Cambridgeshire & Peterborough Integrated Care System

NHS Cambridgeshire & Peterborough

Learning from Lives and Deaths

People with a Learning Disability and Autistic People (LeDeR) Annual Report 2024



cpics.org.uk

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1. Executive summary

1.1 Introduction

This is the annual report of the Learning from Lives and Deaths – People with a Learning Disability and Autistic People (LeDeR) service improvement programme. The annual report details different stages of the LeDeR review process. This document reports on LeDeR reviews completed in the year 1 April 2023 to 31 March 2024 and reports on the demographic information received in notifications over the same period.

1.2 Performance

The completed reviews in this report relate to deaths that occurred between 2018 and 31 March 2023. NHS England expects LeDeR reviews to be completed within six months of notification. NHS Cambridgeshire & Peterborough ICB (CPICB) has not met this requirement and is currently addressing a backlog of reviews relating to death notifications in the year 2023-24.

1.3 Completed reviews

There were 39 LeDeR reviews completed in the period 1 April 2023 to 31 March 2024. There were no autism only reviews. Thirty-seven reviews were for learning disability only; two reviews were for people with a dual diagnosis of a learning disability and autism.

1.4 Notifications

There were 50 unique, eligible deaths notified to LeDeR in the period 1 April 2023 to 31 March 2024, down from 54 notifications in 2022-23. These deaths had not been reviewed in the reporting period, but the following data has been extracted from the notifications. Thirty-nine notifications were for people with a learning disability only; five notifications were autism only; six notifications were for people with a dual diagnosis of a learning disability and autism.

1.5 Peak month for deaths

July was the peak month for deaths, with six deaths occurring, then five deaths in each of the months June, August and December for the period 1 April 2023 to 31 March 2024.

1.6 Median age at death

Median age at death for people with a learning disability was 61 years old, for death notifications 1 April 2023 to 31 March 2024, and 60 years old, for reviews completed in the same period. This is lower than the last national median age at death for people with a learning disability of 62.9 years old, reported in LeDeR 2022.

1.7 Autism only deaths

There were five notifications of deaths of autistic adults without a learning disability. All were of white British ethnicity. The median age at death for this group was 48 years old which is seven years younger than the median age at death of autistic people reported nationally.

1.8 Ethnicity

Less than five death notifications and completed reviews were of the lives and deaths of people from Black or Asian ethnicity. No notifications and less than five completed reviews were of the lives and deaths of people of white ethnicity other than white British. To protect personal data further analysis on ethnicity risks identifying the people, so these notifications and completed reviews will be considered in the whole dataset for this report.

1.9 Proportion of deaths by gender

Sixty-two percent of the death notifications received regarded men with a learning disability. This is a greater proportion than the 55% of male notifications reported nationally (LeDeR, 2022) but comparable with the 60% of men with a learning disability on the primary care learning disability registers in Cambridgeshire and Peterborough.

1.10 Median age at death by home postcode

Median age at death in PE postcodes was a decade younger than CB postcodes. There was a greater difference in age at death amongst males.

1.11 Cause of death (people with a learning disability)

Aspiration pneumonia was notified as the most common cause of death, recorded in section 1a of the medical cause of death certificate for death notifications 1 April 2023 to 31 March 2024, and for reviews completed in the period.

1.12 Place of death

Fifty-eight percent of people with a learning disability died in an acute hospital which is slightly lower than previously reported in Cambridgeshire and Peterborough (65%). The combined length of stay for the 24 admissions totalled 551 days, including 54 days in intensive care.

1.13 Summary

There are systems and teams in place to administer the LeDeR programme effectively. The ages and causes of death, proportions of each gender, and ethnicity and place of death are broadly similar to the last national LeDeR report (LeDeR 2022). There are examples of reasonable adjustments being made and more work is underway to improve quality and consistency of care.

1.14 Recommendations

1.14.1 Rationalisation of all outstanding LeDeR actions from completed reviews in collaboration with providers to map these across the five learning disability service remodelling workstreams.

1.14.2 Facilitate involvement of family carers as part of an individual's care team, if they wish, when service users change setting, eg not restricted access as visitors.

1.14.3 Focus on improving data quality to provide context and assurance about the equitable access to care and treatment for people with a learning disability, and autistic people. The opportunity to update ethnicity and reasonable adjustments on all records over the coming year then cut all performance data for learning disability and autism, will highlight any intersectionality or gaps in equitable outcomes in routinely collected performance data.

1.14.4 Prevention and early intervention

1.14.4.1 Apply Continuous Quality Improvement (CQI) methodology to Annual health checks and Health Action Plans.

1.14.4.2 Engage partners throughout the system, at every touch point, throughout the year to reference the annual health check and health action plan in that service, to ensure the health action plan informs care and improves outcomes for the service user.

1.14.4.3 Educate and empower people with a mild-moderate learning disability about the content and rationale for an annual health check. Raise expectations of what great care looks like, what serious signs to look out for and when and how to seek help. Consider starting this work in deprived areas for maximum impact.

1.14.4.4 Support the development of processes to identify those with a learning disability who are at risk of aspiration pneumonia with training and education on how the risk can be reduced and any cases identified early. This will include the British Thoracic Society recommendations for aspiration pneumonia.

1.14.4.5 Support public health objectives to improve the uptake of vaccinations and cancer screening amongst people with a learning disability.

1.14.5 Late intervention

1.14.5.1 Conduct a deep dive into acute hospital admissions to contextualise the long lengths of stay highlighted in completed reviews.

1.14.5.2 Working with providers, apply Continuous Quality Improvement (CQI) methodology to develop an evidence-based care bundle focusing on harm free care, prevention of aspiration pneumonia and prevention of deconditioning amongst people with a learning disability.

1.14.6 End of life

1.14.6.1 Implement End of Life Care board objectives, designing in the needs of people with a learning disability and autistic people in collaboration with providers.

1.14.6.2 Seek assurance from each provider that Do Not Attempt Cardiopulmonary Resuscitation (DNACPR/ReSPECT) forms for people with a learning disability are being completed in line with current best practice and the Mental Capacity Act.

2. Acknowledgements

2.1 We would like to acknowledge and remember the people with a learning disability and autistic people whose lives and deaths have informed this report. It has been a privilege to get to know them through their carers and loved ones. There is much to celebrate about lives well-lived and people well-loved as well as lessons to learn and things that could be done better.

2.2 We would like to thank everyone who has contributed to the LeDeR review process, especially bereaved friends and family members who took the time to share their memories. We would like to acknowledge and thank the health and social care partners and those working with voluntary organisations who are committed to service improvement, putting into action the learning from LeDeR.

2.3 There has been a change of personnel amongst the LeDeR team this year. We would like to acknowledge the work and thank the outgoing team for their commitment to high quality reviews and good governance of the programme.

2.4 Finally, we would like to acknowledge and thank the work of all frontline health and social care staff who deliver care and services in an increasingly resource strapped environment. Your 'can-do' attitude and commitment to raising expectations will bring equality of experience and equality of outcome closer for the people with a learning disability and autistic people living in Cambridgeshire and Peterborough.

3. Glossary

BMI Body Mass Index, a measure used to indicate weight ranges

CPICS Cambridgeshire and Peterborough Integrated Care System

DNACPR Do Not Attempt Cardiopulmonary Resuscitation – an order to not attempt chest compressions and other resuscitation intervention should someone's heart stop.

ICD-10 International Classification of Diseases, Tenth Revision, a coding system to classify medical diagnoses

ICB Integrated Care Board

ICS Integrated Care System

IMCA Independent Mental Capacity Advocate

KPI Key Performance Indicator

LeDeR Learning from Lives and Deaths – People with a Learning Disability and Autistic People Programme. A service improvement programme previously known as the Learning Disability Mortality Review Programme.

Median the "middle number" of a group of numbers. It is used to give readers the middle number of a range of numbers, such as age calculations, to determine the average.

MCCD Medical Certificate of Cause of Death

MCA Mental Capacity Act

NHSE NHS England: the NHS commissioning board for England

NICE National Institute for Health and Care Excellence

PEG Percutaneous Endoscopic Gastrostomy – a feeding tube that goes directly into the stomach

ReSPECT RESPECT Resuscitation Council UK ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) process

VCFSE Voluntary, Charity, Faith and Social Enterprise partners

4. Foreword

Carol Anderson

Chief Nursing Officer Cambridgeshire & Peterborough Integrated Care Board and Senior Responsible Officer for the Learning Disability and Autism Programme

On behalf of Cambridgeshire & Peterborough Integrated Care Board, I would like to thank everyone involved with the LeDeR review process. I would especially like to thank the families, friends and carers who have told us about the lives and deaths of people with a learning disability and autistic people. Their stories are central to this report and to helping us improve services. I appreciate each story is personal and offer my condolences to everyone affected by the passing of a loved one.

I would like to acknowledge and thank staff from health and social care settings across Cambridgeshire and Peterborough for contributing to the review process. I acknowledge that reviews have not been completed as fast as we would like. To improve this, NHS Cambridgeshire & Peterborough has appointed a new inhouse LeDeR team committed to timely reviewing of deaths and evidence-based service improvement.

We have heard from parent carers of adults with a learning disability about when services fell short. We heard you. We are committed to bring the voices and experiences of our service users and carers into making things better.

NHS Cambridgeshire & Peterborough commissioned a piece of work to evaluate the provision of learning disability services. This work has led to five workstreams for service remodelling over the coming months including:

- Joined-up working across the system.
- Reasonable adjustments to improve accessibility of mainstream services.
- Speciality pathways for people with complex health needs.
- Learning disability specialist staffing model and future pipeline.
- Community-led support for people with behaviours of concern and in crisis.

This ambitious programme of work will embed the learning from LeDeR at every level as we seek to prevent every avoidable death.



Carol Anderson
Chief Nursing Officer

5. Introduction

5.1 The Learning from Lives and Deaths – People with a Learning Disability and Autistic People (LeDeR) service improvement programme is mandated as NHS business as usual. The LeDeR programme aims to improve care, reduce health inequalities and prevent premature mortality of people with a learning disability and autistic people.

5.2 The LeDeR programme has gone through change in governance and organisation nationally over the last few years. NHS England made a commitment to continue to fund the LeDeR programme in the NHS Long Term Plan (2019). In 2021 management of the LeDeR programme moved from the University of Bristol to Kings College, London. The scope of the LeDeR programme was expanded in 2022, to include deaths of autistic people without a learning disability.

5.3 Local integrated care systems (ICS) are responsible for ensuring prompt completion of LeDeR reviews for their local area and timely implementation of action from learning. Recurrent themes and significant issues identified in reviews are escalated to be addressed at a systematic level, locally, regionally and nationally.

5.4 In Cambridgeshire & Peterborough Integrated Care System (CPICS) there were 4,893 people on the primary care learning disability registers in April 2024, up from 4,559 people with a learning disability the previous July. This report looks at death notifications received during the last financial year (2023-24), reviews completed during the same period and updates on the delivery of actions identified in earlier reviews.

6. The LeDeR process

6.1 Scope

6.1.1 There is a requirement within the NHS standard contract for deaths of people with a learning disability and autistic people, aged 18 years or older, to be reported to the LeDeR programme. However, reporting is not a mandatory process so when interpreting data and reading reports such as this, it must be acknowledged that there may be some eligible people whose deaths have not been notified to the programme.

6.1.2 All deaths of children are subject to the statutory child death review process. There is a joined-up approach with LeDeR to share the findings and learning of child death reviews of children with a learning disability and autistic children.

6.2 Methodology

6.2.1 Anyone can notify the LeDeR programme of a death using the open NHS portal. It does not matter if the death is notified more than once; duplicate notifications will be merged.

6.2.2 Notifications are checked for eligibility with the LeDeR terms of reference. Any deaths of people without a clinical diagnosis of learning disability or autism are out of scope. Each notification is given a unique identity number and allocated to a reviewer. The reviewer conducts an initial review which entails gathering information about the deceased person's life and the circumstances of their death. The reviewer will speak to a family member or someone else who knew the deceased well and will access GP and other medical and social care records through a data sharing agreement.

6.2.3 A proportion of reviews progress to a focused review. This includes reviews where the reviewer believes there may be system learning. Families can request a focused review. All autism only notifications and anyone from an ethnic minority background will have a focused review, plus people who have been in a detained setting in the criminal justice system or who have been detained under the Mental Health Act restriction within five years of death.

6.2.4 During the review process, the local LeDeR team verifies and reviews both the immediate cause of death, taken from part 1a of the Medical Certificate of Cause of Death and the underlying cause(s) of death, taken from the lowest completed part of section 1 of the Medical Certificate of Cause of Death.

6.2.5 The immediate cause of death informs service improvement work in front line services. It is possible to compare this across other LeDeR reports regionally.

6.2.6 When comparing national and international mortality data, analysis is only based on the underlying cause of death. This appears on the lowest completed line of part one of a death certificate (1a, 1b or 1c) which is then assigned an International Classification of Diseases, Tenth Revision, (or ICD-10) chapter code. The ICD-10 is a standardised system used to code diseases and medical conditions to allow national and international comparison of health and illness data.

6.2.7 ICD-10 chapter codes are compared with the list of avoidable mortality codes agreed by the Organisation for Economic Co-operation and Development (OECD). Avoidable mortality comprises causes of deaths that were preventable, mainly through effective public health and primary prevention or treatable mainly through timely and effective healthcare interventions.

6.2.8 More information on Medical Certification of Cause of Death and ICD-10 chapters can be found here:

- ICD-10 Version:2019 (who.int)
- Guidance for medical practitioners completing medical certificates of cause of death in England and Wales - GOV.UK (www.gov.uk)
- Avoidable mortality in the UK QMI - Office for National Statistics (ons.gov.uk)

7. Cambridgeshire & Peterborough ICS LeDeR programme

7.1 LeDeR data used in this report

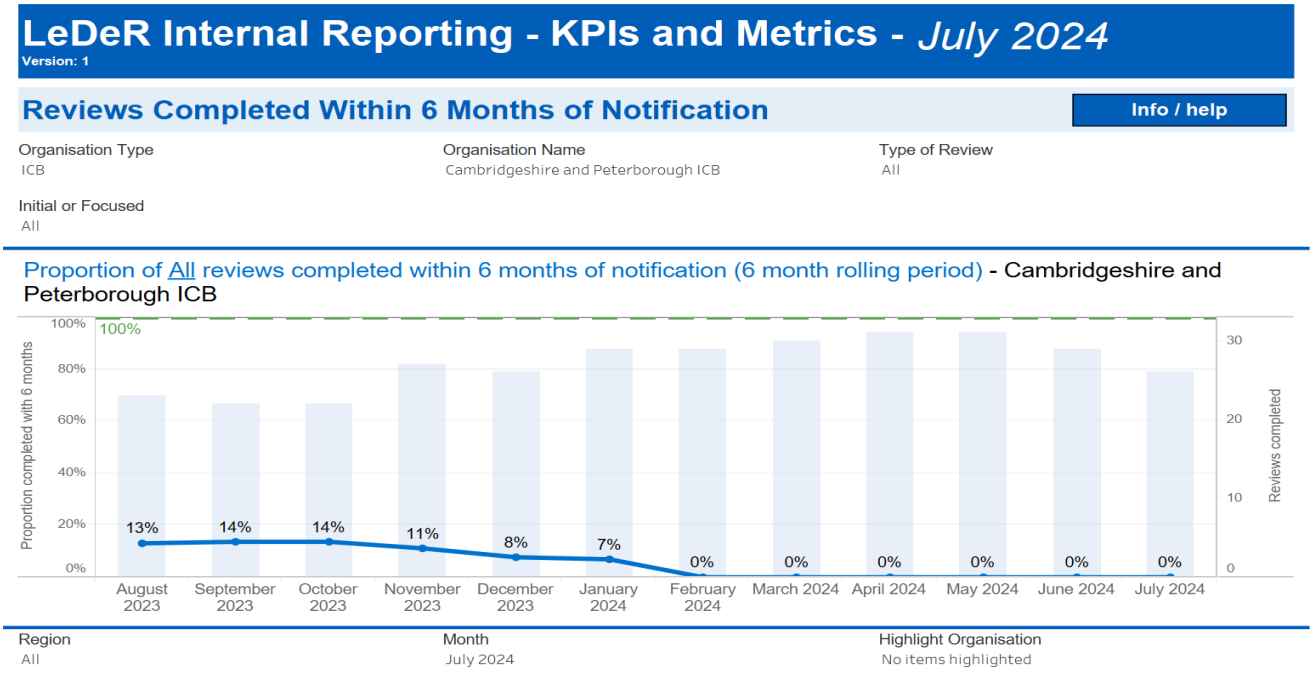
7.1.1 The annual report details different stages of the LeDeR review process. This document reports on LeDeR reviews completed in the year 1 April 2023 to 31 March 2024 and reports on the demographic information received in notifications over the same period. The completed reviews give detailed information about the life and death of the person. The notification data will be further verified during the review process and may change from that reported here, for example, if a person had no evidence of a clinical diagnosis of a learning disability or autism.

7.2 Performance

7.2.1 NHS England expect ICBs to complete 100% of their LeDeR reviews within six months (182 days) of them being notified on the LeDeR web platform. The exceptions are if statutory processes prevent that being possible if family members of those bereaved have asked for the review to be delayed (LeDeR Policy 2021). To achieve the Key Performance Indicator (KPI) of completion within six months of notification, reviews need to be started within three months of notification. CPICB has approached management of the LeDeR programme in different ways over the past few years but has not yet met this requirement (see chart 1 below).

Chart 1: LeDeR reviews completed within six months CPICS

LeDeR Internal Reporting - KPIs and Metrics: Completed within six months - Tableau Server (england.nhs.uk)
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7.2.2 To address the performance there is now an inhouse LeDeR team. This team is substantive, with experienced reviewers in post since quarter 1, 2024/25. There is a trajectory for addressing the backlog and a local area contact in post since quarter 2, 2024/25 focusing on actions from learning with partners across the system. Twenty-eight LeDeR reviews have been signed off since April 2024.

7.2.3 The learning from LeDeR is firmly embedded in current service redesign work, demonstrating the commitment of Cambridgeshire & Peterborough ICS to improving the health and outcomes for autistic people and people with a learning disability.

7.2.4 The completed reviews in this report relate to people who died between 2018 and 31/03/2023. It will be explained which data set is being referenced in each section. During this period, the time to completion of reviews in CPICS has been more than double the national average, see charts 2a and 2b below.

Chart 2a. Time to completion of LeDeR reviews England

LeDeR Internal Reporting - KPIs and Metrics: Time to Completion - Tableau Server (england.nhs.uk)
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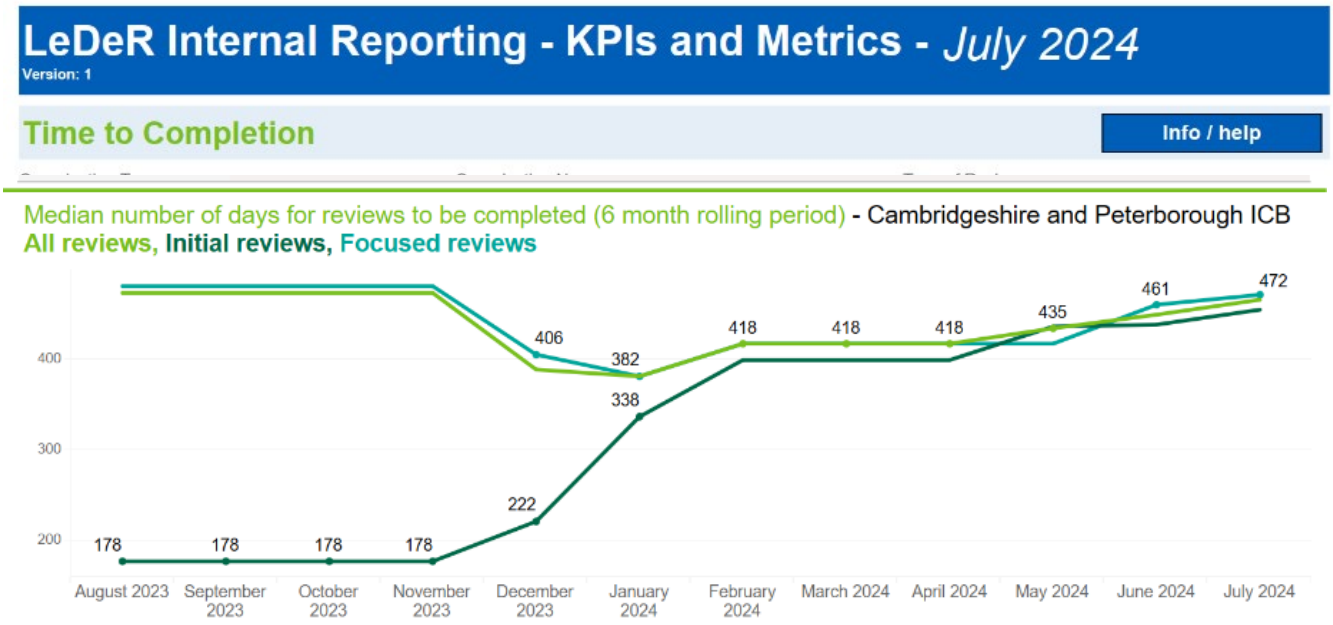
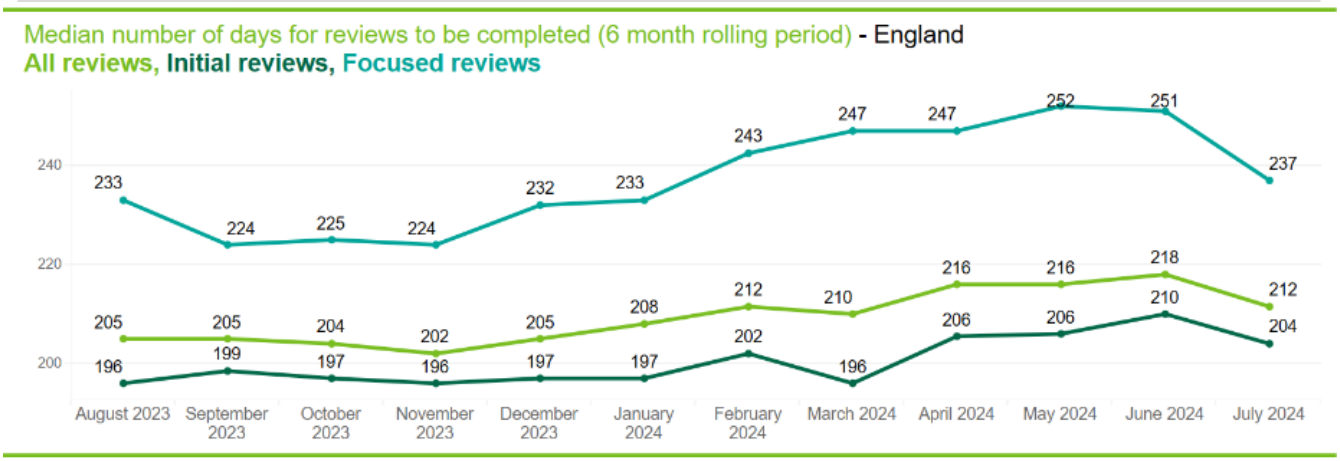


Chart 2b. Time to completion of LeDeR reviews CPICS

LeDeR Internal Reporting - KPIs and Metrics: Time to Completion - Tableau Server (england.nhs.uk)
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7.2.5 There were 39 LeDeR reviews completed in the period 1 April 2023 to 31 March 2024. There were no autism only reviews. 37 reviews were for learning disability only; two reviews were for people with a dual diagnosis of a learning disability and autism.

7.2.6 Focused reviews take longer to complete and must be presented to a multidisciplinary quality assurance panel to agree learning and actions before signing off as completed. NHS England expect at least 35% of reviews to be focused.

7.2.7 In Cambridgeshire and Peterborough, 85% of the reviews completed in the reporting period, were focused. This was often due to concerns about care noted in the initial review rather than for the other reasons mentioned in paragraph 6.2.3.

7.3 Demographic information

7.3.1 Ethnicity

7.3.1.1 There were less than five death notifications and completed reviews of the lives and deaths of people of Black or Asian ethnicity in the reporting period. All were male and their ages at death were within four years of the overall median age at death.

7.3.1.2 There were no notifications and less than five completed reviews of the lives and deaths of people of white ethnicity other than white British. These were both genders and their ages at death were distant from the median, both older and younger.

7.3.1.3 The Cambridgeshire and Peterborough Joint Strategic Needs Assessment v1.02 (Sept 2023) noted the low number of death notifications of people with a learning disability from diverse ethnic groups may be due to underreporting of deaths of people from minority ethnic backgrounds, or due to the population structure, for example fewer older people from minority ethnic groups.

7.3.1.4 All deaths of people with a learning disability of Black and Asian ethnicity have a focused review to explore health inequalities and intersectionality.

7.3.1.5 To protect personal data, analysis of data sets smaller than five risks identifying people so these notifications and completed reviews will be considered within the whole dataset for this report.

8. Analysis of eligible notifications received by LeDeR in the year 1 April 2023 to 31 March 2024

8.1 Notification data

8.1.1 There were 50 unique eligible notifications received by LeDeR CPICB during the year 1 April 2023 to 31 March 2024, following removal of one duplicate record and one notification classified as out of scope due to no formal clinical diagnosis of autism. This was down from 54 notifications in 2022-23. Deaths were notified to LeDeR by a variety of health and social care professionals, most often a learning disability nurse.

8.1.2 These deaths had not been reviewed in the reporting period, but the following data has been extracted from the notifications. Thirty-nine notifications were for people with a learning disability only; five notifications were autism only; six notifications were for people with a dual diagnosis of a learning disability and autism.

8.1.3 The 45 deaths of people with a learning disability, with or without autism, notified to LeDeR comprise just under 1% of the population of people with a learning disability known on primary care learning disability registers in Cambridgeshire & Peterborough ICS. There is no comparable register for autistic people.

8.2 Autism only notifications

8.2.1 There were five notifications of deaths of autistic adults without a learning disability. All were of White British ethnicity. The median age at death for this group was 48 years old which is seven years lower than the median age at death of autistic people reported nationally.

8.2.2 Limited conclusions can be drawn as this group will not be representative of all autistic adults. To protect personal data, as numbers will be less than five, and to avoid the risk of identifying these people there will be no further comment on autism only death notifications until the reviews are complete.

8.3 Median age at death for people with a learning disability notified to LeDeR 1 April 2023 to 31 March 2024

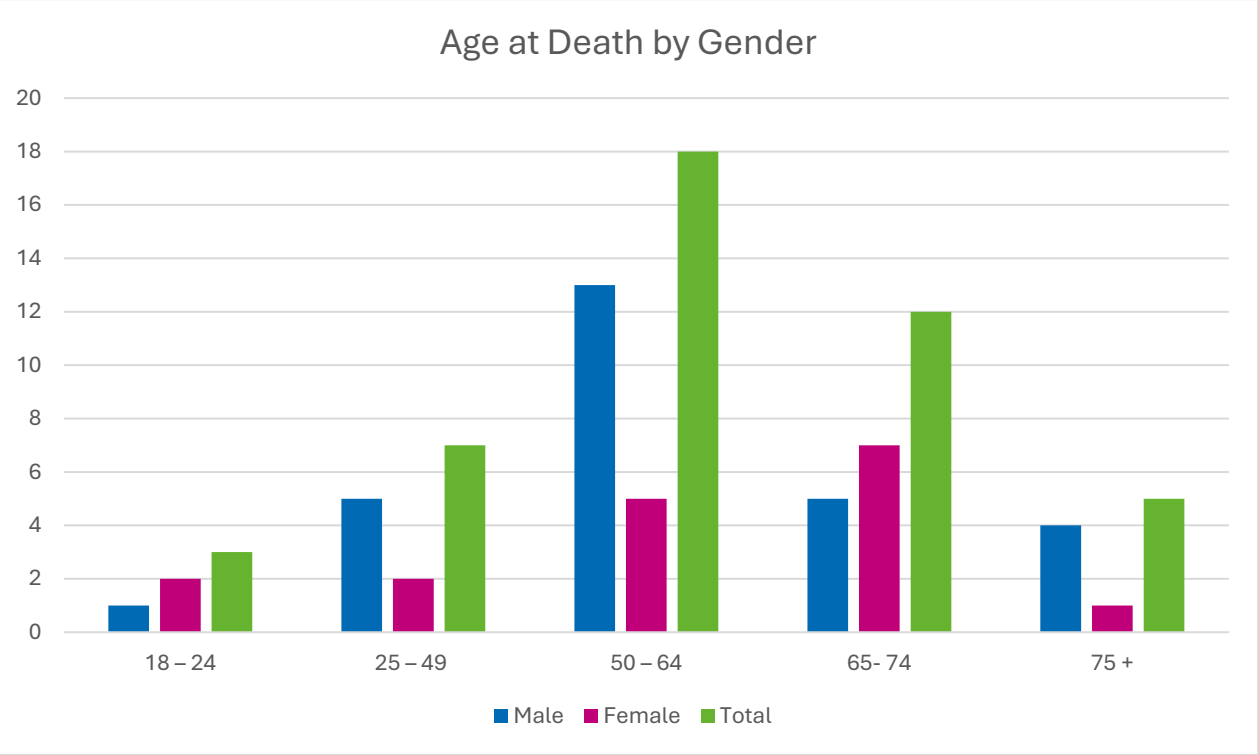
8.3.1 Median age at death for people with a learning disability was 61 years old which is lower than the nationally reported median age at death for people with a learning disability of 62.9 years old (LeDeR, 2022).

8.3.2 Sixty-two percent of the death notifications received regarded men with a learning disability. This is a greater proportion than the 55% of male notifications reported nationally (LeDeR, 2022) but comparable with the 60% of men with a learning disability on the primary care learning disability registers in Cambridgeshire and Peterborough.

8.3.3 When split by gender, the median age at death for men with a learning disability in Cambridgeshire and Peterborough remained 61 years old. Median age at death for women with a learning disability was 62 years old. See chart 3 below for the distribution across age groups at death by gender.

8.3.4 Sixty-two percent of people with a learning disability died before they reached 65 years old. This is a far greater proportion than the 15% of people in the general population who die before they reach 65 years old.

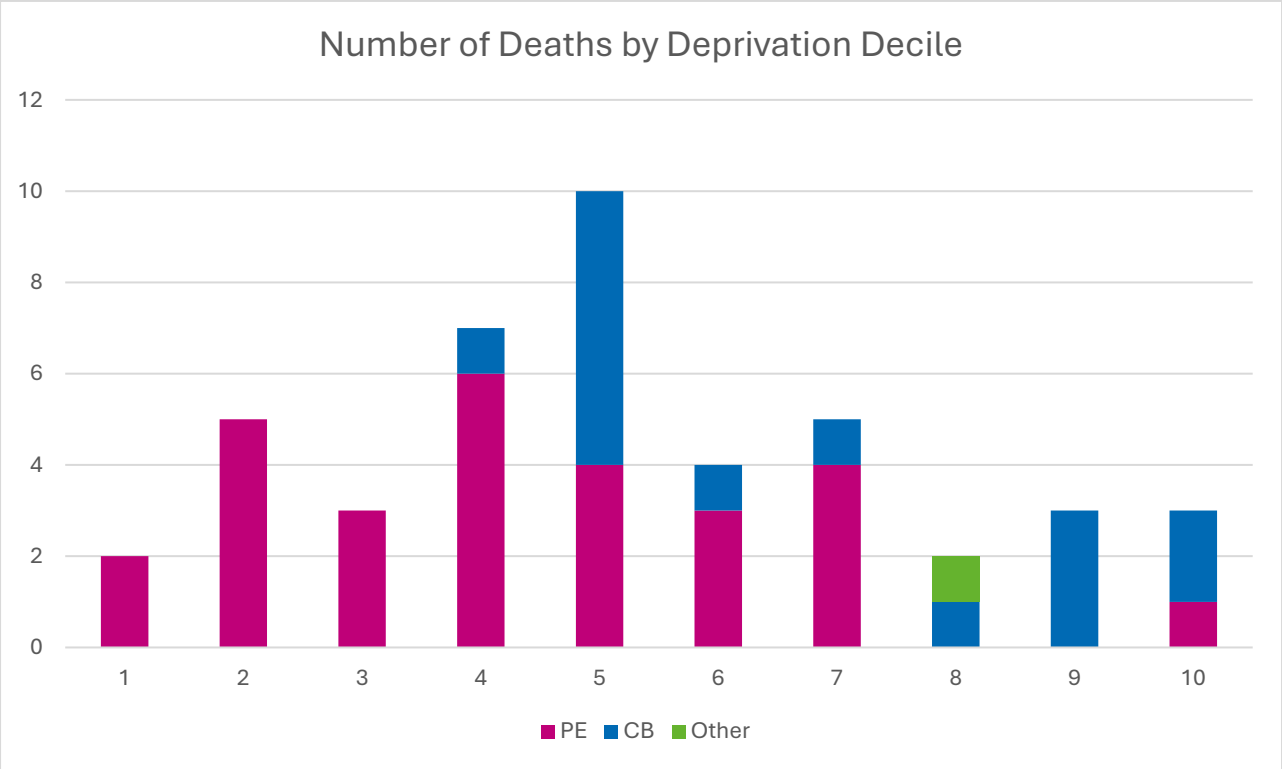
Chart 3: Age at death by gender for people with a learning disability notified to LeDeR 1 April 2023 to 31 March 2024



8.4 Deprivation

8.4.1 Deprivation is measured by assessing living conditions and factors such as average income, employment and health status by postcode area. Home postcodes are ranked one to 10 with one being the most deprived areas and 10 being the least deprived. Peterborough and Fenland (both PE postcode areas) are known to be more deprived areas than Cambridgeshire. The people with a learning disability living in the most deprived deciles, all had 'PE' home postcodes (see chart 4 below).

Chart 4: Deaths of people with a learning disability notified to LeDeR 1 April 2023 to 31 March 2024 by deprivation decile split for first part of postcode



8.4.2 When data was analysed by postcode and gender there were stark differences in the age at death (see table 1 below). People living in a 'PE' postcode area died over a decade earlier than people living in a 'CB' postcode area.

8.4.3 There were two women who died in postcodes other than PE or CB. Both were under the age of 50 years old but to protect personal data, there will not be further analysis in this report to avoid the risk of identifying these people.

Table 1: Median age at death, by postcode and gender of people with a learning disability notified to LeDeR 1 April 2023 to 31 March 2024

Median age at death	Female	Male	All
PE postcode	60 (n=11)	57 (n=17)	58 (n=28)
CB postcode	72 (n=4)	68 (n=11)	70 (n=15)
Other	32 (n=2)	0	32 (n=2)
All	64 (n=17)	61 (n=28)	61 (n=45)

8.5 Severity of learning disability

The notification of severity of learning disability was incomplete in notifications. This will be verified during the review process and reported next year.

8.6 Causes of deaths of people with a learning disability notified to LeDeR 1 April 2023 to 31 March 2024

8.6.1 The information provided on the notification form about the circumstances of the death of the person who died, including what the notifier thought caused the death is subject to verification during the review process. Once further information is received the cause of death data reported in section 8.6 may change, for example, if a postmortem reveals a different clinical diagnosis.

8.6.2 As described in paragraph 6.2 during the review process, the local LeDeR team review both immediate cause of death, and the underlying cause(s) of death. The immediate cause of death is analysed to consider immediate learning and themes that may lead to earlier recognition, treatment and prevention of a terminal event.

8.6.3 Thirty-two of the 45 notifications of deaths of people with a learning disability gave a cause of death; in 13 notifications this section was left blank or 'unknown' was stated.

8.6.4 Aspiration pneumonia was the most common cause of death recorded in section 1a of the medical cause of death certificate for nine deaths, and the underlying cause of death (section 1b) for one death. Median age at death of people with aspiration pneumonia as the cause of death was 70 years old.

8.6.5 There were seven further notifications of pneumonia as the cause of death. For five of these, pneumonia was also the underlying cause of death, appearing in the lowest completed part of section 1. Two of these death notifications identified hospital acquired pneumonia as the cause. Influenza was given as an underlying cause of aspiration pneumonia twice and COVID once.

8.6.6 There were three deaths from sepsis secondary to chest and/or urine infections or meningitis. Sudden death in epilepsy was given as the cause of two deaths: median age 55 years old.

8.6.7 Cancer was given as the cause of one death. Stroke was given as the cause of one death.

8.6.8 Causes of death in adults aged 18 – 64 years old

8.6.8.1 There were several sudden untimely deaths, including two sudden deaths in epilepsy. Respiratory infection was cited as the immediate or underlying cause of seven deaths. Further analysis will be provided once inquests and reviews have been completed.

8.6.9 Causes of death in adults aged >64 years old

8.6.9.1 Aspiration pneumonia was the most common cause of death recorded in section 1a of the medical cause of death certificate for seven adults aged over 64 years old, and the underlying cause of death (section 1b) for one death. Influenza A was given as an underlying cause of aspiration pneumonia twice.

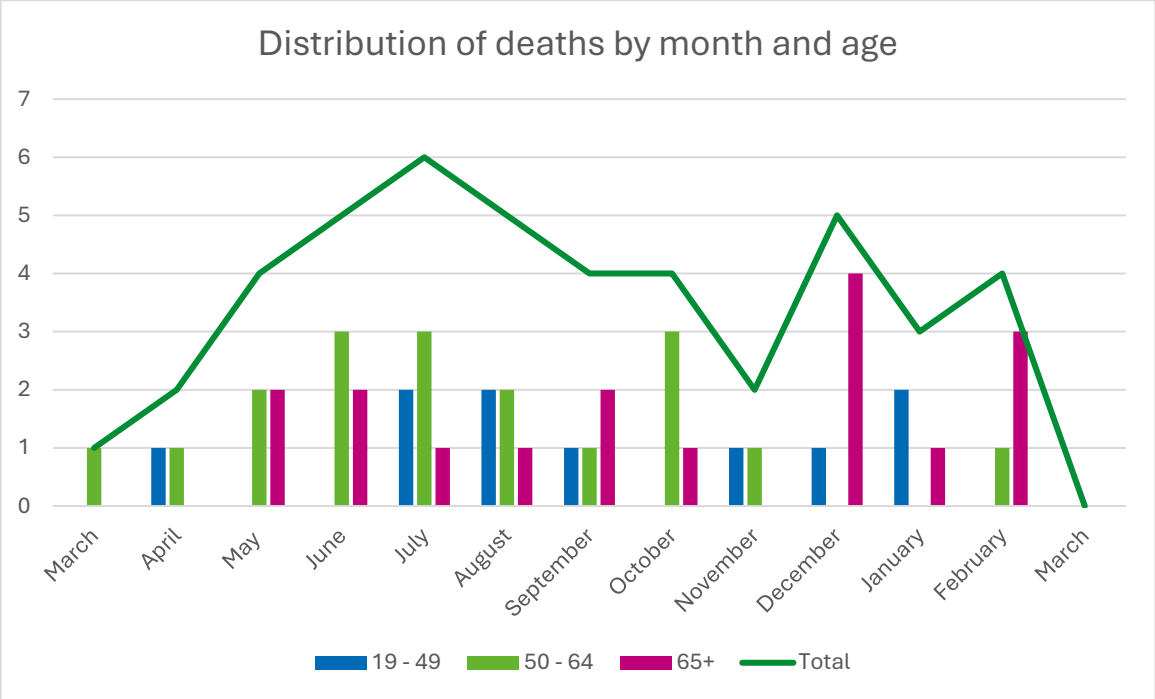
8.6.9.2 There were two further notifications of pneumonia as the immediate and underlying cause of death, 1a being lowest completed part of section 1 of the Medical Certificate of Cause of Death. There were three deaths from sepsis.

8.7 Circumstances of death

8.7.1 Peak month for deaths

8.7.1.1 July was the peak month for deaths, with six deaths occurring, then five deaths in each of the months June, August and December for the period 1/4/2023 – 31/03/2024. There are known seasonal spikes in deaths amongst older adults across winter months. This is evident in deaths amongst those aged over 65 years old in December and February (see chart 5 below). The national LeDeR 2022 report had drawn attention to excess deaths that occurred during hot weather in the summer of 2022. Seasonal variations and temperature extremes will be explored in the analysis of reviews against national data for the same period.

Chart 5: Distribution of deaths of people with a learning disability notified to LeDeR 1 April 2023 to 31 March 2024 by month and age



8.7.2 Place of death

8.7.2.1 Twenty-eight people with a learning disability (62%) died in an acute hospital, whilst 14 people (31%) died in their usual place of residence, either a residential care setting or a private address. Two people died in a hospice.

8.7.2.2 These proportions are comparable to the last national LeDeR report which highlighted that a greater proportion of people with a learning disability died in hospital (57%) than people in the general population (45%), and a smaller proportion of people with a learning disability died in their usual place of residence (34%) compared with 44% of the general population in 2021.

9. Analysis of LeDeR reviews completed in year 1 April 2023 to 31 March 2024

9.1 Demographic information

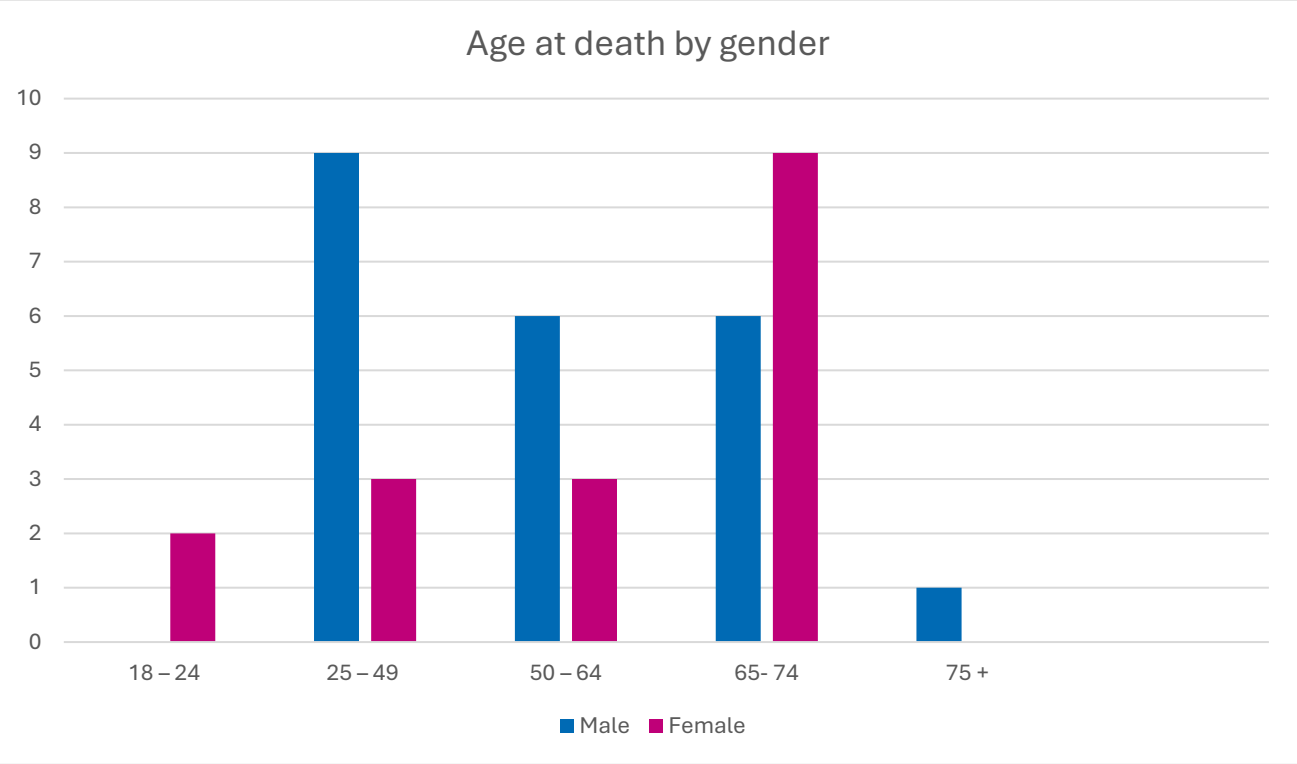
9.1.1 The data in this section relates to LeDeR Reviews completed in the year 1 April 2023 to 31 March 2024. They involve people with a learning disability who died between 2018 and 2023 (see table 2). The were no autism only reviews and no notifications to LeDeR regarding children during this period.

Table 2: Year of death for LeDeR reviews completed 1 April 2023 to 31 March 2024

Date of death	2018/19	2019/20	2020/21	2021/22	2022-23	Total
39 reviews	2	0	2	13	22	39

9.1.2 Age at death ranged from 23-79 years old, giving a median age at death of 60 years old, for completed LeDeR reviews.

Chart 6: Age at death by gender for LeDeR completed reviews



9.1.3 When analysed by gender, the proportion of completed reviews were 56% males, 44% females. The median age at death was 62.5 years old for females and 58 years old for males. Fifty-nine percent of people died before they reached 65 years of age which split into 68% of males and 29% of females. This is a greater proportion than the 15% of people in the general population who die before they reach 65 years of age. Eighty-five percent of people in completed reviews were of white British ethnic origin.

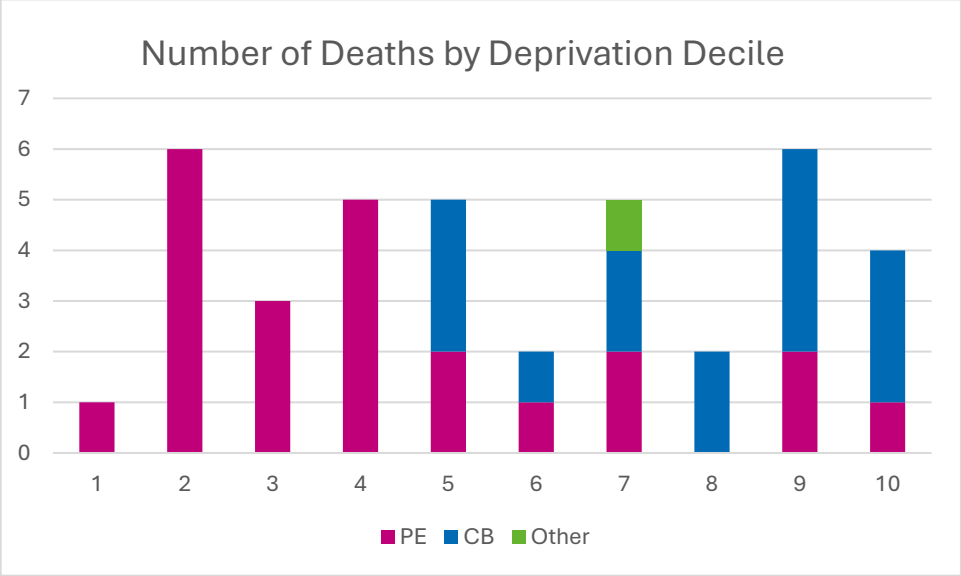
9.1.4 When age at death was analysed by home postcode (one person living out of area excluded for this analysis) there was a greater difference. Median age at death in PE postcodes was 10 years younger than CB postcodes. There was a greater difference in age at death amongst males, with the median age at death of a male in a PE postcode being 11 years younger than males in CB postcodes. For women the difference was five years. There was better parity of age at death between the genders in Cambridgeshire.

Table 3: Median age at death, by home postcode and gender for completed reviews

Median age at death	Female	Male	All
PE Postcode area	60	53.5	55
CB Postcode area	65	64.5	65
All	62.5	58	60

9.1.5 Deprivation is measured by assessing living conditions and factors such as average income, employment and health status by postcode area. The postcodes are ranked 1 to 10 with 1 being the most deprived areas and 10 being the least deprived. Peterborough and Fenland (PE postcode districts) are known to be more deprived areas than Cambridgeshire (JSNA, 2023). The home addresses of the deceased were spread across areas of deprivation (see chart 7 below).

Chart 7: Deaths by deprivation decile split for first part of postcode (completed reviews)



9.2 Causes of death for people with a learning disability: immediate and underlying (completed reviews)

9.2.1 As mentioned above (paragraph 6.2) the LeDeR team review both immediate cause of death, based on reviewing part 1a of the Medical Certificate of Cause of Death and the underlying cause(s) of death based on the lowest completed part of section 1 of the Medical Certificate of Cause of Death.

9.2.2 When comparing national and international mortality data, analysis is only based on the underlying cause of death. This appears on the lowest completed line of part one of a death certificate (1a, 1b or 1c) which is then assigned an ICD-10 chapter code. This informs strategic prevention programmes.

9.2.3 The immediate cause of death on part 1a of the death certificate is analysed to consider immediate learning and themes. This learning can inform systems and processes aiming for earlier recognition, treatment and prevention of a terminal event.

9.2.4 Of the 39 completed reviews, aspiration pneumonia was the most common immediate cause of death, recorded in section 1a of the medical cause of death certificate (seven deaths, median age 55 years old); plus, one person died of aspiration of stomach contents.

9.2.5 Aspiration pneumonia was given as the underlying cause of one death. Other underlying causes of death in aspiration pneumonia included (lowest line of medical certificate of cause of death completed in *italics*) oro-pharyngeal dysphagia, *Alzheimer's dementia*; d*ementia; gastroenteritis; motor/sensory dysphagia; Cockayne syndrome;* epilepsy*, cerebral palsy*.

9.2.6 Pneumonia was the immediate cause of four deaths, two citing COVID-19 as joint or underlying cause. Multiple organ failure with underlying pneumonia was the cause of one death and chest infection was the immediate cause of one death. There was one cause of death from each sepsis of unknown origin and meningitis.

9.2.7 The immediate cause of four deaths was multi-organ failure, with a variety of underlying causes (lowest line of medical certificate of cause of death completed in *italics*) *Klebsiella pneumonia, COVID-19 pneumonitis*; c*ongestive cardiac failure and severe aortic stenosis*; subacute bacterial peritonitis, a*lcohol-related liver cirrhosis*; gastric dilation, d*uodenal obstruction due to aberrant superior mesenteric artery anatomy*.

9.2.8 The immediate and underlying cause of four deaths was cancer. Two cancers had metastasized with an unknown primary.

9.2.9 Avoidable mortality comprises causes of deaths in those people aged under 75 years old, that are preventable or treatable. Preventable mortality includes causes of death that could be avoided through effective public health and primary prevention, such as vaccination. Treatable mortality includes causes of death that could be avoided through timely recognition and effective healthcare interventions.

9.2.10 The proportion of deaths in the general population that are considered avoidable is 22%. In the last national LeDeR report, 44% of deaths of people with a learning disability were designated avoidable. The proportion of avoidable deaths amongst the completed reviews in this reporting period were 29%.

9.2.11 As these deaths occurred over a number of years, but do not represent all deaths in any one year, it would be unwise to draw major conclusions or comparisons between the proportions and median ages in the completed reviews and the national report or notification data in section 8. In future reports, the LeDeR team aim to complete reviews and report on all the deaths that occurred in each year which will allow greater comparison.

9.3 Factors associated with immediate or underlying cause of death (completed reviews)

9.3.1 People with a mild learning disability

9.3.1.1 Four people had a mild learning disability. They each died in their usual place of residence, aged between 50 and 65 years old.

9.3.1.2 Three of the four people had not had an annual health check, including two people living in supported living. All had received flu and COVID-19 vaccinations and bowel cancer screening when eligible. One person did not have a weight on record. The other three were obese; two were morbidly obese with BMI over 40.

9.3.1.3 Two people died of heart failure, underlying ICD-10 Chapter IX Diseases of the circulatory system; both required assistance with mobility and one required a soft diet. The other two people with a mild learning disability were independently mobile and had no need for a special diet. One died with metastatic cancer of an unknown primary, ICD-10 Chapter II Neoplasms; one died with an intestinal infarct ICD-10 Chapter XI Diseases of the digestive system.

9.3.1.4 The learning from the lives and deaths of these people will inform the approach to engaging people with a mild learning disability about their health needs. They had been in touch with health services to receive vaccinations but not all the services for which they were eligible. Opportunities for earlier identification of illness and treatment were missed. This will be addressed through the Continuous Quality Improvement plan for annual health checks and promoting the professional curiosity of health professionals to make every contact count.

9.3.2 Factors associated with aspiration pneumonia or other chest infection as immediate or underlying cause of death

9.3.2.1 All the people whose immediate cause of death, recorded in section 1a of the medical cause of death certificate was aspiration pneumonia, plus three of five the people who died of pneumonia or chest infection, required special diets (puree or PEG feeds). Two-thirds of these people were fully dependant for mobility, with two others requiring at least some assistance.

Table 4: Factors associated with aspiration pneumonia or other chest infection as immediate or underlying cause of death

Level of learning disability	Number of people with aspiration aneumonia or bronchopneumonia as cause of death	Person requires modified diet Eg puree; PEG	Level of mobility **I** Independent **FD** Fully Dependant **RA** Requires Assistance
Mild	0	0	0
Moderate	6	5 / 6	4 FD; 1 I; 1RA
Severe	1	1/1	I
Profound	4	3/4	4 FD
Not noted	1	1/1	RA

9.3.2.2 From all the completed reviews, of 21 people who required a modified diet or PEG feeding, 19 (90%) required at least some assistance with mobility. These are known risk factors for aspiration pneumonia.

9.3.2.3 Of the 16 people who were fully dependent on others for mobility, 14 required special diets including puree and PEG feeding. Five of these people had no weight or BMI recorded. Half of these people died of aspiration pneumonia or pneumonia; one person died of a cardiac arrest, unknown aetiology; one person died with a bronchial obstruction caused by mucus plugging and one person died of hypoxic brain injury following upper airway obstruction caused by a food bolus.

9.3.2.3 There are a cluster of risk factors associated with death from aspiration pneumonia, including modified diet and assistance with mobility needs. There is an opportunity to review the evidence base against current care delivery to ensure everything that can be done to prevent aspiration pneumonia is being implemented amongst people with a learning disability.

9.3.3 Factors associated with cancer as immediate or underlying cause of death

9.3.3.1 The immediate and underlying cause of four deaths was cancer, two of which had metastasized with an unknown primary. Those with known primary were not amenable to screening programmes. Median age at death was 68 years old; two men and two women. One person had a mild learning disability; three people had a moderate learning disability. All lived in supported living or a residential home.

9.3.3.2 Three of the four people died in their usual residence, one in an acute Trust; none died in a hospice. Three reviews were focused: in all three, care and services received were judged to have fallen short of expected good practice which impacted on wellbeing but did not contribute to the cause of death. Learning themes included late identification of deterioration and weight loss, difficulty obtaining an accurate weight for a wheelchair user and difficulties arranging a physical examination.

9.3.3.3 Only two of the four people who died of cancer had had an annual health check. Two of the three people eligible for bowel cancer screening had received this. The one person eligible for breast screening had not received this. Three of the four people had normal body mass index (BMI), one was morbidly obese but independently mobile. Three of the four people were non-smokers and one was an ex-smoker.

9.3.3.4 Opportunities for earlier identification of cancer and potentially treatment were missed. This learning will inform the Continuous Quality Improvement plan for annual health checks and promoting the professional curiosity of health professionals to make every contact count. The provision of weighing facilities for people who use wheelchairs requires a system support.

9.4 Factors associated with prevention

9.4.1 Annual health checks

9.4.1.1 Just over half (20 people, 51%) of the people whose lives and deaths were reviewed had received an annual health check (AHC). Everyone living in a nursing home had an annual health check but only half of people living in other settings had an annual health check in the year before their death. Eleven of the 19 people who died having not received an AHC in the year before their death, died in 2022-23.

9.4.1.2 Having an annual health check did not directly relate to the uptake of vaccinations, suggesting some forms of contact may have had better success than others. Sixty-four percent of people had had a flu vaccine; 69% had had a COVID-19 vaccine and 21% had had a pneumococcal vaccine. Of the 14 people who hadn't had their flu vaccine, five people died of aspiration pneumonia or bronchopneumonia, two of multiple organ failure and two deaths were unascertainable.

9.4.1.3 Four people had received no vaccinations at all. Three of these people had also not had an annual health check. Three of these people lived in their own home with family carers, one person lived in a residential home. Age at death was under 65 for all four people: under 40 years old for three of the four. One person had a severe learning disability, one person has profound and multiple learning disabilities; the level of learning disability was not noted for the other two people. Cause of death was unascertainable (at home) for two people; the other two were aspiration pneumonia and multiple organ failure secondary to pneumonia and COVID-19.

9.4.1.4 Most eligible people had a bowel cancer screening, but no eligible women had a cervical screening and only one had a breast screening. One review found no evidence of compliance with the Mental Capacity Act and best interest decision making process in the removal of an eligible woman from invitations to the national cervical cancer screening programme. These findings will inform the work to improve uptake of cancer screening across the ICS.

9.4.1.5 The quality of annual health checks varied. The following anonymised excerpts are taken from completed reviews:

- J was not weighed at his annual health check and an old weight was recorded. This appears to have been incorrect as his weight four months later was 14.8Kg more.
- The post-mortem stated that K had long standing hypertension. There is no evidence of diagnosis or treatment.
- Lack of proactive measures such as the annual health check, medication reviews, and the pneumonia vaccination.
- No annual health check completed; no flu vaccination received in the last 12 months. No clear management plan in place around bowel monitoring while in respite care. No hospital passport.
- No evidence in the available records that L had an annual learning disability health check since August 2012, or that any mechanism for recall or follow up was in place.
- When M transferred from paediatric to adult services, he was not offered an annual health check until 2019 (gap of two years). His last check was in 2021 and was carried out by phone.

9.4.1.6 There has been a concerted effort across NHS Cambridgeshire & Peterborough to improve the delivery of Annual health checks. Performance is expressed as a percentage of people on the learning disability registers who received an annual health check. The number of people on primary care learning disability registers in Cambridgeshire and Peterborough rose from 4,559 in July 2023, to 4,893 in April 2024. Seventy-one percent of these people received an annual health check against the national target of 75%. Forty-one PCNs met or exceeded the national target by the end of July 2024.

9.4.1.7 The recommendation from these findings is for there to be a service improvement project following Continuous Quality Improvement (CQI) methodology to focus on delivery, and quality of annual health checks and health action plans.

9.5 Circumstances of death

9.5.1 DNACPR (Do Not Attempt Cardiopulmonary Resuscitation) orders

9.5.1.1 Reviewers identified examples of poor completion of DNACPR documentation, inappropriate listing of learning disability as a reason for DNACPR and a DNACPR order not being followed leading to an inappropriate resuscitation attempt.

9.5.1.2 The following examples are taken from completed reviews:

- Death in 2021: Learning disability was included as a reason Q should not be resuscitated.
- When R was found unresponsive (in an acute trust), CPR was commenced although there was a correctly completed valid DNACPR in place in his records.
- Death in 2022: S's family were not involved in discussions regarding DNACPR. ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) forms are not being completed in accordance with best practice.
- The next of kin did not feel their views had been reflected in the completion of the DNACPR.

9.5.1.3 The immediate learning was picked up locally. The NHS England directive that learning disability, autism and dementia are not reasons to put a DNACPR on someone's record were disseminated and this has not been an issue identified in reviews of more recent deaths. However, further assurance will be sought in the coming year that DNACPR forms are being completed in line with current guidance.

9.5.1.4 The LeDeR local area contact is now a member of the Palliative and End of Life Care Board. Learning themes from reviews will be presented quarterly, with any immediate or urgent learning going to the next monthly meeting for timely action and service improvement.

9.5.2 Mental Capacity Act (MCA)

9.5.2.1 Reviewers identified examples of both poor compliance with the Mental Capacity Act, a lack of evidence relating to best interest decision making, and good practice.

9.5.2.2 The following examples are taken from completed reviews:

- Poor compliance
  - Mental Capacity Act and best interest processes not recorded for decision making. There was no assessment of W's capacity during the discussions on DNACPR. While the family were consulted, it is important that consideration of the individual's capacity to engage and understand the process is considered.
  - There was no evidence that mental capacity and best interest decision making processes were recorded for the decision made for V to be removed from invitations to national cervical cancer screening programme.
  - There was no evidence of a mental capacity assessment of U's ability to understand her diagnosis of diabetes or manage her medications particularly considering stockpiling, medications running out and poor blood sugar control.
- Good practice
  - Excellent use of mental capacity documentation in the last episode of care on multiple occasions for consent to treatment involving next of kin.
  - Excellent communications with next of kin (NOK) including mental capacity and best interests documentation completed for each hospital procedure.
  - The involvement of an Independent Mental Capacity Advocate (IMCA) in 2017 regarding decision making for insertion of a Percutaneous Endoscopic Gastrostomy (PEG) tube for nutritional support is considered positive practice.
  - Good use of mental capacity and best interest decision practice with family involvement throughout last episode of care. There was good input and intervention from the learning disability nursing team in T's last episode of care who guided the hospital team to carry out mental capacity and best interests practice with T's family.

9.6 Place of death (completed reviews)

9.6.1 Fifteen people (38%) died in their usual place of residence: for five people this was supported living; for four people it was a residential home; for four people it was their own family home; and for two people it was a nursing home. There were no deaths in hospices amongst the completed reviews.

Table 5: Place of death for people with a learning disability (completed reviews)

Age groups at death	18 – 24	25 – 49	50 – 64	65 +	75 +	Total (%)
Acute Hospital	2	10	4	7	1	24 (62%)
Usual residence		2	5	8		15 (38%)
Total	2	12	9	15	1	39

9.6.2 Twenty-four people (62%) died in an acute hospital. Two thirds of these people were aged under 65 years old. The combined length of stay for the 24 admissions totalled 551 bed days, including 54 days in intensive care.

Table 6: People with a learning disability: Lengths of final stay in acute trusts and intensive care units prior to death (completed reviews)

People with a learning disability who died in acute trusts by year	Date of death	Number of LeDeR notifications	No. of days of final admission	No. of ICU days during final admission
North West Anglia NHS Foundation Trust (NWAFT)	2018 – 04/21	3	7	0
NWAFT	04/21 – 03/22	3	90	2
NWAFT	04/22 – 03/23	8	83	3
NWAFT	Total	14	180	5
Cambridge University Hospitals NHS Foundation Trust (CUH)	04/21 – 03/22	3	62*	48
CUH	04/22 – 03/23	5	291	0
CUH	Total	8	353*	48
Other trust	04/21 – 03/23	2	18	1
Total		24	551*	54

* One person died after a three-day admission but had had an additional 64 in-patient days over six other admissions in the preceding eight months.

9.6.3 Ten people died on the day of admission or within five days. Five people were admitted to intensive care during their final admission: four people for one to two days, one person for 48 days. One third (eight people with a learning disability) had lengths of stay exceeding 21 days; several were medically fit for discharge but were waiting for social care placement prior to becoming unwell with their final illness.

9.6.4 Overall grading of care for people who died in hospital ranged from one, where care fell short of expected good practice and this contributed to the cause of death through to five, where care was considered good and met expected standard. Given these reviews relate to deaths over several years, it is proposed a deep dive into hospital admissions and deaths is conducted this year. This will rationalise action plans with providers, explore extended lengths of stay and highlight any gaps in mealtime and mobility support needs, and compliance with Mental Capacity Act and resuscitation best practice that may contribute poor outcomes.

10. Quality of care

10.1 All focused reviews are discussed at an independently chaired multidisciplinary, multi-agency quality panel. This check and challenge leads to an overall grading for care and services received being agreed. Learning actions are collectively agreed.

10.2 Grading of care

10.2.1 In half (16) of the focused reviews, care and services received were judged to have fallen short of expected good practice and either contributed to or had the potential to contribute to the cause of death. A further 13 reviews graded care as falling short of good practice, impacting the person's wellbeing but not contributing to the cause of death. Care and services were only graded as satisfactory or good in three reviews.

10.2.2 Given these reviews relate to deaths over several years, and with multiple providers, it is proposed a rationalisation of action plans with providers during the remainder of this financial year with selected deep dives, for example into acute hospital care to ensure that everything possible is being done to prevent avoidable deaths through poor care or service delivery.

10.2.3 Hallmarks of good quality care demonstrated in reviews were consistency of care provision, good communication and good relationship between care providers. An example of care that was graded as good concerns a woman, (L) with a severe learning disability who was cared for in her own home by family carers and died aged 24 years old.

- There was effective transition planning and implementation of services. Holistic care provided by L's Mum. Services listened to L's mum and trusted her judgement and expertise. The multidisciplinary team was responsive and involved specialist services including dental provision. Reasonable adjustments were person centred and based on the L's likes and preferences. L also accessed alternative therapies.

10.3 Reasonable adjustments

10.3.1 The acronym **ADJUST** is used across the East of England region to explain what reasonable adjustments mean:

- **Address** - the person with a learning disability by their chosen name.
- **Design** - support around the person's needs, use hospital passports and work in partnership with supporters (carer's passport).
- **Just** - change the way we do things. Under the Equality Act 2010 we have a duty to make reasonable adjustments.
- **Understand** - the best ways to communicate with the person. Use clear, everyday language, pictures and avoid medical jargon.
- **Surroundings** - hospitals can be very busy, strange environments; noise and bright lights can be very distressing for some people with learning disabilities/autism.
- **Time** - people with learning disabilities/autism may need extra time to process and understand information and need to be supported to make their own decisions about care/ treatment.

10.3.2 The Equality Act 2010 applies to all NHS and social care settings. NHS Cambridgeshire & Peterborough is committed to embedding reasonable adjustments in all services to address inequity. NHS Cambridgeshire & Peterborough has commenced remodelling of learning disability services and support. There is a commitment to coproduction and working closely with local authority partners to provide equitable and sustainable services across Cambridgeshire and Peterborough. The LeDeR team are part of these workstreams, ensuring the learning from LeDeR leads to service improvement across all providers.

10.3.3 The ICS is committed to delivering training on care for people with a learning disability and autistic people. Tier one Oliver McGowan training has been rolled out across the system, to 50,000 staff across nine large providers, two local authorities and VCSEs. Tier 2 training will follow this year.

10.3.4 Specific projects to embed reasonable adjustments in the ICS include:

10.3.4.1 A review the local pathway for the medical assessment of individuals at risk of community acquired pneumonia is underway. This will ensure the needs of people with a learning disability are designed in and the British Thoracic Society guidelines are translated into equitable services.

10.3.4.2 Working with epilepsy specialists to develop pathways to ensure diagnosis and treatment for people with a learning disability is in line with NICE guidelines, and that reasonable adjustments are made. A clinical lead for paediatric epilepsy has been appointed and is working to improve the transition pathway.

10.3.4.3 A general anaesthetic pathway is being developed at Cambridge University Hospitals NHS Foundation Trust (CUH) for people with complex needs to facilitate access to routine diagnostic procedures. Timely diagnostic imaging can speed time to diagnosis and treatment. A designated area for sedation and recovery with direct access from a small car park has been secured. The virtual hospital ward systems will be used to safely manage these day admissions. This service improvement has the potential to shorten the time to vital diagnosis and treatment, reducing pain, suffering and even death.

10.3.4.4 Below are two case studies of the acute and mental health Trusts embedding reasonable adjustments into personalised care.

Case study – Cambridge University Hospitals NHS Foundation Trust (CUH) and Cambridgeshire and Peterborough NHS Foundation Trust (CPFT)

A person with a learning disability, autistic traits and emotional unstable personality disorder, who communicated distress by various complex behaviours, was detained under section 3 of the Mental Health Act, in an inpatient unit.

- Collaboration and reasonable adjustments as described below, supported this individual through diagnosis with a blood cancer, treatment and end of life care:
  - Adjusted information for patient and communication fully informed and involved in care.
  - Adjusted dietary requirements.
  - Adjusted environment.
  - Adjustments in time for when treatment delivered adapted to the patient, adapted choice of treatment, medications.

  - Adapted observations.
  - Observation for pain and adjustments for appropriate methods of administration.
  - Clear plan for clinical parameters and intervention.
  - Some interventions carried out in ward environment rather than in the clinical setting, some in theatre.
  - Four familiar staff to be on the ward collaborative joint working between the acute hospital and mental health inpatient staff.
  - Regular MDT meetings between the acute hospital, mental health inpatient team, family, social care, integrated care board and advocate.
  - Home visits to family facilitated when able.
- This was a complex situation, but excellent care was delivered because of the collaboration and adjustments made.

Case study – North West Anglia NHS Foundation Trust (NWAFT) with multi-disciplinary and multi-agency collaboration

A young man needed dental surgery to remove an infected tooth. He was an autistic adult who presented with behaviour that challenged. He had a history of violence towards children triggered by sensory issues such as exposure to noise. This had led to restraint and traumatic experiences during previous attempts to access healthcare. This man had been formally assessed as having mental capacity under the MCA 2005.

- Planning for admission began with family, his support team and the wider multidisciplinary team regarding his needs, presentation, and triggers. A plan was devised with sufficient flexibility to respond to the level of unpredictability. All potential risks were considered throughout the planning phase:
  - The patient's advocate attended the hospital initially, for a walk through, to explore the art of the possible. Potential routes into and through the hospital were explored and final route agreed.
  - The patient then had a drive out in the car and enroute, along with his advocate and support worker, drove around the hospital grounds and past the proposed entrance. Two of the acute learning disability nurses (LDNs) were situated at the entrance.
  - Photos of the entrance and proposed route shared with the patient's advocate in preparation for visit – Journey Passport.
  - Further discussions were held with the hospital security team with regards to having a presence on the day of his visit, the history of previous trauma and admission plan and risks.
  - Further preparation was done with the patient, his advocate and support team, and the wider MDT. He visited the hospital and managed a walk-through, without incident. He viewed the side room he would be admitted into and met additional staff who would be supporting him during his procedure including the Day Surgery Admission team and anaesthetist.
  - With further discussions and planning, support from security and volunteers to stem the flow of patients, staff and visitors throughout the pathway, to minimise the risk of triggers, the patient attended the hospital appointment. All reasonable adjustments had been agreed and facilitated:

- Patient presented to the department later than usual to reduce waiting time – he was the only patient on the afternoon list.
- Alternative entrance and reduced/controlled footfall to mitigate risks of triggers which could dysregulate the patient and potentially increase the risk of harm to self and/or others.
- Side room allocated for quiet, privacy, supported by advocate support staff. Reduced lighting, keeping his phone with him.
- Pre-procedure anxiolytic offered to reduce anxieties, for administration prior to coming in or at hospital, prior to procedure, as desired.
- Able to remain in own clothing.
- Advocate and support staff accompanied down to theatre and were called post procedure to support in recovery.
- Separate bed area arranged in recovery; quiet, private, reduced distractions/triggers.
- Modifications to regular discharge pathway, enabling him to be discharged from recovery area once deemed clinically well/stable.

The success of this desensitisation and experience meant the patient was also able to successfully navigate the emergency department with support from the acute learning disability nursing team, emergency department colleagues and his support networks.

The outcome was relief of significant pain and discomfort from his teeth and prevention of potential complications.

11. Summary

11.1 There are systems and team in place to administer the LeDeR programme effectively. The learning from LeDeR is contributing to the system-wide remodelling of learning disability services.

11.2 There are plans in place to address the backlog of LeDeR reviews and a proposal to rationalise learning actions with providers for timelier and measurable learning into action.

11.3 The ages and causes of death, proportions of each gender and ethnicity and place of death are broadly like the last national LeDeR report (LeDeR, 2022).

11.4 Greater scrutiny is warranted of the delivery and quality of annual health checks, with particular focus on people with a mild learning disability, younger men with a learning disability living in areas of deprivation and uptake of screening.

11.5 There are good examples of reasonable adjustments being made and more work is under way to improve quality of care.

11.6 There are areas of experience warranting greater scrutiny, such as extended hospital stays in services as they are delivered today and how the risk factors for aspiration pneumonia are mitigated in the care of people with a learning disability.

12. Recommendations

12.1 Rationalisation of all outstanding LeDeR actions from completed reviews in collaboration with providers to map these across the five learning disability service remodelling workstreams.

12.2 Facilitate involvement of family carers as part of an individual's care team, if they wish, when service users change setting, eg not restricted access as visitors.

12.3 Focus on improving data quality to provide context and assurance about the equitable access to care and treatment for people with a learning disability, and autistic people. The opportunity to update ethnicity and reasonable adjustments on all records over the coming year, then cut all performance data for learning disability and autism, will highlight any intersectionality or gaps in equitable outcomes, in routinely collected performance data.

12.4 Prevention & early Intervention

12.4.1 Apply Continuous Quality Improvement (CQI) methodology to annual health checks and Health Action Plans.

12.4.2 Engage partners throughout the system, at every touch point, throughout the year to reference the annual health check and health action plan in that service to ensure the health action plan informs care and improves outcomes for the service user.

12.4.3 Educate and empower people with a mild to moderate learning disability about the content and rationale for an annual health check. Raise expectations of what great care looks like, what serious signs to look out for and when and how to seek help. Consider starting this work in deprived areas for maximum impact.

12.3.4 Support the development of processes to identify those with learning disability who are at risk of aspiration pneumonia and training and education on how the risk can be reduced and any cases identified early. This will include the British Thoracic Society recommendations for aspiration pneumonia.

12.4.5 Support public health objectives to improve the uptake of vaccinations and cancer screening amongst people with a learning disability.

12.5 Late Intervention

12.5.1 Conduct a deep dive into acute hospital admissions to contextualise the long lengths of stay highlighted in completed reviews.

12.5.2 Working with providers, apply Continuous Quality Improvement (CQI) methodology to develop an evidence-based care bundle focusing on harm free care, prevention of aspiration pneumonia and prevention of deconditioning amongst people with a learning disability.

12.6 End of Life

12.6.1 Implement End of Life Care Board objectives, designing in the needs of people with a learning disability and autistic people in collaboration with providers.

12.6.2 Seek assurance from each provider that DNACPR (ReSPECT) forms for people with a learning disability are being completed in line with current best practice and the Mental Capacity Act.

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ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) process

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