NHS
Bedfordshire, Luton
and Milton Keynes
Integrated Care Board

BLMK ICB LeDeR Annual Report

April 2021 – end of March 2022

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

The aims are to:

** Improve care for people with a learning disability and autistic people - ** Reduce health inequalities for people with a learning disability and autistic people and

** Prevent people with a learning disability and autistic people dying prematurely

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Executive Summary

The aim of LeDeR locally is to build on the tremendous amount of work undertaken for people with learning disabilities and autistic people across Beds, Luton, and Milton Keynes (BLMK) Integrated Care System (ICS).

The NHS has published its first policy, *'Learning from Lives and Deaths – People with Learning Disability and Autistic People' (*March 2021). The new policy will influence the way LeDeR reviews are undertaken and assume overall responsibility for ensuring the delivery of LeDeR reviews and their recommendations.

BLMK recruited independent reviewers to undertake good quality reviews that were assured through a quality panel with key representation from professionals across health and social care and, agencies working with the learning disability and autistic community.

During 2021 - 22[1] BLMK completed a total of 39 reviews. This included 5 child deaths, aged 4-17 and 14 adults, aged 18 – 98 COVID-19 related deaths.

BLMK has consistently met national targets to ensure reviews are undertaken in a timely manner to a consistently high level of quality, both in the completion of the review and in learning that leads to service improvements.

From the outset, the involvement of families is a core principle and value that sits at the heart of LeDeR. Adequate time and space are allocated to formulate their individual thoughts, feelings of the care delivery experienced over the final twelve months of their loved one's life.

From these discussions the reviewer identifies the areas of good practice, experiences, and areas where they think practice could be improved upon, from this we have identified emerging themes:

- Learning from the impact of COVID-19.
- Increasing the uptake and quality of learning disability annual health checks.
- Improving access to speech and language therapy and assessment.
- Improving epilepsy pathways.
- Improving risk assessment and referral pathways for falls and dementia screening.
- Improving DNCPR decisions and responsibilities and improving advance care and end of life planning.

We want to continue and learn from lives and deaths through an effective review process to identify any causes for concern around their care, identify areas of good practice and areas where care could have been improved.

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[1] 2021 – 22: covers period 1st April 2021 – 31st March 2022

Introduction

During 2021/22[2] we made good progress with LeDeR across Bedfordshire, Luton and Milton Keynes (BLMK) Integrated Care System (ICS), making a key shift from previous years from *'how can we implement LeDeR across BLMK?' to 'how can we use LeDeR to improve the lives of people with a learning disability and autistic people?'* The LeDeR programme has identified many examples of good and excellent person-centred care as well as areas of improvement, such as emerging themes below:

- Learning from the impact of COVID-19.
- Increasing the uptake and quality of learning disability annual health checks.
- Improving access to speech and language therapy, assessment, and practice.
- Improving epilepsy pathways and care.
- Improving risk assessment and referral pathways for falls and dementia screening.
- Improving DNCPR decisions and responsibilities, improving advance care and end of life planning.

Nationally, a total of 3,304 deaths of people with a learning disability[3] were reported to LeDeR during 2021. This includes 208 deaths of children aged 4 -17 and 3,096 deaths of adults aged 18 - 98. There was a significant increase in the number of deaths reported during the peak periods of the COVID-19 pandemic, with spikes in deaths occurring during April 2020 and January 2021. BLMK ICB completed a total of 39 reviews, of these 34 were for adults aged 18 – 98 and 5 were for children aged 14 – 17. Sadly, like the previous year there were 14 people with a learning disability that died due to COVID-19 and learning from these deaths continues to be addressed.

A significant amount of learning has already been embedded and progress made in improving care and reducing inequalities for people with learning disabilities. There is still more work to do though in terms of early identification of vulnerabilities, such as age, care settings, pre-existing conditions, and there are further challenges associated with the emerging themes, COVID-19 diagnosis and treatment as well as supporting carers to reduce the impact of diagnostic overshadowing.

LeDeR has provided a unique opportunity to engage partners to improve the quality of the health and social care services provided to people with a learning disability and address the persistent health inequalities this group of people often face.

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[2] 2021 – 22: covers period 1st April 2021 – 31st March 2022

Statement of Purpose

Deaths of people with a learning disability aged 18 years and over are eligible for a LeDeR review, while child deaths are linked via the national child death review process (CDOP)[4]. Once a notification of a death is received a LeDeR reviewer will gather details on the death and start the review process, with a target for this to be completed within 6 months. The review process also provides a voice for the family and relatives.

An initial review will then be carried out by a trained independent reviewer. For some reviews a more comprehensive 'focused' review will take place, which will look more closely at the person's life and circumstances of death, *please see Appendix 1 for LeDeR process.*

Once the reviews are completed, they will be presented at the BLMK Integrated Care Board (ICB)[5] Quality Assurance Panel for discussion on the findings of the review, positive practice observed, and issues or concerns raised. The reviews are scored using the 'Quality of Care' grading system, *please see Appendix 2 for Grading of Care scoring table.*

Notifying a death to LeDeR is not mandatory and, therefore LeDeR may not have data on all people with a learning disability who have died, and findings must be interpreted with a degree of caution. We strive to deliver our key aims:

- Coordinating learning that improve outcomes, tackling inequalities, enhancing productivity and help address health inequalities.
- Ensuring there was a local, sustainable approach to the new national LeDeR Policy.
- Engaging with partners across the health and social care system to drive local conversations about the changes needed to improve the quality of services.
- Learning Workshops on emerging themes.

During 2021/22 LeDeR review underwent a significant change in the type and detail of data that was collected. Whilst focused reviews continued to be more comprehensive than initial reviews, the data collected during initial reviews after June 2021 differed in some ways to what was done previously. Nationally, more than 10,000 deaths of people with a learning disability have been reviewed with the findings presented in both national and local the LeDeR annual reports. The issues and causes of death identified within the national LeDeR annual report 2021 leder-main-report-hyperlinked.pdf (kcl.ac.uk) alongside the findings from locally completed reviews, reflect the multiple challenges for people with a learning disability.

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[4] The Child Death Overview Panel (CDOP) Process The responsibility for ensuring child death reviews are carried out. Since 1 April 2008, there has been a legal requirement that Child Death Overview Panels (CDOP) conduct a review for all child deaths aged 0-17

[5] Integrated Care Board (ICB) replaced Clinical Commissioning Groups (CCGs) in the NHS in England from 1 July 2022..

Governance and Partnership

The Integrated Care Systems (ICS)[6] are new partnerships between the organisations that provide health and care across an area. It is designed to co-ordinate services and to plan in a way that improves population health and reduces inequalities between different groups. LeDeR utilises partnership approaches already in place making recommendations and providing assurances that can influence and contribute to improvements, such as:

- Improve care, reduce health inequalities, and prevent premature mortality.
- Learning from LeDeR reviews about good quality care and areas of improvement.
- Drive local service improvements based on themes emerging from LeDeR reviews.
- Influence regional and national service improvements via actions that respond to themes commonly arising from analysis of LeDeR reviews.

The new national LeDeR Policy was published in March 2021. The name of the programme changed from the 1st of June 2021 and is now referred to as the *'Learning from lives and deaths –people with a learning disability and autistic people'.* NHS England » Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) policy 2021

BLMK Integrated Care Board (ICB) has already started to put this policy into practice by implementing the revised review process of carrying out initial[7] and focused[8] reviews and employing an independent reviewer to complete these reviews with oversight from a senior reviewer.

Learning into action and good practice are agreed and approved through an established multi-agency quality assurance panel. LeDeR is also an integral part of the wider ICS quality governance process with monthly reporting oversight.

The panel membership is multi-agency with representation from across the ICS who have responsibility for the quality of services. The BLMK quality assurance process has provided a platform for collaborative working and system wide health and social care discussions to identify learning into action.

BLMK continues to work in partnership with all stakeholders and looking to strengthen engagement with Black, Asian, and Minority Ethnic (BAME communities). We want to make all key learning disability stakeholders an equal partner in delivery of the LeDeR.

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[6] **Integrated care systems** (ICSs) are partnerships that bring together NHS organisations, local authorities and others to take collective responsibility

[7] Initial reviews refer to a review carried out for all LeDeR notifications

[8] Focused reviews refer to an initial review which leads to a more comprehensive “focused” review, looking very closely at the person's life and circumstances of death.

LeDeR Notifications

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

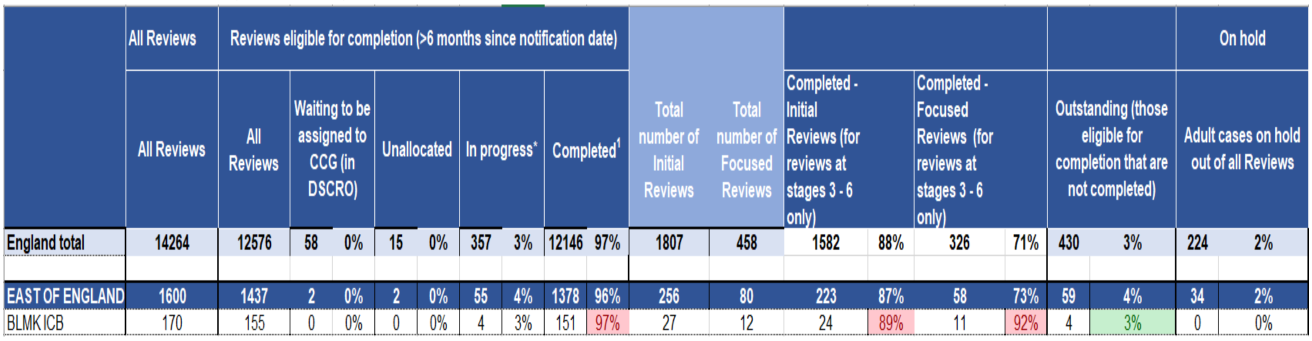
The national LeDeR annual report 2021 reported there was a significant increase in the number of deaths reported during the peak periods of the COVID-19 pandemic, with spikes in deaths occurring during April 2020 and January 2021.

The number of initial reviews completed in 2021 nationally was 2553; plus 109 CDOP reviews for children, aged 4 - 17. Focused reviews look in more detail about the life and death of the person and lessons that can be learnt from their care.

BLMK received a total of 39 notifications in 2021/22. These reviews included 14 COVID-19 related deaths, aged 18 – 98 and 5 child deaths, aged 4 – 17. Table 1 shows that since the LeDeR programme started BLMK has received a total 170 notifications and of these notifications 151 (97%) reviews were completed, with 4 (3%) still in progress as at the end of March 2022.

BLMK's completion rate for LeDeR reviews is in line with the national completion rate at 97% and slightly higher than the East of England region, which had completed 96% with 55 reviews still in progress as at end of March 2022.

Table 1: East of England Region NHSE data



	All Reviews	Reviews eligible for completion (>6 months since notification date)																		
																			On hold	
	All Reviews	All Reviews	Waiting to be assigned to CCG (in DSCRO)		Unallocated		In progress*		Completed[1]		Total number of Initial Reviews	Total number of Focused Reviews	Completed - Initial Reviews (for reviews at stages 3 - 6 only)		Completed - Focused Reviews (for reviews at stages 3 - 6 only)		Outstanding (those eligible for completion that are not completed)		Adult cases on hold out of all Reviews	
England total	**14264**	**12576**	**58**	**0%**	**15**	**0%**	**357**	**3%**	**12146**	**97%**	**1807**	**458**	**1582**	**88%**	**326**	**71%**	**430**	**3%**	**224**	**2%**
EAST OF ENGLAND	**1600**	**1437**	**2**	**0%**	**2**	**0%**	**55**	**4%**	**1378**	**96%**	**256**	**80**	**223**	**87%**	**58**	**73%**	**59**	**4%**	**34**	**2%**
BLMK ICB	170	155	0	0%	0	0%	4	3%	151	97%	27	12	24	89%	11	92%	4	3%	0	0%

The child deaths are not reviewed by the LeDer programme, as they are passed to the relevant CDOP teams within each of the CCG, who will carry out a thorough inquiry. The LeDer programme will be notified when these reviews are completed and will forward on a Form C, which has details of the completed review by CDOP. Relevant learning from the Form C will be reported back to the BLMK LeDer Quality Assurance Panel.

Demographics

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

In 2021 nationally 56% of people who were notified to LeDeR were identified as male, 6 out of 10 people living with a learning disability died before they were 65. Over 50% of people with a learning disability died in areas rated as some of the most deprived in England. In the general population, there were no excess deaths for children with a learning disability.

BLMK data[9] shows that:

- Males with a learning disability in England have a life expectancy of 66 years, 14 years lower than males in the general population. Females with a learning disability in England have a life expectancy of 67 years, 17 years lower than females in the general population.
- Learning disability is more prevalent in males (62%) and in younger populations suggesting reduced longevity and, comparatively higher proportions of people with a learning disability are living in deprived areas.
- In 2020 - 2021 for BLMK the median age of death of people with a learning disability was 56. In 2021 this had **increased** to 58, still 2% lower than the national average.
- People with learning disability morbidity levels are significantly higher in BLMK for diabetes, obesity, stroke and dementia, other diseases show similar or lower prevalence.
- Across BLMK people with learning disabilities are more likely to have epilepsy, severe mental illness or dementia and are more likely to suffer with hypothyroidism, diabetes, heart failure, chronic kidney disease or stroke.
- Females with a learning disability are less than half as likely as females in the general population to have had cervical screening in the last 5 years, but the percentage who have had cervical screening has increased across BLMK.
- People with a learning disability are more likely to have a diagnosis of dysphagia, with the highest prevalence recorded in patients aged 75 and over.

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[9] data taken from Local performance data and NHS England Health and Care of People with Learning Disabilities, Experimental Statistics 2021

Causes and Circumstances

National Context

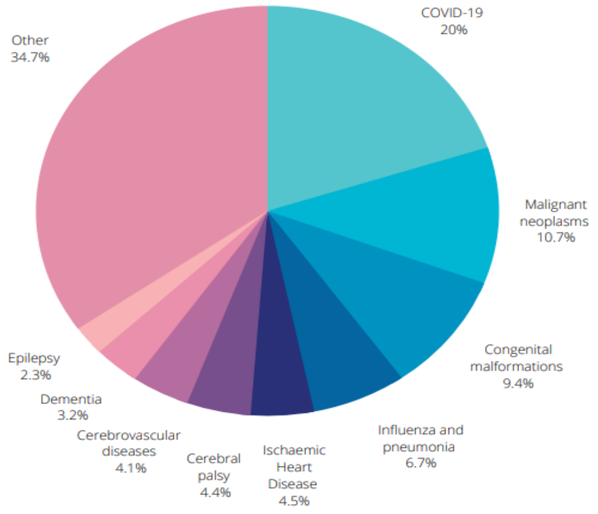
Nationally, the median age at death in the general population was 83 for males and 86 for females in 2016 - 2018. For people with a learning disability who died in 2021 and were notified to LeDeR, the median age at death was 61 for males and 60 for females. The disparity between median age at death in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

The national LeDeR annual report for 2021, showed that nationally 61% of deaths occurred in hospital and that top 5 ICD-10[10] categories of cause of death were:

1: COVID-19
2: Diseases of the Circulatory System
3: Diseases of the Respiratory System
4: Cancers
5: Diseases of the Nervous System

Figure 1 shows nationally the most frequently cited cause of death for all ages, with ‘other’ and COVID 19 being the two highest cause of death.

Figure 1 National LeDeR annual report 2021, page24, causes and circumstances of death



The most frequently cited cause of death for all ages.

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[10] ICD-10 is the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD), a medical classification list by the World Health Organization (WHO). It contains codes for diseases, signs and symptoms, abnormal findings, complaints, social circumstances, and external causes of injury or diseases.

Of the deaths occurring in 2021 which had initial review data, 61% overall (62% adults, 51% children) occurred in hospital. In comparison to deaths in the general population (data from 2018), a greater proportion of people with a learning disability die in hospital (59% of people with a learning disability in 2018-2021 vs 42% of the general population in 2020)

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

BLMK Context

Primary and Secondary Causes of Death

As with the national picture for BLMK the primary cause of death was COVID 19, with secondary cause of death cited as frailty.

Table 2 and 3: BLMK LeDeR data, details the number of primary and secondary causes of death

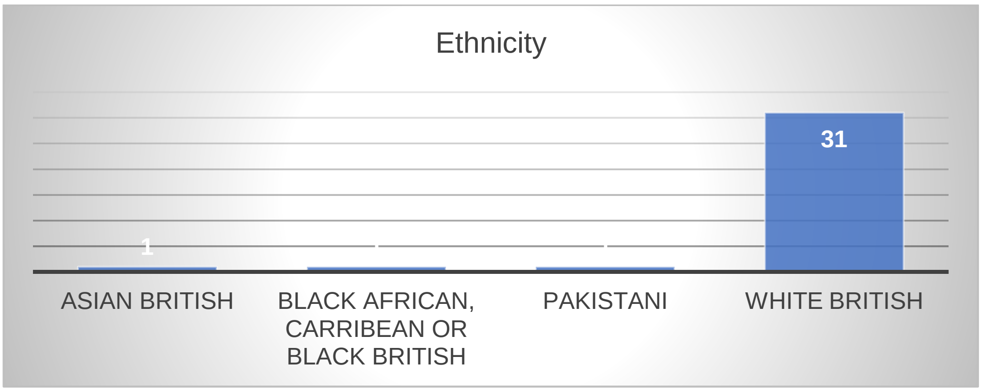
Primary Causes of death	Numbers
Covid pneumonia	7
Aspiration pneumonia	6
Covid 19	5
Pneumonia	5
Frailty in old age	3
Pulmonary thromboembolism	1
Pulmonary embolism	1
Metastatic cancer of the bowel	1
Choking	1
Sepsis	1
Infective endocarditis	1
Multi organ failure	1
Chest infection	1

Secondary Causes of death	Numbers
Frailty	4
Heart failure	3
Dementia	2
Covid 19	1
Angina	1
Colorectal cancer	1
AV Septal defect	1
Pulmonary hypertension	1
Infected leg ulcer	1
Deep vein thrombosis	1
Congenital hydrocephalus	1
Diffuse large and B cell lymphoma	1

Systemic inflammation pneumonia	1
Perforated small bowel during feed tube surgery	1
Urinary tract infection	1

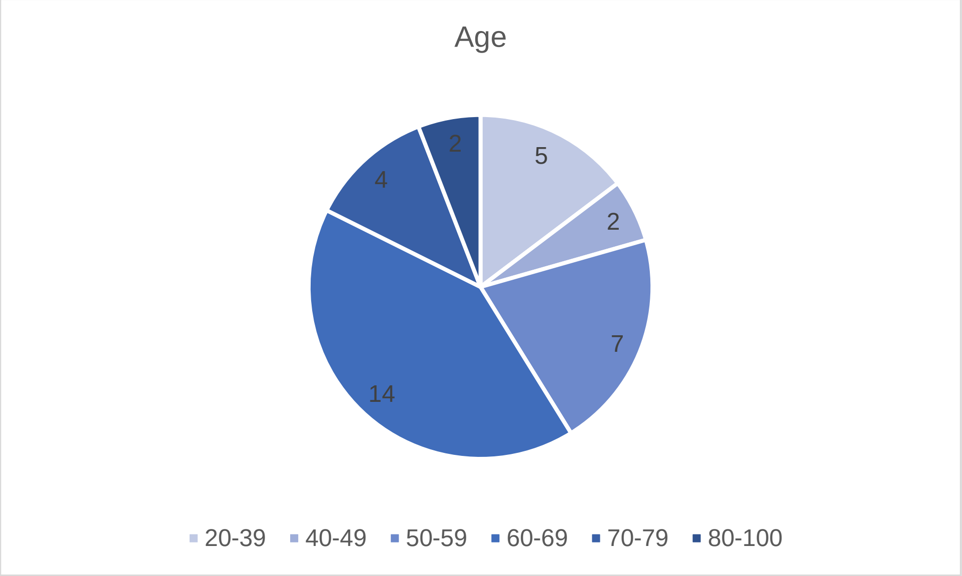
Ethnicity

The LeDeR notifications received were mostly for people whose ethnicity was white British, with a small number for 3% Asian British, 3 % Black African, Caribbean, or black British, 3% Pakistani. This was very similar to the previous year.



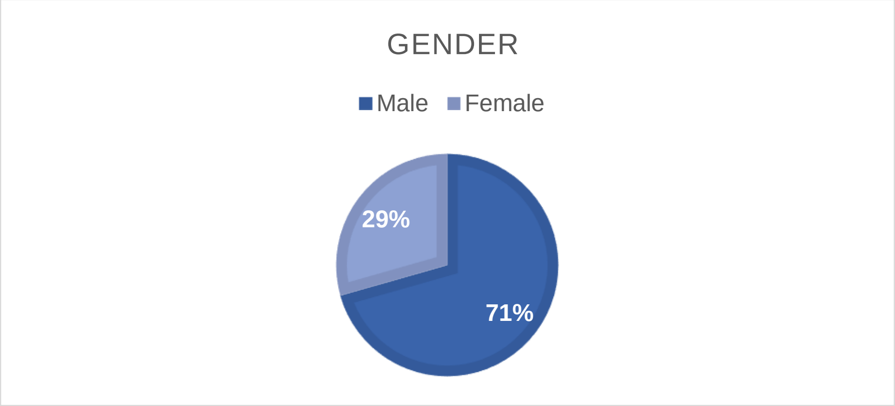
Age of death

In 2020 the median age of death in BLMK was 56. In 2021 the median age was 58, this has increased by 2%. It is still 2% lower than the national median age of death at 60.



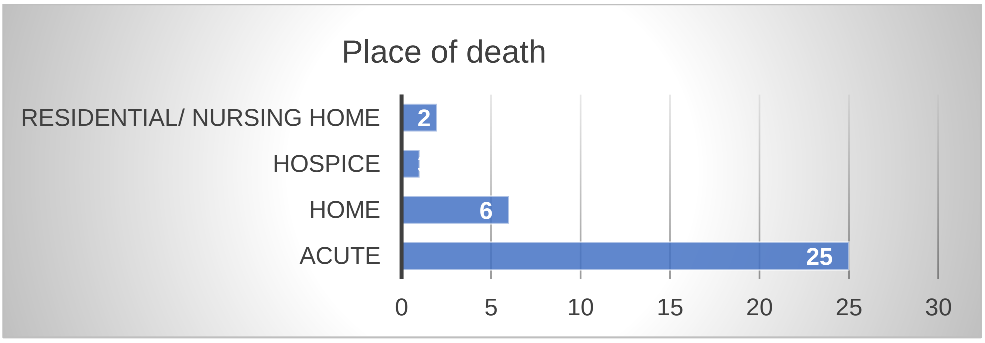
Gender

In 2020 the number of male deaths was slightly higher by 6% than the female deaths (53% male and 47% for female). In 2021 the male deaths were significantly higher with male deaths accounting for 70% of the overall notifications received. Female deaths were much lower in 2021 than 2020 by 14%.



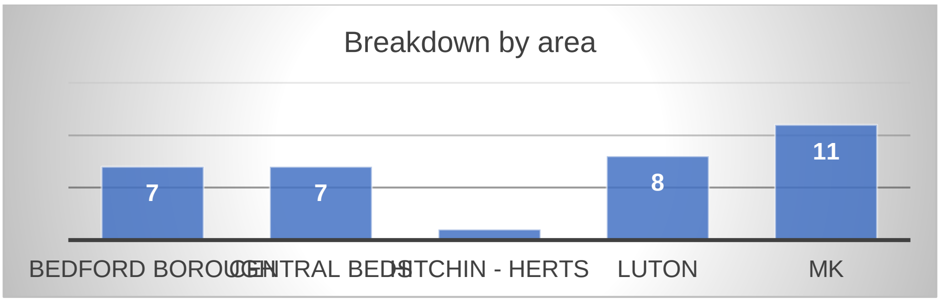
Place of death

As in 2020, the LeDeR notifications in 2021 reported that most people, that is 73% died in hospital, followed by 18% at home, 6% in a residential/nursing home and 3% in a hospice.



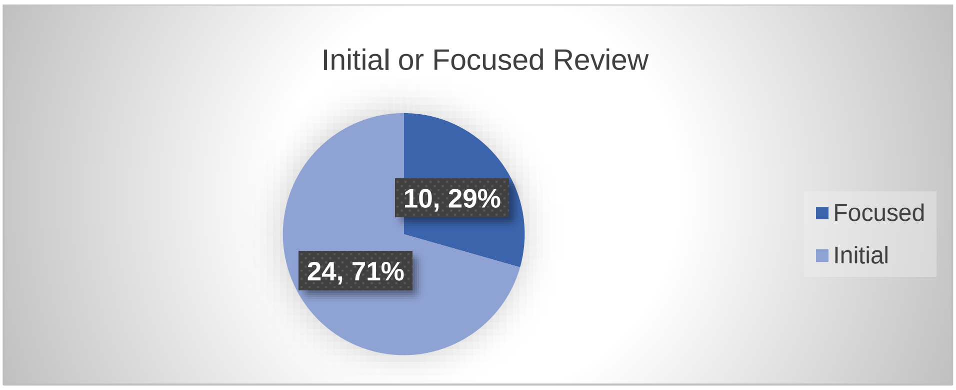
Breakdown by area

Most of the notifications of death were received from Milton Keynes, followed by Luton, Bedford and Central Beds had equal number of deaths reported.



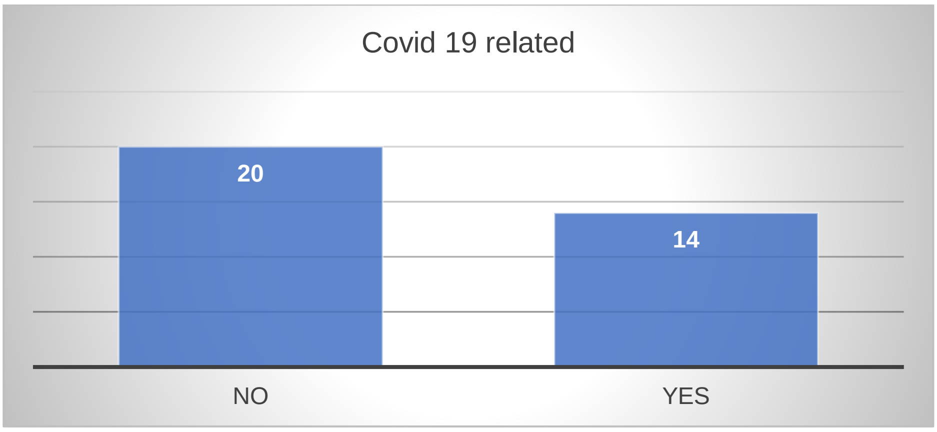
Breakdown by type of review

There was a total of 24 ‘initial’ reviews and 10 ‘focused’ review that were completed. The 10 focused reviews were graded for quality of care and availability and effectiveness of care by the BLMK ICS Quality Assurance Panel. The 5 child deaths were referred to CDOP for reviewing.



COVID-19 related deaths

Out of the 34 reviews carried out 14 of these were COVID-19 related deaths. as illustrated above, 41% in 2021/22 compared to 25% in 2019/2020 (31 of 120).



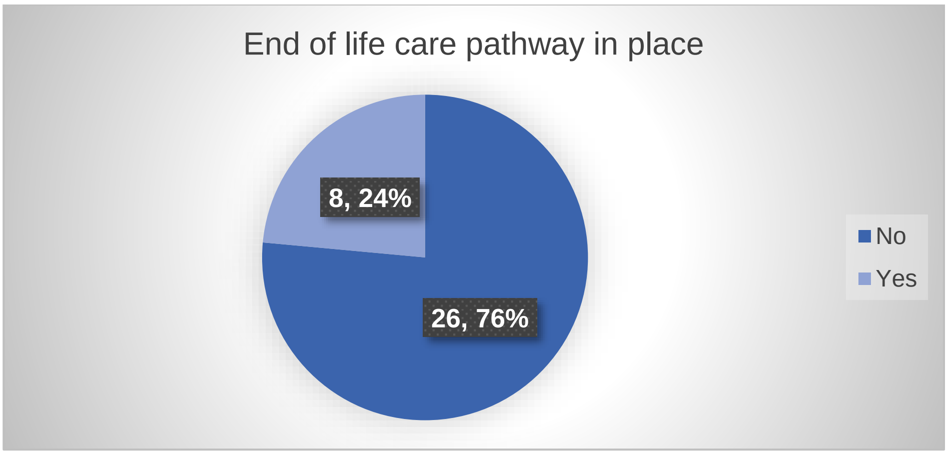
Long term conditions

The notifications received cited that those who died at the following long-term conditions, with 3 people having cerebral palsy and 2 with diabetes.

Condition recorded in LeDeR review	Number of times given in LeDeR reviews
Cerebral palsy	3
Diabetes	2
Parkinson’s	1
Autism	1
Asthma	2
High BMI	1
Hypothyroidism	1
Frailty	1
Acute on chronic pyelonephritis	1
Schizophrenia	1
Chronic constipation	1
Lithium toxicity	1
Hydrocephalus	1
Kyphoscoliosis and scoliosis	1
Reduced lung volumes	1
Viral upper respiratory tract infection	1
Atrial fibrillation	1
Haemorrhagic gastritis	1
Previous medulloblastoma	1
Bilateral schwannomas	1
Tracheostomy	1
Previous rectal surgery	1
Spastic tetraplegia	1
PEG fed	1
Rubenstein – Tayebi syndrome	1
Dementia	1
Bipolar	1
Williams syndrome	1
Down syndrome	1
Obstructive sleep apnoea	1

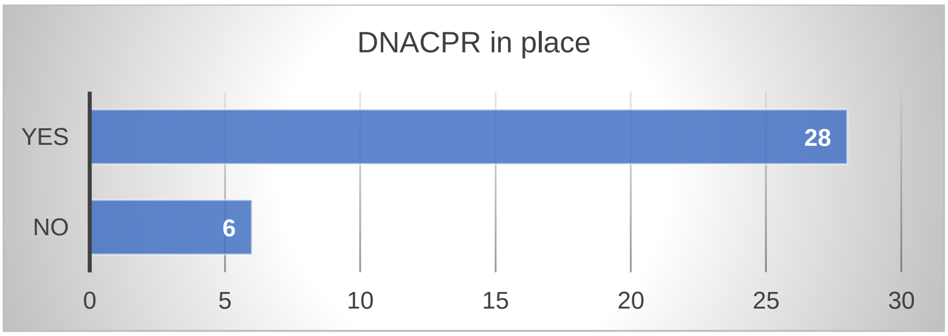
End of life care

Out of the 34 reviews carried out 26 of them citied that there was an end-of-life pathway in place at the time of their death, this has increased by 9% since 2020 when there 67% of plans in place.



DNACPR in place

Out of the 34 carried out 28 (82%) of them cited that a DNACPR was in place at the time of their death, with 6 (17%) not having one in place. This is a similar to 2020, with 83% people had a DNCPR in place and 17% that did not have one in place.

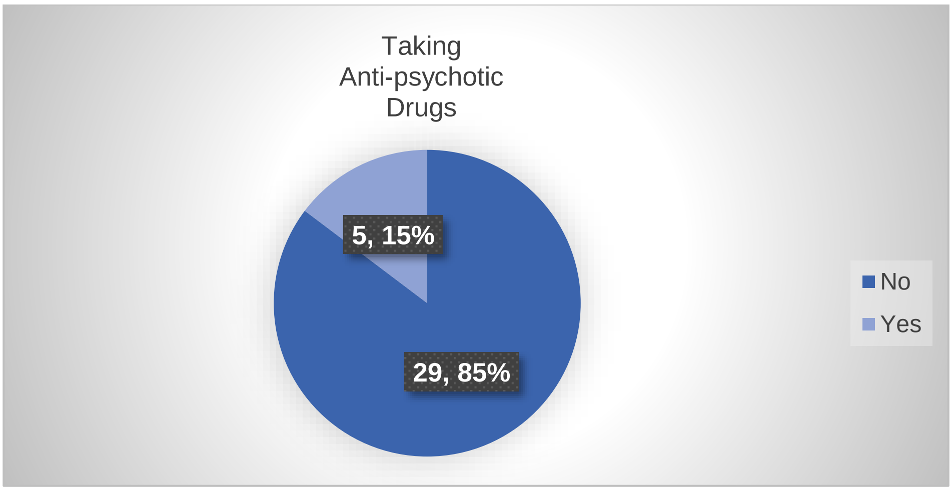


Use of anti-psychotics

The completed reviews include a review of the individual’s medication, when they last had a medical review of medications, and specifically if they were prescribed an anti-psychotic. As reported in 2020, there was a low percentage of people that were taking anti-psychotic drugs.

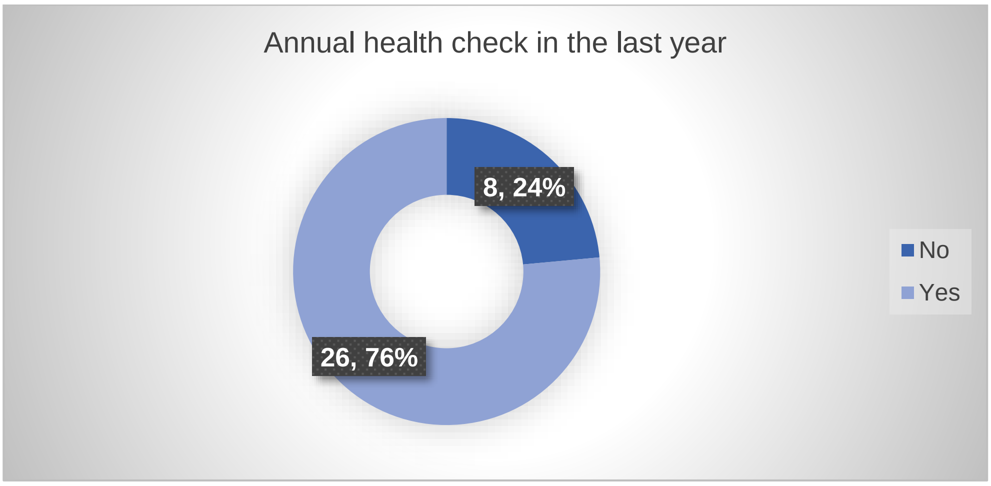
In addition to understanding the individual’s medical history the reviewers also explore if they were receiving specialist services. In the completed cases 95% had received some degree of specialist services input.

Out of the 34 reviews, the majority were not taking anti-psychotic drugs (85%) and small percentage at 15% were taking anti-psychotic drugs.



Annual health check

Evidence suggests that providing health checks to people with learning disabilities in primary care is effective in identifying previously unrecognised health needs, including those associated with life-threatening illnesses. Out of the 34 reviews carried out 26 people had an annual health check within the last year before their death. The 8 that were not completed were either due to be completed or declined.



Quality of Care

Nationally, 9 out of 10 of reviewers indicated that the care package provided met the needs of the individual in deaths that occurred in 2020 and 2021. Overall care was rated as 'good' or 'excellent' in 58% reviews of deaths in 2021, increased from 54% in 2020.

BLMK carried out 10 focused reviews out of 34, the rest were initial reviews. BLMK Quality Assurance Panel scored the focused reviews following their completion by the independent reviewers. The scoring is based on the quality of care and availability/effectiveness of care, *please see Appendix 2 for full Grading of Care table.*

Out of the 10 ‘focused’ reviews the Panel felt that:

- 5 reviews 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.
- 4 reviews fell short of the expected standard, and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death because of the availability and effectiveness of services
- 1 review that could have been avoided and found that care fell far short of expected good practice and this contributed to the cause of death. For this review both availability and effectiveness of services fell far short of the expected standard, and this contributed to the cause of death.
- 1 review received good care and met expected good practice.
- 2 reviews both availability and effectiveness of services was good and met the expected standard.
- 2 reviews found that care fell short of expected good practice and this did impact on the person’s wellbeing but did not contribute to the cause of death.
- 2 reviews found that availability and effectiveness of services fell short of the expected standard, and this did impact on the person's wellbeing but did not contribute to the cause of death.
- 1 review was satisfactory care it fell short of expected good practice in some areas, but this did not significantly impact on the person’s wellbeing. For this review availability and effectiveness of services fell short of the expected standard in some areas but this did not significantly impact on the person's wellbeing.

Learning and recommendations of the care received from these individual reviews are taken forward to be actioned and shared appropriately with relevant health and social care professionals within the ICS to consider how current practice can learn from these reviews and address issues for service improvement. Emerging themes will be considered for wider communications and reported to NHS England.

Summary of Learning

LeDeR reviews will enable the ICS to identify good practice and what has worked well, as well as where improvements in the provision of care could be made and that local actions are taken to address the issues identified in reviews. Recurrent themes and significant issues are identified and addressed at a more systematic level; locally, regionally, and nationally.

One of the key messages has been there is need for continued work to ensure that healthcare services make reasonable adjustments for people with a learning disability. There have been several initiatives that have been introduced over the past few years to improve healthcare for people with a learning disability, including the annual health check, health action plans and learning disability awareness training. *Please see Appendix 3 for Key Learning Themes from these reviews.*

The following thematic reviews were reported with the greatest degree of frequency. Several initiatives and workshops have taken place to address the learning and how service improvement and pathways to care and support can be improved. *Please see Appendix 4.*

- Learning from the impact of COVID-19.
    - A successful vaccination programme saw 96% of people with a learning disability have their first, second and booster vaccinations.
    - Since the reviews were completed there have been no further deaths reported as COVID-19 related.
- Increasing the uptake and quality of learning disability annual health checks.
    - There has been an increase by 20% with the uptake since 2020.
    - There are 67% health action plans in place
    - People who did not received an annual health are being contacted and supported to have their check by September 2022.
- Improving access to speech and language therapy and assessment.
    - Dysphagia and Nutrition Team (DANT) offer training 2-4 times annually.
- Improving epilepsy pathways.
    - Generic epilepsy care planning and awareness training is available to all.
- Improving risk assessment and referral pathways for falls and dementia screening.
    - Reviewing referral criteria and actively improving awareness.
- DNCPR decisions and responsibilities, improving advance care and end of life planning.
    - Improving processes for DNACPR, reviews found 82% did have DNACPR in place.
    - Skills for care and Principles of end of care rolling programmes in place.

Implementing the New Policy

The new policy focuses not only on completing reviews, but on ensuring that local health and social care systems implement actions at a local level to reduce mortality and improve quality of care. Our plans for the forthcoming year will be to:

- Ensure new governance processes are in place, including ICS level oversight of the LeDeR to include people with lived experience. LeDeR must not sit separate to and remote from wider ICS quality governance.
- A workforce dedicated to the LeDeR with Local Area Contacts (LACs), senior reviewers and reviewers' part of a wider team with good support mechanisms in place. All reviewers must use appropriate Information Governance enabled Information Technology around the use and storage of personal identifiable data.
- Going forward, reviews will be extended to every adult over the age of 18 with a diagnosis of autism.
- Under the new policy, an initial review will be carried out for all cases. There will then be an option to carry out an additional focused review where significant learning can be gained to drive service improvement.
- We fully appreciate that significant and sustained system-wide change can only be achieved through collaboration to implement the improvements needed and address the health inequalities that people with a learning disability face.
- LeDeR Reviews are allocated and completed to a high standard within the stipulated programme timescales.
- Identified learnings and recommendations become Learning into Action Plans.
- Learning into Action plans will improve the quality of health and social care services and reduces the health inequality faced by people with learning disabilities and autistic people.
- All stakeholders, including people with learning disabilities and their family, friends, and carers, feel an equal partner in the LeDeR programme.
- Forward planning and achieving key milestones set within the NHSEI and BLMK frameworks for improvement plans and reducing health inequalities.
- Analysing and addressing themes from completed reviews within set timescales.
- Recording and monitoring timely delivery and impact of recommendations.
- Collating evidence of local actions taken to improve care and address the health inequalities faced by people with a learning disability and autistic people.
- Identifying good practice locally and sharing this locally and with NHSEI regional teams.

Moving forward

Moving forward the BLMK ICB LeDeR Action Plan will set out the key deliverables to achieve our vision and objectives over the next three years in line with the 5 priorities for the BLMK Integrated Care System (ICS) vision below:

Vision

"Our vision is to work with our population to optimise health and wellbeing, advance equality in our communities and make the best use of our resources."

01 **Start Well**

Every child has a strong, healthy start to life: from maternal health, through the first thousand days to reaching adulthood.

02 **Live Well**

People are supported to engage with and manage their health and wellbeing.

03 **Age Well**

People age well, with proactive interventions to stay healthy, independent and active as long as possible.

04 **Growth**

We work together to help build the economy and support sustainable growth.

05 **Reducing Inequalities**

In everything we do we promote equalities in the health and wellbeing of our population.

What we will deliver	What we need to do	How we will measure this
Meeting wider ICS health inequalities objectives	• Meeting the wider ICS objectives and the Long-Term Plan (LTP) priorities targeted at improvements in health outcomes, health inequalities and improving the care and the quality of lives for people with a learning disability and autistic people.	• Attending management, Board, NHSE, local authority, provider, and System meetings as necessary as representation of BLMK LeDeR and /or to report on progress of LeDeR. • Align the governance and assurance processes of LeDeR with the Transforming Care Programme, • Achieve NHSE trajectory targets for LeDeR.
Robust governance to assure quality reviews and monitor and review leaning into action	• Quality assurance of reviews through the BLMK Quality Assurance Panel and ensuring the Panel meetings are scheduled monthly along with additional meetings as required. • Governance approvals	• The quality assurance of reviews is executed appropriately within the national quality assurance framework and BLMK terms of reference; with the terms of reference being reviewed and agreed with panel members every 6 months or as necessary. • Ensuring all relevant paperwork is circulated to Panel members in accordance with agreed timeframes prior to panel meetings. • Chairing the Panel meetings and ensuring learning recommendations are signed off by

		the panel and transported to the learning into action
Developing and implementing of the 3-year LeDeR Strategy, producing Annual Reports	• Full implementation of the 3-year LeDeR Strategy, including the workforce model and Action Plan aligned to the new national LeDeR Strategy	• A yearly forward priorities plan coproduced with key stakeholders delivering on SMART objectives, aligned to achieving the 4-point outcomes plan • Engaging with key partners and stakeholders, including families and cares to develop the Annual Reports which will inform the forward priorities plan
Monitoring progress on reviews, escalating issues, risks and exception reporting on delays	• Meeting trajectory targets for completion of reviews.	• Keeping up to date the Action Tracker for the Reviews, identifying early issues and risks for escalation and exception reporting on delays • Identifying and putting in ‘Enablers’ to assist Reviewers with the completion of reviews, including the facilitation of System networks and contacts. • Overseeing the completion of Reviews and ensuring these are scheduled at the Quality Assurance Panels in a timely manner in line with the trajectory targets. • Once reviews are completed to ensure these are signed off on the LeDeR Dashboard with the agreement of the Panel and TCP manager.
Holistic perspective leading to reflective learning	• Learning into Action plans implemented	• Formulating service, system and clinical learning into action from recommendations, at place, BLMK, regional and national levels, includes learning themes that address health inequality with key partners and stakeholders • Thematic learning workshops throughout the year
Collaboration with all stakeholders, people with lived experience and family carers, strengthen this	• Development and implementation of a Communications and Engagement Plan to communicate and provide complex information- where necessary,	• Explore and identify appropriate IAG *(Information, Advice and Guidance)* methods of communications, for instance workshops, training, webinars and networking events. • Raising any service, system or clinical concerns and issues within the local area

from BAME communities	including clinical information to a wide range of internal and external stakeholders, • Working collaboratively with a variety of stakeholders on the delivery of good practice, initiatives, and services.	and/or regionally to management, key partners and relevant parties. • Raising awareness of LeDeR and ensuring LeDeR interface as necessary with other investigatory bodies and their work such as local authorities, CDOP, serious incident, safeguarding, coroners etc.
Evidencing and measuring successful implementation of learning into action achieving 5 point outcomes plan	• Develop, review and monitor the Learning into Action Plan with a 3-tier approach, i.e., place-based actions, BLMK themes, Regional and national themes. • reasonable adjustments.	• Coordinating and evidencing the delivery of service improvements for people with a learning disability across BLMK. • Providing progress reports, including reporting data on LeDeR to Boards and other relevant meetings. • Identifying risks and issues with delivery implementing controls and escalating appropriately.

Appendices

Appendix One: LeDeR Process

- The LeDeR Process Deaths of people with a learning disability aged 18 years and over are eligible for a LeDeR review, while child deaths are linked via the national child death review process (CDOP).
- Following confirmation that the death is within scope of the programme, a trained LeDeR reviewer will gather details on the death and start the review process, to be completed within 6 months.
- For some reviews, this will lead to a more comprehensive “focused” review, looking very closely at the person's life and circumstances of death. These focused reviews, once completed, are then sent to local governance groups with areas of good practice, areas of concern, and wider learning from the case being outlined.
- The process is outlined in detail on the website https://leder.nhs.uk/about LeDeR data In the LeDeR report we use pseudonymised data which reflect different stages of the LeDeR review process.
  Note: Child deaths follow a separate statutory review process overseen by the Child Death Overview Panels (CDOP), including deaths of children with a learning disability, with relevant information (children aged 4 years or older) being included in the LeDeR data.
- Notification data Anyone can report a death by submitting a notification to LeDeR via the website (Report the death of someone with a learning disability (leder.nhs.uk))[SA1] . The notification form includes basic demographic information about the person who died, such as their name, NHS number, address, date of birth, sex, and ethnicity.
- The person submitting the form is also asked to provide information about the circumstances of death, including where the death occurred, what they thought caused the death, and whether they had any concerns around the care of the person.
- During this process, it may become apparent that the notification is not suitable for LeDeR, for example, on further examination the deceased person did not have a diagnosed learning disability in their clinical records. In these cases, a LeDeR review is not completed, and the notification is discounted.
- Initial Review Data If the notification is found to be suitable for inclusion in LeDeR it is then passed to a reviewer for further information gathering.
- The reviewer gains more information through talking with people who knew or were involved in the care of the person who died, which includes the family of the person who died and clinicians (or their clinical records).
- The reviewers also look to speak to at least one other person involved in the care of the person who died to build up a clear picture of the person’s life and their health and care leading up to the time of their death.
- The review data are supplemented by linkage with medical certificate of cause of death (MCCD) data provided by the Office of National Statistics (ONS) and NHS Digital. Focused Review Data Focused reviews explore in more detail the life and death of the person and lessons that can be learnt from their care.
- Deaths are forwarded for a focused review if the reviewer feels that there is significant learning to be gained from the death based on the initial review or the family of the deceased request a focused review.
- From summer 2021, if the person was from a minority ethnic group, a focused review was also completed. Reviewers add to data from the initial review by looking further into the health and social care of the person who died and circumstances surrounding their death.
- More detailed information about their medical history, care and treatment and their social care arrangements are obtained through liaison with professionals involved in their care and accessing additional records.

Appendix Two: Grading of Care

Grade	Quality of care	Availability and effectiveness of services
6	This was excellent care, it exceeded expected good practice. **NO REVIEWS WERE GRADED AT THIS LEVEL**	Availability and effectiveness of services was excellent and exceeded the expected standard **NO REVIEWS WERE GRADED AT THIS LEVEL**
5	This was good care (it met expected good practice). **1 REVIEW WAS SCORED AT THIS LEVEL**	Availability and effectiveness of services was good and met the expected standard **2 REVIEW WAS SCORED AT THIS LEVEL**
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). **1 REVIEW WAS SCORED AT THIS LEVEL**	Availability and effectiveness of services fell short of the expected standard in some areas, but this did not significantly impact on the person's wellbeing. **1 REVIEW WAS SCORED AT THIS LEVEL**
3	Care fell short of expected good practice and this did impact on the person’s wellbeing but did not contribute to the cause of death. **2 REVIEWS WAS SCORED AT THIS LEVEL**	Availability and effectiveness of services fell short of the expected standard, and this did impact on the person's wellbeing but did not contribute to the cause of death. **2 REVIEWS WAS SCORED AT THIS LEVEL**
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. **5 REVIEWS WAS SCORED AT THIS LEVEL**	Availability and effectiveness of services fell short of the expected standard, and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death. **4 REVIEWS WAS SCORED AT THIS LEVEL**
1	Care fell far short of expected good practice and this contributed to the cause of death. **1 REVIEW WAS SCORED AT THIS LEVEL**	Availability and effectiveness of services fell far short of the expected standard, and this contributed to the cause of death. **1 REVIEW WAS SCORED AT THIS LEVEL**

Appendix Three: Key Leaning Themes

Dementia pathway	• Implement a Downs Syndrome dementia pathway for screening to take place at 30 and 40 years old and then every two years from 40-50 years of age. Ensure that this Screening Tool is used and is embedded in everyday working practice and that all health practitioners are aware of this. • Processes to be put in place for baseline memory assessments to be undertaken for those living with learning disabilities as part of routine care. • All people living with learning disabilities requiring a dementia assessment to be sent to specialist LD memory assessment services.
Falls pathway	• Following falls ensure falls risk assessments are undertaken and documented, OT input secured, and a safeguarding concern raised. • NOK/cares should be notified following falls.
Stroke pathway	• Consider national best practice from the stroke clinical network in managing patients with challenging behaviour who have a CVA. Put in place a mechanism for carers to support clinical decision making relating to emergency interventions following a suspected CVAs. • Develop a pathway with timeframes to support good use of services such as the Psychiatric Liaison Team and the Psychiatric Intensive Support Team when managing life threatening events such as CVAs. Put in place a training programme for A&E staff to understand and manage challenging behaviour.
Epilepsy pathway	• Map the epilepsy pathway across acute and primary care to assess what the NICE guidance says and how this impacts on people living with a learning disability.
Mental Health	• Specialist LD behavioural and psychological approaches to be in place before prescribing antipsychotics. Wider work re use of antipsychotics to be shared with the LD QA group and steering group, including audit of patients on Quetiapine and output of STOMP/STAMP audit. • Hospital admission avoidance plans should document the process for facilitating attendance at hospital for those with challenging behaviour experiencing an acute illness.
Emerging health needs	• Care co-ordination and risk stratification models to be implemented when care needs increase. • MDT approach to be used to explore the full range of options to meet care needs. • Ensure pathways enable management of complex conditions in the community setting including end of life care with access to acute services for specific interventions only if necessary. • An MDT approach should be implemented when families make frequent contact with health services in order to determine how to meet new/emerging health needs.
End of Life pathways	• Ensure that opportunities are taken to develop advanced care planning e.g. change in care setting or significant changes in care and support needs. • In discussion with NOK ensure plans for admission avoidance, end of life care, ceilings of care and palliative care are in place where necessary in the community setting. • Review process for initiation of end-of-life pathways for acutely ill patients with poor prognosis.

	Ensure support from the palliative care team is in place. Put in place support from NOK/carers as a reasonable adjustment in acute trust settings at end of life. Review the need for palliative care education and training for clinical staff. • Once palliative care decisions are made in an acute trust provide appropriate fast track pathways and end of life care in a care home setting where appropriate. • Ensure processes are in place to make timely end of life care decisions 24/7. • Ensure access to cares and family at the end of life.
Dental pathway	• Raise awareness by use existing information and teaching aids and sharing good practice for people with Learning Disabilities and carers relating to the checking and fitting of dentures and oral hygiene.
Anti-coagulants	• Explore why alternative medication is not considered to prevent blood tests 2 weekly to monitor prothrombin times.
DoLs	• Sustain good practice of processing DOLS applications in a lawful manner. • Provide a simple guide of relatives concerning the implication of DOLs orders put in place including legal implications.
MCA/Best interest decision making/reasonable adjustments	• Ensure that when in unfamiliar settings a person with a learning disability have the full range of reasonable adjustments in place including access to those who knew then such as family or carers. • Ensure MCA assessments and best interest decision making processes are clearly documented in all care settings. • Ensure that MCA assessment take place prior to procedures and best interest decisions are recorded. • If unable to undertake the full MCA process, engage in early discussions with NOK and document best interest decisions. • Strengthen best interest decision making process to improve families understanding and ensure they feel their views are taken into account.
DNACPR orders	• Reviewed the DNACPR policy and documentation across the system and provide training on DNACPR principles, practice and guidance including; capacity to consent, medical decisions in all care settings, the requirement for consult with NOK, LD nurse input as part of the conversation, the need for follow-up conversations with family/carers and dates for review if necessary. • Initiate DNACPR discussions in the community setting with the GP and put in place DNACPR orders applicable across all care settings. • Provide education and training to increase confidence in facilitating DNACPR orders in all settings to ensure best practice is followed. • Clients with LD who do not lack capacity should have advocacy support and easy read material made available prior to giving consent for DNACPR orders. This support should be clearly documented. • If a person does not have capacity to consent to DNACPR ensure family/LPOA representatives are involved in discussions. Communication with families should clarify that decisions are not made on the basis of an existing learning disability and that treatment plans and escalation processes are in place and will continue to be monitored. • Ensure DNACPRs are revisited at each admission if they are not indefinite. • Acute trusts to review DNACPR orders at an earlier stage when prognosis is poor.

Health Checks	• Risks in relation to self-injurious behaviours to be considered at annual health checks and mitigation plans put in place as required. This could include reviewing medication, ascertaining and communicating behavioural baselines and mental capacity, and use of hospital passports. • Patients prescribed antipsychotics by the GP should have them reviewed at least annually by GP e.g. at health checks. Service users with a learning disability to be supported by providers to attend annual health checks in all settings. • Ensure decisions not to participate in cancer screening programmes are clearly documented. • Ensure that commissioned services facilitate attendance at LD health checks though contractual arrangements. • The Health facilitation team to work with care homes to implement a process to flag up to GPs when Annual health checks are due.
Families/carers	• Ensure that relatives are clear about roles and responsibilities of staff they interact with in both health and social care. • Incorporate families/carers perceptions of changing needs of vulnerable people into risk assessments.
Care providers	• Ensure care providers have an understanding of service user's family tree and preferred contact details. Ensure that families of service users are notified them when a service user becomes unwell. This will need to be made in line with MCA / best interest decisions. Registered managers to draft protocols detailing how this will be achieved including timeframes. • Care provider on-call records/handover should be completed each night and on-call protocols reviewed in light of delays in escalating deteriorating condition. • Supported living staff to record reason for prn medication in notes and MAR charts. This should be linked to PRN guidelines. • Staff to ensure case notes are detailed, descriptive and record full details of events including times of events. Staff signing notes to ensure that initial and name is printed in capital letters. • Appropriate monitoring of temperatures should take place. • Ensure hospital passports or equivalent are regularly reviewed. • Ensure SW or GP is informed when LD patients decline assessment. • Consider how communication with carers from the acute trust can be improved, thereby improving support from carers.
Acute trust	• Acute teams to link with care home managers early during an acute admission to ascertain information and baselines. • A comprehensive history should be taken on admission to hospital which should include history of depression or psychosis. This information should inform risk assessments and care co-ordination to ensure that mental health and wellbeing needs are met within the acute trust setting. This will ensure assessing and meeting emotional needs of LD patients in acute trust settings, linking with specialist teams, is prioritised at the same level as meeting physical needs. • Processes for informing acute trust LD nurses of hospital admissions of patients with LD should be in place. • Improve the standard of hospital discharge letters.

	• Ensure families can access support from the hospital help line and facilitate regular direct conversations with clinical staff particularly medical staff.
GP practices	• GP practices to consider the benefit of having an LD lead who could act as a point of contact for the multi-disciplinary team caring for LD patients. • Clarification required for GP's relating to what constitutes a Learning Disability, the process for formal LD diagnosis and details of thresholds and referral pathways to access specialist services. • Ensure all options explored to support service users to reduce BMI.
Commissioning	• Reduce risks to patients by extending access to hospital transport to ensure LD patients are not admitted to hospital when fit for transfer home. • Commission home visits for specialist services when necessary. Health and social care to work together to strengthen the complex discharge process of LD patients to prevent pro-longed hospital stays and associated health deterioration, utilising step-down facilities if appropriate. • Ensure that LD nurse support for care providers is sustainable and is not impacted by system pressures.
Safeguarding section 42 reviews	• The Adult safeguarding team should receive assurance that the recommendations from the Section 42 Safeguarding Enquiry relating to the care home have been implemented. Evidence that all necessary changes are embedded to be obtained through a follow-up assurance visit. • Outcomes of safeguarding referrals should be fed back to referrers.

Appendix Four: Outcome of Thematic Reviews

Learning		Improvements and Good Practice
Impact of COVID-19	• Short- and medium-term impact and learning from the first wave in preparation for a second wave	• Families and carers have reported that they cannot fault communication from the Acute Trusts • Timely discussions are taking place concerning DNACPR orders and ceilings of care and next of kin are reporting satisfaction with the process. Increasingly community DNACPRs are being put in place and reviewed by Acute Trust medical staff. • Care providers report that they have access to PPE and pulse oximeters. • Examples of NHS 111 improving support to care providers include national review of COVID-19 pathways and attention to ascertaining the existence of a learning disability. • Significant improvements are in place in terms of reasonable adjustment including NOK now having the option to support a loved one in hospital (within parameters), provision of 1:1 care when required and being present at the end of life. • There are good examples of mental capacity assessments and best interest decision making processes which include the next of kin and of fast-track discharge plans and of life care being provided in the residential care setting.
Annual health checks	• How the checks are currently carried out and what are the issues and barriers to completing checks	• Developing clinical LDAHC training, leaflets, Comms for practices, patients and families/carers, care homes. • Data analyst appointed to ensure data accuracy. • Ardens Ltd have developed a data entry template guide for LDAHCs. • Regular Primary Care Bulletin messages. • BLMK Annual Health Check Steering Group in place Bringing together the partners to look at some of the complex issues which we know affect the health of people with a learning disability. • Working with partner organisations to understand more about how services could be changed to help people with a learning disability to live healthier and happier lives. • Looking at ways of making sure people with a learning disability are on a GP learning disability register so that they get the care and treatment they need at the right time. • Sharing what they have learnt and what is working well with other health and social care organisations. • Health Facilitation service engaging with GP practices, families/carers and a focus on children and young people.

		- Focus on understanding barriers to engagement as well as driving uptake and quality. - Focus on quality of health action plans. - Plans for outreach into local Black Asian and minority ethnic communities using specialist expertise. - Looking to building on exemplar work with plans for longer term sustainability.
Speech and language therapy – assessment and practice	- Dysphasia training be provided for carers and professionals - Dysphasia and nutrition plan is in place what is the best way to ensure ongoing monitoring and review of the condition	- Dysphagia and Nutrition Team (DANT) offer Training 2-4 times annually through Milton Keynes Council Training Department and is a full day course delivered by Speech & Language Therapy, Dietician, Community Nursing, Physiotherapy and Occupational Therapy. Carers, professionals and provider services can attend. It is mandatory for Council staff who support people with a learning disability to attend every 4 years with refresher training (online) at the 2-year point. This is not the case for external provider services; however, the training does encourage attendance at the training or access to available online learning. All DANT Plans give details of available training on the back – DANT Course, Dysphagia training through Health Education England and Grey Matter Learning. - Once a service user has been assessed and a DANT plan is sent, the service user is then telephone reviewed at 6 months, or earlier, if necessary, with a face-to-face assessment at 12 months. A care plan summary is sent to carers following the telephone review and a full DANT plan is sent after each face-to-face assessment/review. Care staff are encouraged to email if they have concerns outside of the reviews and those contact details are written on both the DANT plan and DANT Summary. - Outcomes are measured using both Therapy Outcome Measure system (TOMS) and outcome sheets, both on SystmOne. Between reviews a safe oral feeding package is opened and is evaluated following each review, TOMS are evaluated annually. TOMS focuses on 4 areas – Impairment, Activity, participation, and wellbeing. - Outcome sheets and safe oral feeding package focus on maintenance of current recommendations for the service user and how effective they have been in reducing the risk of aspiration.
Epilepsy pathways and care	- What system-wide training and support is required to improve epilepsy	- There has been a lack of understanding and awareness in relation to epilepsy. - Offer of generic epilepsy care planning and awareness training to all; this is offered an open session and people need to book a place. The training provides information

	care for people with a learning disability	in relation to epilepsy, first aid, Buccolam protocols, Care planning, Sudden Unexpected Death (SUDEP) awareness. There is a person-centred approach, when booking an appointment we telephone prior to the appointment, offering either a virtual/Face to face or home assessment depending on needs. Ongoing appointments are booked based upon patients' needs and support required/ wanted. • There are links with the learning disability teams, Hospital liaison teams, ALDT, special needs school nurses and Twinwoods, to gain background information and if additional support is required, we can work together. • Easy read information has been developed, which is shared openly, therefore can be accessed for patients who may not come under our service. • Undergone social story training provided for patients who may need this. • There is a gap in service in relation to absence seizures and Sensory processing disorder. • Beginning to work with mental health team and people participation manager in relation to developing a guide.
Falls and dementia – screening, risk and assessments and referrals	• How can we improve risk assessments and risk mitigation around someone's seizures	• In the process of amending our referral criteria to enable the Luton falls service to accept self-referrals (this was as direct feedback from the LeDer review on falls) which would make it easier/ improve accessibility for all patients including those with learning disabilities to access our service • Actively trying to improve awareness among the falls team around learning disabilities and trying to think differently about how to improve the support to learning disability patients to accept offers of a falls assessment and onward referrals/ signposting to be more inclusive, for example - a recent learning disability patient that had difficulties contacting over the phone, a cold call visit was made but on arrival the patient became very frightened with staff wearing PPE/ nervous and declined our offer of a falls assessment initially/ asked not to come back but with his consent the team contacted his support worker who in turn helped his understanding. Information was shared prior to the visit which his support worker helped explain to him and he did agree to a falls assessment with his support worker present. • There are still gaps in the wider system as it's not always easy to identify the patient has learning disability on the Systmone record does not always make it clear the patient has additional needs/ needs more support.

		• There is a wider gap too around learning disability and aging people living longer. In terms of falls and frailty there is a need to consider how services and systems can support these patients as they age and but also ensure they have early intervention and prevention and proactive care of their health and wellbeing so in turn they be supported to live/ age well.
DNACPR, Palliative and End of Life Care Pathway	• DNACPR timing, process, communication • Training for end-of-life pathway	• There have been times in which the reviewer was unable to determine whether the process for making a DNACPR decision had been correctly followed, however the reviews found that the majority of people did have a DNACPR in place. • Skills for care training to provide care workers with a greater understanding and confidence when caring for individuals near end of life, with recommended e-learning sessions. • Keech have put in place Principles of End of Life Care Rolling Programme, where any unregistered health care professional, such as health care assistants, carer, support worker etc can gain more confidence for the care of patients with a palliative and end of life care diagnosis