deaths of people with learning disabilities were coded with an underlying cause of death as being '*Developmental disorder of scholastic skills, unspecified*', a commonly used code for 'learning disabilities'. Our assumption is that this error is due to a lack of training and knowledge on behalf of certifiers, and/or 'diagnostic overshadowing' where health problems are attributed to a person's learning disabilities rather than to a physical condition.

Of the 15 people with their underlying cause of death coded as 'learning disabilities', seven had severe or profound learning disabilities. Eleven had died in their usual place of residence so their MCCD would probably have been completed by a GP, and six of the deaths had been discussed with a coroner, suggesting that the lack of training and knowledge, and potential for 'diagnostic over-shadowing', may

³³ We have raised our concerns about this to ONS but the current automated coding convention as directed by the World Health Organisation is that when a person with Down's syndrome dies with Alzheimer's disease, Down's syndrome will continue to be coded as the underlying cause of death.

³⁴ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/757010/guidance-for-doctors-completing-medical-certificates-of-cause-of-death.pdf see Section 4.6

extend across primary and secondary care and into the coroners service.

x

I have concern that the cause of death on the death certificate was severe learning disability and autistic spectrum disorder (reviewer).

Underlying causes of death by condition

Table 6 compares the proportion of the most frequently occurring underlying causes of death by condition in people with learning disabilities and their distribution in the general population.

As Table 6 shows, Down’s syndrome was the most frequently reported individual condition described as the underlying cause of death in people with learning disabilities, despite this being a syndrome and not a cause of death in itself.

Table 6: Most frequently occurring individual conditions described as the underlying cause of death in people with learning disabilities for whom ONS ICD-10 coding is available, compared to general population data³⁵

| | ICD-10 codes | People with learning disabilities | | General population of England 2017 | |
|---|--------------|-----------------------------------|--------------|------------------------------------|----------------|
| | | % | Number | % | Number |
| Down’s syndrome | Q901-909 | 13 | 246 | <1 | 429 |
| Pneumonia | J13-18 | 11 | 206 | 5 | 27,113 |
| Ischaemic heart disease | I20-25 | 6 | 114 | 11 | 57,922 |
| Epilepsy | G40 | 4 | 72 | <1 | 763 |
| Dementia | F01-03 | 3 | 60 | 9 | 49,657 |
| Aspiration pneumonia | J690 | 3 | 54 | <1 | 1,896 |
| Total number of deaths for which coding is available | | | 1,938 | | 530,154 |

³⁵ From: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables>

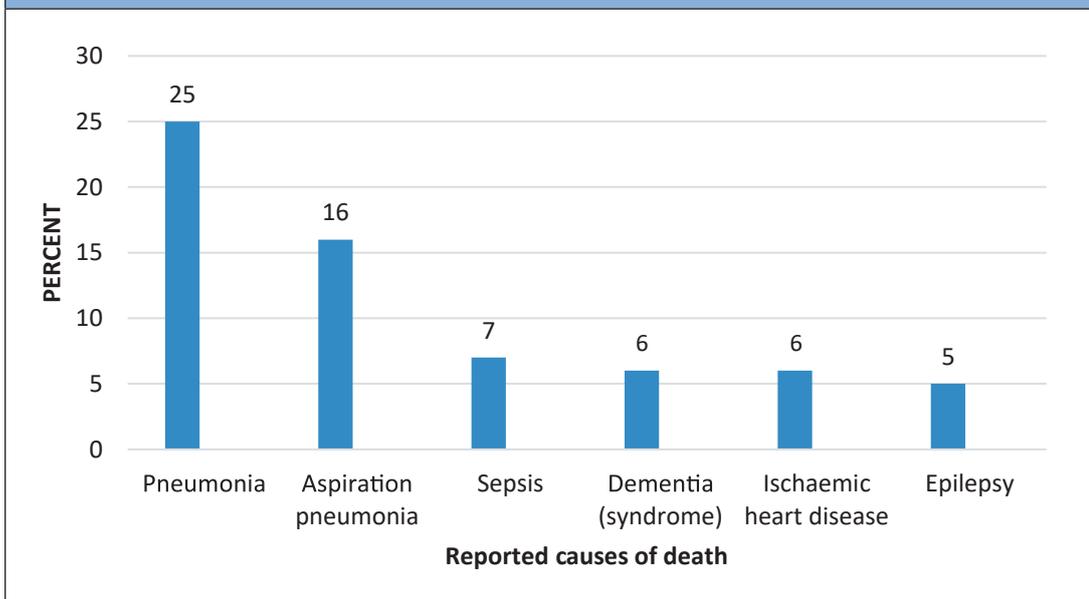
The six most common conditions mentioned on Part I of the MCCD

Although the underlying cause of death is most commonly used in national statistics, given its perceived inaccuracies in reporting deaths of people with learning disabilities, it is instructive to consider those conditions that are mentioned anywhere in Part I of the MCCD.

The conditions most frequently cited in Part I of the MCCD³⁶ for 1,938 people with learning disabilities aged 4 years and over for whom we have a verified ICD-10 code for the causes of death are (Figure 13):

- Pneumonia.
- Aspiration pneumonia.
- Sepsis.
- Dementia (syndrome).
- Ischaemic heart disease.
- Epilepsy.

Figure 13: The six most common conditions mentioned on Part I of the MCCD³⁷ of people with learning disabilities for whom a verified ICD-10 code has been provided



³⁶ We have excluded deaths reportedly being from Down's syndrome.

³⁷ Excluding Down's syndrome

Pneumonia

Pneumonia was the condition most frequently cited in Part I of the MCCD of people with learning disabilities (25% of all deaths, n=476).

Pneumonia was more frequently the cause of death in people with severe or profound and multiple learning disabilities (28%) compared to people with mild/moderate learning disabilities (22%).

There was no significant difference in the proportion of people with learning disabilities dying from pneumonia, taking into consideration their age, gender, ethnicity, whether the death occurred in the winter and the following quality of care indicators:

- Whether there were any concerns about the death.
- If there had been any delays in the person's care or treatment that adversely affected their health.
- If there were problems with organisational systems and processes that led to a poor standard of care.
- If there were any gaps in service provision that may have contributed to the person's death.
- The overall grading of care given by the reviewer.

For more information about these quality of care indicators, see Chapter 5.

Aspiration pneumonia

The second most frequently reported condition in Part I of the MCCD of people with learning disabilities was aspiration pneumonia (16% of all deaths, n=314).

Aspiration pneumonia was more frequent in males (18%) than females (14%), in adults (16%) compared to children (6%), and in people with severe or profound and multiple learning disabilities (24%) compared to mild or moderate learning disabilities (14%).

A greater proportion of people with learning disabilities died from aspiration pneumonia in the three-month period between October – December (19%) than they did in the nine months between January and September (15%).

Sepsis

Deaths from sepsis accounted for 7% of deaths overall (n=126).

People with learning disabilities who had experienced gaps in service provision that may have contributed to their death more frequently died from sepsis (10%) compared to others (5%).

Dementia (syndrome)

Deaths from dementia (syndrome) accounted for 6% of deaths overall (n=123). As might be expected, dementia (syndrome) was strongly associated with age, with almost all deaths occurring at age 50 or older. It was also strongly associated with ethnicity: people of white British ethnicity died with dementia more frequently (7%) than people of BAME groups (1%). This is likely to be a consequence of the younger median age at death of people from BAME groups.

Ischaemic heart disease

Ischaemic heart disease was reported in 6% of all deaths (n=121). As in the general population it was significantly associated with age (8% of deaths aged 65 and over, compared with no deaths before the age of 25) and with gender (males 8% compared with females 4%). People with mild or moderate learning disabilities died from ischaemic heart disease more frequently (8%) than did those with severe or profound and multiple learning disabilities.

Epilepsy

Epilepsy was the sixth most frequently cited condition in Part I of the MCCD of people with learning disabilities (5% of all deaths, n=104).

Deaths from epilepsy occurred more frequently in younger age groups (8% of children; 9% of those aged 18-24; 9% of those aged 25-49 years), compared to 3% of those aged 65 and over.

People with severe and profound or multiple learning disabilities died from epilepsy more frequently (8%) than those with mild or moderate learning disabilities.



Chapter 5: Indicators of the quality of care provided *

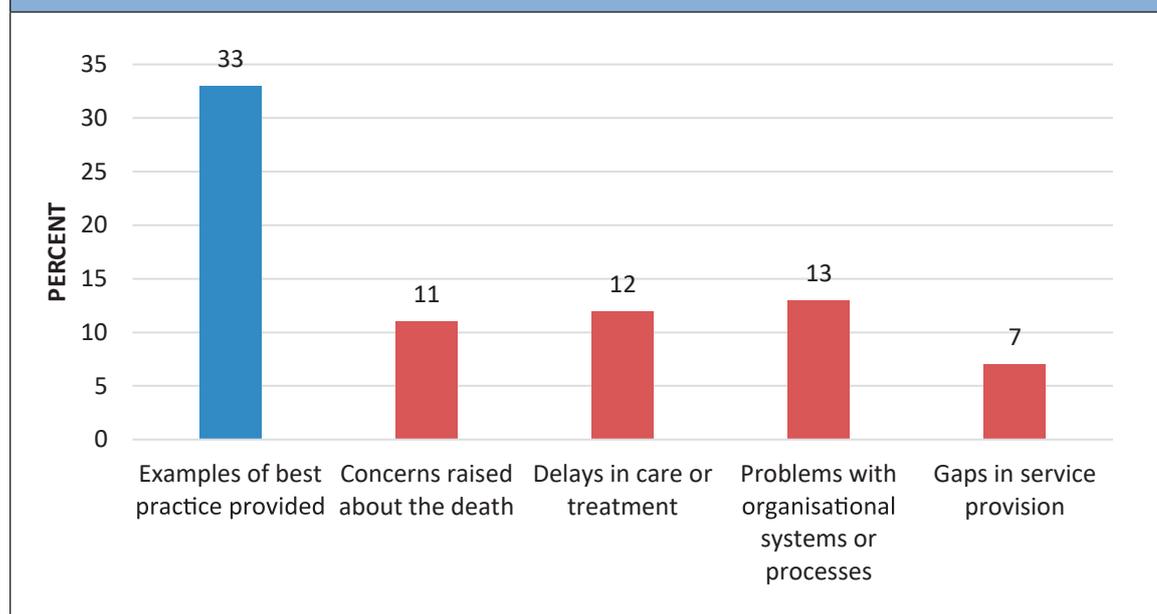
‘At first, I thought the review might be a tick box exercise, but the depth of information that they asked for was very encouraging that they really wanted to get to the bottom of things that went well and things that didn’t go so well’ (family member)

LeDeR reviewers are asked about several different aspects of the quality of care provided, including any best practice, based on what they had learnt. Here we consider indicators of the quality of care for the 962 deaths reviewed in 2018 (Figure 14). These are:

- Examples of best practice provided.
- If there were any concerns about the death.

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

Figure 14: Indicators of the quality of care provided for people with learning disabilities aged 4 years and over



Examples of best practice provided

A third of reviews completed in 2018 for whom information was provided (33%, n=273) provided one or more examples of best practice. The proportion of such reviews was 44% (n=11) of 25 reviews of deaths of young people aged 18-24 years, and 34% (n=23) of 68 reviews of deaths of people from BAME groups.

Some of the comments described good quality, person-centred care that everyone should be able to expect; one reviewer commented:

The care delivered was very good throughout - the learning disability team don't consider good care to be best practice - 'it's just as it should always be'.

There were three key areas in which best practice was most frequently mentioned for all people with learning disabilities:

- Strong, effective inter-agency work.
- Person-centred care.
- End-of-life care.

Many involved the provision of 'reasonable adjustments'³⁸.

³⁸ The Equality Act 2010 requires services to make adjustments to the way they support disabled people so that disabled people are not disadvantaged from accessing services.



The establishment of a shared code word facilitated good communication between the ward and the care home (reviewer).



The care home identified a pub that would puree Ben's food for him so he could continue to enjoy a meal out. They worked with the speech and language team to support Ben to continue to enjoy a pint by adding thickener to it (reviewer).



The 7-day discharge follow-up, implemented by the community treatment team on each hospital discharge, was very effective in monitoring Reyna's health effectively. The introduction of digital equipment and social care staff training in the use of the NEWS tool was fundamental; on two occasions it alerted the staff team to Reyna's deterioration in health and the requirement for hospital admission (reviewer).



Allocation of named GP and a Practice Nurse who had a special interest in patients with learning disability and knew him well and how best to approach him (reviewer).



Highly personalised level of care from his paediatrician; continuity of paediatric care beyond age 18, so allowing continued use of paediatric emergency department and ward (his parents told me of their fear that Russ would suddenly be admitted to an unfamiliar adult ward) (reviewer).



The Speech Therapist in hospital contacted the Speech and Language Therapist from the children's service (who had worked with him at school) for information, support and advice about the limitations to his movement and functioning, as she needed to make eating and drinking recommendations, but Dalton's needs were different to those of adult acute patients with dysphagia (reviewer).

Where good practice was described for young people aged 18-24 years, it was commonly in relation to:

- Palliative and end-of-life care.
- Coordination between children's and adults' services.
- Listening and respecting the views of the young person and their family.

Where good practice was described for people from BAME groups, it was most commonly in relation to:

- The provision of 'reasonable adjustments' for the person.
- Good coordination of care.
- The involvement of social care agencies in supporting a person at the end of their life.
- Respecting the views of the family.
- Professionals seeking the advice of others with more experience in supporting people with learning disabilities.

Any concerns about the death

Of the deaths that were reviewed in 2018, the majority (89%) noted that there had been no concerns about the death. One in ten reviews (11%, n=99) noted that some concerns had been raised in relation to the person's death.

The concerns originated from a range of sources, but almost half (45%) were from family members, emphasising the importance of the LeDeR reviewer involving the family at an early stage. There was a wide range of concerns, but they were commonly in relation to:

- Delays in diagnosing and treating illness.
- The quality of health or social care received by the person.

Of the 30 completed reviews of deaths of young people aged 18-24 years, fewer than five recorded some concerns, most in relation to:

- Clinical decisions.
- The support provided for the young person.

Fifteen of 72 (21%) reviews of deaths of people from BAME groups recorded some concerns, most frequently in relation to:

- Clarity about care plans.
- The appropriateness of the support provided to the person and their family.
- The timeliness of summoning medical assistance.

x

Three different clinicians and staff working with Joe shared concerns about the delay and the timeframe from a Best Interest meeting in August to the date of the scan and subsequent confirmed diagnosis in October (reviewer).

x

There was no advanced care planning discussion with the staff about the actions to be taken if Mr Spring deteriorated (reviewer).

x

Eugenie's sister felt that she should not have died from sepsis and pneumonia and felt the home should have called for medical assistance sooner (reviewer).

x

Parents feel that Yusuf should have had investigations in hospital to enable him to receive the correct treatment. He was treated for over a month with antibiotics at home, and later prescribed IV antibiotics which were administered at home to prevent a hospital admission. Parents feel that he should have had further investigations, including an x-ray and a scan, and hospital admission (reviewer).

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

Reviewers were asked if, from the evidence they had, they felt there were any delays in the person's care or treatment that had adversely affected their health. The majority of reviews (88%) indicated that there had been no such delays.

108 reviews (12%) noted that delays had been apparent. The delays described are various:

- Identifying that a person was unwell.
- Raising concerns with a medical professional.
- Appropriate investigations being carried out and treatment started.
- The availability of assessments.
- Discharge from hospital.
- Delayed recognition of approaching end of life - affecting the provision of appropriate end-of-life care.

Four of 30 (13%) reviews of deaths of young people aged 18-24 years mentioned some delays, mostly in relation to:

- The timeliness with which medical treatment was provided.
- The provision of essential equipment and training for carers in its use.

Sixteen of 69 (23%) reviews of deaths of people from BAME groups mentioned some delays, mostly in relation to:

- The timeliness with which medical treatment was sought or provided.

x

Late first dose of antibiotics in A&E and no obvious medical review for several hours after admission (reviewer).

x

Kane's mother described how his treatment was delayed for over a year when he was discharged from the children's hospital (reviewer).

x

There was a delay in surgery being undertaken for a variety of reasons, including the physical health of Leroy, lack of interpreter and lack of family members at out-patient appointments (reviewer).

x

Social care annual review should have been completed in September 2017. It was carried out in December 2017, when extra support at mealtimes in line with Speech and Language Therapist guidelines was identified as a need and risks associated with not providing this support were identified. The extra support was not actioned before her death in February (reviewer).

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

Based on the evidence they had, reviewers were asked if they thought that there were any problems with organisational systems and processes that led to a poor standard of care for the person. The majority (87%) of reviews reported no such problems.

Approximately one in ten reviews (13%, n=117) did note such concerns. The concerns were wide-ranging, including issues relating to:

- The coordination of care.
- Information sharing between agencies.
- Fragmented transition planning.
- Policies for specialist referral, including PEG insertion.
- Staff resources and skills.

Six of 29 (21%) reviews of deaths of young people aged 18-24 years mentioned some organisational problems, mostly in relation to:

- The transition from children's to adults' services, with fragmented care and lack of clarity about decision-making.

Fourteen of 71 (20%) reviews of deaths of people of BAME groups mentioned some problems with organisational systems and processes that led to a poor standard of care, mostly in relation to:

- The coordination of care.
- The timeliness of decisions about support package agreements.
- Adequate recording and reporting systems.



No concerns noted. Local services appeared well coordinated to meet his needs (reviewer).



Staff need a clear protocol that states how residents should be supported if unwell and the observation levels required when to call assistance (reviewer).



Lack of coordination of care regarding placement in County 1 and formal referral from County 2 to CLDT services (reviewer).



Organisational dysfunction due to fragmented transition planning preventing holistic and timely transfer from child to adult services, and with a lack of an identified key worker with oversight of his health needs within the community (reviewer).

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

Most reviews (93%) reported no gaps in service provision that may have contributed to the person's death.

The small proportion of reviews (7%, n=61) that reported there were such gaps identified a range of issues, including:

- The lack of skilled postural care expertise.
- Absence of a clinical lead for epilepsy.
- Support not being available for accessing cancer screening.
- A lack of 'joined-up' working.
- A lack of holistic assessment.

Fewer than five reviews of deaths of young people aged 18-24 years, and eleven of 70 (16%) of reviews of deaths of people from BAME groups reported gaps in service provision that may have contributed to the person's death, in relation to a range of issues.



The need for specialist assessment with regards to posture and a sleep bed system was outstanding (reviewer).

Assessment of the quality of care

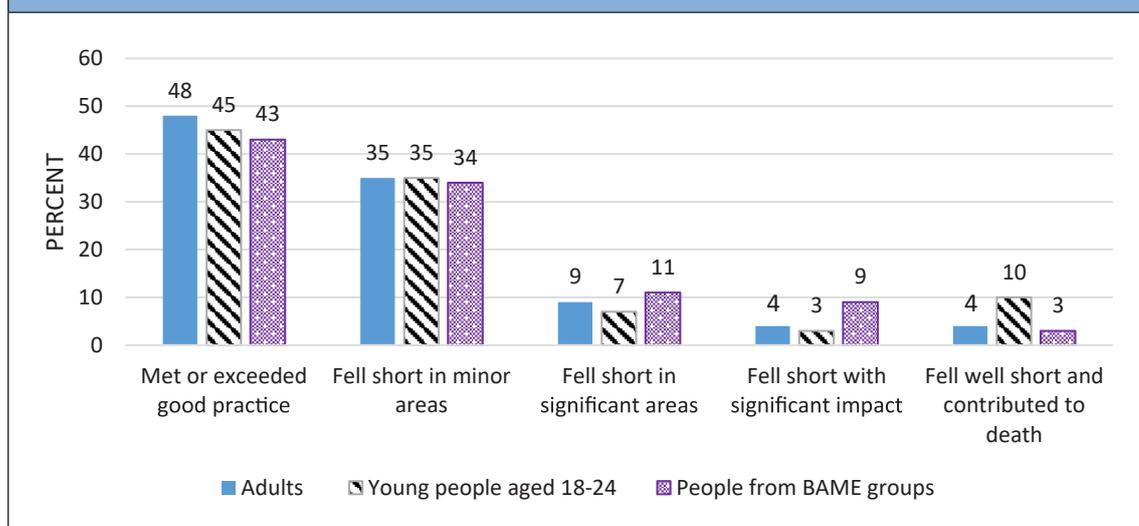
At the end of their review, having considered all of the evidence available to them, reviewers are requested to provide an overall assessment of the quality of care provided to the person.³⁹

The statutory child death review process does not assess the quality of care in the same way, so

children aged 4-17 years have been excluded from the analysis.

Figure 15 and Table 7 present the reviewer assessment of the quality of care provided to adults with learning disabilities, people aged 18-24 and people from BAME groups.

Figure 15: Reviewer assessment of the quality of care provided to people with learning disabilities



³⁹ The question and grading scale have changed slightly in response to feedback from reviewers and local area contacts over time, so the grading has been reworded slightly to combine different versions.

Table 7: Reviewer assessment of the quality of care provided to people with learning disabilities

| Grade | Grading of care | Adults with learning disabilities (age 18+) | | Young people aged 18-24 years ⁴⁰ | | People from BAME groups | |
|-------|---|---|------------|---|-----------|-------------------------|-----------|
| | | % | N | % | N | % | N |
| 1 | Care met or exceeded good practice | 48 | 426 | 45 | 13 | 43 | 28 |
| 2 | Care fell short of good practice in one or more minor areas, but this did not significantly impact on the person's well-being | 35 | 305 | 35 | 10 | 34 | 22 |
| 3 | Care fell short of expected good practice in one or more significant areas, but this did not significantly impact on the person's well-being | 9 | 80 | * | * | * | * |
| 4 | Care fell short of expected good practice and this significantly impacted on the person's well-being and/or had the potential to contribute to the cause of death | 4 | 36 | * | * | * | * |
| 5 | Care fell far short of expected good practice and this contributed to the cause of death | 4 | 35 | * | * | * | * |
| | Total | 100 | 882 | 100 | 29 | 100 | 65 |

*Numbers or proportions equate to fewer than 10 deaths

Care that met or exceeded good practice

Almost half (48%) of deaths reviewed in 2018 received care that the reviewer felt met or exceeded good practice. This is slightly more than the 44% we reported in our last annual report.

Similar proportions were reported for people aged 18-24 years, and people from BAME groups.

People whose deaths met or exceeded good practice were more likely than others to be on an end-of-life care pathway, to have had any DNACPR documentation completed correctly, and to have had an annual health check in the last 12 months.



The residential team did an excellent job caring for Keith through his journey at the end of his life. Keith was the centre of the plan and all the care was wrapped around what he would want. Really comprehensive recording keeping and end of life planning with the wider team evident (reviewer).

⁴⁰ Due to the small number of deaths, this information should be interpreted cautiously.

Care that fell short of good practice but without significant impact on the person’s well-being

35% of adults with learning disabilities were felt to have received care that fell short of good practice in minor or significant areas, but it did not significantly impact their well-being. Other reviews of deaths suggest that it would be usual to find some areas for improvement although the extent varies according to the population being sampled. Again, similar proportions were reported for people aged 18-24 years, and people from BAME groups.

Care that fell so far short of expected good practice that it significantly impacted on the person’s well-being or directly contributed to their cause of death

Seventy-one adults with learning disabilities (8%), including fewer than 5 people aged 18-24 years old and 8 people from BAME groups, were reported to have received care that fell so far short of expected good practice that it significantly impacted on their well-being or directly contributed to their cause of death. Each of these deaths would receive further investigation and/or multi-agency review.

The reasons for falling short of good practice varied, but included problems with care that were related to:

- Clinical care.
- Medication and equipment.
- Not summoning medical attention in a timely way.
- A lack of coordination of a person’s care and treatment.

Those whose care that fell far short of expected good practice were more frequently reported to have had:

- Gaps in service provision that may have contributed to their death (44% compared to 4% of others).

x

Holistic care cannot be identified (reviewer).

x

Her mental health was prioritised over her physical health...There is evidence of diagnostic overshadowing (reviewer).

x

There was poor communication to identify and treat her constipation. She aspirated as a direct result of her constipation because there was a delay in administering enemas and the insertion of nasogastric tube (reviewer).

x

There was a lack of observation of a deteriorating patient. Earlier intervention may have resulted in a different outcome (reviewer).

x

Consideration of his presenting behaviours needed further investigation sooner. People started to notice when there were clear and obvious health issues such as weight loss and changed physical appearance, but there was a lack of timeliness and urgency to diagnosing his illness (reviewer).

- Delays in their care or treatment that adversely affected their health (73% compared with 7% of others).
- Problems with organisational systems and processes that led to a poor standard of care (80% compared to 7% of others).

The findings of multi-agency review panels

Multi-agency review panels reviewed 112 deaths. After reflecting on the sequence of events leading to the person’s death, panels reflect, jointly, on a series of questions about any contributory factors to the death that may have been potentially avoidable.

Potentially avoidable contributory factors

Potentially avoidable contributory factors to a death were considered in relation to the person’s care and its provision (e.g. the quality of pain relief, nutritional support, provision of reasonable adjustments) and the way services were organised and accessed (e.g. assessment processes, eligibility criteria, protocols between agencies).

Those relating to the person’s care were identified in 45% (n=51) of deaths, and in relation to the way services were organised and accessed in 49% (n=55).

Lessons learned

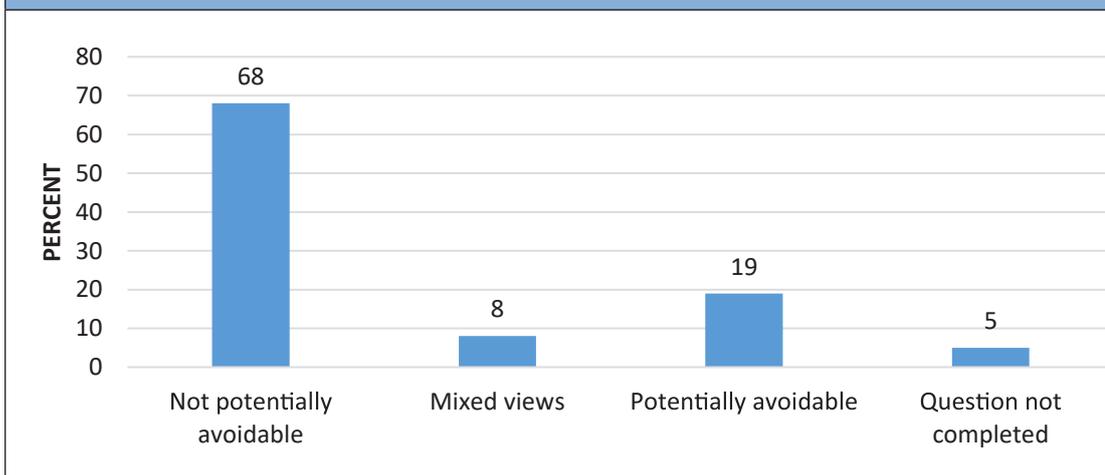
Lessons learned were identified in 70% (n=79) of deaths reviewed by multi-agency panels.

Potentially avoidable deaths

Potentially avoidable deaths are those where there are aspects of care and support that, had they been identified and addressed, may have avoided the person dying at that time from that cause.

Of the 112 deaths reviewed in multi-agency review panels, most panels (68%, n=76) reported that the death was not potentially avoidable, 19% (n=21) felt the death had been potentially avoidable, and the panel could not reach a unanimous decision on a further 8% (9 deaths). The question was unanswered by six panels (5%) (Figure 16).

Figure 16: Multi-agency review panel decisions about whether the death was potentially avoidable



Priority Theme Review panel comments

An important part of the review of deaths of those subject to priority theme review is the independent external scrutiny of the completed report of the death. After reviewing the completed reports of deaths, panel members commented on a number of issues that they felt could strengthen local recommendations.

For young people aged 18-24 years, these were largely in relation to transition planning, and the decision-making process once a young person becomes 16 years of age and is subject to the Mental Capacity Act.⁴¹

For people from BAME groups, these were largely in relation to cultural perspectives, language issues and consanguinity.

Children's services should be trained regarding their role and responsibilities in the application of the Mental Capacity Act for young people aged 16 and above (PTR panel member).

Unclear if the consanguinity risk has been raised with the family... the risk in a next pregnancy is 1 in 4 (PTR panel member).

A hospital passport is helpful especially if you're becoming more independent (Self-advocate, PTR panel member).

A named care coordinator would be beneficial for young adults requiring support from a number of different NHS Trusts (PTR panel member).

For some people there is a risk they will be shunned by their community if they agree to certain procedures (Self-advocate PTR panel member).

There may have been cultural issues that affected the family engagement with services. The assumption is that the family didn't engage because of the earlier deaths of other family members to the same syndrome. Whilst this may be true, it is worth reviewing whether there is a cultural/religious issue in relation to engaging with health and social care services. This may highlight a training need for staff around supporting people from diverse backgrounds and working with the wider cultural community and religious leaders to improve access to healthcare support (PTR panel member).

⁴¹ The Mental Capacity Act applies to people aged 16 years and older. Prior to this age, those with parental responsibility can make decisions on behalf of their children. At age 16, the decision-making process for a young person is subject to the Mental Capacity Act principles and requirements.



Chapter 6: Focus on deaths of children

'I'd encourage all families to take this opportunity to say what's happened, what was good, what wasn't so good and to really let the services know what they've done well, so they can do more of that, what they've done badly, so they can stop it, and any good ideas they've had' (family member)

The statutory child death review process examines deaths of children aged 0-17 years. The Child Death Review Statutory and Operational Guidance (England)⁴², published in 2018, clarifies the interface between the statutory review process for children and the LeDeR programme for deaths of children aged 4 years and over who have learning disabilities.

The LeDeR programme is not required to review the deaths of children with learning disabilities in addition to the statutory review process; rather, LeDeR reviewers are encouraged to engage with the child death review process if appropriate and for the final report from the child death review process to be shared with the LeDeR team in order to collate findings.

The findings summarised in this chapter bring together those that have been threaded through the report. They relate to deaths of 281 children with learning disabilities aged 4-17 years whose deaths have been notified to the LeDeR programme; 70 of the reviews of these deaths have been completed, all but three in 2018.

Demographic details

The demographic profile of the children with learning disabilities was very different to that of adults with learning disabilities. Almost half (47%, n=34) of the children for whom this information was provided had profound and multiple learning disabilities; similar to the 43%, (n=28) of 18-24 year olds, but very different to the 9% of those aged 25 years and over.

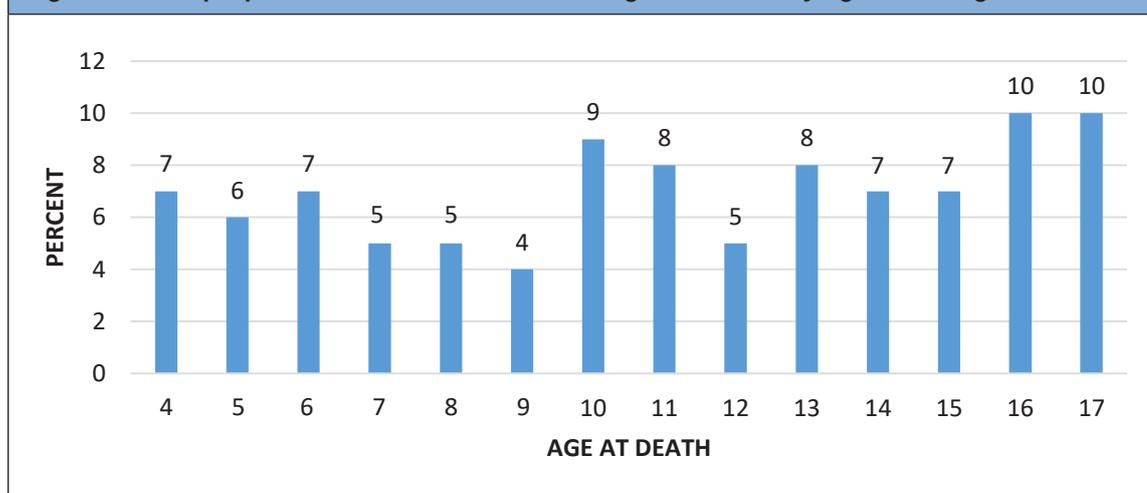
Two-fifths (42%, n=95) of the children were from BAME groups, again a significant difference to the 26% (n=34) of those aged 18-24 years, but very different to the 7% of adults from BAME groups.

Over half (58%, n=162) of the children were male, similar to other age groups.

Age at death

The median age at death for the 281 children with learning disabilities aged 4-17 years was 11 years. The most commonly occurring age at death (the mode) was 17 years. The age at death rises at age 10 years and generally remains elevated through teenage years (Figure 17).

Figure 17: The proportion of children with learning disabilities dying at each age



⁴² <https://www.gov.uk/government/publications/child-death-review-statutory-and-operational-guidance-england>

Who is most at risk of dying early?

The median age at death for children of white British ethnicity was 12 years (n=129); for children from BAME groups it was 10 years (n=95).

The median age at death of children with mild or moderate learning disabilities was 10 years (n=19); for children with severe or profound and multiple learning disabilities it was 13 years (n=53). The small number of deaths here means that the data should be interpreted cautiously. Many children with severe or profound and multiple learning disabilities would have complex medical conditions or life-limiting genetic conditions, so this finding is different to that which we might expect.

Cause of death

The underlying cause of death for children aged 4-17 with learning disabilities has a different profile than for children aged 5-14 in the general population (Table 8).

A greater proportion of children with learning disabilities died from disorders of the nervous system (e.g. epilepsy, meningitis); congenital malformations and chromosomal abnormalities; endocrine nutritional and metabolic diseases; and diseases of the circulatory system compared to the general population.

A greater proportion of children in the general population died from neoplasm (cancer) and external causes (e.g. accidents and injuries) compared to children with learning disabilities.

The most common conditions mentioned in Part I of the MCCD in children

A wide range of conditions was included in Part I of the MCCD for children with learning disabilities for whom we have a verified ICD-10 code for the causes of death.

Metabolic disorders were the conditions most frequently cited anywhere in Part I of the MCCD for children with learning disabilities, but this applied to only 15 children.

Table 8: Underlying cause of death by ICD-10 chapter (Office for National Statistics data) for children aged 4-17 years with learning disabilities, and data about children in the general population

(*indicates numbers or proportions that equate to fewer than 10 deaths)

| | Underlying cause of deaths of children with learning disabilities aged 4-17 years (n=97) % | Underlying cause of death of children in general population aged 5-14 years ⁴³ (n=549) % |
|--|---|--|
| Nervous system | 21 | 10 |
| Congenital malformations and chromosomal abnormalities | 17 | 8 |
| Endocrine, nutritional and metabolic diseases | 14 | 5 |
| Diseases of the respiratory system | 11 | 9 |
| Diseases of the circulatory system | 10 | 5 |
| Infections | * | 5 |
| Diseases of the digestive system | * | 2 |
| External causes | * | 21 |
| Neoplasm (cancer) | * | 30 |
| Other underlying causes of death | * | 5 |

⁴³ From: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables>

Indicators of the quality of care provided

We considered quality of care indicators in Chapter 5. Here we present indicators of the quality of care provided from the 70 completed reviews of the deaths of children.

Due to the small number of reviews, the examples are for illustrative purposes.

Examples of best practice provided

Eight reviews shared examples of good practice. Most related to:

- Care coordination.
- Listening to the views of the child.
- Support for the family.
- Adjusting the way services are usually provided to accommodate the child and their family.

Concerns or problems about the quality of care provided

The majority of completed reviews did not note any concerns about the death. Of those that did seven reported either:

- Concerns about the death (these were taken forward into a serious incident investigation).
- Problems with organisational systems and processes that led to a poor standard of care.
- Delays in the child's care or treatment that had adversely affected their health.
- Gaps in service provision that may have contributed to the child's death.



Lily's mother reported that the care and support provided was extremely person centred and provided a great deal of support to both Lily and her family (reviewer).



Arjun's family report that the children's hospital was very mindful of Arjun's many hospital appointments due to his complex health needs. They co-ordinated his appointments so they took place on the same day so he could be seen by multiple disciplines in one visit - reducing the need for further disruption and travel to the family's life (reviewer).



Clinical communication across the service overwhelmingly relies on contact by email, telephone and contact at schools. They do not meet formally to plan or review the treatment and risks for children where there is multi-therapy involvement (reviewer).



Kye's parents had many concerns for their son and felt that no one was listening to them, including their GP, until they changed practices. They are unsure whether his life could have been prolonged if he had been diagnosed earlier (reviewer).



Chapter 7: Recommendations made by reviewers for local action

'I was very keen to take part... to highlight the issues that people with learning disabilities have as they grow older, especially when perhaps their parents have died, and to ensure that they have good health, good care and a good quality of life'
(family member)

Recommendations from initial reviews

Of the 962 deaths reviewed in 2018, reviewers made 167 recommendations for service improvements; some reviewers commented that recommendations had already been actioned by the time the review had been completed.

A small number of recommendations were in relation to sharing good practice and what had worked well for a patient, as one reviewer commented:

The good practice demonstrated by ward staff and the Learning Disability Liaison Nurse service needs to be replicated across other services. The examples of best practice as evidenced in this review will be shared.

There was a wide variety of recommendations made and actions taken, but most commonly, they were in relation to:

- System-level issues.
- Training for staff about supporting people with learning disabilities.
- Care coordination and better communication between agencies.
- DNACPR orders and end-of-life care.
- Recognising signs of deteriorating health in a person with learning disabilities.

Appendix 1 describes a wider range of recommendations made in reviews than the illustrative examples presented here.

His parents hope there will be service improvements which include parents being listened to, health professionals learning from parents' experience, health and care services understanding their failures and learning from their mistakes, and diversifying procedures to meet individuals' needs rather than organisational policy.

The standard operating procedure for discharging patients from care pathways when there are two consecutive non-attendances needs to be re-considered in relation to people with learning disabilities.

Those with repeated chest infections should have a referral to, and review by, speech and language therapists to assess whether their swallow has been impaired.

Awareness of the link between poor oral hygiene and chest infections is needed, particularly for people who are PEG fed. Training for care home staff to include the importance of good oral hygiene and how to refer to special care dental services if there are problems with oral hygiene.

Care home contacted the learning disability nurse on each admission to help with support and the consistency of the person's care. All care homes and supported living providers should do this.

The learning disability specialist healthcare team recently developed an Assess, Respond, Call for help (ARC) assessment and care plan to help skill carers to identify signs of deterioration/infection and promptly seek help from the GP/local health team.

Recommendations from multi-agency review panels

Of the 112 multi-agency review panels, 57 (51%) made recommendations for service improvements; again, some reviewers commented that recommendations had already been actioned by the time the review had been completed.

Most of the multi-agency review panels included a number of recommendations for action and action plans covered a wide range of topics, but most commonly they were in relation to:

- Providing reasonable adjustments for people with learning disabilities to access primary care (GP) services.
- Supporting care providers to recognise early signs of deterioration in people with a range of medical conditions, and to know how to respond.
- Better understanding of, and adherence to the Mental Capacity Act.
- The provision of learning disability awareness training.
- Development and implementation of specific care pathways (e.g. for PEG).
- The provision of care coordination for people with complex needs.
- Informing a coroner about inaccuracies in recording the causes of death of people with learning disabilities.

Appendix 1 describes a wider range of recommendations made by multi-agency review panels than the illustrative examples presented here.

Review people on learning disability register with epilepsy, identify if they are on anti-epileptic medication and the effect this is having.

The local authority to consider and improve how postural care is provided to children in care settings.

The revised local Mental Capacity Act documentation to be shared with the provider agency and then launched more widely. This will need to be supported by scenario-based workshops in how the Act can be used in the 16 - 18 years age group.

Safeguarding Adult team to review the self-neglect procedures. Refreshed self-neglect pathway to be re-launched in tandem with refreshed safeguarding adults' pathway.

Improve the pathway for carers to escalate concerns.

Care coordination of service users with complex health problems to be prioritised as a service need.



Chapter 8: Conclusions and recommendations

'I think... that the best outcome is where professionals and families work together and come round the table and really communicate well with each other... certainly the most positive experiences I've had of care is where that's the case' (family member)

Conclusions and recommendations

This report presents findings from reviews of the deaths of people with learning disabilities notified to the LeDeR programme from 1st July 2016 – 31st December 2018, with a focus on information about deaths reviewed during the last calendar year (1st January – 31st December 2018).

The number of completed reviews covered in this report is greater than in our last annual report so allowing a greater depth of information, but the number of deaths in some analyses are small, requiring cautious interpretation of the data.

We have highlighted a number of concerns in this report about the deaths of people with learning disabilities. We discussed the key findings with three consultation groups: one of self-advocates, and two of professionals and family members. Together, we prioritised the concerns and discussed potential recommendations that are presented in this chapter. We would like to thank those who helped us in this way.

| Recommendations | |
|-----------------|---|
| 1. | Consider designating national leads within NHS England and local authority social care to continue active centralised oversight of the LeDeR programme. |
| 2. | NHS England to support Clinical Commissioning Groups to ensure the timely completion of mortality reviews to the recognised standard. |
| 3. | There should be a clear national statement that describes, and references to relevant legislation, the differences in terminology between education, health and social care so that 'learning disability' has a common understanding across each of the sectors and between children's and adults' services. |
| 4. | Clinical Commissioning Groups and local LeDeR steering groups to use local population demographic data to compare trends within the population of people with learning disabilities. They should be able to evidence whether the number of deaths of people from Black, Asian and Minority Ethnic groups notified to LeDeR are representative of that area and use the findings to take appropriate action. |
| 5. | The Department of Health and Social Care and NHS England to support national mortality review programmes to work with 'Ask, Listen, Do' and jointly develop and share guidelines that provide a routine opportunity for any family to raise any concerns about their relative's death. |
| 6. | The Department of Health and Social Care, working with a range of agencies and people with learning disabilities and their families, to prioritise programmes of work to address key themes emerging from the LeDeR programme as potentially avoidable causes of death. The recommended priorities for 2019 include: i) recognising deteriorating health or early signs of illness in people with learning disabilities and ii) minimising the risks of pneumonia and aspiration pneumonia. |
| 7. | Guidance continues to be needed on care-coordination and information sharing in relation to people with learning disabilities, at individual and strategic levels. |
| 8. | Shortfalls in adherence to the statutory guidance in the Special Educational Needs and Disability Code of Practice in relation to identifying and sharing information about people with learning disabilities approaching transition, transition planning and care coordination must be addressed. |
| 9. | The Royal College of Paediatrics and Child Health to be asked to identify and publish case examples of best practice and effective, active transition planning and implementation for people with learning disabilities as they move from children's to adults' health services. |
| 10. | The Department of Health and Social Care, working with a range of agencies and the Royal Colleges to issue guidance for doctors that 'learning disabilities' should never be an acceptable rationale for a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order, or to be described as the underlying or only cause of death on Part I of the Medical Certificate Cause of Death. |
| 11. | Medical Examiners to be asked to raise and discuss with clinicians any instances of unconscious bias they or families identify e.g. in recording 'learning disabilities' as the rationale for DNACPR orders or where it is described as the cause of death. |
| 12. | The Care Quality Commission to be asked to identify and review DNACPR orders and Treatment Escalation Personal Plans relating to people with learning disabilities at inspection visits. Any issues identified should be raised with the provider for action and resolution. |

Availability of data

Recommendation 1:

Consider designating national leads within NHS England and local authority social care to continue active centralised oversight of the LeDeR programme.

Recommendation 2:

NHS England to support Clinical Commissioning Groups to ensure the timely completion of mortality reviews to the recognised standard.

Our first two recommendations are in response to the availability of data. There has been variation in local delivery and accountability of the programme, and continuing and significant problems with the timeliness with which reviews of deaths take place, as mentioned on pages 15 and 16.

We are aware of, and grateful for, the support provided by NHS England to local areas to improve the timeliness with which mortality reviews are completed. We are also aware of efforts to streamline the review process in local areas.

Variation in local delivery of the LeDeR programme has resulted in some local areas doing what works best for them and demonstrating creative and considered ways of conducting reviews of deaths. In other local areas, there is considerable variation and inconsistency and the core principles and values⁴⁴ of the LeDeR programme, agreed at its outset, are under pressure.

We want to guard against this drift, with national leads within NHS England and local authority social care to continue robust, active centralised oversight of the LeDeR programme, maintain the specific LeDeR approach to reviewing deaths, ensure the quality of completed reviews, the translation of learning into action, and ongoing alignment with the NHS Long-term Plan.

The LeDeR programme is now included in the NHS Operational Planning and Contracting Guidance 2019/20⁴⁵ with specific responsibilities for Clinical Commissioning Groups. However, some Clinical Commissioning Groups will need support with this, particularly in ensuring the timely completion of mortality reviews to the recognised standard. We recommend that NHS England provide targeted support in this respect.

Identification of people with learning disabilities

Recommendation 3:

There should be a clear national statement that describes, and references to relevant legislation, the differences in terminology between education, health and social care so that ‘learning disability’ has a common understanding across each of the sectors and between children’s and adults’ services.

⁴⁴ <http://www.bristol.ac.uk/sps/leder/about/core-principles-and-values/>

⁴⁵ <https://www.england.nhs.uk/wp-content/uploads/2018/12/nhs-operational-planning-and-contracting-guidance.pdf> p.29.

Recommendation 4:

Clinical Commissioning Groups and local LeDeR steering groups to use local population demographic data to compare trends within the population of people with learning disabilities. They should be able to evidence whether the number of deaths of people from Black, Asian and Minority Ethnic (BAME) groups notified to LeDeR are representative of that area and use the findings to take appropriate action.

The focus of our next two recommendations is being able to identify young people at transition to adult services, and people from BAME groups.

Some reviews of deaths have noted problems with health and social care systems identifying young people with learning disabilities at transition from children's services to adults' service. The notification of deaths of adults from BAME groups has also appeared to be less than we would expect.

Some of the problem with the identification of young people at transition centres on the use of different terminology in education, health and social care. The Special Educational Needs and Disability Code of Practice⁴⁶ uses the terms 'learning difficulty' and 'learning disabilities' to refer to children with special educational needs. Health and social care settings refer to people with learning disabilities. The different terminology is used in legislation, but we need a clear national statement that describes the differences in terminology and references the relevant legislation, so that there is a common understanding across each of the sectors and between children's and adults' services about the population of people with learning disabilities.

Recommendation 4 is specifically in relation to the identification of people from BAME communities. Our findings suggest that adults with learning disabilities from BAME groups may be under-represented in notifications of deaths to LeDeR, and that there is a higher proportion of adults and children from BAME groups who have severe or profound multiple learning disabilities. We have to be cautious in interpreting this data. If it is adults with mild and moderate learning disabilities whose deaths are under-represented in notifications to LeDeR, as we suspect, the data would be skewed to show an artificially elevated proportion of people from BAME groups who have severe or profound and multiple learning disabilities.

This is part of a wider issue about having information and knowledge about local BAME communities in order to understand the needs of people with learning disabilities and their families from these communities. Clinical Commissioning Groups and LeDeR steering groups should have a clear oversight and be required to report on the population of people from BAME groups in their area, assess whether the number of deaths notified to LeDeR are representative of that area and use the findings to take appropriate action and inform local planning.

⁴⁶ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf

Listening to families

Recommendation 5:

The Department of Health and Social Care and NHS England to support national mortality review programmes to work with 'Ask, Listen, Do' and jointly develop and share guidelines that provide a routine opportunity for any family to raise any concerns about their relative's death.

One in ten reviews noted that some concerns had been raised in relation to the person's death; almost half of the concerns were raised by family members. This indicates the need for families to be routinely invited to be involved in a review of a death of their relative and for them to be able to raise any concerns they had, as well as share what worked well in the care of their relative.

We are aware of the Ask, Listen Do initiative⁴⁷ that supports organisations to learn from and improve the experiences of people with learning disabilities and their families when raising a concern. However, we are keen that families should be *routinely* invited to provide feedback after the death of a relative, and not have to do so in a reactive way.

We are aware that not all mortality review processes afford this opportunity to families, and differences in approach could put some families at a disadvantage. We recommend that the national mortality review programmes, in conjunction with the Learning from Deaths Programme Board, jointly develop and disseminate guidelines that provide a routine opportunity for any family to raise any concerns about their relative's death.

The introduction of Medical Examiners may help in this regard, as they will be required to contact relatives of those who have died in acute care and inquire if they have any concerns. However, deaths in the community will not, at least initially, be reviewed by Medical Examiners, again setting inequitable and confusing differences in the experiences of families, a discrepancy that needs to be addressed urgently.

Priority programmes of work needed

Recommendation 6:

The Department of Health and Social Care, working with a range of agencies and people with learning disabilities and their families, to prioritise programmes of work to address key themes emerging from the LeDeR programme as potentially avoidable causes of death. The recommended priorities for 2019 include:

- i) recognising deteriorating health or early signs of illness in people with learning disabilities and
- ii) minimising the risks of pneumonia and aspiration pneumonia.

Recommendation 6 describes two priority programmes of work needed. These are: to improve the recognition of deteriorating health or early signs of illness in people with learning disabilities and to minimise the risks of pneumonia and aspiration pneumonia.

A number of issues related to the quality of care of people with learning disabilities are highlighted in this report, including delays in identifying that a person was ill, recognising further deterioration, and accessing and receiving appropriate medical care.

⁴⁷ <https://www.england.nhs.uk/learning-disabilities/about/ask-listen-do/>

Our recommendation is that the Department of Health and Social Care and NHS England should prioritise a programme of work to support health and social care professionals and families to recognise deteriorating health. The programme of work should include consideration the following:

- Awareness-raising of the ‘soft signs’ of deteriorating health.
- An electronic healthcare ‘passport’ or similar document that includes baseline observations of temperature, pulse and respiratory rate and oxygen saturation, and a description about how the person shows pain or distress, to act as a measure of ‘what is normal’ for the person.
- The adaptation and use of recognised tools (e.g. National Early Warning Score 2 (NEWS2)) for use in acute and community settings.
- A calendar indicating the risks of particular health conditions at particular times of the year, and how to identify early signs of developing conditions.
- Providing information about how to effectively raise concerns about deteriorating health to medical professionals, including the use of the Situation, Background, Assessment, Recommendation (SBAR) technique.
- Working with colleagues at NHS 111 phone lines to provide easy to understand prompt lists for people with learning disabilities phoning the service.

In addition, this recommendation is about minimising the risks of pneumonia and aspiration pneumonia, which are identified as a cause of death (in Part I of the MCCD) in 41% of deaths people with learning disabilities. Although some people are likely to die from pneumonia or aspiration pneumonia despite preventative strategies in place, addressing this is likely to make significant inroads into reducing premature deaths of people with learning disabilities. There appears to be a degree of urgency for this.

Specifically, we recommend the provision of

national guidance about how to minimise the risk of pneumonia or aspiration pneumonia in people with learning disabilities. A dissemination plan should be available as part of the guidance to ensure its availability to professionals, people with learning disabilities and their families. Key outcomes of this would include:

- All health and social care professionals, support staff and families supporting a person with learning disabilities having a clear understanding about:
 - what is ‘usual’ for the person as identified through baseline measures.
 - approaches that will reduce the risks to that person (e.g. postural care, safe feeding, dental hygiene etc) that are clearly documented in a person-centred care pathway or plan.
 - the range of effects that minor illnesses (e.g. coughs and colds, diarrhoea) may have for that person which may change the person’s level of risk, and how to respond to a change in risk level.
 - the appropriate immunisations to be given.
 - the early recognition of lower respiratory tract or other infections.
 - how to effectively raise concerns to medical practitioners and/or NHS 111.
 - the review of risk and care planning if the person has a significant episode of illness.

- A reminder to GPs that for people presenting with symptoms of lower respiratory tract infection in primary care, an urgent point of care C-reactive protein test should be undertaken if after clinical assessment a diagnosis of pneumonia has not been made and it is not clear whether antibiotics should be prescribed (as advised by NICE Clinical Guideline [CG191]).
- Agreement about the identification of those at high risk of pneumonia or aspiration pneumonia, and the preventative strategies to apply.

Service and care coordination

Recommendation 7:

Guidance continues to be needed on care-coordination and information sharing in relation to people with learning disabilities, at individual and strategic levels.

Recommendation 7 is about service and care coordination. The inadequate coordination of care and appropriate information sharing is a continuing problem in the provision of support of people with learning disabilities. This was the first recommendation of the 2017/18 LeDeR annual report, and we are disappointed that reviews of deaths continue to identify this as being a potential contributory factor to deaths.

As a response to the last LeDeR annual report, the Department of Health and Social Care committed to commissioning a rapid review of best practice in care-coordination/key working for people with learning disabilities by March 2019. Such national guidance on care-coordination and information sharing for people with learning disabilities, at individual and strategic levels, is urgently needed.

Transition from children's to adults' services

Recommendation 8:

Shortfalls in adherence to the statutory guidance in the Special Educational Needs and Disability Code of Practice in relation to identifying and sharing information about people with learning disabilities approaching transition, transition planning and care coordination must be addressed.

Recommendation 9:

The Royal College of Paediatrics and Child Health to be asked to identify and publish case examples of best practice and effective, active transition planning and implementation for people with learning disabilities as they move from children's to adults' health services.

The Special Educational Needs Code of Practice (see Footnote 46) provides the legislative framework for services to work together as young people move from children's to adults' services. Despite this, significant shortfalls are apparent in adherence to the legislation which need to be addressed. Contracting arrangements should allow commissioners or the commissioning authority to take firm action to ensure compliance. They should take decisive action when breaches of the law and regulation are identified and should be held to account for the quality of service delivered.

In order to better support the transition from children's to adults' services, we also recommend that the Royal College of Paediatrics and Child Health should be asked to publish case examples of best practice and effective, active transition planning for people with learning disabilities as they move from children's to adults' health services.

Addressing bias

Recommendation 10:

The Department of Health and Social Care, working with a range of agencies and the Royal Colleges to issue guidance for doctors that 'learning disabilities' should never be an acceptable rationale for a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order, or to be described as the underlying or only cause of death on Part I of the Medical Certificate Cause of Death.

Recommendation 11:

Medical Examiners to be asked to raise and discuss with clinicians any instances of unconscious bias they or families identify e.g. in recording 'learning disabilities' as the rationale for DNACPR orders or where it is described as the cause of death.

Recommendation 12:

The Care Quality Commission to be asked to identify and review DNACPR orders and Treatment Escalation Personal Plans relating to people with learning disabilities at inspection visits. Any issues identified should be raised with the provider for action and resolution.

Our final three recommendations relate to concerns about potential unconscious bias (diagnostic over-shadowing).

We reported that:

- 15 people with learning disabilities had their underlying cause of death erroneously coded as 'developmental disorder of scholastic skills, unspecified' – (a commonly used code for 'learning disabilities').
- 19 reviews reported that the term 'learning disabilities' or 'Down's syndrome' was given as the rationale for the DNACPR order.
- Fewer deaths of people with learning disabilities were reported to a coroner in 2018 than for the general population.

Diagnostic over-shadowing should have no place in any care setting. As the self-advocate consultation group commented: *You don't die because you have learning disabilities. ...Does it show they don't care? Are they only seeing the learning disabilities and not seeing, or treating, the medical cause?*

Diagnostic over-shadowing often has, at its root, limited knowledge about people with learning disabilities, lack of familiarity with the Equality Act 2010, and workload pressures with insufficient time to communicate effectively with the person and, if necessary, their family or paid supporters. But it can also be symptomatic of a wider disregard for people with learning disabilities; an attitude that devalues their lives, makes ill-founded assumptions about their quality of life, and perpetuates health and other inequalities experienced by people with learning disabilities. It is overcoming these societal, discriminatory attitudes that is arguably our most significant challenge.

As a start, we need increased scrutiny of where such attitudes may manifest in the care of people with learning disabilities. NHS England and the Royal Colleges have a role to play, as does the Care Quality Commission. Each and every health or care professional needs to be alert to discriminatory attitudes and to challenge them. We hope that the forthcoming mandatory training for those supporting people with learning disabilities will equip staff to be able to do so.

Final comments

This annual report has reinforced the importance of having sufficient data to be able to draw robust conclusions. However, it is also about the deaths of individuals and the unique set of circumstances leading to their death.

The balance between narrative of the story and the reflections it invites, against the collection of standardised formulaic data is a challenging one. That we will be considering over the next year.

There were many issues and potential recommendations we discussed with consultation groups. We have been careful to focus the issues for which recommendations seemed appropriate.

For other issues we have identified, we will target appropriate actions. As an example, the data about antipsychotic medication suggests that a fifth of people with learning disabilities were taking this when they died, and 27 people were prescribed more than one type of antipsychotic. This is of concern. So for specific issues such as this we will be liaising with appropriate programmes and/or agencies (e.g. the Stopping Over-Medication of People with a Learning Disability, autism or both (STOMP / STAMP) programme).

The recommendations that we have made in this report are targeted at national level. Yet there is much that can and should be done at local level to reflect on the learning coming from the reviews of deaths, and to translate that into actions for improvement.

Appendix 1 presents examples about some actions already undertaken and provides some helpful ideas that could be more widely implemented. Evidencing the effectiveness of these interventions would be helpful in contributing to our knowledge about what works best for people with learning disabilities and their families.

It is for all of us, in whatever role we have in life, to reflect and take action on how we could better support people with learning disabilities in our local communities. Working with positive commitment to reduce health inequalities for people with learning disabilities must remain top of our agenda until we can see more substantial changes occur.



Appendices

Appendix 1:

Examples from the range of recommendations made by reviewers and multi-agency review panels based on the findings from LeDeR reviews

These are comments drawn from completed reviews illustrating the range of recommendations made and, in some cases, actions taken as a result of the review of a death. We have presented these thematically.

System-level actions or recommendations

- His parents hope there will be service improvements, which include parents being listened to, health professionals learning from parents' experience, health and care services understanding their failures and learning from their mistakes, and diversifying procedures to meet individuals' needs rather than organisational policy.
- The independent advocacy service should be asked to review their timescales when asked to be involved, and to prioritise DNACPR decisions.
- There should be better information provided about NHS Continuing Healthcare, particularly on the 'fast track' process.
- A review of triage by the Community Learning Disabilities Team is required, to expedite support for people near the end of their life.
- A named clinician from the community learning disability team has been identified as a contact for GP practices for advice and support.
- Consideration needs to be given to keeping people open to learning disability nurses if they have multi-morbidity or coexisting conditions.
- The community learning disability team do desensitisation work to help with issues such as blood taking. This information should be shared with providers and GPs.
- All GP practices should have a robust and effective learning disability register highlighting all reasonable adjustments required, health check schedules, and preferred methods of communication.
- It was agreed to review the learning disability registers for each of the GP practices across the city to identify key diagnoses within each practice in order that bespoke targeted training could be delivered.
- GP staff are to check the learning disability register when patients or carers call for an appointment to ensure that if the person has learning disabilities the staff ask if they would like a longer appointment as part of the reasonable adjustments protocol.
- To liaise with NHS England about adding additional questions about swallowing difficulties into annual health check documentation.
- To develop a pathway in partnership with the learning disability team and dietetics for people who are at risk of aspiration pneumonia.
- To develop a pathway for people with learning disabilities that have repeated admissions due to aspiration pneumonia.
- A pathway to be developed so there is coordination between inpatient and community videofluoroscopy bookings to ensure patients are not delayed in having investigations.
- To establish a standard for all care establishments to have speech and language training within a set timeframe if they have clients who are at risk of aspiration, and to have a process to monitor that this training has been undertaken.
- Those with repeated chest infections should have

a referral to, and review by, speech and language therapists to assess whether their swallow has been impaired.

- The PEG referral process should be reviewed to ensure appropriate allocation and scheduling of general anaesthetic endoscopy lists.
- The provision of reasonable adjustments for people with learning disabilities using endoscopy services has been discussed at a governance meeting. The service has now put a question in their referral form about whether the person has learning disabilities, so the booking staff will automatically make a pre-assessment clinic appointment for these patients so any support the patient needs can be identified and provided.
- The standard operating procedure for discharging patients from care pathways when there are two consecutive non-attendances needs to be re-considered in relation to people with learning disabilities.
- To introduce a care bundle for supporting patients with learning disabilities and/or autism.
- To introduce a named person on each ward for people with learning disabilities.
- A robust process for DNACPRs must be implemented to ensure that all those involved in an individual's care are able to access this, including the ambulance service.
- To consider developing a system-wide transition protocol to facilitate transition of care between children to adult services, including shared documentation that is common, easily available and understood amongst all providers.
- A multi-agency audit to be undertaken to establish how well understood, embedded and effective the transition protocol and pathway is in practice.
- The local authority to consider and improve how postural care is provided to children in care settings.
- The safeguarding adult team to review the self-neglect procedures. Refreshed self-neglect

pathway to be re-launched in tandem with refreshed safeguarding adults pathway.

- Improve the pathway for carers to escalate concerns.
- Consider developing a sepsis handover between primary and secondary care.
- Develop clear protocols and training for clinicians to support bereaved families.
- To review processes and systems around people with learning disabilities who do not attend appointments.
- Clinical Commissioning Group to have more scrutiny of providers, especially out-of-area placements.
- Liaise with HM Coroner about the use of cerebral palsy as a primary cause of death on a death certificate.
- To consider developing a standard operating procedure which outlines the expectation of and limitations to specialist teams that offer an advisory in-reach role to inpatient services.

Training for staff about supporting people with learning disabilities

- There needs to be training available for residential care staff about end-of-life care pathways that includes an individual's right to plan for their future care and the need for care plans to specifically address a person's choice to refuse healthcare.
- The care provider has reflected on the use of bowel charts; they will commence using them in people who are taking laxatives, and educate carers in the signs and symptoms of constipation.
- The provider should ensure that systems are in place to accurately monitor stool type and frequency for those who have a history of, or are at risk of constipation.

- Training is required for care home staff about constipation, what it means, how it presents, the possible risks and how to address them.
- Awareness of the link between poor oral hygiene and chest infections is needed particularly for people who are PEG fed. Training for care home staff should include the importance of good oral hygiene and how to refer to special care dental services if there are problems with oral hygiene.
- Epilepsy awareness training for all carers working with people who have seizures.
- The care and management of people at risk of aspiration, the symptoms of aspiration pneumonia and the need to seek early medical attention.
- All medical staff working with people with learning disabilities need to receive specialist training and advice about supporting people with learning disabilities, especially in relation to managing behaviour.
- Training for ambulance staff in working with people with learning disabilities is needed.
- All nursing staff should have mandatory learning disability awareness training which includes how to make relevant reasonable adjustments and understand communication needs.
- More education about the use of pain assessment tools for people with learning disability is required. Care staff need to be trained in how to observe, monitor and record observations of a person who may be in pain and unable to vocalise their distress.
- Record keeping was raised as part of quality assurance and commissioning process and record-keeping training is being provided for the staff team.
- Training is required in hospital settings about what a 'reasonable adjustment' may look like.
- The general lack of awareness around the application of the Mental Capacity Act needs addressing.
- The acute trust needs to review the training available about mental capacity and audit mental capacity assessments and best interest decisions to ensure the transparency decision-making.
- A multi-agency approach to delivering Mental Capacity Act training is needed.
- The revised local Mental Capacity Act documentation to be shared with care provider and then launched more widely for use. This will need to be supported by scenario based workshops in how the Act can be used in the 16 - 18 years age group.
- Better training for local residential provisions to be available so that they can support people with learning disabilities and complex health needs.
- Dementia training in relation to people with learning disabilities.

Care coordination and better communication between agencies

- Care home contacted the learning disability nurse on each admission to help with support and the consistency of the person's care. All care homes and supported living providers should do this.
- We will share an anonymised case exemplar that highlights good practice in multi-disciplinary team working for a person with learning disabilities with multiple co-morbidities.
- GPs should review all health conditions at each contact or appointment with a person with learning disabilities and take the opportunity to assess them more holistically.
- Individuals with learning disabilities should have a named and regular coordinator/care manager that knows the person. They should be experienced in caring for individuals with learning disabilities and understand reasonable adjustments.
- Identify whether people on learning disabilities registers have a care coordinator.
- Discharge planning meetings should include multidisciplinary input from all professionals and family or carers involved.
- The Clinical Commissioning Group needs to

consider identifying a link person for people with learning disabilities.

- There will be reinforcement of multi-agency working and partnerships between the adult learning disability service and other professionals such as diabetes specialists, the hospital trust, general practitioners the re-ablement team, day services, support services and residential and nursing homes.
- Care coordination of people with complex health problems to be prioritised as a service need.
- Adoption of a multi-disciplinary approach to care planning for complex care management, including the identification of a named professional.

DNACPR orders and end-of-life care

- Person-centred care was provided by the care provider with support from the GP and specialist support from the local hospice, community nursing and specialist end of life care teams. We will share the learning with other local homes as an example of supporting residents at their end of life.
- The care provider will be invited to the next end of life care planning course, and be given specific feedback from this review on end of life care plans.
- Funding bodies should be responsive to changing needs when somebody with a learning disability is approaching the end of life to enable more person-centred, dynamic care provision.
- It is important for ongoing continual professional development for staff in end-of-life care, especially if these skills are required sporadically.
- There is a need to ensure that the recognition of imminent death and the use of individualised care plans are fully documented.

- The palliative care team is to raise awareness of services offered.
- The Clinical Commissioning Group quality lead will carry out a review and audit of current DNACPR forms in local care homes and re-visit the policy with local practices. The care home involved will review all DNACPR forms in use and liaise with local practices about compliance with policy.
- The enhanced care support team at the Trust are to raise the appropriate use of DNACPR and mental capacity assessments for patients with learning disabilities within corporate governance structures at the hospital.
- The person's mum commented that she would have appreciated words of condolences from the care provider after 36 years of her son living there. Care providers should always write to the family following the death of a person in their care to express their condolences and offer the opportunity for them to talk about their loved one's life.

Recognising deteriorating health in a person with learning disabilities

- Care homes to have thermometers to enable them to take temperatures.
- The use of an assessment tool to identify softer changes in a person's deteriorating condition would be helpful.
- Annual Health Checks to specifically ask about any new or existing lumps on a person's body.
- The care provider has added care of the deteriorating patient and escalation processes to their first aid training.
- Base-line observations charting three individual readings of temperature, pulse, blood pressure and respirations are to be recorded individually, to identify any deviation in future.
- The learning disability specialist healthcare team recently developed an ARC (Assess, Respond,

Call for help) assessment and care plan to help skill carers to identify signs of deterioration or infection and promptly seek help from the GP or local health team.

- The care home has provided staff with training in observations, walk-rounds and hourly checks, as well as ensuring that staff know whom to contact in case they need assistance with an unwell patient.
- The care home has now purchased an oxygen saturation monitor to be able to better inform a GP of someone's condition, especially if they have a respiratory condition.

Appendix 2:

Summary of recommendations made in the LeDeR Annual Report 2016/2017, and response from Department of Health and Social Care and NHS England

The second annual report for the LeDeR programme was published in May 2018. It reported on the completed reviews into the deaths of 103 people with learning disabilities, between July 2016 and November 2017, and made nine key recommendations. In September 2018, the Department of Health and Social Care (DHSC) and NHS England published its response to the report⁴⁸.

The table below summarises the recommendations and the action points agreed by the DHSC and NHS England, detailing responsible bodies and timeframes.

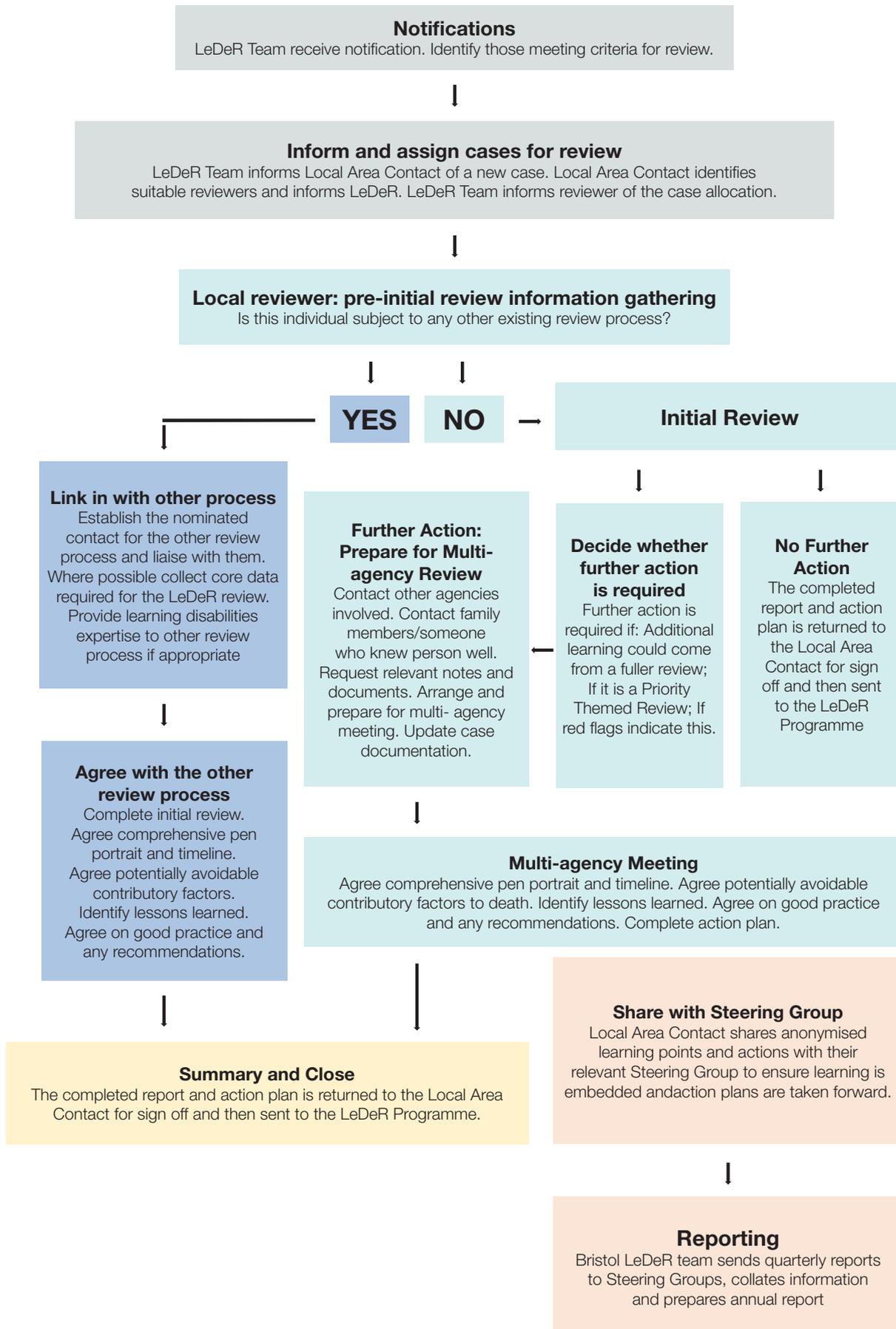
| Recommendation | DHSC and NHS England Action Points |
|--|--|
| <p>1. Strengthen collaboration and information sharing, and effective communication, between different care providers or agencies.</p> | <p>1. Report on accessible information in learning disability services in NHS Trusts. Care Quality Commission/NHS Improvement, October 2019</p> <p>2. NHS England to report annually to DHSC on progress made on the learning into action work-stream regarding improvements in interagency communication achieved through local action. NHS England, March 2019</p> |
| <p>2. Push forward the electronic integration (with appropriate security controls) of health and social care records to ensure that agencies can communicate effectively, and share relevant information in a timely way.</p> | <p>3. Update to DHSC on progress made in Flagging and Summary Care Record (SCR) work. NHS Digital/NHS England, November 2018</p> <p>4. Once testing is complete, NHS England and NHS Digital to develop clear guidance on how the 'flagging system' will support clinical practice. NHS England to continue to support the use of additional information in the SCR through the Annual Health Check Programme. NHS England/NHS Digital, March 2020</p> <p>5. NHS England to review how Local Health and Care Record Exemplars (LHCRE) could better integrate the approach to sharing of pertinent information between health and care providers for people with a learning disability. NHS England, March 2019</p> |
| <p>3. Health Action Plans, developed as part of the Learning Disabilities Annual Health Check should be shared with relevant health and social care agencies involved in supporting the person (either with consent or following the appropriate Mental Capacity Act [MCA] decision-making process).</p> | <p>6. NHS England to report progress on uptake of Annual Health Checks to DHSC via Clinical Commissioning Group Improvement and Assessment Framework. NHS England, Annually</p> |

⁴⁸ <https://www.gov.uk/government/publications/government-response-to-the-learning-disabilities-mortality-review-leader-programme-2nd-annual-report>

| | | |
|----|---|---|
| 4. | All people with learning disabilities with two or more long-term conditions (related to either physical or mental health) should have a local, named health care coordinator. | <p>7. Disseminate the evaluation of the Named Social Worker model. DHSC, July 2018</p> <p>8. Undertake a rapid review of best practice in care-coordination/key working for people with a learning disability, focused on health and well-being, to inform guidance for the NHS on care-coordination. DHSC, March 2019</p> |
| 5. | Providers should clearly identify people requiring the provision of reasonable adjustments, record the adjustments that are required, and regularly audit their provision. | <p>9. Publish update to DHSC on progress made in adding a Reasonable Adjustment flag to the Summary Care Record application. NHS England, Feb 2019</p> <p>10. Implement NHS Digital Reasonable Adjustment Project roll-out and as part of this align with the LHCREs to ensure the same information is being used in both. NHS Digital/NHS England, 2020</p> |
| 6. | Mandatory learning disability awareness training should be provided to all staff, delivered in conjunction with people with learning disabilities and their families. | <p>11. DHSC in conjunction with partners, will complete a consultation on proposals for mandatory learning disability awareness training. DHSC, March 2019</p> <p>12. NHS England and DHSC to write to providers and employers promoting the Learning Disability Core Skills Education and Training Framework and reminding them of responsibilities in respect of training. NHS England/DHSC, September 2018</p> <p>13. Health Education England to develop and publish a Tier 1 training offer. Health Education England, 2019</p> <p>14. Health Education England to audit provision of learning disability training. Health Education England, June 2021</p> <p>15. NHS Improvement to implement and then monitor adherence to Trust learning disability standards. NHS Improvement, September 2018</p> <p>16. DHSC to commission Skills for Care to undertake a comprehensive skills and training audit of the social care workforce based on the learning disability core skills framework. DHSC/Skills for Care, March 2019</p> <p>17. Care Quality Commission to monitor uptake of mandatory training (see action point 11) through regulatory and inspection processes; and update DHSC on progress (subject to consultation). Care Quality Commission, from introduction of mandatory training.</p> |

| | | |
|----|--|--|
| 7. | There should be a national focus on pneumonia and sepsis in people with learning disabilities, to raise awareness about their prevention, identification and early treatment. | <p>18. NHS England to publish Right Care pathways for dysphagia, epilepsy, sepsis and constipation. NHS England, March 2019</p> <p>19. NHS England to report annually to DHSC on progress made on the learning into action work-stream regarding work on pneumonia, sepsis, constipation early warning scores and other identified themes that require action. NHS England, March 2019</p> <p>20. Public Health England to improve uptake of the flu-vaccine for people with a learning disability. Public Heath England/NHS England, March 2019</p> |
| 8. | Local services strengthen their governance in relation to adherence to the MCA, and provide training and audit of compliance 'on the ground' so that professionals fully appreciate the requirements of the Act in relation to their own role. | <p>21. DHSC to update on progress regarding the National Mental Capacity Forum. Department of Health and Social Care, 2019</p> <p>22. NHS England to distribute additional best practice guidance on the MCA, learning disabilities and urgent care situations. NHS England, November 2018</p> <p>23. The Care Quality Commission to further develop inspection expertise to assess the quality of MCA application and practice. Care Quality Commission, October 2019</p> |
| 9. | A strategic approach is required nationally for the training of those conducting mortality reviews or investigations, with a core module about the principles of undertaking reviews or investigations, and additional tailored modules for the different mortality review or investigation methodologies. | <p>24. Health Education England to publish eLearning on learning from deaths. Health Education England, August 2018</p> |

Appendix 3: The LeDeR review process



The LeDeR review process

Notification of deaths: Anyone can notify the death of a person with learning disabilities and provide relevant core information. The appropriate local area contact is informed of the death and allocates the review to a local reviewer.

Child death review: All deaths of children with learning disabilities aged 4-17 years are reviewed by the statutory child death review process, with input from the local LeDeR review team if appropriate. The findings of the review are sent to the LeDeR team for collation and analysis.

Initial review: An initial review is completed for all deaths of adults with learning disabilities that meet the inclusion criteria. The purpose of the initial review is to provide sufficient information to determine if there are any areas of concern in relation to the care of the person who has died, or if any further learning could be gained from a multi-agency review of the death that would contribute to improving practice. If a multi-agency review is not felt to be necessary, the reviewer concludes the review by noting what they have learned from the review of the person's death that could lead to service improvements of benefit to others.

Multi-agency review: A multi-agency review of a death involves the range of agencies that had been supporting the individual who had died. It considers:

- Any good practice that has been identified in relation to the person's death.
- Any potentially avoidable contributory factors to the death.
- If, on balance, there were any aspects of care and support that, had they been identified and addressed, may have changed the outcome.
- If there have been any lessons learned as a result of the review of the death.
- If there should be any changes made to local practices as a result of the findings of the review.

- If there are any wider recommendations that should be made.

Priority theme reviews: The Priority Theme Review (PTR) aspect of the LeDeR programme examines the deaths of a subset of people with learning disabilities in more detail. Since the start of the LeDeR programme, these have been:

- Young people aged 18 to 24 years.
- People from a Black, Asian or Minority ethnic group.

Until September 2018, all deaths subject to PTR were expected to receive an initial and full multi-agency review. Since September 2018, NHS England has loosened the requirement for a multi-agency review; this is now agreed locally on a case by case basis. The review documentation is anonymised by the LeDeR team, and then sent to PTR panel members for further comment: a multi-agency panel (of health and social care professionals and family members) and a self-advocate panel (of people with learning disabilities), each operating differently in terms of selection, training and processes used.

Quality assurance process: The quality assurance process until October 2018 has involved a small panel of LeDeR team members looking at recently submitted reviews to ensure national consistency in the quality of mortality reviews and to provide constructive feedback to reviewers to enrich their future reviews. Since October 2018, quality assurance of completed reviews has been conducted locally by local area contacts.

Appendix 4:

Notification of deaths and progress of reviews to 31st December 2018, notification period, by region

| | Total notifications | Review progress at 31st December 2018, by notification period | | | | | |
|----------------|---------------------|---|-----|-------------|-----|-----------|------|
| | | Of the deaths notified in the relevant quarter: | | | | | |
| | | Not yet started | | In progress | | Completed | |
| North | No. | No. | % | No. | % | No. | % |
| Total | 1,434 | 508 | 35% | 501 | 35% | 425 | 30% |
| Jul - Sep 2016 | 10 | 0 | 0% | 0 | 0% | 10 | 100% |
| Oct - Dec 2016 | 46 | 1 | 2% | 6 | 13% | 39 | 85% |
| Jan - Mar 2017 | 125 | 5 | 4% | 35 | 28% | 85 | 68% |
| Apr - Jun 2017 | 128 | 12 | 9% | 50 | 39% | 66 | 52% |
| Jul - Sep 2017 | 132 | 16 | 12% | 45 | 34% | 71 | 54% |
| Oct - Dec 2017 | 180 | 31 | 17% | 77 | 43% | 72 | 40% |
| Jan - Mar 2018 | 182 | 56 | 31% | 87 | 48% | 39 | 21% |
| Apr - Jun 2018 | 213 | 95 | 45% | 88 | 41% | 30 | 14% |
| Jul - Sep 2018 | 179 | 94 | 53% | 75 | 42% | 10 | 6% |
| Oct - Dec 2018 | 239 | 198 | 83% | 38 | 16% | 3 | 1% |

| | Total notifications | Review progress at 31st December 2018, by notification period | | | | | |
|-----------------|---------------------|---|-----|-------------|------|-----------|-----|
| | | Of the deaths notified in the relevant quarter: | | | | | |
| | | Not yet started | | In progress | | Completed | |
| Midlands & East | No. | No. | % | No. | % | No. | % |
| Total | 1,217 | 593 | 49% | 396 | 33% | 228 | 19% |
| Jul - Sep 2016 | 1 | 0 | 0% | 1 | 100% | 0 | 0% |
| Oct - Dec 2016 | 0 | 0 | - | 0 | - | 0 | - |
| Jan - Mar 2017 | 2 | 0 | 0% | 2 | 100% | 0 | 0% |
| Apr - Jun 2017 | 39 | 1 | 3% | 18 | 46% | 20 | 51% |
| Jul - Sep 2017 | 62 | 1 | 2% | 22 | 35% | 39 | 63% |
| Oct - Dec 2017 | 165 | 8 | 5% | 85 | 52% | 72 | 44% |
| Jan - Mar 2018 | 238 | 59 | 25% | 119 | 50% | 60 | 25% |
| Apr - Jun 2018 | 228 | 128 | 56% | 76 | 33% | 24 | 11% |
| Jul - Sep 2018 | 216 | 162 | 75% | 46 | 21% | 8 | 4% |
| Oct - Dec 2018 | 266 | 234 | 88% | 27 | 10% | 5 | 2% |

| | Total notifications | Review progress at 31st December 2018, by notification period Of the deaths notified in the relevant quarter: | | | | | |
|----------------|---------------------|--|-----|-------------|-----|-----------|-----|
| | | Not yet started | | In progress | | Completed | |
| South East | No. | No. | % | No. | % | No. | % |
| Total | 748 | 349 | 47% | 253 | 34% | 146 | 20% |
| Jul - Sep 2016 | 5 | 0 | 0% | 3 | 60% | 2 | 40% |
| Oct - Dec 2016 | 22 | 2 | 9% | 3 | 14% | 17 | 77% |
| Jan - Mar 2017 | 9 | 0 | 0% | 6 | 67% | 3 | 33% |
| Apr - Jun 2017 | 16 | 1 | 6% | 10 | 63% | 5 | 31% |
| Jul - Sep 2017 | 23 | 0 | 0% | 12 | 52% | 11 | 48% |
| Oct - Dec 2017 | 86 | 26 | 30% | 34 | 40% | 26 | 30% |
| Jan - Mar 2018 | 167 | 43 | 26% | 80 | 48% | 44 | 26% |
| Apr - Jun 2018 | 126 | 61 | 48% | 45 | 36% | 20 | 16% |
| Jul - Sep 2018 | 112 | 67 | 60% | 33 | 29% | 12 | 11% |
| Oct - Dec 2018 | 182 | 149 | 82% | 27 | 15% | 6 | 3% |

| | Total notifications | Review progress at 31st December 2018, by notification period Of the deaths notified in the relevant quarter: | | | | | |
|----------------|---------------------|--|-----|-------------|------|-----------|-----|
| | | Not yet started | | In progress | | Completed | |
| South West | No. | No. | % | No. | % | No. | % |
| Total | 394 | 103 | 26% | 182 | 46% | 109 | 28% |
| Jul - Sep 2016 | 2 | 0 | 0% | 2 | 100% | 0 | 0% |
| Oct - Dec 2016 | 12 | 0 | 0% | 3 | 25% | 9 | 75% |
| Jan - Mar 2017 | 16 | 0 | 0% | 6 | 38% | 10 | 63% |
| Apr - Jun 2017 | 19 | 1 | 5% | 10 | 53% | 8 | 42% |
| Jul - Sep 2017 | 33 | 0 | 0% | 17 | 52% | 16 | 48% |
| Oct - Dec 2017 | 58 | 1 | 2% | 26 | 45% | 31 | 53% |
| Jan - Mar 2018 | 68 | 5 | 7% | 41 | 60% | 22 | 32% |
| Apr - Jun 2018 | 70 | 15 | 21% | 43 | 61% | 12 | 17% |
| Jul - Sep 2018 | 50 | 30 | 60% | 19 | 38% | 1 | 2% |
| Oct - Dec 2018 | 66 | 51 | 77% | 15 | 23% | 0 | 0% |

| | Total notifications | Review progress at 31st December 2018, by notification period Of the deaths notified in the relevant quarter: | | | | | |
|----------------|---------------------|--|-----|-------------|-----|-----------|-----|
| | | Not yet started | | In progress | | Completed | |
| London | No. | No. | % | No. | % | No. | % |
| Total | 509 | 83 | 16% | 253 | 50% | 173 | 34% |
| Jul - Sep 2016 | 0 | 0 | - | 0 | - | 0 | - |
| Oct - Dec 2016 | 4 | 0 | 0% | 2 | 50% | 2 | 50% |
| Jan - Mar 2017 | 18 | 0 | 0% | 4 | 22% | 14 | 78% |
| Apr - Jun 2017 | 39 | 0 | 0% | 12 | 31% | 27 | 69% |
| Jul - Sep 2017 | 53 | 0 | 0% | 23 | 43% | 30 | 57% |
| Oct - Dec 2017 | 71 | 1 | 1% | 31 | 44% | 39 | 55% |
| Jan - Mar 2018 | 103 | 5 | 5% | 64 | 62% | 34 | 33% |
| Apr - Jun 2018 | 73 | 17 | 23% | 37 | 51% | 19 | 26% |
| Jul - Sep 2018 | 66 | 21 | 32% | 39 | 59% | 6 | 9% |
| Oct - Dec 2018 | 82 | 39 | 48% | 41 | 50% | 2 | 2% |

List of abbreviations

| | |
|--------|---|
| CPR | Cardiopulmonary resuscitation |
| DHSC | Department of Health and Social Care |
| DNACPR | Do not attempt cardio-pulmonary resuscitation |
| ICD-10 | International classification of diseases – version 10 |
| IT | Information technology |
| LeDeR | Learning disabilities mortality (death) review |
| MCCD | Medical certificate of cause of death |
| ONS | Office for National Statistics |
| PEG | Percutaneous endoscopic gastrostomy |
| PTR | Priority theme review |
| STAMP | Supporting treatment and appropriate medication in paediatrics |
| STOMP | Stopping over medication of people with a learning disability, autism or both |

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www.hqip.org.uk/national-programmes'.

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