

Learning from Lives and Deaths – People with a Learning Disability and People with Autism (LeDeR)

Norfolk and Waveney Annual Report 2022-2023

Title	Norfolk and Waveney LeDeR Annual Report 2022-2023
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Forewords

Patricia D'Orsi: Director of Nursing for the Norfolk and Waveney Integrated Care Board (NWICB) - Senior Responsible Officer (SRO) for the Learning Disability and Autism (LD&A) Programme Board

NHS Norfolk and Waveney Integrated Care Board (ICB) is grateful to the families, carers, and friends affected by the passing of a loved one, friend or colleague, for their input into the review process and for helping to tell the stories of the lives and deaths of people living with learning disabilities and/or autism in Norfolk and Waveney. The value of the knowledge and insight held by families and friends is particularly evident in the report's section on lived experiences, which can be found on pages 54-57. We would also like to recognise and thank all staff from across the health and social care system for their involvement, sharing invaluable insights from their professional practice and for their time spent working with and supporting the people and families whose lived experiences are central to this report.

Sadly, people living with learning disabilities and/or autism people continue to have a much shorter life expectancy with the average being over 20 years younger than the general population for women and for men. Mortality data shows that the leading single cause of death for the learning disability and autism population relates to aspiration pneumonia and pneumonia, followed by cancer and sepsis. We have observed a heightened number of excess deaths in younger ages, through our reviews, as well as an increase in deaths of people aged over 65, due to the impact of the global COVID-19 pandemic in 2020/2021. This year's report found several themes for improvement, including:

- Prevention of respiratory illness, particularly pneumonia, needs to be a focus for learning and action following this report and Annual Health Checks should be routinely used to offer cancer and other screenings, and to identify people eligible for a pneumonia and other preventative vaccines.
- A consistent primary care Health Action Plan template for use across the Norfolk and Waveney Integrated Care System (ICS) could help to standardise practice for quality purposes and support its use across other services involved in a person's health and wellbeing

- Transitional care between child and adult services remains a difficult experience for young people and their family. Greater collaboration between paediatric and adult services is needed and better preparation for families as to what to expect could be beneficial.
- A Norfolk and Waveney strategy for stopping over medication of people (STOMP) would be a welcome step to embed its principles for people with a learning disability, autism or both with psychotropic medicines, into all prescribing practice.

It is also important to acknowledge the excellent work of the Learning Disability Mortality Review (LeDeR) system working groups this year, around end of life and palliative care support, improving uptake and quality of Annual Health Checks (AHC), dietetic weight management support, a pilot pathway for non-invasive long-term ventilation care and a project improving communication between care organisations at the point of hospital admission and discharge, to improve service user and carer experiences and coordinate community-based care more seamlessly.

We welcome the publication of this, our sixth LeDeR Annual Report in Norfolk and Waveney. The ICB continues to be committed to ensuring that Norfolk and Waveney people living with learning disabilities and/or autism live well, and we recognise that this work must be informed by the learning identified within the report, using lived experiences to help identify opportunities to improve services and support. Our focus for the year ahead must be on using these insights to improve the quality of care offered, working collaboratively with partners to deliver care with better oversight and monitoring of placements and training for staff.

Paul Benton: Director for Quality in Care for the Norfolk and Waveney Integrated Care Board (NWICB) - Chair of the LeDeR Steering Group

I would like to start by expressing how immensely proud and grateful I am of all the staff who are working tirelessly keeping our people and communities safe across the whole of Norfolk and Waveney.

The LeDeR steering group only functions as effectively as it does due to the commitment of our dedicated team. Despite being new in my role, it's very clear the people who work in our directorate and partners across the system are very committed to providing outstanding quality and care. Norfolk and Waveney had some significant challenges during the winter which all the partners witnessed. The system faced unprecedented challenges in delays and finding appropriate and safe care settings for the most vulnerable.

It would be fair to describe the experience as one of the most challenging winters we have ever had. Whilst the pandemic is now becoming a more distant memory, the impact will continue for some time as the system continues its recovery phase. The LeDeR steering group has, despite the challenges, kept its principles and direction focused on the things that matter the most, quality and

safety of the residents within our care and whilst we know that we are still on this journey, we as partners are committed to improving the lives of those around us.

There have been significant changes in 2022/2023 with the new Integrated Care System was formed on July 1st 2022 and all system partners working in a new and exciting way together. This has been a long and awaited journey to reach this point and should therefore allow us to make significant improvements in the lives of the most vulnerable. Now that the new financial year is upon us it's important for us to evaluate the direction the steering group takes ensuring that for 2023/2024, we are meeting the needs of the population, reaffirm the importance of making change happen across all aspects of care, and more importantly despite the financial challenges that lay ahead, we see an improvement in all domains of care. We cannot do this alone, but we are confident that the partners that we work with will make the changes required that have a positive impact for all our people and communities.

Rachel Clarke: Co-ordinator for Family Voice Norfolk

My name is Rachel Clarke, and I am the co-ordinator of Family Voice Norfolk (FVN). Family Voice Norfolk is the Norfolk parent carer forum for families who have children with special educational needs and/or disability aged 0-25 years. We are not a support group, nor are we an advisory and guidance service. We are a forum which gathers real-lived experiences and views of families to work in co-production to improve services within health, education, and social care.

FVN has been attending the LeDeR working groups, the Learning into Action Group and the LeDeR Steering Group for the past 18 months. We currently have two parent carer representatives attending these meeting, namely Laura Godfrey and myself. Both Laura and I are parents of children and young people who have autism, learning disability and other conditions.

We believe that having parent carers present at the meetings brings a different dynamic and different perspectives at times. We are able to put ourselves in the shoes of families involved and, hard as it may sometimes feel, think about the future care for adults with autism and/or have a learning disability, whether they be independent in their community or within a supported/residential setting. What would we expect to see from care for these adults, what would we want to see done differently in the care of adults as our young people will become adults themselves? There have been some extremely 'difficult to read' and, rightly so, emotive cases to review. We are struck by how dedicated everyone is within the meetings to make improvements, prevent recurrences of failings and to truly take learning from each case we review. Laura and I are grateful for the support and 'open ears' that are offered to us by colleagues should we find a case to be upsetting.

We have been part of, and brought our own lived experiences, to the Learning Disability Health Check Working Group and we actively take part in the respiratory, nutrition and end of life groups. There are plans for colleagues from the meetings to bring some of the

important topics we have discussed, such as mental capacity and the Learning Disability health checks to a Family Voice Norfolk parent carer engagement sessions called Let's Talk About... We look forward to getting these in place in the next academic year and to continuing to learn from the LeDeR meetings we attend.

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1. Acknowledgments

Firstly, the team would like to remember, and thank, all the people who have contributed to LeDeR by sharing their stories with us, following their death. It is our greatest privilege to be given the opportunity to explore their experiences, and our primary aim is always to use all information in a compassionate and respectful way. Thanks also go to families, friends, and the keyworkers of those we are reviewing, who contributed their time to enrich the information we had and help us find their voice.

Secondly, the LeDeR programme would not have made the achievements and progress it has over that last year without the care, expertise and time given by health, social care, and voluntary sector colleagues. Delivering real and sustainable change takes a real commitment of resource, and this has been freely given and gratefully received. Colleagues have supported the LeDeR groups and our learning into action project work. Special thanks go to our partners with lived experience for their guidance, support and challenge. LeDeR reviews are not an investigation of a death but an assessment of a person's experience. This aims to bring to life the circumstances leading up to the person's death and provide a life portrait of the people we have reviewed. This can be a difficult and challenging role but has been fulfilled by a team of highly experienced and dedicated nurses and administrators, who have been central to delivering the programme.

We would also like to acknowledge with much appreciation the crucial role of the health and social care staff, who have diligently delivered high quality care to people with learning disabilities and/or people with autism over the last year.

2. Executive Summary

Welcome to the Norfolk and Waveney Integrated Care Board (NWICB) LeDeR report. This is the sixth annual report in Norfolk and Waveney on the reviews of the lives and deaths of people with a learning disability and/or autism since the inception of the LeDeR programme in England in 2017. It is the responsibility of all Integrated Care Boards (ICB) to have established a LeDeR programme within their system and implement any actions identified by the learning taken from reviews.

ICBs must publish a LeDeR annual report describing their progress in completing reviews, provide interpretations of the collected data and detail completed and ongoing service improvements made in response to any learning. It also provides an opportunity to reassess local priorities in response to any themes or trends. This report from the Norfolk and Waveney LeDeR programme demonstrates the work covered in the reporting period from 1st April 2022 to 31st March 2023. The deaths reviewed can cover a longer period dating back to 2018. This is due to death reporting delays but also delays in the review completion which is addressed in section 5.

There is little comparison available between this and last years' annual report. Local data collection has been significantly more robust this year, allowing for analysis of all 72 reviews. Last year's available reviews were restricted to 18, due to the significant change in the

review format and therefore it would not give a reliable or accurate comparison. As such, figures have been presented to describe the current situation in Norfolk and Waveney and future reviews will be able to better highlight trends and improvements.

Comparisons can be made between Norfolk and Waveney and the regional and national picture by reading this report alongside the East of England and National Reports¹. Summary findings from the Norfolk and Waveney reviews in 2022/2023 can be seen on the next page:

¹ <https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf>

<p>The quality of residential services needs to be improved in our region, with a focus on performance and quality monitoring.</p>	<p>As a region we achieved over 70% completion of annual health checks for those eligible, and we hope to continue improving quality.</p>	<p>Nearly 80% of focused reviews indicate the person experienced care and service availability which fell short of expected good practice.</p>	<p>Health action plans are an important part of an annual health check and they need to be robust and collaborative.</p>
<p>Oversight of care quality in specialist inpatient services has increased, thanks to health and wellbeing reviews and C(E)TRs.</p>	<p>Uptake for screening programmes is poor, and could be increased with better preparation and follow up for non-attendance.</p>	<p>Acute and community learning disability nurses are key supports for improving service access and reasonable adjustments.</p>	<p>Primary care are good at offering face to face appointments but we could improve preparation for interventions such as blood tests.</p>
<p>Notifications for those with autism have been low and we hope to improve this through engagement, to support our learning.</p>	<p>Our hospitals really value the importance of familiar carers, but could improve the use of hospital passports.</p>	<p>ReSPECT documents and end of life care planning needs to happen earlier and in a more collaborative manner.</p>	<p>Paediatric end of life care in Norfolk and Waveney is excellent, providing a holistic approach for the whole family.</p>
<p>System partners could benefit from auditing their compliance, and staff knowledge, of the Mental Capacity Act; and address gaps in practice.</p>	<p>System use of the Gold Standards Framework could help with earlier identification of deterioration and referral to palliative support.</p>	<p>As young people move into adult services there is still a notable decline in care co-ordination, despite excellent moves to improve transitional care.</p>	<p>Earlier referrals are needed for advocacy and care co-ordination, for those with complex health profiles and limited social support.</p>
<p>Primary care and residential services need to be more proactive in supporting weight management.</p>	<p>Our region had a brilliant uptake in COVID-19 and flu vaccinations. However pneumonia vaccinations remain scarce for those eligible.</p>	<p>Best practice in the use of the Mental Capacity Act was mostly seen when the acute learning disability teams were involved.</p>	<p>Prevention of respiratory illness is a priority for the whole system, including dysphagia management, dental care and vaccination.</p>

3. Introduction and Purpose (Local and National)

3.1 What is LeDeR?

The LeDeR programme reports on deaths of people with a learning disability aged four years and over. We report on deaths of people with a diagnosis of autism, with no learning disability, for those aged eighteen years and over. Latest figures available estimate there are approximately 1.2 million people (951,000 adults and 299,000 children) living in England, known to have a learning disability². 6683 are registered with GP practices in Norfolk and Waveney out of a total population estimate of 916,120.³ This gives our area one of the highest percentage representations in England⁴.

People with a learning disability are considerably more likely to be impacted by health inequalities, including higher levels of avoidable and premature deaths. For example, the latest data from the 2021 National LeDeR Report demonstrates the disparity in age of death for those with a learning disability. Compared with the general population, males with a learning disability die 22 years younger and females die 26 years younger⁵. This inequity is something we wish to address within Norfolk and Waveney, through a continuing programme of change informed by learning from LeDeR.

The LeDeR programme⁶ uses the national policies definition of a learning disability. For people with autism to be included within the LeDeR programme they must have a diagnosis of autism recorded within their health records prior to their death and be over the age of 18. The child death review (CDR) process reviews the deaths of all children aged under 18 years. This is the primary review process for children with learning disabilities and autism, which is completed collaboratively with the LeDeR programme. A full explanation of the review process including national priorities for a focused review can be found in the LeDeR policy⁷.

When reading the findings of this report it should be kept in mind that the LeDeR programme is not mandatory so may not have complete coverage of all deaths of people with a learning disability and/or autism. Comparatively, numbers are also small compared to the general population, especially in some sub-categories (such as children) and as such must be interpreted with caution. Data interpretation and analysis is an important part of finding trends in poor practice and identifying gaps where improvement is needed.

² https://www.norfolkinsight.org.uk/wp-content/uploads/2022/03/Briefing_paper_Disability_Adults_with_Learning_Disabilities_May_2018_accessible.pdf

³ <https://www.norfolkinsight.org.uk/>

⁴ [Quality Assessment Framework 2021/2022](#)

⁵ <https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf>

⁶ <https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf>

⁷ Section 3/page 12 of <https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf>

However, we also aim to present person focused qualitative learning which represents people's strengths, talents, hopes and ambitions.

3.2 Reporting a Death

Anyone can notify the programme of a death or person with learning disabilities and/or autism at <https://leder.nhs.uk/report>

3.3 Local Programme

Within Norfolk and Waveney, we are committed to improving services for people with learning disabilities and/or people with autism and use the framework set out in the LeDeR policy by NHS England. Data collection significantly changed for 2022/2023 and this has allowed us to provide a more detailed report than previous years, with more information to analyse and draw themes from. This does mean, however, that we are limited in our ability to draw reliable comparisons between previous reports and this one. With consistency in data collection however, future annual reports will start to show trends.

4. Challenges and changes to delivery of the LeDeR review programme

The success of the LeDeR programme is built on the efforts and input of the LeDeR team and the wider contribution from ICS partners and colleagues. Significant changes have been implemented over the last year to fully realise the LeDeR policy published in 2021⁸.

This includes:

- Establishing local governance groups responsible for signing off initial and focused reviews, agreeing care grading and setting appropriate actions.
- Establishing robust escalation routes where learning requires a systemic approach or support.
- Expanding the LeDeR programme to accommodate referrals for adults with a diagnosis of autism without a learning disability.
- Delivering focused reviews for national and local priorities. For example: people from ethnic minorities, adults with autism, or on request by family.
- Creating appropriate reporting and education routes to update the wider health and social care community on learning from LeDeR.

⁸ <https://www.england.nhs.uk/learning-disabilities/care/monitoring-the-quality-of-care-and-safety-for-people-with-a-learning-disability-and-or-people-who-are-autistic-in-inpatient-care/>

As a result of the incredible hard work of all involved, the longstanding backlog of reviews was completed by June 2022. The team is also exceeding its target of 95% of reviews completed within 6 months and it has reduced the number of reviews carried over by more than 50%. A more detailed breakdown can be found in section 5.

We have experienced many challenges in delivering LeDeR over the past year, due to both national changes and local barriers. Firstly, the online platform which the team uses to complete reviews has been through multiple formatting changes. This has presented challenges with consistency of reviews but has benefitted the completeness.

In the case of someone with a learning disability who has died in hospital, the trust will complete a Structured Judgement Review (SJR). Ideally these should be completed in a timely manner and made available to the LeDeR review team as part of the hospital notes, complementing the available information for the review. There have been significant delays in completion of SJRs which has meant the LeDeR review has often been completed first. However, mortality leads from all trusts have worked well with LeDeR over the last year to share findings and learning for all shared reviews, with a reviewer attending all SJRs for a person with a learning disability. Moving forward all trusts in Norfolk and Waveney have made significant improvements over the past year and this is resolving.

All reviewers are reliant on the timely provision of notes from all involved services to complete a review within the 6-month target. This includes notes from acute trusts, primary care, community trusts and social care. Mostly the team will receive at least one set of notes back within 2 weeks of the request being sent. However, responses to all requests can take up to several months which significantly delays allocation and completion of reviews. Reviewers also rely heavily on talking to carers and professionals who knew the person well to get a complete picture of the person they are writing about. Care providers can sometimes be difficult to engage in this process which restricts the information available to really tell a person's story and describe their lived experience.

Since completion of the review backlog, families are being contacted and invited to participate in the LeDeR process much sooner after the death of their loved one and we believe due to this, we are seeing more families choosing not to be part of the review. We have delayed completing reviews at the request of the family to give them more time, even if this takes the review over 6 months, as we recognise the importance of a loved one's contribution. We will also still offer families the option of receiving a copy of the completed review should they wish. We will explore this moving forward to try and see if there is anything the team can do differently to support families in contributing to the review.

5. Governance Arrangements

In line with the national policy, we have governance arrangements to support reviewing and signing off completed reviews. As well as clear reporting routes into the Learning Disability and Autism Programme Board and Learning from Death Forum.

5.1 Initial reviews

Initial reviews are presented at the Local Quality Assurance Panel (LQAP) which is chaired by one of the Local Area Contacts (LAC) or another suitably senior person within the Learning Disability and Autism Team within the NWICB. The panel will scrutinise the review for quality and ascertain if the recommendations address the identified learning. Initial reviews are signed off and themes and trends are presented at the LeDeR steering group.

5.2 Focused Reviews

Focused reviews go through the same quality assurance and scrutiny process above but are then presented at the Learning into Action Group (LIAG) for sign off which is chaired by either the NWICB LAC or the NWICB Senior Reviewer. This group is attended by key operational stakeholders who will agree the SMART recommendations, care grading, and identify any good practice of note.

5.3 LeDeR Steering Group

The LeDeR steering group is chaired by the NWICB Director for Quality in Care and is a subgroup of the Learning Disability and Autism Partnership Board. It is attended by a wide range of senior stakeholders to review identified learning, the strategic actions and quality improvement work streams. Work undertaken in this group is presented at the Learning Disability and Autism Programme Board which is chaired by the Senior Responsible Officer for Learning Disability and Autism for Norfolk and Waveney.

5.4 Reporting Structures

The Learning Disability and Autism Partnership Board and the NWICB Quality and Performance Committee receive monthly reports on the performance of reviews undertaken and the learning into action. The team also report to the ICS Learning from Deaths Forum. The team follow a specifically written safeguarding policy for the reporting of safeguarding concerns which is detailed in Section 11.

6. Performance

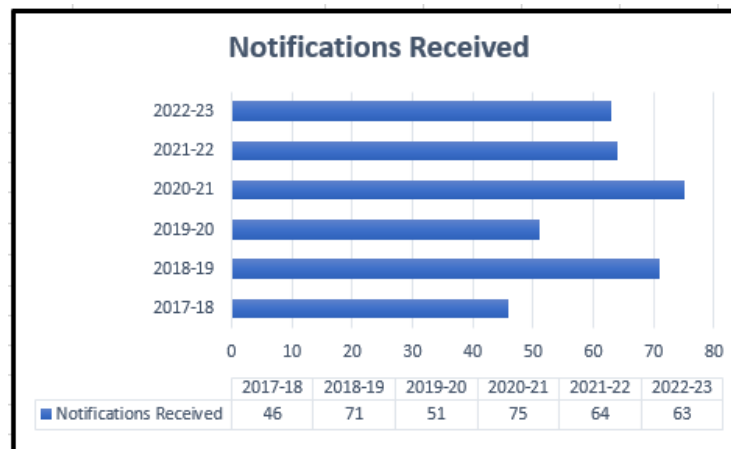
The team works to achieve 95% of reviews completed within 6 months of notification. Due to the backlog of reviews accumulated over past years additional reviewers were commissioned to address this. The last of these reviews were completed and signed off in June 2022, however, it still impacts our performance figures for the year. At the end of Quarter 4 (Q4) the team has completed 66% (44 out of 66 adult reviews) within 6 months of notification in the 2022/2023 year. However, looking at performance just in Q3 and Q4, once the backlog had been resolved, the LeDeR team has a combined completion target of 96% reviews completed in under 6 months of notification.

Some reviews may take over the 6 months to enable any statutory process to be completed such as police investigations, coroner proceedings or safeguarding inquiries. It is important that LeDeR pauses and gives precedence to these to avoid prejudicing any investigations. We can put these reviews on hold, which in effect “stops the clock” so the delay doesn’t count towards the 6-month timeframe. Reviews which are counted to have exceeded the 6-month timescale have included those delayed for reasons such as clinical notes not being received, capacity issues within the review team and giving families time who may not be ready to engage but want to be part of their loved one’s review.

We carried forward 41 reviews from the 2021/2022 review period and this year we are carrying over 32 reviews into 2023/24, so 20% fewer than previous years. This is on top of receiving 25% more referrals in 2022/2023 than before Covid. The team is also tasked by NHS England to convert a minimum of 35% of adult reviews from initial too focused. This year the team has exceeded this target and achieved 37% of reviews being focused.

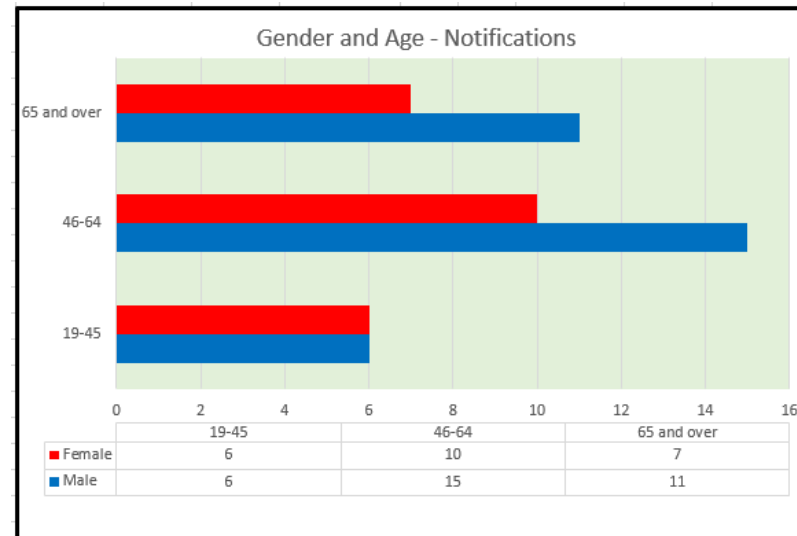
7. Overview of Notifications

Since the start of the LeDeR programme in 2017, England has recorded 15690 deaths, 1768 of which were within the East of England region and of those 369 were Norfolk and Waveney deaths. These numbers are only based on the numbers of referrals received and as reporting to LeDeR is not mandatory, the true number of deaths is likely to be higher. The graph below shows how the number of notifications has changed over the years. To compare the number of notifications, 2019/2020 is used due to the number of excess deaths from COVID which is also exemplified in the graph below. Overall, our notifications have increased by 24%.



7.1 Gender and Age

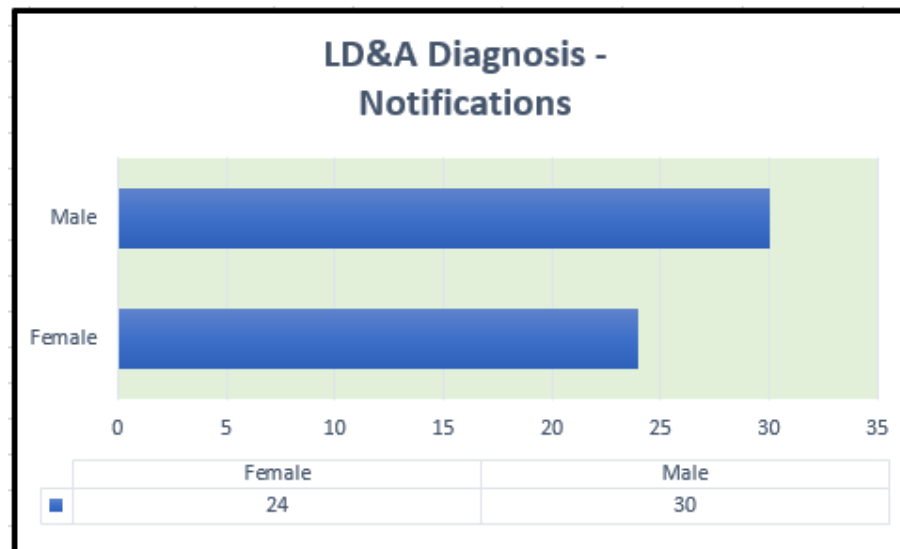
Overall, we had more referrals for men than women, a difference of 20%, and this was represented in all the age groups except one, where the numbers for men and women were the same. Due to the low number in the under 18 category these have been omitted from the graph, however 75% of these notifications were for boys. The youngest reported death during 2022/2023 was 8 years of age and the oldest was 84 years. Most of our referrals were for people between the ages of 46 and 64, which fits with the median age of death of 57.5 years of age for those referred to us. This year's data shows a fall in the median age at death from 60 years of age for notifications in the 2021/2022 year. Data collection is difficult for previous years, but we know that more reviews in previous years have been for people 65 and over. Potentially due to the increased COVID-19 mortality in older people, which may account for the drop in age this year. For the general population in Norfolk and Waveney the average age of death between 2018 and 2020 for men is 79 years old and for women is 84 years old.⁹



⁹ https://www.norfolksight.org.uk/wp-content/uploads/2022/08/State-of-Norfolk-and-Waveney-health-report-2022_correctedByPAVE.pdf

7.2 Diagnosis

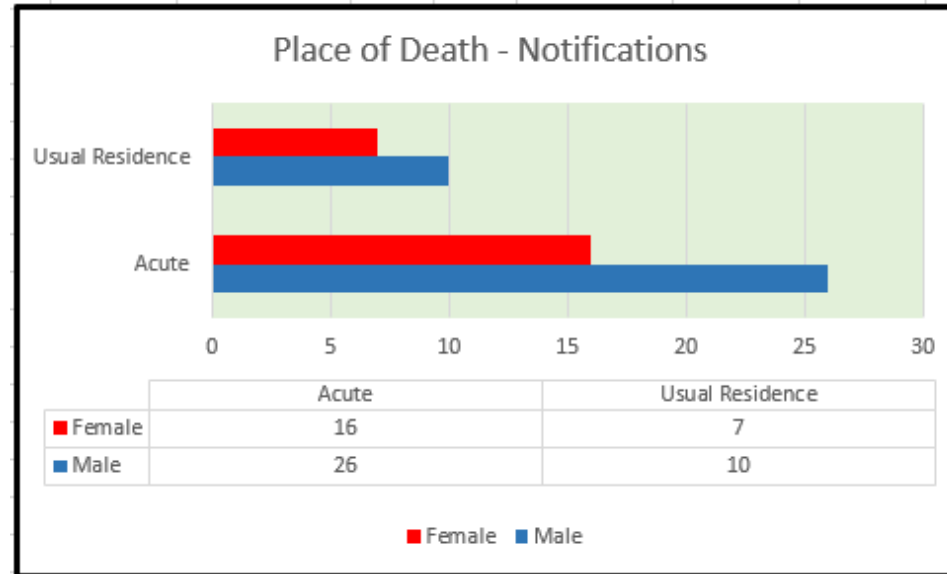
The majority of our referrals were for those with a diagnosis of a learning disability with a smaller number referred with a diagnosis of both a learning disability and autism. As would be expected with the gender difference in our overall referrals there were more men in both categories. However, the difference between men and women for each diagnosis is notable, with it being much higher when the person has an autism diagnosis. This has been omitted from the graph below due to the low numbers, however only 11% were female in the Learning Disability and Autism category. This could be due to substantially lower diagnosis rates in women for autism. The team has not received any referrals in 2022/2023 for anyone with a sole autism diagnosis. It is thought that 1% of the population has autism which would mean approximately 10,330 people in Norfolk and Waveney. The latest standardised mortality rate for people with autism is 17 deaths per 10,000. This shows the LeDeR team what is being missed and the need for communicating the importance of autism referrals will be a priority for 2022/2023. The team also hopes with the establishment of the medical examiner role for acute and community will aid these referrals as well work done to secure referral pathways with the coroner's court.



7.3 Place of Death

Most deaths referred to us in 2022/2023 happened in hospital, 67% ($n=42$) overall. 27% ($n=17$) occurred in the person's usual residence. Less than 10% happened in other areas including hospice care. This has been omitted from the graph due to the low

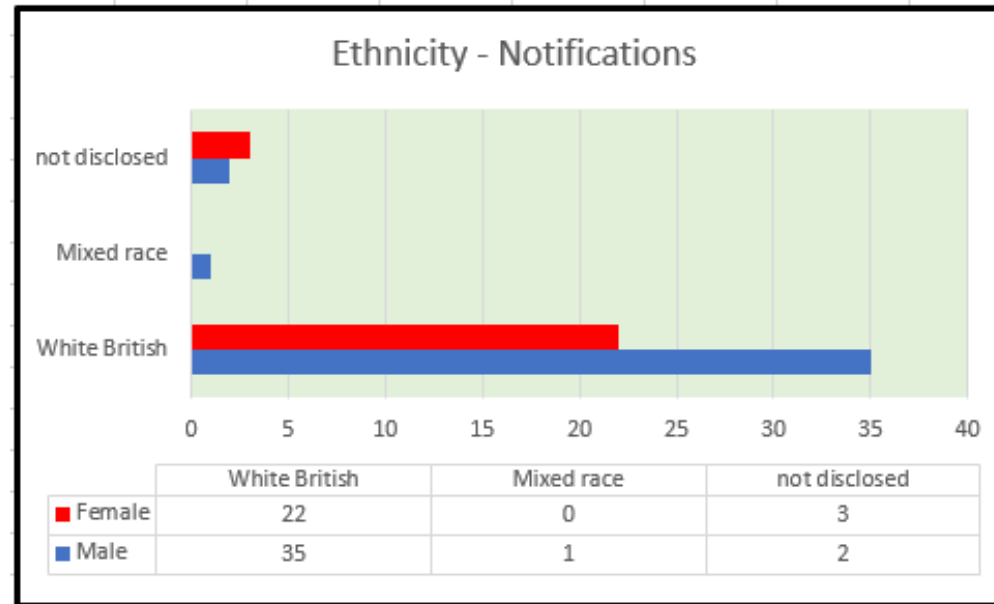
numbers. In contrast, the general population has a higher combined percentage of people dying in their usual residence, whether this be home or residential services.¹⁰



7.4 Ethnicity

Of the notifications from 2022/2023 where the ethnicity was disclosed, 98% ($n=58$) were for white British people. Only one referral was for someone from an ethnic minority. Usually, we would not report such low numbers to protect anonymity. However, it has been reported here to demonstrate the disparity in notifications. Ethnicity is not a mandatory question for a referral, so we do have a few notifications where the reviews have not yet been completed, and we are unaware of the person ethnicity. Therefore, there may be more representation than we are aware of.

¹⁰ <https://fingertips.phe.org.uk/profile/end-of-life/data#page/1/gid/1938132883/pat/15/par/E92000001/ati/167/are/E38000239/yr/1/cid/4/tbm/1/page-options/car-do-0>



7.5 Leading Cause of Death

From notifications the leading single cause of death (COD) in Norfolk and Waveney was aspiration pneumonia, with all pneumonias combined being the leading cause of death. This is also seen in the completed reviews. This profile is different to the general population where the top three COD in 2021 were diseases of the circulatory system, then COVID-19 and then cancers. Again, a COD is not a mandatory question for referral completion. As such, at the time of writing, only 54 of the notifications had an identifiable COD in the referral or in the available notes. This means some of the figures below may change if all COD were available. There were other causes of death with under 5 incidences which have not been listed to protect anonymity.

Cause of Death	Number of Notifications	Percentage
Aspiration pneumonia	17	27%
Pneumonia	9	14%
Cancers	7	11%
Sepsis	5	8%

7.6 Area of Deprivation

The Indices of Multiple Deprivation (IMD) show a mode score of 6 which is slightly higher than the completed reviews. However, the overall breakdown in representation into the higher and lower IMD areas are very reflective of the completed reviews for 2022/2023, with more people with a learning disability and autism living in areas with an IMD score of 5 or less. This is higher than the general population where 2019 data shows 52% in Norfolk live in an area with an IMD score of 5 or less.¹¹

IMD Score	Number of Notifications	Percentage	Number of Notifications	Percentage
1	8	13%	42	67%
2	10	16%		
3	6	10%		
4	8	13%		
5	10	16%		
6	11	17%	21	33%
7	4	6%		
8	2	3%		
9	4	6%		
10	0	0%		

8. Overview of Completed Reviews

The LeDeR review performance report as at the end of March 2023 shows that 91% ($n=337$) of 370 reviews received since 2017 have been completed by year end 2023. The table below breaks down the number of referrals received, and the number of reviews completed every year since the programme began.

Years	No of adult notifications	No of reviews completed	No of reviews carried forward
2017-18	46	3	43
2018 -19	71	23	91
2019-20	51	77	65
2020-21	75	77	63

¹¹ <https://www.norfolkinsight.org.uk/deprivation/reports/#/view-report/8b97d75c317745b3a6016fc0788469d1/E1000020/G3>

2021-22	63	85	41
2022-23	63	72	32
Total	369	337	

In 2022/2023 72 initial and focused reviews have been signed off as complete. At year end (March 2023), the team have 10 reviews in progress and 18 unallocated. This includes 4 which are on hold, awaiting statutory processes to be concluded. For some demographics, our 2022/2023 data collection allows us to break these down into initial and focused reviews. This will allow us to see if improvements can be made in how we select which reviews convert to a focused review. CDOP cases are not included in the initial review section, as this is covered in section 8.

For certain variables such as cause of death, avoidable deaths, areas of deprivation and chronic conditions all reviews, including CDOP have been included to get the best breadth of information possible to draw conclusions. Quality of Care grading has only been discussed with the focused reviews as the national policy does not currently require care and service provision grading for initial reviews.

8.1 Initial Reviews

Of the 64 adult reviews completed in 2022/2023, 40 were initial reviews.

8.1.1 Gender and Age

As with our notification data, we had a higher percentage of men (60%) than women who had an initial review. The median age of death for initial reviews was relatively similar, with 62 years old for women and 59 years old for men. This matches the table below showing most had an age of death between 46 and 64. It is of note however in this age range there were many more men dying than in the 65 and over range, which was mostly women at 73%. The total median age of death was 58.5 years old.

Age at Death – Initial Reviews	Men	Women
19 - 45	<5	<5
46 - 64	19	7
65 and over	<5	8

8.1.2 Ethnic Groups

All initial reviews were for people who were white British, as any person from an ethnic minority would automatically have a focused review as per the national priorities.

8.1.3 Diagnosis

In 2022/2023 all 40 initial reviews had a learning disability diagnosis. None had a diagnosis of a learning disability and autism as they were all converted to focused.

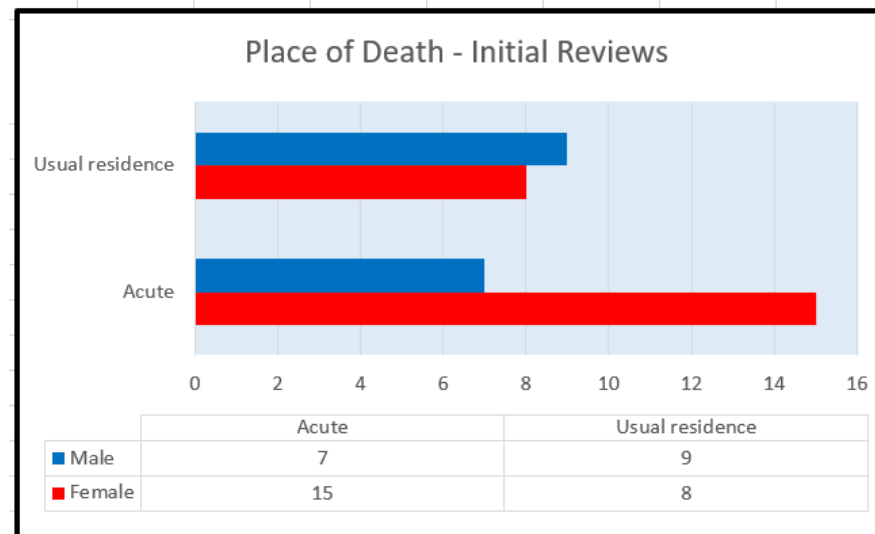
8.1.4 Level of Learning Disability Severity

Most initial reviews (43%) were for people with a moderate learning disability. Followed by severe (35%) and then mild (22%). More men had a moderate and severe learning disability whereas more women had a diagnosis of a mild learning disability.

Level of Learning Disability – Initial Reviews	Men	Women
Mild	<5	6
Moderate	11	6
Severe	10	<5

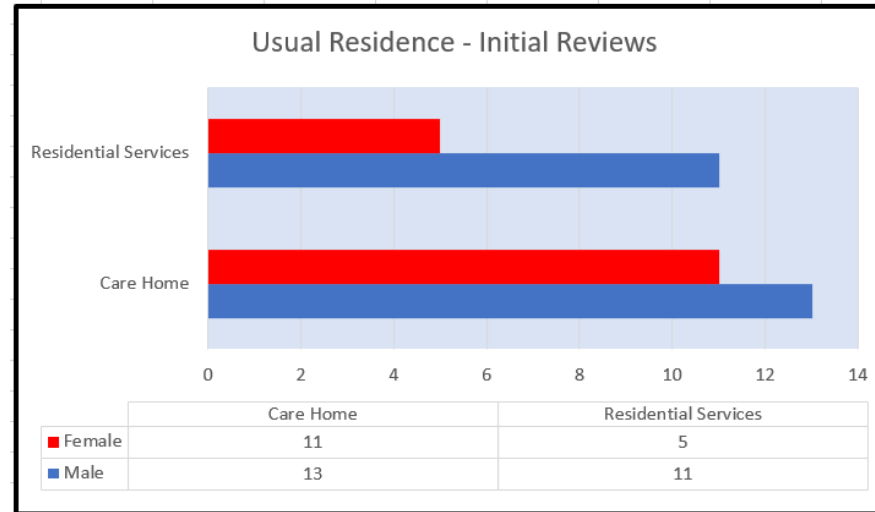
8.1.5 Place of Death

From our initial reviews, most people died in hospital (55%), followed by a care home as a usual residence (35%). The least represented place of death was in hospice, with only slightly more dying in their home when they were living independently.



8.1.6 Types of Accommodation

The overwhelming majority of people who had an initial review lived in a care home (60%), increasing to 75% living in residential services when combined with supported living.



8.2 Focused Reviews

Of the 64 adult reviews completed in 2022/2023, 24 were focused. Only focused reviews are graded on the delivery of quality of care and accessibility and effectiveness of services. The table below show the breakdown of reasons why a review was moved to focused.

Reason for Focused Review	Number	Percentage
Care Quality Concerns	9	38%
Reviewer Professional Judgement	5	21%
Under Section of the Mental Health Act	4	17%
Case Complexity	2	8%
Family Request	2	8%
Ethnic Minority	1	4%
Autism	1	4%

8.2.1 Age and Gender

Of the 24 focused reviews there were slightly more women (54%) represented. Most reviews were conducted within the 18-45 age group, which suggests the team are prioritising focused reviews for those who have died significantly more prematurely. The least number of focused reviews happened in the 65+ age group. This is especially telling as Norfolk and Waveney typically has a higher-than-average population over the age of 65. The median age of death for focused reviews was 57 years for the 2023 annual report.

Age at Death – Focused Reviews	Men	Women
18 - 45	5	6
46 - 64	<5	5
65 and over	<5	<5

8.2.2 Ethnic Groups

Norfolk and Waveney general population data from 2021 shows 94.7% people reported themselves to be white, with the broad minority groups representing 5.3%¹² of the population. However, this year LeDeR only completed one adult review from an ethnic minority (2%).

8.2.3 Diagnosis

In total there were 6 reviews for people with a diagnosis of autism and a learning disability.

Diagnosis – Focused Reviews	Men	Women
Learning Disability	8	10
Learning Disability and Autism	<5	<5

8.2.4 Level of Learning Disability Severity

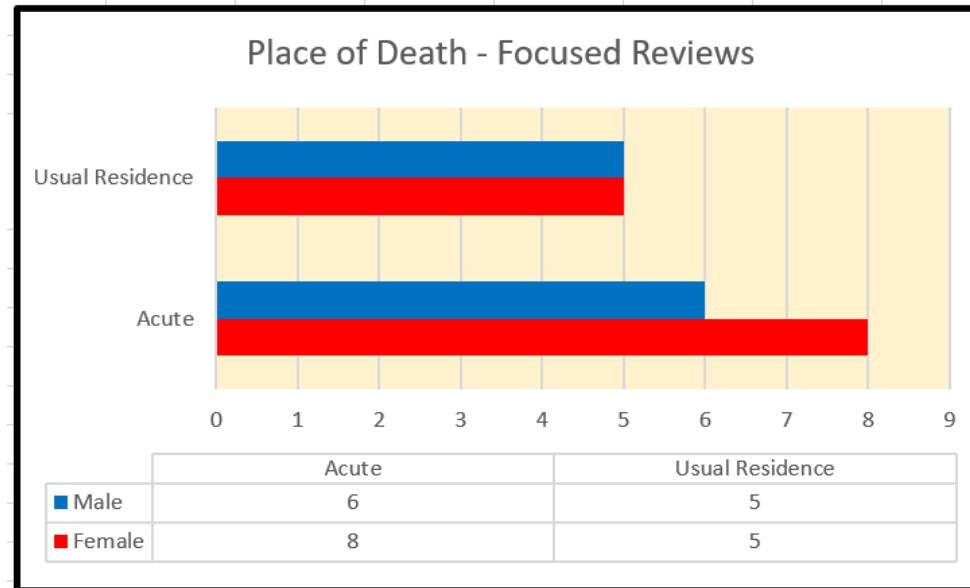
Most focused reviews were completed for those with a moderate learning disability (50%), followed by severe (25%) and then mild (21%). The only review completed in 2022/2023 for a person with a profound learning disability was a focused review, likely due to the complexity of the case. This distribution is similar to our initial reviews, and likely explained by the prevalence of moderate level learning disabilities in all our adult reviews for 2022/2023 (45% $n=29$).

¹² [Norfolk - Population - STP | Norfolk and Waveney | InstantAtlas Reports \(norfolkinsight.org.uk\)](https://norfolkinsight.org.uk)

Level of Learning Disability – Focused Reviews	Men	Women
Mild	<5	<5
Moderate	5	7
Severe	<5	<5
Profound	<5	0

8.2.5 Place of Death

Again, our focused reviews reflect that most people died in the acute setting (58%), with similar number dying in their own home, whether that from living in the family home (21%) or in a care home or supported living (21%). The improvement on this year's review quality means we have no places of death recorded as unknown, this year.



8.2.6 Quality of Care

The national policy requests that the LIAG grade the care received and the effectiveness and availability of services for all focused reviews. Grading is based on the information the reviewer has gathered and presented at panel. Of the 24 completed focused reviews

from 2022/2023, 5 of the reviews graded the quality of care as being satisfactory or above; 79% fell short of expected good practice with 14 cases (58%) where this was judged to have impacted the person's wellbeing. The below table shows the grading of Care for completed reviews for 2022/2023.

Rating	Standard	Number	Percentage
6	This was excellent care (it exceeded current good practice).	0	0
5	This was good care (it met current good practice in all areas).	0	0
4	This was satisfactory care (it fell short of expected good practice in some areas, but this did not significantly impact on the person's wellbeing).	5	21%
3	Care fell short of expected good practice but did not contribute to the cause of death.	5	21%
2	Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.	9	37%
1	Care fell short of current best practice in one or more significant areas resulting in the potential for, or actual, adverse impact on the person.	5	21%

Of the 24 completed focused reviews from 2022/2023, 5 of the reviews graded the Effectiveness and Availability of Services as being satisfactory or above; 79% fell short of expected good practice with 12 cases (50%) where this was judged to have impacted the person's wellbeing. The below table shows the grading of Availability and Effectiveness of Services for completed reviews for 2022/2023.

Rating	Standard	Number	Percentage
6	This was excellent Service Effectiveness and Availability (it exceeded current good practice).	0	0
5	This was good Service Effectiveness and Availability (it met current good practice in all areas).	1	4%
4	This was satisfactory Service Effectiveness and Availability (it fell short of expected good practice in some areas, but this did not significantly impact on the person's wellbeing).	4	17%
3	Service Effectiveness and Availability fell short of expected good practice but did not contribute to the cause of death.	7	29%
2	Service Effectiveness and Availability fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.	7	29%
1	Service Effectiveness and Availability fell short of current best practice in one or more significant areas resulting in the potential for, or actual, adverse impact on the person.	5	21%

Learning identified from the reviewers:

Reviewers recommended that before any change in care setting is made, the person should be involved in this decision and a thorough health and social care assessment completed to ensure the new placement is suitable and, in the person's, best interest. Better quality oversight and monitoring of placements is also required with an expectation as to staff training and competence.

8.3 All Reviews

8.3.1 Age

The table below shows the total number of reviews in each category, since LeDeR began in Norfolk and Waveney. Overall, the 65+ age group currently has the highest number of reviews. However, looking at the last two years you can see the 46 – 64 age group has surpassed it in numbers. The 65+ age category also saw a heightened number of excess deaths due to COVID-19 in 2020/2021 potentially due to the added mortality risk of age. We suspect in the next couple of years the overall majority will reflect our current findings.

Year of death	Number of Reviews by Age Group (in years)			
	Under 18	18-45	46-64	65 and over
2017-18	0	10	17	19
2018 -19	5	9	25	32
2019-20	<5	11	19	20
2020-21	<5	21	18	33
2021-22	<5	10	27	23
2022-23	7	12	25	19
Total	19	73	131	146

The overall median age of death for all adult reviews was 57.5 years old. As the number of reviews continue to increase and our review method governance strengthens, we believe this represents a more accurate representation of the current picture, compared to previous years. Local historical comparison is difficult and currently we cannot accurately measure any trends. We can, however, compare this to the median age of death of 61 years old from the 2021 annual LeDeR report.

8.3.2 Areas of Deprivation

Our local data collection methods allow us to review the Indices of Multiple Deprivation (IMD) for all the completed reviews. As seen in the below table, most people reviewed lived in an area with an IMD score of 5. Areas with a rating of 10 were the least represented in the completed reviews. Overall, as with our notifications for 2022/2023, most of the people we reviewed lived in an area scoring 5 and below on the IMD scale. This tells us people with a learning disability predominantly live in areas of higher deprivation and more so than the general population.

IMD Score	Number of Notifications	Percentage	Number of Notifications	Percentage
1	8	11%	46	64%
2	8	11%		
3	9	13%		
4	8	11%		
5	13	18%		
6	8	11%	26	36%
7	5	7%		
8	6	8%		
9	6	8%		
10	1	2%		

8.3.3 Chronic Conditions

Most people with a learning disability and/or people with autism are known to have other complex physical health complications. Analysis of the 64 completed adult reviews demonstrate all but one of the people we reviewed had one or more chronic physical health conditions. This is thought to be due to a combination of factors more likely to occur in people with a learning disability, including congenital conditions, progressive degenerative illness, obesity and poor mobility, difficulties accessing services and many more. The table below is a list of some of the common health conditions and number of people affected, recorded from completed adult reviews (most people had more than one condition recorded). There were multiple other chronic conditions seen in less than 5 reviews which have not been listed here to protect anonymity:

Health Condition	Frequency	Percentage
Epilepsy	23	34%
Hypertension	11	17%

Depression/Anxiety	10	16%
Congenital Syndrome	10	16%
Dysphagia	10	16%
Cerebral Palsy	9	14%
T2 Diabetes	8	13%
Hypothyroidism	8	13%
Asthma	6	9%

8.3.4 Causes of Death

As part of our post review process, we collate causes of death for all reviews. In Norfolk and Waveney, a review is not signed off as complete unless the Medical Certificate of Cause of Death (MCCD) determination of COD has been seen. An MCCD indicates the sequence of conditions which lead to death, including the underlying, and in turn the leading, cause of death. The leading cause of death is taken from the first line of Part 1 of the MCCD. The World Health Organization (WHO) defines the underlying cause of death as the disease or injury that initiated the train of events directly leading to death or the circumstances of the accident or violence that produced the fatal injury. An underlying cause of death is extracted from the lowest line of Part 1 of the MCCD.

COD can be and assigned one of approximately 14,200 codes according to the International Statistical Classification of Diseases and Related Health Problems: 10th Revision (ICD-10). This allows for better comparison between annual reports. Causes of death can then be grouped by code into ICD-10 chapters. Chapters are split according to general types of injury or disease (e.g., Diseases of the Respiratory system).

8.3.5 Leading Causes of Death

In comparison to last year, <5 completed reviews were a COVID related death, which is markedly less than the two previous years which can be seen in the table below. This is consistent with the national trend of COVID disease and disease mortality decline.

Year	COVID-19 Deaths
2020/2021	20
2021/2022	13
2022/2023	<5

The most common leading causes of death for all of the 72 reviews completed in 2022/2023 are set out in the table below. There were multiple other leading causes of death seen in less than 5 reviews which have not been listed here to protect anonymity.

Leading Cause of Death	Number	Percentage
Aspiration Pneumonia	15	21%
Cancers	13	20%
Pneumonia	11	15%
Type 2 Respiratory Failure	5	7%

Our completed reviews tell us aspiration pneumonia is the most common leading cause of death for the learning disability community in Norfolk and Waveney. Combined aspiration and other pneumonias accounted for 36% of all leading causes of death in the 72 reviews completed in 2022/2023. This mirrors what was seen last year, although the percentage is much higher which could be accounted for by the drop in COVID related deaths. The cancer related death percentage has also increased for this year.

Cancers accounted for 20% of the 72 reviews completed in 2022/2023. There wasn't one leading cancer responsible for a majority of the deaths, but the varying diagnoses seen include breast, bowel, lung, lymphoma, womb and pancreatic cancers.

Figures on the three main national cancer screening programmes were recorded and are discussed more in section 10. These comprise cervical screening, breast screening and bowel cancer screening. Only 3 of the reviewed deaths from 2022/2023 were from a cancer that is currently nationally screened for, and only 2 would have been eligible by the current criteria. Of these 2, only 1 had been screened. The below table looks at the number of leading causes of death by ICD-10 Chapter. There were other chapters allocated a leading cause of death in less than 5 reviews which have not been listed here to protect anonymity.

Leading Cause of Death Chapter	Number	Percentage
Diseases of the Respiratory System	35	49%
Neoplasms (Cancers)	13	18%
Diseases of the Circulatory System	8	11%
Diseases of the Nervous System	5	7%

8.3.6 Underlying Causes of Death

The most common underlying causes of death for all the reviews completed in 2022/2023 are set out in the table below. Some underlying causes of death may also be the leading cause of death as there may only be the first line of Part 1 completed on the MCCD. Underlying causes of death are often more varied and as such to protect anonymity only the top three have been listed.

Underlying Cause of Death	Number	Percentage
Cancers	13	18%
Pneumonia	11	15%
Cerebral Palsy	5	7%

The below table looks at the number of underlying causes of death by ICD-10 Chapter. There were other chapters allocated an underlying cause of death in less than 5 reviews which have not been listed here to protect anonymity.

Underlying Cause of Death Chapter	Number	Percentage
Diseases of the Respiratory System	16	22%
Neoplasms (Cancers)	13	18%
Diseases of the nervous system	10	14%
Endocrine, nutritional, and metabolic diseases	7	10%
Diseases of the digestive system	6	8%
Congenital malformations, deformations, and chromosomal abnormalities	6	8%

Learning identified from the reviewers:

Reviews have made it clear that prevention of respiratory illness, particularly pneumonia needs to be to be a focus for learning and action following this report. Respiratory illness is the primary leading and underlying cause of death for those with a learning disability and autism by a significant margin.

Due to diagnostic overshadowing and other issues in accessing healthcare, diagnosis is often delayed and not made until the person's disease is severe, meaning it is harder to treat and requires an extended hospital admission. Focus then is needed on preventative measures such as training for care staff in the use of Speech and Language Therapy (SALT) care plans and soft signs of deterioration. Further work to increase the provision and uptake of pneumonia vaccines is also required.

8.3.7 Avoidable Deaths

Avoidable deaths are defined by applying the Organisation for Economic Cooperation and Development (OECD)/Eurostat list of preventable and treatable causes of death¹³ using the underlying cause of death recorded on death certificates, for people who died younger than 75 years old. This is the same definition as used by the Office of National Statistic (ONS). Of the 66 Norfolk and Waveney reviews included in this definition 48% ($n=32$) were coded as avoidable, which is representative of the regional and national figures from their latest (2021) annual report. This still far exceeds the avoidable death rate of the general population of 23%.¹⁴

Appropriate classifications for causes of death are vital to ensuring these figures are accurate. ONS Guidance for the completion of MCCD¹⁵ state that physical and intellectual disabilities and congenital syndromes which are not fatal in themselves should be avoided in Part 1. As seen above, from the completed reviews, classifications in the first part of the MCCD include Cerebral Palsy and Downs syndrome, which can lead to post-mortem diagnostic overshadowing. To maintain the integrity and comparability of the data analysis, the author has strictly followed the coding process used by the regional and national team and assigned these deaths as non-avoidable as per the OECD list. However, were it open to clinical interpretation the avoidable death percentage for Norfolk and Waveney would be higher.

9. Child Deaths

Child deaths are reviewed under the child death review (CDR) process. This is a statutory provision, which involves collection and analysis of information from known agencies who were involved with the care provision, before the child died. This is with a view to identifying any matters of concern affecting the health, safety, or welfare of children or any wider public health concerns.

Where the CDR team has a referral for a child or young person with a learning disability aged over 4 years, they invite the senior reviewer to the CDR panel and the Child Death Overview Panel (CDOP) to share in the review process and highlight any learning specific to the young person's learning disability needs.

¹³<https://www.oecd.org/health/health-systems/Avoidable-mortality-2019-Joint-OECD-Eurostat-List-preventable-treatable-causes-of-death.pdf>

¹⁴<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/bulletins/avoidablemortalityinenglandandwales/2020>

¹⁵https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1062236/Guidance_for_Doctors_completing_medical_certificates_Mar_22.pdf

The team has one senior reviewer, who is also a paediatric nurse dedicated to supporting the CDR team with these reviews. The reviewer will complete a referral on the LeDeR platform once notified. After CDOP the CDR team will share their review with the LeDeR team, which is then uploaded to the LeDeR system, and the review is completed.

There were 7 child death reviews shared with LeDeR in 2022/2023. Limited description of data can be given due to the small numbers and the need to protect anonymity. However, it can be shared that 75% of the reviews were for boys and over half of the young people had a Severe or Profound learning disability with multiple co-morbidities. Most young people died in hospital with other places of death including hospice and home. All our young people lived in their family home. Of the completed reviews for 2022/2023, the median age of death for children was 8.5 years old.

Learning identified from the reviewers:

Children's services differ significantly from adult provision, and this is most noticeable in the context of end-of-life care. Norfolk and Waveney are very lucky to have the services of East Anglia Children's Hospice (EACH) in Poringland, who provide Respite, End-Of Life and Bereavement support for children and their families. The provision of wrap around care including ReSPECT, symptom management, named nurses and expert clinicians on call are but a few of the factors that result in personalised and holistic end-of-life care.

Transitional care remains a difficult experience for young people and their family. New services including the Preparing for Adult Life team, acute transition nurses and navigator teams are working well to smooth out the process and support the move however greater collaboration between paediatric and adult services is needed and better preparation for families as to what to expect could be beneficial. Other areas of learning from these reviews have been included in the breakdown in Section 9.

10. Themes, Learning and Recommendations

This section focuses on the findings from the main aspects of care provided to people with learning disabilities and, where data is available, how this compares to other areas. This includes AHC, weight management, overmedication of antipsychotic medications, provision of reasonable adjustments, cancer screening programmes and MCA assessments as well as end-of-life care.

10.1 Annual Health Checks (AHCs)

Evidence shows that people with learning disabilities are more likely to experience a greater number of health conditions than the general population. They are also less likely to receive regular health checks or access routine screening¹⁶. All people with learning disabilities are entitled to an AHC. Regular health checks help identify unmet and unrecognised health conditions, leading to early actions to address and treat these health conditions. Work has been ongoing within primary care to increase the number of checks completed and their quality. Including the ICB utilising Health Improvement Support Workers to mentor and provide training for surgeries in best practice for AHCs.

Performance for 2022/2023, across the different localities in Norfolk and Waveney, is measured and can be seen in the table below. Notably there is approximately a 20% difference between the best and worst performing areas, suggesting inequality across the region. However, there has been an increase in the number of AHCs completed for all people with a learning disability across the Norfolk and Waveney system. Starting in 2019/2020, 63.5% was achieved. This performance went down to 51.5% in 2020/2021, thought to be due to the impact of COVID-19. In 2021/2022 68% was achieved, increasing to over 70% in 2022/2023.

Locality	# on Learning Disability Register	# AHC Declined	# of AHC completed	Percentage (without declines)	Percentage (including declines)
Great Yarmouth and Waveney	1734	114	1346	78%	73%
North Norfolk	1131	105	966	85%	78%
Norwich	1467	36	938	64%	62%
South Norfolk	1371	92	1061	77%	73%
West Norfolk	980	34	701	72%	69%
Total	6683	381	5012	75%	71%

¹⁶ <https://www.england.nhs.uk/learning-disabilities/improving-health/mortality-review/>

In the above table there are two columns showing our percentage of completion. This is due to discrepancies in how NHS England and the ICB measure this data. The ICB count declines, as the person has been invited to their AHC, however NHS England only report on AHCs attended and completed.

Comparing this with the LeDeR reviews, out of the 64 completed for those who were eligible for regular AHCs (aged 14 years and over), 47 (73%) had been offered an AHC in the 12 months before they died. Our post review data collection is also able to tell us that 44 (69%) actually attended their AHC, in the last 12 months before they died. The percentages from LeDeR reviews are slightly behind the Primary Care and national figures. This may be explained by the fact our team have completed a few historical reviews in 2022/2023, for people who died before the improvement work of the health inequalities team started to show progress.

AHCs are a foundation of preventative care for people with a learning disability, and an essential part of managing co-morbidities and reducing mortality. Below, when discussing the main themes found in this year's review, AHC will be discussed to reflect how the attendance of a good quality AHC impacts a person's whole wellbeing. It's of note below that those with a mild learning disability are more likely to not have had an AHC compared to those with a more severe diagnosis.

Level of Learning Disability	AHC Completed (n=44)	% AHC Completed	AHC not Completed (n=20)	% AHC not Completed
Mild	7	16%	7	35%
Moderate	21	48%	8	40%
Severe	15	34%	5	25%
Profound	<5	xx%	0	0

Those who had had an AHC were 20% more likely to have had an annual medication review, this is an important part of healthcare in that it supports the review of chronic conditions as well as abides by STOMP principles to reduce unnecessary overmedication.

	AHC Completed (n=44)	% AHC Completed	AHC not Completed (n=20)	% AHC not Completed
Recorded Annual Medication Review	35	80%	12	60%

The average BMI of those who did and did not have an AHC in the 12 months before they died was relatively similar. Reviewers find this to be more reflective of the quality of AHC and the need for proactive weight management in future, especially as the average BMI for both groups fall into the overweight category.

	AHC Completed (n=44)	AHC not Completed (n=20)
Mean BMI	26 kg/m ²	25.5 kg/m ²

Of those on an end-of-life pathway before they died, a higher percentage had not had an AHC completed. This is also true of those who had a completed ReSPECT document. This may be explained by the higher percentage of those without an AHC dying in hospital where ReSPECT documents and end-of-life pathways are more commonly used as demonstrated later.

On an End-of-Life Pathway	AHC Completed (n=44)	% AHC Completed	AHC not Completed (n=20)	% AHC not Completed
Total	26	59%	17	85%
<1 week	13	50%	8	47%
1-4 Week	8	31%	<5	xx%
1-6 Month	<5	xx%	<5	xx%
6+ Month	<5	xx%	<5	xx%

Place of Death	AHC Completed (n=44)	% AHC Completed	AHC not Completed (n=20)	% AHC not Completed
Usual Residence	20	45%	7	35%
Hospital	24	55%	12	60%
Hospice	0	0%	<5	xx%

	AHC Completed (n=44)	% AHC Completed	AHC not Completed (n=20)	% AHC not Completed
ReSPECT Document Completed	34	77%	16	80%

Learning identified from the reviewers:

Reviews are often done solely by nurses and allied health professionals, and there is no time spent with the GP, which is an essential part of the AHC process. Completed reviews can also appear to lack documentation of the conversations happening at the review, giving voice to the person, and showing the quality interactions happening during an appointment. As such an AHC can appear to be used as a “checklist” exercise. More thorough documentation would demonstrate the work being done and better example the quality of AHC. Primary care needs to increase the uptake for those with mild learning disability diagnosis as they are more to be overlooked. Coordination of care to include chronic condition reviews (e.g., asthma and diabetes etc) may be beneficial in the holistic assessment and planning for a person’s wellbeing.

10.2 Health Action Plans (HAP)

A HAP identifies a person’s health needs and how best they can be managed, including what the person needs to do, who will help and when this will be reviewed. Completing and providing a HAP is an essential part of a good quality AHC. A HAP is expected to include information such as:

- Health promotion activity
- Weight monitoring
- Referrals to community health, social care, acute and specialist services
- Pain management
- Sight tests
- Dental checks
- Advanced care plan
- ReSPECT paperwork

The person needs to be given a copy, as well as shared with any carers or home environments which may support them. The practice should then scan a copy into the electronic record.

Of the 44 completed reviews where there was an AHC in the last year of their life, 25 (57%) had evidence of a HAP in place. The information from data collected by the Primary Care Team for HAP completion in 2022/2023 is very different as seen in the table below. It is important to again note that LeDeR reviews have been completed this year for deaths as far back as 2018. As such current performance in some categories, such as HAP, is hard to measure as it doesn’t consider the year-on-year improvements. For example, compared to this year’s primary care figure of 70%, in 2021/2022 only 56% had a HAP.

Locality	No on Learning Disability Register	No of HAP completed	Percentage
Great Yarmouth and Waveney	1734	1276	74%
North Norfolk	1131	920	81%
Norwich	1467	841	57%
South Norfolk	1371	955	70%
West Norfolk	980	679	69%
Total	6683	4671	70%

Learning identified from the reviewers:

A completed HAP is difficult for reviewers to assess, as they are often demonstrated in the notes in different ways. Ideally a HAP will be created in the style of care plan with an identified need, the desired goal and then the SMART actions needed to achieve this. These will then be put onto one document which is shared with the person, any carers and a copy uploaded to their clinical notes. This is rarely seen by reviewers and evidence of a HAP is often seen in actions demonstrated as per the AHC consultation notes, for example a referral to the SALT team.

Primary Care agreeing to use a HAP template for across the ICS would be hugely beneficial. This would standardise practice for quality purposes and support its use across other services, for example dietetics and SALT.

10.3 Screening

It is of note that we often only receive the last 3 years of primary care notes for a review; therefore, our knowledge of historical screening is limited. So, to give as accurate portrayal of current practice as possible we have only included people who were eligible for the screening at the time of their death in the below analysis.

10.3.1 Abdominal Aortic Aneurysm (AAA) Screening

AAA screening is a way of checking if there's a bulge or swelling in the aorta, the main blood vessel that runs from the heart down through the abdomen. Screening for AAA is offered to men after they turn 65. Of the 5 reviews with these eligibility criteria, none had evidence of a AAA screening being offered, despite 3 having had an AHC in their last year of life.

10.3.2 Cervical screening

Cervical screening is offered to all those with a cervix aged 25-64 years. Invitations should be sent every 3 years up to the age of 49 years and every 5 years up to the age of 64 years. Despite the low numbers of cervical screening uptake as seen below, 13 of the 17 reviews evidenced an annual health check in their last year of life.

10.3.3 Breast screening

All people registered with a GP as female and aged between 50 and 71 years should have breast screening offered every 3 years. Breast screening involves use of an x-ray test (a mammogram test) to identify any cancers (when too small to feel) plus any other abnormalities in a breast. Despite the low numbers of breast screening uptake as seen below, 12 of the 16 reviews evidenced an annual health check in their last year of life.

10.3.4 Bowel screening

Everyone aged 60-75 years should have bowel screening. A home testing kit is sent to a person's home address every two years to collect a small stool sample to be checked for tiny amounts of blood which could be early signs of cancer. Of the 20 reviews, 12 evidenced an annual health check in their last year of life.

The table below shows engagement with national cancer screening programmes. Bowel cancer has the highest percentage of eligible people screened, of all three. This could be because it is the least invasive and can be done at home without having to attend an appointment. Cervical screening had the worst performance from screening of the reviews from 2022/2023. The refusal rate for this intervention was similar to breast cancer screening. The number of eligible people not invited for cervical screening is the highest percentage of the three programmes. Anecdotally reviews have shown health care professionals deciding screening is not appropriate as the person is not sexually active, and therefore deemed to be a low risk.

Attendance	Bowel (n=20)		Breast (n=16)		Cervical (n=17)	
	Number	%	Number	%	Number	%
Did not Respond	9	45%	<5	xx%	<5	xx%
Not Invited/Offered	<5	xx%	<5	xx%	5	29%
Screened	9	45%	6	38%	<5	xx%
Refused	<5	xx%	6	38%	6	35%

Learning identified from the reviewers:

Reviewers felt that more needs to be done to promote the cancer health screening programme, increase uptake and refer for early intervention and treatment as may be indicated. The value of AHCs in the uptake of cancer and other screenings cannot be underestimated, and the appointment should be used to try and engage the person in all the screening programmes they are eligible for. The Mental Capacity Act (MCA) should be used when someone declines screening for themselves or if someone attempts to decline on their behalf. Also, use should be made of support such as the community Learning disability teams where appropriate to support understanding and attendance.

10.4 Vaccinations

New data collection this year has enabled a closer look at the uptake of pneumonia vaccines for those eligible. Chapter 25 of The Green Book of Immunisations¹⁷ states which comorbidities meet the eligibility criteria for the vaccine. Despite recommendations from the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) report¹⁸, Learning Disability is still not included in this.

Of the 26 reviews, where the persons cause of death was a pneumonia, 23 (88%) would have been eligible for a pneumonia immunisation. This is either due to their age or meeting the current high-risk criteria according to the green book. Of these 23 reviews, only 3 had evidence of having a pneumococcal vaccine, meaning 87% didn't.

The influenza ('flu') vaccine is a safe and effective vaccine. It is offered every year by the NHS to help protect people at risk of flu and its complications. The flu vaccine is offered to everyone aged 65 and over and everyone under 65 years of age known to have a medical condition (including children and people with a learning disability) that puts them at risk of flu complications.

Uptake of the flu vaccine was much better, with 72% ($n=52$) of all completed reviews having evidence that the person had a flu vaccine regularly. 37 (71%) of those immunised had attended their annual health check (AHC) within the year before they died. This is in contrast with only 35% ($n=7$) who had not had a regular flu vaccine, highlighting the importance of AHC on public health initiatives and preventative care.

¹⁷<https://www.gov.uk/government/publications/pneumococcal-the-green-book-chapter-25>

¹⁸<https://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf>

The COVID-19 vaccine is a safe and effective vaccine and began distribution from December 2020. Those with a learning disability and associated co-morbidities were highlighted as being more at risk from severe COVID-19 complications and, as such, fell into the priority groups for being offered the vaccine.

The first vaccines were rolled out in January 2021. 63 of the 72 completed reviews had a date of death after the COVID-19 vaccine roll out. Of those 63, 57 (90%) had had at least one dose. A second dose followed, with uptake starting towards the end of March 2021. 61 of the 72 completed reviews had a date of death after this time and 54 (89%) of reviews had evidence of the person having had the recommended 2 doses. A third dose was offered from the beginning of October 2021. 55 of the 72 completed reviews had a date of death after this time and 42 (76%) of reviews had evidence of the person having had the recommended 3 doses.

Learning identified from the reviewers:

Pneumonia vaccine uptake continues to be very poor amongst those who are currently eligible, and deaths from pneumonia are consistently the most common. Annual Health Checks (AHC) are an ideal opportunity to correctly identify someone as being eligible for a pneumonia vaccine. There is a clear willingness to engage in vaccination programmes from those with a learning disability, looking at the uptake for the flu and COVID vaccines. However, all declines to vaccines should consider the MCA for best practice including a robust capacity assessment and a best interest decision if appropriate.

10.5 Obesity/Weight Management

When a person carries excess weight or body fat it can affect their health. Evidence shows that people with learning disabilities are more likely to have poor diet and are more likely to be underweight or obese than people in the general population¹⁹. The Body Mass Index (BMI) is a measure that uses a person's height and weight to calculate whether their weight is healthy. BMI should be used with caution for those with learning disabilities as certain co-morbidities can impact someone's weight such as chronic constipation. It can also be difficult to accurately capture measurements for people with an atypical body shape or poor posture (postural kyphosis) which are more common with persons with a learning disability. The BMI tool is currently the most used and acceptable measure of weight and health, but some other options could include waist circumference or measuring a fold of skin. BMI categories can be seen below:

¹⁹ <https://www.gov.uk/government/publications/obesity-weight-management-and-people-with-learning-disabilities/obesity-and-weight-management-for-people-with-learning-disabilities-guidance>

- <18 is underweight.
- Between 19 and 24.9 is healthy.
- Between 25 and 29.9 is overweight.
- >30 is obese.

Being underweight (malnourished) or overweight raises the risk of serious health problems and is known to have a direct impact on the person's quality of life. The table below shows the outcome and analysis of data of BMIs recorded for the 64 adult reviews.

Gender	BMI (kg/m ²)									
	<18	%	19-24	%	25-29	%	>30	%	Unknown	%
Males (n=35)	<5	xx%	16	46%	7	20%	<5	xx%	5	14%
Females (n=29)	<5	xx%	10	34%	6	21%	8	28%	2	7%
Total (n=64)	6	9%	26	41%	13	20%	12	19%	7	11%

In the 64 completed adult reviews both men and women mostly had a healthy BMI recorded. In men, this includes a higher percentage in the 19-24 than even the overweight and obese categories combined. For women however, a higher combined percentage were overweight or obese. There were also more women who were underweight than men. Reviewers identified that being overweight or obese was a common issue amongst people with a learning disability and this is complicated by diet, poor mobility and/or wheelchair dependency.

Learning identified by reviewers:

AHC and HAP need to be utilised to support people maintaining a healthy weight. Reviewers too often see weight highlighted as an issue, with no intervention or follow up to review progress. There needs to be earlier and more robust management at primary care level. Including referral to specialist dietician services to be utilised when needed. Supported living and care home environments need better staff training and a shift in focus to support better nutrition and build more exercise into social activities. Care commissioners should focus on weight management as a quality indicator and pick this up during quality visits and in reviewing provider performance.

10.6 BMI and Psychotropic Mediations

Psychotropic medicines are used for psychosis, depression, anxiety, sleep problems, epilepsy and sometimes given to people because their behaviour is seen as challenging. Weight gain can be associated with use of psychotropic medicines including

antidepressants, mood stabilizers and antipsychotic drugs²⁰. Of our completed adult reviews, 59% ($n=38$) had evidence of psychotropic medications being prescribed.

It is suggested that patients with a BMI of 25 or over should be regularly reviewed and where appropriate, supported to stop or reduce psychotropic medicines. In all our adult reviews recorded as being on a psychotropic medication, 29% ($n=11$) had a BMI considered overweight or obese.

Long term psychotropic use with epilepsy is expected. This is often a first line treatment and effectively managing epilepsy is essential at avoiding SUDEP. However, 64% ($n=7$) who were prescribed psychotropics, had them for a mental health condition or to support in behavioural management, and 71% of those ($n=5$) had been on psychotropics for over 5 years.

10.7 Stopping Overmedication of People with a Learning Disability (STOMP)

STOMP²¹ is about helping people to stay well and have a good quality of life by stopping the overuse of medicines for those with a learning disability, mainly comprising psychotropic medicines.

58% ($n=22$) had a psychotropic prescribed due to an epilepsy diagnosis and the overwhelming majority of these cases (68% $n=15$) has been prescribed them for over 10 years, as expected with a chronic condition. The reviews evidenced that 91% ($n=20$) had a regular medication review.

42% ($n=16$) had a psychotropic prescribed due to a mental health diagnosis and/or for behaviour management, only 56% ($n=9$) had evidence of a regular medication review, which is markedly lower than those prescribed psychotropics for epilepsy.

29% ($n=11$) had multiple psychotropics prescribed for multiple diagnosis. Mostly this was a diagnosis of epilepsy with a mental health condition and/or behaviour management.

Most people prescribed psychotropics had a moderate learning disability, followed by severe and then mild. The table below shows the findings from completed reviews.

²⁰ https://www.bap.org.uk/pdfs/BAP_Guidelines-Metabolic.pdf

²¹ <https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>

Learning Disability	Mild	Moderate	Severe	Profound	Total
Psychotropics prescribed	7	17	13	<5	38
Percentage	18%	45%	34%	xx%	

Learning from the reviewers:

An AHC is an excellent opportunity to review a person's medication. With proper preparatory work with the person and/or their carer you can get a picture of how medication is being used, especially "as required" medication that may not be managing a chronic condition. Reviewers found psychotropic medications used for epilepsy were very well reviewed by the epilepsy team. However, medications used for mental health conditions or for behaviour management were not. A Norfolk and Waveney strategy for STOMP would be a welcome step to imbed its principles into all prescribing.

10.8 Mental Capacity Act (2005) Assessments and Restrictive Legislation

Mental Capacity Act (MCA) assessments are applied to people aged 16 years and over. The aim is to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment. The MCA covers a wide range of decisions such as day to day decisions on what to wear, personal care, where to shop, to significant and serious life-changing decisions such as changing homes, major surgery, and financial management.

The MCA states²²:

- Assume a person has the capacity to make a decision themselves, unless it is proved otherwise.
- Wherever possible, help people to make their own decisions.
- Do not treat a person as lacking the capacity to make a decision just because they make an unwise decision.
- If you make a decision for someone who does not have capacity, it must be in their best interests.
- Treatment and care provided to someone who lacks capacity should be the least restrictive of their basic rights and freedoms.

It is expected that all our reviews for people over the age of 16 would have required a capacity assessment at some point in their care. From the reviews 72% ($n=46$) had evidence of a capacity assessment being completed. This year we were also able to

²² Section 1 of <https://www.legislation.gov.uk/ukpga/2005/9/contents>

document those where adherence to the MCA was variable, which accounted for 29% ($n=12$) of reviews. Only 6 reviews had no evidence of a capacity assessment having been completed at all.

Learning from Reviewers:

Compliance with the MCA is largely variable; with quality and accuracy of documentation being the most identified problem by reviewers. This was most apparent in acute settings. Improvement is needed to demonstrate a robust capacity assessment and best interest decision making. Both to evidence good practice but also to give to voice and representation to the person being discussed. An Independent Mental Capacity Advocate (IMCA) should be a better utilised service. It is expected that a referral should be made for any non-emergent capacity assessment where advocacy is needed. Reviewers see multiple missed opportunities for this. IMCA commissioners could also look at quality requirements for the service. For example, the time taken for an IMCA assessment and the need for a face-to-face meeting with the person before a decision is made.

10.9 Deprivation of Liberty Safeguards (DoLS)

DoLS ensure people who cannot consent to their care arrangements (i.e., in a care home or hospital) are protected if those arrangements deprive them of their liberty. Arrangements are assessed to check they are necessary and in the person's best interest. Representation and the right to challenge a deprivation are other safeguards that are part of DoLS. This safeguard is also appropriate if a person lives in supportive living or in their own home and is under 'continuous supervision and control'. The point of the authorisation is the same as in a care home or hospital, and the same criteria apply. However, the process is slightly different. Most reviews highlighted that DoLS had not been used when it was required to safeguard a person's liberty.

DoLS Used	Number	Percentage
Yes	20	31%
No	33	52%
Variable	<5	xx%
Not Applicable	9	14%

10.10 End-of-Life Care

End-of-life care is also referred to as palliative care or advanced care planning. It involves conversations between people with learning disabilities, their families, and carers and those supporting them about their future wishes and priorities for care. Out of all the completed reviews, 43 (60%) had evidence of the person being on an end-of-life pathway before they died, however the length of time varied from a couple of days to over 6 months. A higher percentage of people who died on an end-of-life pathway, died in the acute setting.

End-of-life Pathway	Place of Death					
	Acute	Percentage	Usual Residence	Percentage	Hospice	Percentage
Yes	26	60%	15	48%	<5	xx%
No	14	35%	14	48%	<5	xx%

However, from all the completed reviews, most people died in the acute setting. Second highest was the persons usual residence including private residences and residential services. As with last year, we had a very low number of people dying in hospice care with the majority who did being children. There is no data available to indicate whether people's wishes were observed in all settings.

Place of Death	Number	Percentage
Acute	40	56%
Usual Residence	29	40%
Hospice	<5	xx%

Learning from the reviewers:

More people are dying in hospital than anywhere else, despite this not always being their preference. We have seen some excellent examples of care from residential homes, in supporting people to die at home. Also there have been examples of carers working in the acute setting when someone is at end-of-life to reassure and comfort them when care at home is not possible. However, there were also many examples of late admissions to hospital which potentially could have been avoided by better provision of collaborative end-of-life care.

Earlier referrals to palliative care and implementation of an end-of-life care plan would aid in symptom control for the deteriorating patient. Especially pain management, which poses extra challenges for care staff due to the lack of parent and/or carer advocacy, variability of communication and interpretation of pain indicators. Seizure management poses a challenge in community end-of-life care, which has been distressing for the person and their carers. Closer involvement with specialist epilepsy teams and those planning a person's end-of-life care could improve seizure management and react quicker to any deterioration.

We continue to see a lack of confidence in residential services (including care homes and supporting living) in supporting people to die in their home. More robust care plans and symptom management plans would help carers respond to symptoms and identify when escalation is needed. Better training for staff would also be beneficial in building knowledge and competence. Discharge planning from acute settings also needs improving, especially when a person is being discharged on palliative care. Better liaison is needed between the discharging team and the residential home to ensure they are equipped and prepared to deliver good end-of-life care.

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

The Recommended Summary Plan for Emergency Care and Treatment²³ (ReSPECT) process creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices. It would be reasonable to expect everyone who we reviewed to have had a ReSPECT form in place, when they died. Out of all the completed reviews 53 (74%) had evidence of a completed ReSPECT document at the time of their death, with most having died in hospital (62%). As previously mentioned, ReSPECT is a discussion which should happen as part of the AHC. According to reviews, 64% of those who had a ReSPECT document completed, had attended an AHC in the last 12 months of their life. Of the 43 people who were on an end-of-life pathway, 93% had a ReSPECT form completed. This is compared to only 45% of those who were not on an end-of-life pathway.

Learning from the reviewers:

ReSPECT document completion is often seen by reviewers however the quality and utility of these forms is not good and too often completed in hospital soon before the person dies. ReSPECT document education and training should be a focus for Norfolk and Waveney. Providers should support wider registered health care professionals becoming competent in completing and signing off ReSPECT forms, including registered staff in nursing homes and GP practices. Proper training will increase the number of staff able to complete the form, but also open it up to staff who know the person well and better able to advocate for their wishes.

10.12 Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

The guidelines state that it is good practice for decisions about DNACPR to be clearly communicated to all those involved in the patient's care. It is important that healthcare professionals, patients, families and those close to patients understand that a

²³ <https://www.resus.org.uk/respect/respect-healthcare-professionals>

DNACPR decision applies only to cardiopulmonary resuscitation (CPR) and not to any other element of care or treatment. A DNACPR decision must not be allowed to compromise high quality delivery of any other aspect of care. Out of all the completed reviews 52 (72%) patients had a DNACPR order in place before they died, with 66% of these being deemed appropriate according to the evidence available.

Learning from the reviewers:

DNACPR are seen in most reviews. This is likely due to high number of acute deaths, however with an increase in properly planned community care we may see a similar, if not a higher, percentage. Most DNACPR were seen as being appropriately put in place, however documentation of the decision-making process is often poor, including use of an IMCA, inclusion of those who know the person well and use of the MCA.

10.13 Reasonable Adjustments

Making reasonable adjustments is a statutory duty under the Equality Act 2010. This states that all health and social care providers must make reasonable adjustments to remove any barriers, physical or otherwise, that could make it difficult for disabled people to use their services or prevent them from using them altogether.

A lack of reasonable adjustments can be a significant barrier to accessing healthcare and healthcare settings. Reasonable adjustments are not just stand-alone interventions and are woven into people's daily care and support. Below are highlighted some of the themes seen in reviews, regarding good provision of reasonable adjustments and where practice needs improvement. Looking at the reviews examined, reasonable adjustments fell into multiple themes, which were either accommodated or not, and are summarised in the tables below.

Theme	Examples of good use of reasonable adjustments
Adapted Access	<ul style="list-style-type: none"> • Environmental controls such as side rooms and admitting straight to wards to avoid A&E. • Extended appointments to build relationships and encourage engagement. • Face to face appointments and home visits from primary care. • Use of hospital passports. • Acute Learning Disability Liaison Teams.
Communication	<ul style="list-style-type: none"> • Provision of communication care plans. • Adapted communication which meets individual needs.

	<ul style="list-style-type: none"> • Easy read communication to support with decision making. • Easy read information to support self-management. • Time allowed for processing.
Familiar Carers	<ul style="list-style-type: none"> • Parent/carers are supported to stay with their children while admitted. • Using care staff to support with end-of-life care. • Involving familiar carers in best interest decision making. • Allowing community care staff into the acute care environment. • Staff are encouraged to attend appointments with people for support and advocacy.
Bespoke Care	<ul style="list-style-type: none"> • Collaborative needs-based care planning. • Good response to soft signs of deterioration. • Balancing of deprivation of liberty and risk assessment to make a best interest care plan. • Care provision commissioned based on what is best for the person. • Paediatric hospice provision. • Additional provision of 1:1 support where necessary to keep someone safe in the short term. • Support for people to meet their goals and aspirations.
MCA Principles	<ul style="list-style-type: none"> • Good and appropriate documentation of the MCA process and decision making by the ALDLT. • Involving IMCA where no advocacy is available. • Involving people in decisions made about them, using adapted means to communicate.

Theme	Examples of poor use of reasonable adjustments
Adapted Access	<ul style="list-style-type: none"> • No admission plans to avoid busy and distressing environments which can impact concordance with care. • Poor time allowance for someone to process instructions given for diagnostic imaging. • Lack of preparatory work to reduce stress and encourage engagement with interventions, for example blood tests and cancer screening. • Lack of appropriate equipment in acute settings to meet needs, for example hoists and adapted scales. • Inflexibility in prioritising face to face assessments for those at higher risk of diagnostic overshadowing.
Communication	<ul style="list-style-type: none"> • Lack of inclusion for people in decision making about their care.

	<ul style="list-style-type: none"> • Lack of adapted communication to aid and assess understanding. • Services not using or not having communication plans for people, which disadvantage people being invited to appointments or learning how to self-manage chronic conditions.
Familiar Carers	<ul style="list-style-type: none"> • No familiar carers provided during admissions by the person's home. • Acute hospitals not prioritising a small group of ward staff working with a person to help build trust and relationships.
Bespoke Care	<ul style="list-style-type: none"> • Personalised homecare packages have been difficult to put in place due to housing availability and available of suitable residential services.
MCA Principles	<ul style="list-style-type: none"> • Limited use of advocacy services. • Poor adaptive communication to best inform a person and assess understanding. • Best interest meetings may not always need to be strictly formalised, but documentation is required to evidence the work.
Service Availability	<ul style="list-style-type: none"> • Referral opportunities are missed for specialist learning disability and other universal services. • Follow up for missed or declined screening appointments is lacking. • People are not added to learning disability lists so not invited for annual health checks. • Availability of respite facilities that can meet the needs of people with complex health needs is poor. • Quality monitoring of residential services can be limited and lead to poor outcomes.
Diagnostic Overshadowing	<ul style="list-style-type: none"> • Services not considering a person's vulnerabilities when setting a threshold to consider neglect and other abuse. • Recognition of the menopause for women with learning disabilities is poor. • Use of telephone assessments, even with carer support is not ideal when properly assessing an unwell person who may be unable to properly express what is wrong. • Inappropriate use of non-adapted measurement scales including pain and impairment of consciousness.

Use of reasonable adjustments is variable across the different reviews examined for this section. There is also evidence of variability within the same reviews and some cases showed evidence of multiple adjustments to make services more accessible and a lack of adjustments which have created barriers for people to access the care they need. It is notable that more reviews demonstrated no examples of missed reasonable adjustments than reviews where no reasonable adjustments were seen. Overall,

there is definitely evidence of more use of reasonable adjustments than not. The table below shows the numbers of reviews with evidence of reasonable adjustments being made and reasonable adjustments being missed.

Theme	Number of reasonable adjustments seen	Number of reasonable adjustments required
Adapted Access	25	17
Communication	19	12
Familiar Carers	24	<5
Bespoke Care	22	<5
MCA Principles	5	8
Service Availability	0	13
Diagnostic Overshadowing	0	5
None	6	26

Learning from reviewers:

Reasonable adjustments are hard to measure as each person's needs are different. Some are very clear and obvious whereas others are subtle. Overall, there was a prevalence in reasonable adjustments being used. This was predominantly led by learning disability specialist staff in acute and community settings. The value of these colleagues cannot be underestimated and is evidenced in the reviews. The best way to identify and communicate what adjustments are needed is by having updated care plans such as hospital passports, health action plans and ReSPECT forms. These should be electronically added to someone's file where possible.

10.14 Staff Training

10.14.1 Restore2™

Delayed recognition of deterioration is an area impacting on the quality of care. 'Train the trainer' in Restore2™ tool has been delivered to 15 people in the community learning disability teams across Norfolk and Waveney. From here the community learning disability team achieved its target of delivering this training to all care staff by 2023. Restore2™ is a tool designed to support care staff and health care professionals to:

- Recognise when a person may be deteriorating or is at risk of physical deterioration.
- Act appropriately according to the person's care plan to protect and manage them.
- Complete a set of physical observations to inform escalation and conversations with health professionals.

- Contact the most appropriate health professionals in a timely way to obtain the right support.
- Provide a concise escalation history to health professionals to support their professional decision making.

10.14.2 ReSPECT

All LeDeR reviewers have undertaken Level 3 ReSPECT training over the last year to ensure they are fully equipped to assess the quality and completeness of the forms we see, and the process undergone to complete them. As a major initiative for admission avoidance, Norfolk Community Health and Care NHS Trust (NCH&C) commenced ReSPECT Level 3 Education in 2020. This education package needs to be underpinned with comprehensive and on-going clinical support and governance. This would help prepare both competence and confidence in those registered clinicians wishing to hold ReSPECT conversations and complete ReSPECT documentation with the people they support, including those with a learning disability and/or autism.

In 2022/2023, the team delivering the training has supported 78 clinicians to complete this training, from across the ICS including primary care, social care, community services and the acute setting. It is hoped further sessions will be commissioned into 2023/2024 to continue this work.

10.14.3 Knowledge Anglia

A QR code has been shared below where providers can access resources to evidence based health and wellbeing from our NHS website [Care Providers \(knowledgeanglia.nhs.uk\)](https://www.knowledgeanglia.nhs.uk)



11. Safeguarding

Reviewing the deaths of people known to have a learning disability and/or people with autism helps identify avoidable factors that lead to early deaths and supports services to improve their quality of care. This is a major step forward towards tackling inequalities within health and social care provision. As part of the review process, safeguarding is always a consideration and forms the

foundation for any case discussions the team has. The national LeDeR policy provides a robust governance process for safety and abuse concerns to be highlighted, and the Norfolk and Waveney team has been structured to meet this.

A review will often be presented at multiple panels for Quality and Assurance checks and sign off. This allows the multi-agency panel the opportunity to go beyond the remit of LeDeR and promote challenge, assurance, and service improvement. In addition, this year the team has structured its local arrangements through guidance co-authored with the ICB designated safeguarding team and the Norfolk Safeguarding Adults Board (NSAB).

This has proceeded the agreement of appropriate safeguarding training and supervision for the LeDeR Team as per the collegiate document²⁴ and a structured process for referring for Safeguarding Adult Reviews (SAR). More recently, with the formation of the ICS Learning from Death Forum, the Senior Nurse Manager and LAC for the LeDeR programme will be presenting the findings of reviews every quarter to share key learning with representatives from the wider NHS providers and the ICB's Safeguarding Team. Over the last year our team has made three referrals for a SAR, following the agreed process. For LeDeR, the basis for a SAR is to learn lessons from particularly complex or serious safeguarding adult cases. This is where an adult has died, and abuse or neglect has been suspected due to services not working collaboratively to adequately safeguard the person. If the referral is accepted a detailed review is undertaken and recommendations are made to change or improve practice and services.

Learning from reviewers:

A general theme in all safeguarding referrals was the impact of poor collaborative working between services and professionals on a person's treatment and outcome. Also noted was poor use of the MCA in decision making for life changing interventions and procedures. Lastly was the provision of appropriate residential care in the community which protected the person from harm and met their basic care needs.

12. Examples of Lived Experiences

This section is about the stories of people who have died. They have families and friends who cherished their lives and whose deaths will never be forgotten by their loved ones. Therefore, we are sharing some of the stories and experiences from completed

²⁴<https://www.rcn.org.uk/Professional-Development/publications/adult-safeguarding-roles-and-competencies-for-health-care-staff-uk-pub-007-069>

reviews. This information has been provided by family members or carers who knew the person well. The details have been anonymised and names changed to further protect their identities.

Samantha was a 34-year-old woman who lived at home with her family. Samantha liked horse riding and listening to music. She loved being with people and had a very busy social life, which unfortunately was impacted by the pandemic. Samantha had a very loving and involved family who adapted to keep her occupied and busy, but the isolation was hard for her to understand. Samantha had very complex chronic health needs which were managed both locally and with specialist teams at a tertiary centre. Samantha and her family had very different experiences of care between these environments. At the tertiary centre Samantha would often be given a side room to avoid the busy ward environment which she would find distressing and her family were also accommodated so they could stay with her, giving her an advocate and the reassurance of a loved one.

Locally Samantha's care was less well managed. There were difficulties for Samantha's family in getting appropriate housing solutions to meet her needs as well as issues in sourcing home care to fulfil her Continuing Health Care package. Sourcing appropriate equipment and consumables, which Samantha was prescribed to prevent ill health, was very difficult as this was not part of a commissioned service. Neither was their sufficient respite provision that could meet Samantha's complex health needs locally, meaning long waiting lists to attend.

Angela was a 19-year-old young lady who lived with her parents. Angela attended college three days per week and was supported via her Personal Health Budget to attend multiple clubs and groups. Angela liked the theatre and was learning braille. Angela had recently transitioned to adult services, which had been problematic. Most notably was a lack of coordination between the wide-ranging services that supported her. This caused delays in provision of care and duplication. Positively however, when the learning disability community nurses accepted the case, it appeared to join up some provision which improved things.

Angela also benefitted from the work of the Acute Learning Disability Liaison Team (ALDLT), who supported her with an emergency admission plan, supported her clinicians with best interest decision making and discharge planning and other reasonable adjustments such as a quieter side room. Also, despite having turned 19, Angela's end-of-life care was on the paediatric ward where she was familiar and knew the staff. Angela also had the support of a condition specific specialist nurse from a charity organisation. They were involved in supporting Angela and her family on almost a daily basis, even at weekends and advising health professionals, participating in therapy sessions and best interest meetings.

Jacob was an 81-year-old gentleman who lived in a residential care home. He loved nature and attended a farm day centre before the pandemic. He also enjoyed arts and crafts, getting out on the bus, and was described as having a great sense of humour.

Jacob had an excellent experience of care. His GP practice were very responsive to his needs, for example continuing with reasonable adjustments such as home visits, even during the COVID-19 pandemic. His care was proactive, and clinicians were aware of the risk of diagnostic overshadowing due to the impact of his limited communication, so in one case they ordered additional imaging for a minor ailment to rule out anything more serious.

Jacob had a few admissions to hospital in the last year of this life, and thanks to the meticulous work of the ALDLT, the Mental Capacity Act (MCA) was used well to make appropriate best interest decisions where Jacob's voice was heard. His ALDLT involved his community teams including the dieticians who knew him well and supported the collaborative care planning that happened.

Christine was a 69-year-old lady who lived independently, with the support of some close friends and neighbours who she described as being like family. Her neighbours were a huge practical and emotional support for Christine, especially towards the end of her life when she became less able to manage independently. This care ultimately allowed Christine to stay at home for as long as she did which was very important to her. Christine had been married and been widowed. She attended an activity centre twice a week which was a big part of her life and when at home she liked to knit and colour pictures.

Christine had not had an annual health check as he has never been put onto her surgery's learning disability register. However, Christine did have other annual reviews for her chronic conditions. Yet, despite being recognised as vulnerable by those that knew her, Christine was left by district nursing teams to arrange and order various consumables by herself. This was too difficult for Christine who did not understand what was being asked of her, especially as instructions were in letter format and Christine was not able to read or write.

Christine was unknown to the ALDLT until her referral for support at her cancer diagnosis. At her last admission the ALDLT were very attentive with Christine, building a relationship with her and visiting often to reassure her with a friendly face as she did not like being in hospital.

Harriet was a 32-year-old woman who lived in supported living. Harriet was very sociable and had close ties with her family who supported her to live as independently as possible. Harriet liked her routine and loved being out and about, meeting friends for a hot chocolate and spending time with her family. She loved life, was very happy and cheerful.

Due to her chronic health conditions, Harriet had regular hospital appointments and admissions. Despite having a hospital passport this was rarely referred to which could be frustrating as Harriet and her family frequently felt they were not listened to. Harriet's personal and skin care was a vital part of her daily routine and essential to keeping her well. This took time to complete, and Harriet could not do it independently, but was viewed as being a low priority for hospital staff. However, Harriet was included in decision making regarding her treatment and family were given open access 24/7 to visit her.

Harriet's GP continued to see her face to face throughout the COVID pandemic and provided information in advance to help her prepare for her annual health check. She was also supported with an appointment before her cervical smear test to prepare her for the procedure.

Barry was a 56-year-old gentleman who lived in a supported living environment. He was always laughing and joking with friends and carers, and he loved country music, watching television and spending time with his siblings. Barry had a few hospital admissions in the year before he died. His carers always made sure he went in with his hospital passport which was well used. The ALDLT supported clinical teams while Barry was on the wards and there were excellent examples of the MCA being used properly to make decisions in his best interest and with his voice heard.

It was recognised early that Barry was moving towards end-of-life and a ReSPECT form, and an end-of-life plan were completed early which supported Barry to stay at home and avoid any further hospital admissions, which is what Barry wanted. Barry avoided hospital for 12 months, despite having chest infections and requiring wound management. This was well managed by primary and community care in liaison with the care home. This working relationship continued when Barry died. The care home wasn't overly confident in supporting Barry to die at home, but with the support of the GP they supported his wishes.

Kathy was a 57-year-old lady. She had previously been married but was widowed so had moved back in with family. Kathy enjoyed going shopping and especially enjoyed car boot sales. Kathy had attended her annual health checks however management and response to her chronic conditions did not meet best practice and impacted on her health and wellbeing. Both on acute admissions and when at the GP, professional curiosity was lacking in assessing Kathy's safeguarding risk and appropriate referrals were not made.

Advocacy for Kathy was lacking, and this meant her medicines were not appropriately managed, and referrals were not made in response to chronic obesity and poor symptom control. The day before her death Kathy had attended the GP, but due to

diagnostic overshadowing necessary tests were not conducted which may have highlighted earlier, the underlying cause of her death.

Terry was a 59-year-old gentleman who lived at home with his family. Terry was described as great fun and a real character. Keeping Terry at home was important to him, and his family and community learning disability teams worked to support this.

The GP practice considered reasonable adjustments to Terry's care and completed home visits, even during the COVID period. They also conducted home visits to explain to everyone end-of-life plans and ReSPECT forms. Terry had attended for his annual health checks but did not have one in the year that he died. However, he had a lot of support from his GP in this year due to his deteriorating health including medication reviews and referrals for specialist support with symptom management.

Terry had a loving family who cared and advocated for him, and they were consulted in many aspects of Terry's care, along with social workers, to come to a best interest decision for procedures in hospital. However, there was little documentation of the use of the MCA and best interest decision making for Terry's vaccinations. There were records of his influenza and COVID vaccinations either being declined or not brought to invitations, with no follow up to explore why and attempt to encourage access to public health initiatives.

13. Learning into Action

Once a review has been completed and learning has been identified, the team works with system partners including people with lived experience to make changes to services locally. Locally this is called Learning into Action and has the aim of preventing people dying from something that could have been treated and/or prevented and reducing health inequalities. Every review will generate areas of learning and most follow similar themes. Those which fit into current workstreams are fed into the appropriate working groups. Otherwise, actions are agreed at LIAG and assigned a responsible person. They are recorded on an action log which is reviewed and updated every meeting.

From last year's annual report, a lot of work has been done to respond to what we found and is summarised below. Firstly, there are the projects undertaken by the working groups. Secondly the actions and work undertaken on behalf of the LIAG, and lastly other works completed by the LeDeR team to further the aims of LeDeR within Norfolk and Waveney.

13.1 Working Group Projects

13.1.1 LD Dietetic Weight Management Pack Pilot

Weight management was highlighted in last year's annual report so a nutrition working group was established with members representing organisations across the ICS learning disability services. We established there was already an excellent resource provided by the learning disability dietitians, for eligible referrals (Anyone with a BMI >25 with a weight related comorbidities or anyone with a BMI >30). This would be provided to the persons care staff or family with instructions on how to complete but progress was unmonitored and there was no follow up.

The working group wanted to see if more oversight and support using the weight management pack would give better results. The Local Authority Supported Living and Residential Review Team recommended one care environment to take part in a small pilot and 8 eligible residents were identified. The team also agreed to support the work by providing an assistant practitioner to collate progress forms for review.

There is dietitian oversight throughout, with a protocol formulated with safety netting for the provider on support services should they need it, for example SALT and Learning Disability Community Nurses (LDCN). The social prescribing team provided a prescriber to support the work and undertake assessments on all participants to suggest options to support their goals.

Capacity assessments were conducted jointly between an experienced LDCN, working as a reviewer, and the dietitians. Easy read supplements of the workbook and progress forms were reviewed and advised on by Opening Doors and shared with the home, once completed. A half day training package for key staff was completed by the Senior LeDeR Nurse Manager and the dietetic team to explain the pilot and fully inform them on the pack, how to use it and give them the opportunity to ask questions.

Following preparations the pilot began at the beginning of March 2023, with an anticipated 6 months run time. So far, the provider has started "Heathy Eating Meetings" which people are excited about and engaged in. They have been looking at topics including healthy foods, diabetes, and cooking. Sessions are varied have included collage making and use of IT for research as well as their workbooks.

People are becoming more involved in meal planning and cooking, using cookbooks to get ideas. Social prescribing has arranged 2 half an hour fitness classes per week with a personal trainer and Coopers Mill are doing a 3rd self-run fitness class. Making 3 per week. Plans are in progress to dig and care for a vegetable patch on the grounds.

The dietitian team attended the provider again in May to give a workshop to vary the programme delivery and help motivate the participants and explain the importance of monitoring measurements such as weights and waist circumference. We had our first monthly feedback meeting in April with feedback forms which do show a weight loss for most participants. Hopefully this trend will continue and if benefit can be shown then a case can be put forward for service change.

13.1.2 Residential Services End-of-Life Toolkit

Supporting residential services was highlighted in last year's annual report to better end-of-life care in the community and allow more people to die in a place of their choice. The end-of-life working group took on a project, to adapt a resource developed in Derbyshire, which had already been recognised as useful for carers, professionals, and families.

The toolkit charts the support available locally from diagnosis, through bereavement and into aftercare. The idea is to give as much information to providers as possible so they can plan and arrange appropriate services are in place to meet the persons need at home where possible.

The group worked with multiple professionals across the system to update and adapt the toolkit to reflect local information. There were also areas that were missing, which were included to better reflect the needs of people in Norfolk and Waveney. The toolkit has been finished and given to the ICB Communications and Engagement team for design and branding. Once complete the toolkit will be rolled out to providers, supported by the local authority.

13.1.3 Non-Invasive Long-Term Ventilation (NILTV) Care Pathway

Following the learning from Cawston Park, the focus of the respiratory working group has been improving NILTV care for people with a learning disability and autism. Locally, only one hospital in our system assesses, prescribes, and manages NILTV and progress here has been largely driven by the ALDLT Matron.

The outcomes of the project included:

- To improve training and education for care providers supporting someone being prescribed NILTV.
- Better care planning, to advise parents and/or carers when to respond to changes.
- Establishing pathways for servicing and consumables replacement.
- Better involvement from learning disability specialist teams.

Progress has been made firstly by establishing a Multi-Disciplinary Team (MDT) review to include the ALDLT prior to discharge when a person is started on NILTV. A pathway for referring to the dietetic team is in place to review referrals when weight is a factor in the requirement for LTNIV. Education materials have been created by Baywater; a company commissioned by NSHE to develop accessible education materials for another region. The team arranged local focus groups and shared a survey on behalf of Baywater to gain feedback and coproduce localised information. Videos with local teams who would support a person newly prescribed NILTV have also been arranged including the CLDN, ALDLT and the respiratory team.

The respiratory and ALDL teams have created a more formal process for capacity assessments and best interest decision making when there is non-concordance. If a person is to be discharged from the respiratory team because NILTV is no longer a viable option, then suitable planning for end-of-life care is required including the acute and community learning disability teams.

13.1.4 Improving Uptake and Quality of Annual Health Checks (AHC)

A working group to look at improving AHC was arranged in response to last year's annual report, however its success in engaging primary care was limited. To better use resources, this group was disbanded and the team focused on supporting current pieces of work across the ICB.

Firstly, the health improvement team have been focussing their support on South Norfolk. This has included:

- Outreaching to patients (or their carers) who have not had their Annual Health Check for more than 12 months to support with attendance.
- Contacted 26 surgeries and visited 18 surgeries and trained 11 from South Norfolk and 3 from other localities.
- Called 158 patients from 8 surgeries and called patients who are not responding 2-3 times. Next step is home visits.
- Supporting surgeries with a learning disability register review to ensure its accuracy.
- Engaging care and residential homes to arrange visits to promote best practice and supporting residents with annual health checks.
- Representing AHC at Learning Disability events, including those targeting ethnic minorities.

The LeDeR team have also supported establishing a Point of Care Testing (POCT) Pilot, led by the Primary Care Commissioning Team. Following allocation of some resource from the NHSE Digital Team, a 12-month project was devised to demonstrate that the use of POCT can make every visit to general practice count and lead to improvements in overall patient experience and care for those living with a learning disability. It is hoped that General Practices will undertake the point of care blood tests as part of the AHC with the results available for clinical use shortly after to inform goals incorporated in the HAP.

The LeDeR team supported with clinical advice and the selection of an appropriate device which was done in collaboration with representatives from general practice. The pilot had a fantastic response from surgeries and more than expected signed up to the project. At the end, the team expects to know if POCT improves the quality of AHC and if so, look at how this can be rolled out across the system.

13.1.5 Learning Disability Notification of Admission Pathway Pilot

The acute working group has been focussing on improving the communication between acute and community services who support those with a learning disability including physiotherapy, occupational therapy, dietetics, and SALT. A pathway was proposed based on a model currently working between SALT in the community and one of the hospitals.

The proposed outcome of the pathway is that on admission, during admission and at discharge for someone with a learning disability and/or autism; the sharing of information could be improved to enable a better experience for patient and health care professionals. It would provide up to date care plans to services on admission to support acute teams in assessment and intervention. Also, on discharge so community teams can support continuity of care in the community setting.

By improving discharge planning and care this could reduce “failed discharges”. A communication network could allow a more holistic picture of a person’s experience to identify increasing hospital attendance, known risks, soft signs of deterioration and safeguarding concerns. Also, it could create a good professional network to encourage collaborative working for when MCA and best interest decisions are required.

A draft pathway has been developed between the community services and one acute hospital, once finalised and established this will be introduced to the two other hospitals in Norfolk and Waveney to deliver consistency across our area.

13.1.6 East Anglia Children’s Hospice (EACH) Hospital Passports

A piece of work which came out of a children’s review was considering how best to support an emergency admission from EACH for a young person having respite care. EACH support children and young people from across Norfolk and as such there is the possibility a child may be admitted to the closest hospital from their centre, despite this not being the child’s local hospital. As such they may not be familiar to staff or have an open access arrangement in place.

A task and finish group was arranged to explore sharing hospital passports and arranging for learning disability flags to be put into the system. It was agreed that it would be useful for every child who lives out of the catchment area of the hospital closest to EACH to have an Emergency Admission Plan and be registered digitally with a learning disability flag. It is hoped this will support staff in meeting their reasonable adjustments on admission, which would like to be through A&E while also notifying the ALDLT.

It was agreed that EACH and the ALDLT would work together to identify which children and young people are from out of area and access respite at EACH. A letter will be sent to each family to invite them to contact the ALDLT, should they wish to share an updated hospital passport and register with the hospital. EACH will also complete an EAP for all their respite children and share this with the hospital to be added to electronic records. In the case of an admission a paper copy will also be sent in with the discharge letter.

13.2 Learning into Action Group Work

Not all learning from completed reviews fits into current workstreams, nor is it big enough to warrant it. As such, if an action is identified it is allocated to the most appropriate person. Below is a selection of some of the work which has come out of LIAG in 2022/2023:

- Completing the governance arrangements for LeDeR including Terms of Reference and action plans with easy read versions for experts by experience.
- Establishing a safeguarding process including training needs, a safeguarding record log and supervision arrangements.
- Established close working with mortality leads with agreement for reviewers to attend all SJRs for those with a learning disability and/or autism.
- Working towards a collaborative model for SJRs across Norfolk and Waveney to ensure consistency and quality.
- A joint statement from the acute working group was shared describing concerns regarding MCA and BI use in the acute environment which was escalated to the NSAB who established MCA training led by social care and the ICB designated safeguarding team.
- Work to highlight some issues with the application and assessments of Disability Facilities Grants for those with progressive neurological conditions.
- LeDeR reviewers are now gauging IMCA quality in reviews to enable feedback of problems to the commissioning team.
- Working with ambulance services to confirm practise around DNACPR.
- Ongoing escalations regarding acute discharges and referral quality.
- Working with community healthcare provision to clarify that respite units have updated risk assessments and the current service provision post COVID, to better support families.

- Communicating with the transition networks regarding the importance of current diagnosis coding to protect learning disability registers and access to AHC.
- Supporting work between inpatient mental health wards and acute and community services to look at memorandums of understanding for staff escorting mental health patients into hospitals. This includes MDT practices for complex patients and ensuring annual health checks are completed.
- Noting and sharing of positive practice from reviews including letters to providers to celebrate success.

13.3 Other Work

The LeDeR team looks at any opportunity to share the learning from LeDeR and improve services wherever possible. The senior nurse manager has supported many workstreams in 2022/2023, some of which are mentioned below:

- Education sessions for colleagues within the ICS on the 2021/2022 LeDeR annual report including safeguarding leads, Continuing Healthcare Nurses, social care and community learning disability teams.
- University lectures for learning disability nursing students.
- Arranging and chairing the monthly primary care LD leads meeting with a varied training sessions agenda including SEND, Trauma Informed Practice, MCA/LPS, SALT, Portage and C(E)TRs amongst others.
- Supporting with testing for the new LeDeR review proforma on the platform.
- County National Power Outage and Rolling Power Outage Planning Working Group.
- Collaboration to share LeDeR learning with the LA to develop their residential care strategy.
- Liaising with the regional team to look at work in Menopause care for those with a learning disability.
- Providing placement experience for nursing students.
- Attending the regional Reasonable Adjustment and Digital Flag working group.
- Attending the regional Annual Health Check delivery and improvement group
- Attending and presenting learning to the ICB Learning from Death Forum.
- Contributing to the National Learning from Deaths definitions Task and Finish Group for Severe Mental Illness and Learning Disability.

13.4 Looking forward to 2023/2024

Some of the workstreams mentioned above will continue into next year and develop in response to any changes. However, from the reviews undertaken in 2022/2023, we know that we need to do more work in the following areas:

- Prevention of respiratory illness through better preventative and dental care.

- Increasing the uptake of screening programmes.
- Improving end-of-life care provision with earlier identification and better symptom management and care planning.
- Improving the quality and uptake in Annual Health Checks and Health Action Plans.
- Better provision in the care market to supply personalised care in a community setting.
- Increasing the awareness of LeDeR for those with autism and increasing our referrals for those who have died.
- Improve the co-ordination of care for people with learning disabilities and chronic health conditions and physical disabilities.
- Improve application of the Mental Capacity Act across our partner organisations.
- More comprehensive completion of ReSPECT documentation by a wider range of trained health professionals.

14. Local and Regional Partnership and Collaboration

14.1 Moving towards an Integrated Care Board

NWICB came into effect on 1st July 2022. New governance structures were finalised to support LeDeR delivery across the system.

14.2 Working in Partnership

If you have a learning disability and/or autism, we want you to tell us what your own lived experience is like. We want you to tell us whether what we are doing is making any difference to your life. We want you to tell us if we are not doing enough to make change happen. We will find better ways of asking you, and better ways of listening to what you say. We will use the learning from the LeDeR programme and from your experiences to keep improving and make changes.

Please contact us via these links:

nwccg.haveyoursay@nhs.net

[Facebook](#)

[Twitter](#)

14.3 Educating Colleagues and the Future Workforce

Plans are underway to build LeDeR into the curriculum for all nursing and allied health professional studies at the University of East Anglia (UEA). Programme leads have been very supportive and working collaboratively with the LeDeR senior nurse manager to achieve this. The next step will be to establish similar relationships with the UEA medical school. Following the publishing of every annual report, the LeDeR team tours the ICS to share the learning from last year. So far bookings include talks with services including the Coroners, Norfolk Safeguarding Adults Board, Social Prescribing, Primary Care and community learning disability teams amongst others.

15. Conclusion

The last year has seen a dramatic change in the way LeDeR is delivered in Norfolk and Waveney; with performance, quality and learning into action improving significantly. Review data collation this year has given the team a wealth of information from which to identify what needs to change and what is working well. However, it does represent a reset, and our ability to look at historical trends with any accuracy is limited.

Our work is incredibly well supported by health and social care providers across the ICS. We are also very indebted to the contribution from experts by experience and people with lived experience. Collectively, we have developed many workstreams to action the areas of learning identified last year which have been well received by colleagues.

We continue to see improvements in the uptake of annual health checks, something we will continue to promote and ensure all people with a learning disability from the age of 14 find a benefit to their long-term health and wellbeing. We also have seen really good examples of widespread use of reasonable adjustment to support people to access healthcare.

We will endeavour to explore improving respiratory care and reducing respiratory related deaths, especially pneumonia. We will look to better listen to the voices of those we support through improved use of the Mental Capacity Act and advocacy. We hope to look at care coordination and develop collaborative working in care planning for those with chronic conditions and at end-of-life. We aim to better represent the experience of those with a sole diagnosis of Autism by outreaching into services, raising awareness and supporting more referrals for those who have died.

Lastly, it is important we conclude this annual report by again remembering each death which has been reported. Each referral was for a person from our community, with hopes, feeling and loved ones. It is vital therefore that we continue to use their stories and experiences to improve the service provision for all people with learning disabilities and/or autism across health and social care.