NHS
Stockport
Clinical Commissioning Group

Learning Disabilities Mortality Review (LeDeR) Programme Stockport Annual Report 2020/2021

Stockport LeDeR Steering Group

NHS Stockport Clinical Commissioning Group will allow people to access health services that empower them to live healthier, longer and more independent lives.

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Policy Impact:	The National Learning Disability Mortality Review Programme (LeDeR) was established to drive improvement in the quality of health and social care service delivery for people with learning disabilities, by looking at why people with learning disabilities typically die much earlier than average.
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Learning Disabilities Mortality Review (LeDeR) Programme
Stockport Annual Report 2020/2021

Executive Summary

This is the 2020/21 Stockport LeDeR Annual Report. The report outlines progress made against the priorities from the 2019/20 annual report and identifies themes and learning from the reviews completed over the last 12 months. The author will make recommendations for consideration by the LeDeR Steering Group, Health Equalities Group and Health and Wellbeing Board.

While there is no LeDeR action plan, this does not mean that learning and improvement has not taken place across our systems in Stockport in relation to some of the emerging learning over this year.

Covid-19 has highlighted fundamental inequalities, not least for those with a learning disability. The reviews into the lives and deaths completed through the LeDeR programme allow us the opportunity to learn and develop as a system, with the objective of improving the lives of those with a learning disability and supporting the strategic aim to reduce health and social care inequalities.

The key themes emerging from the reviews completed in 2020/21 are:

- Nutritional needs and oral care
- Managing constipation
- Learning disability support and expertise in the acute hospital
- Implementation of health passports
- Reviews of medication, most notably psychiatric medicines
- Learning disability annual health checks
- Health screening for people with a learning disability
- End of Life Care
- Cross agency communication, especially when transferring between services
- Application of Mental Capacity Act
- Learning for care and nursing homes
- Carers assessments

There are a number of ‘best practice’ examples within the report and they illustrate the progress made across the health and social care system, to ensure reasonable adjustments are considered and that the needs and views of people with a learning disability are listened to.

It is accepted that there is work to be done in Stockport and that a system wide action plan needs to be developed in order to realise improvements and embed change.

Glossary of Terms

ASC Adult Social Care sits within the Authority and refers to a system of support designed to maintain and promote the independence and well-being of disabled and older people, and informal carers. The Care Act 2014 is the law that sets out how adult social care in England should be provided.

CCG Clinical Commissioning Groups commission most of the hospital and community NHS services in the local areas for which they are responsible.

PCN Primary Care Networks are a general practices being a part of a network. The networks provide the structure and funding for services to be developed locally, in response to the needs of the patients they serve.

SALT Speech and Language Therapists provide treatment, support and care for children and adults who have difficulties with communication, eating, drinking and swallowing.

MCA The **Mental Capacity Act** is designed to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment. It applies to people aged 16 and over.

DNACPR Do Not Attempt Cardio-Pulmonary Resuscitation is a decision not to attempt CPR, made and recorded in advance, to guide those present if a person subsequently suffers a cardiac arrest.

STOMP Stopping over Medication of People aims to stop the overuse of psychotropic medications for people with a learning disability, autism or both when appropriate and in a safe way.

STAMP Supporting Treatment and Appropriate Medication in Paediatrics aims to ensure that children and families can access other treatment and support when children display behaviours that challenge.

Acknowledgments

Thanks go to all those who have contributed to the development of the annual report and their continued commitment to improving the lives and experience of people with a learning disability in Stockport:

Catherine Watson: Integrated Clinical Team Manager, Community Learning Disability Team
Rick Craven: Senior Information Analyst, NHS Stockport CCG
Gina Evans: Joint Commissioning Lead, NHS Stockport CCG
Dr James Higgins: Clinical Director, Tame Valley PCN & GP Brinnington Surgery
Sue Jeeves: Safeguarding Team Co-ordinator, NHS Stockport CCG
Serena Kent: Patient Experience Manager, NHS Stockport CCG
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Wendy Stewart: Named Nurse for Safeguarding Adults, Stockport NHS Foundation Trust
Lee Woolfe: Safeguarding Adults Board Business Manager, SMBC
The families and carers who have contributed to the LeDeR reviews
All of the LeDeR reviewers from the CCG and NHSE/CSU.

Introduction

❑ About Stockport

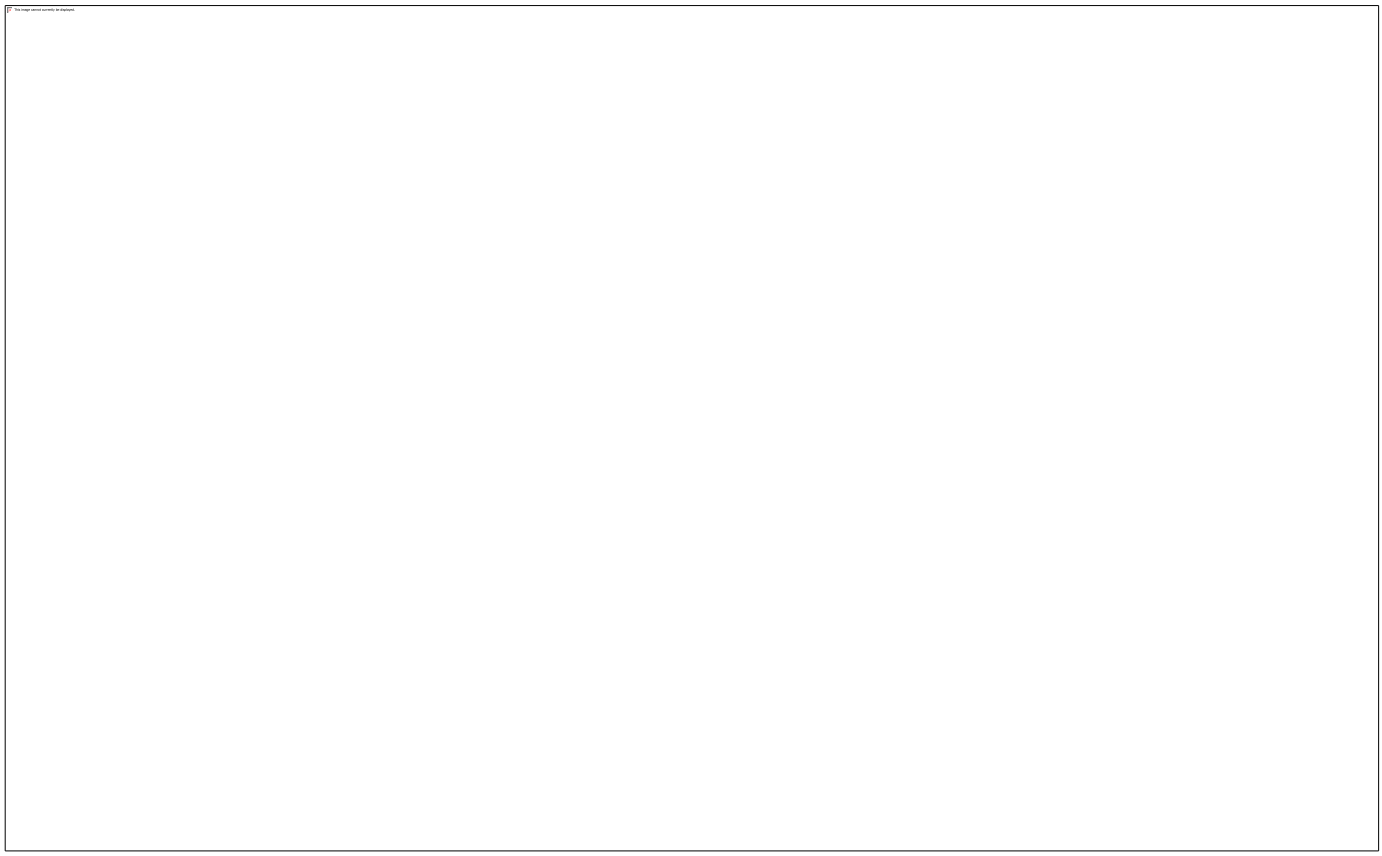
Stockport is a large town to the South East of Manchester, and is within the borough of the same name. Stockport is one of the ten boroughs making up Greater Manchester.

The population in the borough of Stockport for 2020/2021 is recorded as 293, 423; with just under 1400 people on GP learning disability registers.

The borough is served by Stockport NHS Foundation Trust, with its main acute hospital based at Stepping Hill. Mental health services are provided by Pennine Care NHS Foundation Trust (FT). Learning disability services are provided in an integrated model across Pennine Care NHS FT and Stockport Local Authority.

Stockport has a limited ethnic diversity, with over 95% of the population identifying as white, 2% as Asian and 0.4% as black.

Although there are some suburbs of Stockport which rank amongst the wealthiest in the North West, there are also areas of widespread poverty and deprivation.



(Source: Stockport Safeguarding Adults Annual Report, 2019/20)

❑ The LeDeR Programme in Stockport

This report is the second annual report on the learning from deaths of those with learning disabilities (LeDeR) within Stockport. The report covers the period from **01 April 2020 to 31 March 2021 (2020/21).**

The LeDeR programme is aimed at making improvements to the lives of people with learning disabilities. Reviews are being carried out with a view to improve the standard and quality of care for people with learning disabilities. People with learning disabilities, their families and carers have been central to developing and delivering the programme. Within Stockport, the programme is led and managed by NHS Stockport CCG but is delivered in conjunction with health, social care, families, carers, advocates and providers within Stockport.

Throughout the report, examples of learning and good practice from reviews will be highlighted in green banners.

The LeDeR process in Stockport (Appendix 1) remained unchanged for 2020/21, although Steering Group and Health Inequality Group meetings were suspended during the height of Covid-19, which has had an impact on the local system developing an action plan and implementing learning from LeDeR reviews during the last year.

The completion of reviews has been more challenging during 2020/21, with local staff who provide the information and case notes to inform reviews focussing on core statutory roles and pandemic response. This has had a clear impact on the capacity of staff in hospitals, nursing homes, community services and GP practices to source, scan and upload notes to the LeDeR system.

There has also been an impact on the resilience of local reviewers during the pandemic, who under the current system of managing the LeDeR programme in Stockport, have committed to taking on reviewer roles outside of their core roles and functions. As LeDeR is not yet mandated, pandemic response and statutory roles have taken priority for organisations across the health and social care system.

Progress from 2019/2020 Annual Report

The 2019/20 LeDeR Annual Report identified a number of 'next steps' for action and implementation during 2020/21. Despite the challenges of responding to the Pandemic and the impact on services from Covid-19, there has been progress against some of these identified priorities.

Ensure STOMP and STAMP is rolled out across Stockport by partners.
Work has been undertaken by the CCG Pharmacist with the Consultant Psychiatrist for LD to check GP records for people to whom STOMP would apply and to do some analysis and comparison with those on the LD psychiatry caseload. The Consultant Psychiatrist for LD has been working on medication reducing regimes for people with LD and will be sharing this data with the Health Equalities Group when it

reconvenes post-Covid.

Pennine Care NHS FT developed 'good practice guidance' for prescribing psychotropic medications for adults with learning disabilities presenting with 'behaviours that challenge'; this is currently going through their quality and governance approval process. It covers the prescription of any psychotropic medication including antipsychotics, antidepressants, anxiolytics or mood stabilisers and sets out a framework for clinicians on how to rationalise their prescribing practice and where appropriate, taper and stop psychotropic drugs.

Working group to implement Health Inequalities policy as part of the learning disability strategy implementation

There is currently no policy around LD health inequalities for Stockport, however the Health Equality Group will be supporting and monitoring practice in this area when it reconvenes post- pandemic. The leadership for implementation of policy and delivery of health equalities sits with the Local Authority with input and collaboration of system partners.

Increase the uptake of age and gender appropriate health screening utilising the Learning Disability GP Liaison Role in order to increase awareness

The development of this role has been helpful in supporting practices to validate their LD registers and with practical advice and guidance, to help people with a learning disability to access health checks and health services. A number of practices report that they have contacted the liaison worker for advice and support over the last year.

Feedback is generally positive regarding this initiative, however as there is only one Learning Disability GP Liaison Worker, there are times when this support is not available. Consideration is being given to establishing a Vulnerabilities Care Co-ordinator in one Primary Care Network in order to enable more comprehensive support and input.

Continue to share the learning into action and consideration of a learning event during 2020/21

The CCG and partner agencies have continued to share learning into action during 2020/21 and the outcomes are described in the learning section of this report.

Due to the Covid-19 pandemic, there has not been the opportunity to hold a learning event during 2020/21. The LeDeR Steering Group has agreed that an event to share good practice and learning will be delivered in 2021/22, utilising a 'learning circle' approach and inviting providers to share the learning, good practice and achievements.

Increase the numbers of reviewers to reduce the length of time it takes for a review to be assigned

During 2020/21, Stockport had access to one additional local reviewer. Due to the Covid-19 pandemic, while there was an additional reviewer, the pressure on services meant that staff were focussed on priority areas within organisations. This had a direct impact on the resource available to complete reviews.

The CCG was supported by NHSE/I and the NE Commissioning Support Unit to complete reviews and a significant number of reviews were assigned in a timely manner to those

workers. It is of note that this support will not extend in to 2021/22.

Developing a business case for investment in an employed part-time reviewer and for a part time LeDeR Nurse/Practitioner who can support the reviewers and provide training around the identified learning
A business case was submitted to the CCG Executive Team and Workforce Group for a part time LeDeR Nurse/Practitioner, in order to support the CCG in meeting the contractual key performance indicators for completing reviews. The post has been successfully recruited to, with the Nurse/Practitioner due to start in late July 2021. In light of the publication of the National LeDeR Policy and the implementation of a new process and system from June 2021, consideration will need to be given to the resource allocated to LeDeR delivery.

To increase the awareness of Sepsis in people with a learning disability including prevention, early identification and treatment amongst people with a learning disability, their families and paid carers
The LeDeR briefing poster for carers about Sepsis has been shared widely across learning disability services, providers and the Stockport Metropolitan Borough Council Quality Team. Assurance has been sought from teams that the briefing is available and accessible to all staff and carers. A series of social media posts with the hashtag #SpotTheSigns were posted by NHS Stockport CCG to promote understanding of the signs and symptoms of sepsis to the wider community.

Increase professionals' knowledge, confidence and competence with the understanding and application of MCA, ensuring that mental capacity assessments are completed fully, appropriately and in a timely manner
There has been clear progress against this priority, with some measurable improvements in practice. This work is outlined in the learning section of this report. The CCG, Stockport NHS Foundation Trust, Local Authority and Primary Care Networks have developed tools and training within their organisations, to support all staff in applying the MCA appropriately across the health and social care economy. There is still a great deal of work to be done to fully embed MCA in practice and this will remain a priority.

Further assurances are requested from the Stockport Health Equalities Group that providers are implementing the learning from reviews, to ensure robust processes and procedures are in place across Stockport to address the lessons and themes found in the completed reviews
There has been a pause in the Health Equalities Group during the pandemic, with meetings scheduled to resume in 2021/22.

As the governance and oversight process for LeDeR is reviewed over 2021/22, a comprehensive system to monitor implementation of learning from reviews will be developed. This will require system wide engagement from steering group partners.

Governance Arrangements

Stockport has a well-established LeDeR Steering Group. The purpose of the Steering Group is to work in partnership to support, promote and implement the process for reviewing deaths of people with learning disabilities. The group has a responsibility to consider the lessons learned from the reviews and take forward any subsequent actions and improvements to care provision in Stockport.

The Steering Group brings together representations from all areas of Stockport including commissioners, provider organisations and those representatives with a specific area of interest to share best practice, with the ultimate outcome to reduce avoidable deaths in people with a learning disability in Stockport.

During Covid-19, some meetings of the Steering Group have been stood-down in order that services are able to prioritise the pandemic response and recovery. This has provided an opportunity to reflect on the effectiveness of the governance arrangements and a priority for 2021/22 will be to review the terms of reference, membership and output from the Steering Group.

The Local Area Contacts present the LeDeR Annual Report to the Health and Wellbeing Board for scrutiny and sign off and do a 6 month update on progress against actions and implementation of learning.

Performance oversight is with NHS England/Improvement, with clear key performance indicators in the contract with the CCG.

The performance indicators for 2020/21 are:

1. CCGs will complete 100% of reviews within 6 months of notification;
2. CCGs will produce a LeDeR Annual Report, which will be published by 30 June 2021.

The CCG also retains responsibility for extracting learning and themes, which are presented to the Steering Group in order to formulate an achievable and measurable system wide action plan.

There is currently no system wide action plan in place and this is something which will need to be addressed in the coming year through the governance and oversight processes within Stockport. The arrangements for governance and oversight of LeDeR sit with the local multi-agency LeDeR Steering Group and the Stockport Health Equalities Group.

Performance Data

- There were 23 notifications made to the LeDeR platform in 2020/21. Of these, 5 reviews have not been completed. There are a further 6 reviews which were completed in April 2021 and are therefore outside the reporting period and not included in this report.

- There were 37 reviews of the deaths of people with a learning disability completed in 2020/21 and one Child Death Overview Panel (CDOP) review (total: 38).

- In Stockport we completed no Multi-Agency Reviews (MAR) during 2020/21; however there were 6 reviews which met the threshold for MAR. These were not progressed as MAR due to parallel processes meeting the requirements, such as incident and multi-agency safeguarding investigations.

During 2020/21, 13 reviews were completed by 8 CCG reviewers

Stockport CCG achieved a 95% review completion rate against the Contractual KPI of 100% for reviews notified before June 2020

During 2020/21, 23 reviews were completed by CSU/ NHS England reviewers

During 2020/21 the CCG commissioned 1 independent review

During 2020/21 there was 1 CDOP review

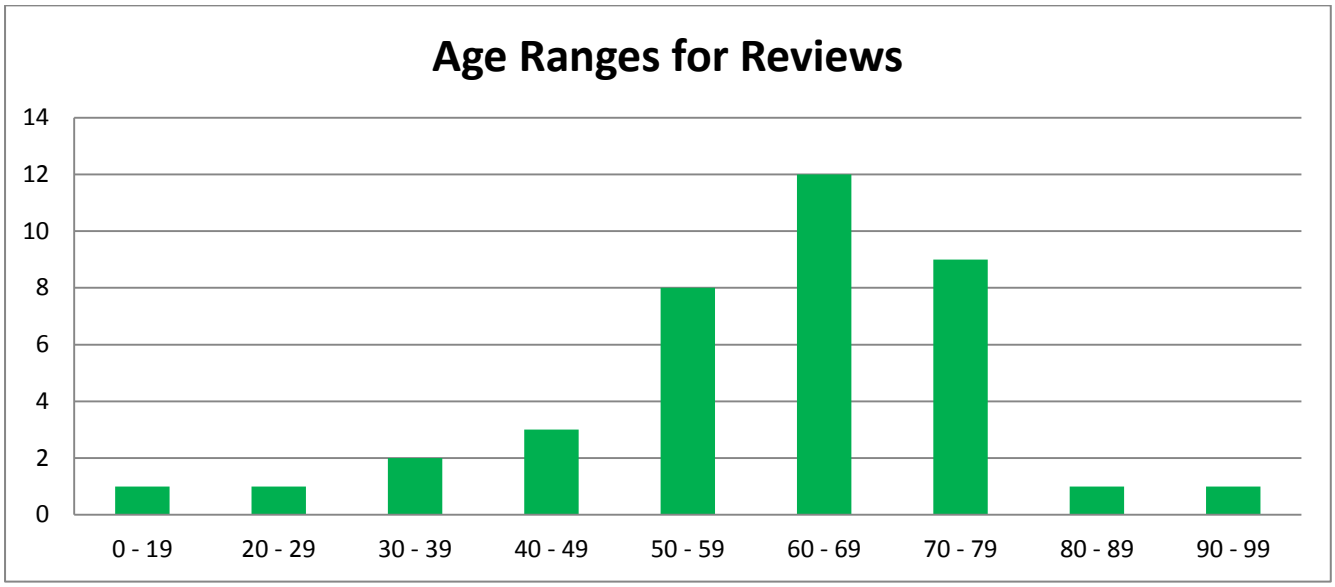
Stockport CCG achieved a 56% review completion rate against the Contractual KPI of 100% for reviews notified after June 2020*

*An additional 6 reviews were submitted and approved in April 2021 which are not eligible for inclusion within this reporting period

Demographic Data

❑ Age ranges

The majority of reviews (29/38) were undertaken for people who died between the ages of 50 and 79 years old, with the 60 – 69 age group being the highest with 12 reviews.



❑ Average age at death

Stockport LD deaths 2020/21

Average age of death was **60 years old** for LD deaths

Average age for **males = 65 years old**

Average age for **females = 54 years old**

National LD deaths

Average age for **males = 61 years old**

Average age for **females = 59 years old**

ONS data for general population deaths

Average age for **males = 79 years old**

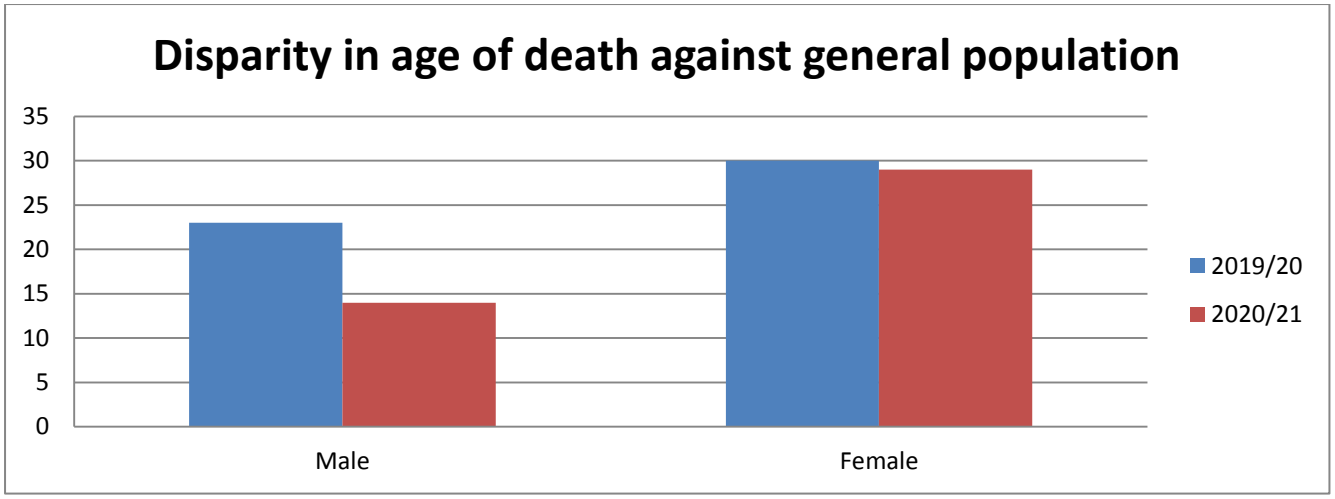
Average age for **females = 83 years old**

The Learning Disability Mortality Review (LeDeR) Programme. Annual Report 2019/20. University of Bristol Norah Fry Centre for Disability Studies

The gap between the ages at death reported nationally for people with learning disabilities (aged 4 years and over) and the general population (all ages) is 23 years for males and 27 years for females.

In Stockport, the data for average age of death for females with LD is lower as there is a child death included. Without the child death, the average age of death for adult females with a learning disability is 57 years old. While still below the national average age of death for people with a learning disability, it provides a more comparable reflection.

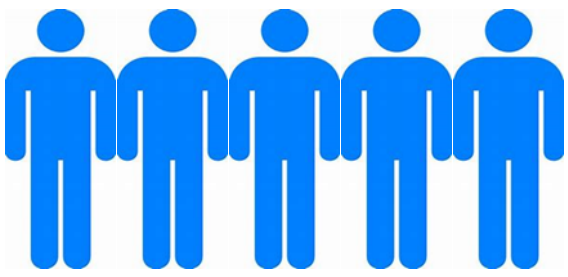
The Stockport data suggests that the disparity between the age at death for people with a LD (aged 4 years and over) and the general population (all ages) is 14 years for males and 29 years for females. This shows an overall reduction in the disparity from 2019/2020 data:

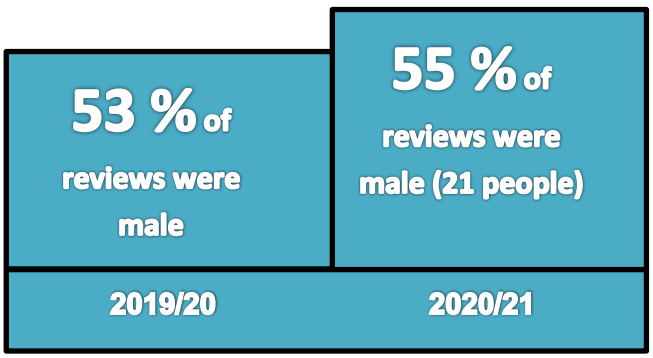


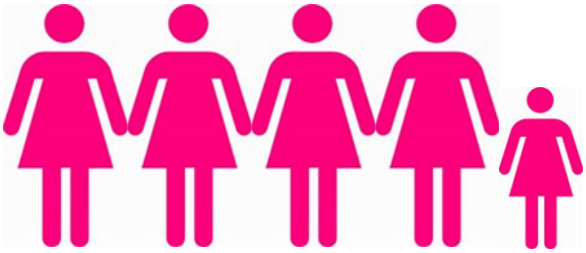
Nationally, the median age at death for someone with profound learning disability is 40 years. The Stockport reviews of people with a profound learning disability (3 reviews) show an average age at death as 31 years.

❑ Gender

The gender of those who have had reviews shows little percentage variation from the figures reported in from 2019/20, although there is a significant increase in the number of completed reviews overall.







47 % of reviews were female (7 people)	45 % of reviews were female (17 people, including 1 child)
2019/20	2020/21

- Ethnicity

The 2019/20 National LeDeR Annual Report provides insights into the ethnicity of those whose care has been reviewed as part of the LeDeR programme. Nationally, 90% of reported deaths were for people who identified as White British.

The Stockport data from reviews completed in 2020/21 shows a slightly higher percentage of those whose ethnicity was recorded as white British, however this does largely reflect the ethnic groups in the general population in Stockport.

92% of deaths ethnicity was given as White British (35 out of 38 reviews)

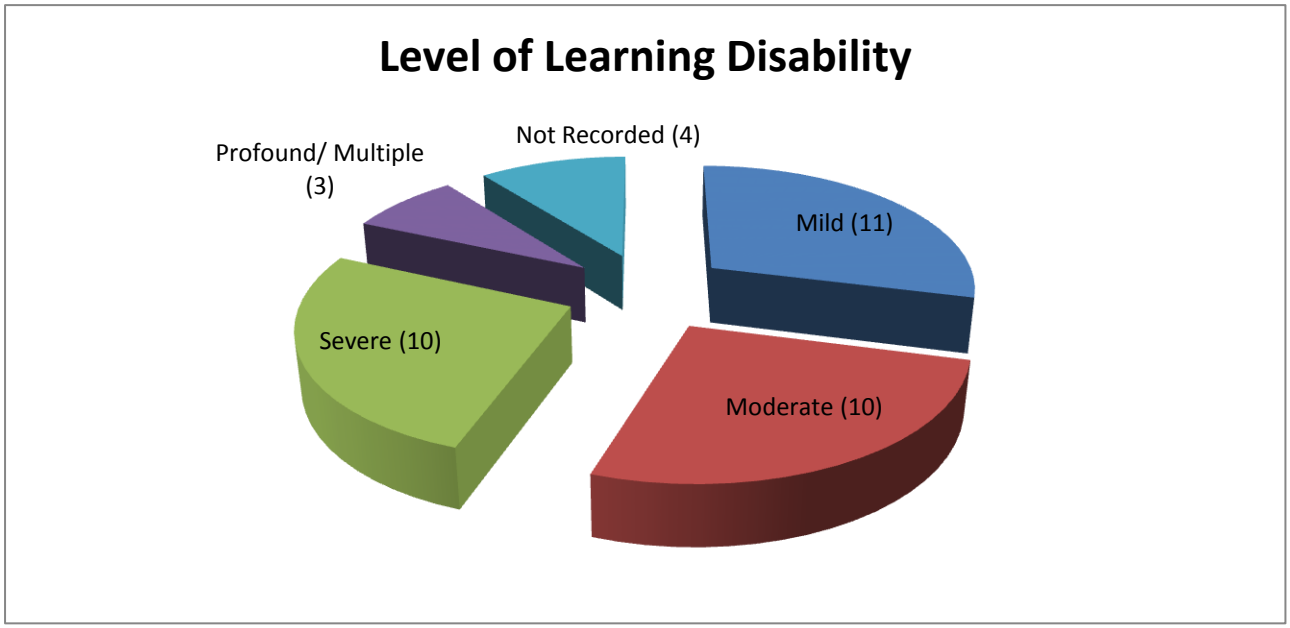
3% of deaths ethnicity was given as Pakistani (1 out of 38 reviews)

5% of deaths ethnicity was not recorded (2 out of 38 reviews)

Nationally, people with a learning disability from Black, Asian and Minority Ethnic groups died disproportionately at younger ages than white British people. Of those who died in childhood (ages 4-17 years), 43% were from BAME groups.

In Stockport, there was one notification for a person who died in childhood and that person's ethnicity was recorded as Pakistani.

- Level of learning disability



Staff reassured the person of any changes in routine at least a week before they happened. This included visitors, appointments and signposting to all events, using social stories and communicating in a way which promoted choice and independence.

- Place of death

42 % of people died in their usual place of residence

11% from 2019/20

47% of people died in hospital,

13% from 2019/20

A lower proportion of people with a learning disability died in hospital than in 2019/20. There is good practice identified in reviews to evidence that people, where possible, are supported to die in the place of their choice.

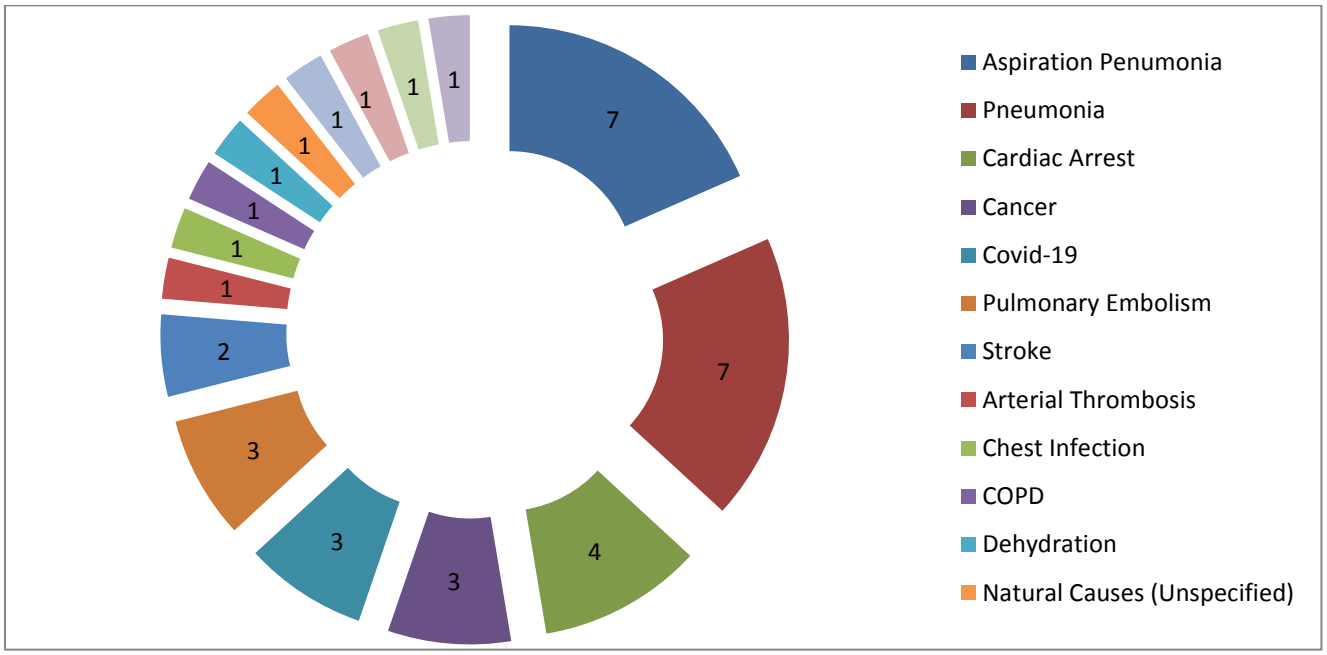
Where people died in a hospice or nursing home, these placements were appropriately used to meet an identified health need, and there is evidence in all cases that this was agreed as part of an Advanced Care Plan.

A person was admitted to hospital, and when it became clear that they would be on an end of life pathway, they were supported to return to their usual residence to die. The supported living staff had already been working with the person on a 'when I die' template, which meant that the persons care needs, wishes and preferences were clear and could be met.

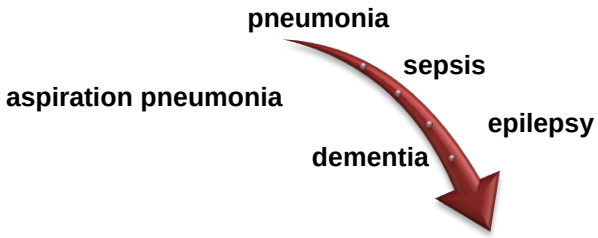
Cause of Death and Quality of Care Data

❑ Causes of death

The chart illustrates the recorded causes of death from completed LeDeR reviews during the reporting period. There were 16 causes of death recorded across 38 reviews.

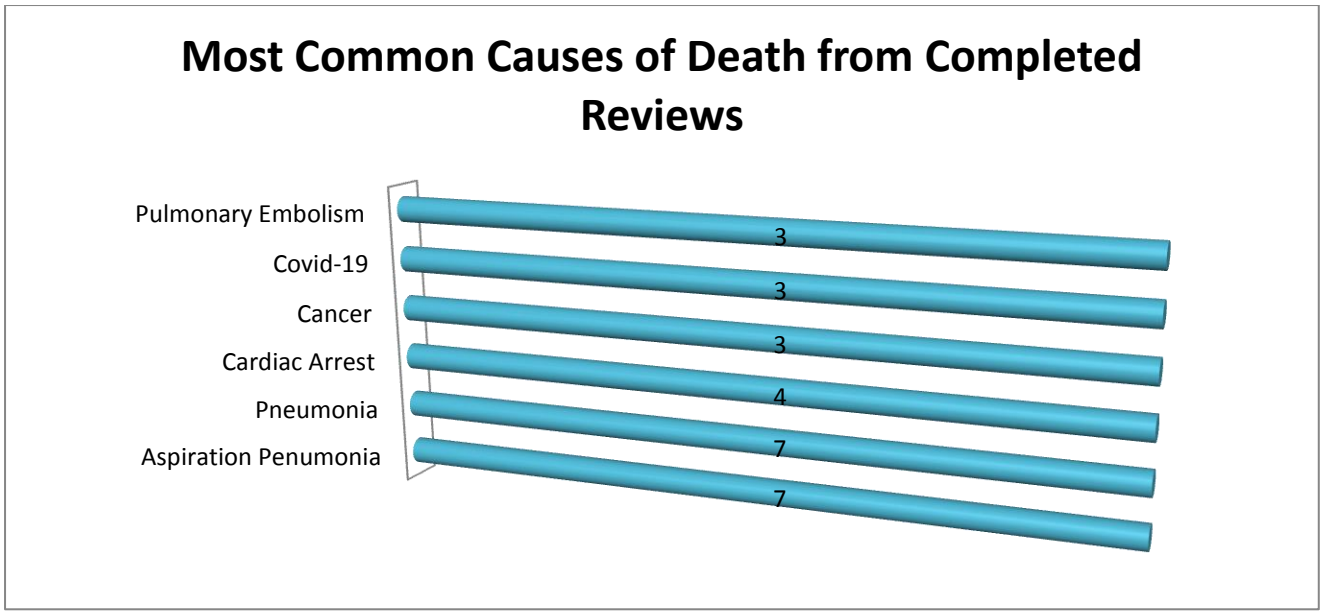


It is reported nationally that the commonest recorded causes of death for people with LD, with pneumonia and aspiration pneumonia being the most reported, are (in order):



For Stockport, the most common causes of death were recorded as pneumonia and aspiration pneumonia, which is consistent with national reporting.

Locally one person was recorded as having died of Sepsis and one from Epilepsy, presenting a differing picture to that nationally.



- Learning from Covid

Stockport recorded lower numbers of deaths of people with a learning disability from Covid-19 being the primary cause of death. During 2020/21 there were 3 deaths for which Covid-19 was the primary cause, with another 2 recording Covid-19 as a contributory cause (primary cause in both these cases was pneumonia).

Data is only available for deaths where Covid-19 is the primary cause of death and in Stockport, those with a learning disability accounted for 0.5% of Covid-19 deaths locally (against a national estimated average of 2.5%).

There is clear evidence in reviews that people have been supported effectively during the pandemic and that there is no specific learning to come out of the completed reviews locally.

Easy read information was provided by the care provider on COVID 19. Staff spoke to residents about this regularly and made sure they had masks and hand sanitiser when they accessed the community; they supported them around understanding and maintaining social distancing.

❑ Quality of care

At the end of a review having considered all of the information available, reviewers are asked to provide an overall assessment of the care provided to the individual and grade this against clear standards.

In one review, the GP surgery in particular played a central role in not only health needs but in going the 'extra mile' to support the person with immediate crises, which were often social rather than health related; they also supported with housing issues, recognising the impact on anxiety that these had.

The reviews where care fell short of expected good practice and had the potential to contribute to cause of death, were graded as such due to:

- Delayed testing and diagnosis in commencing treatment for sepsis could have contributed to the death of the person, due to the time sensitive need to commence treatment.

The table below shows the grading of care and the LeDeR reviewers' overall assessment of the care received:

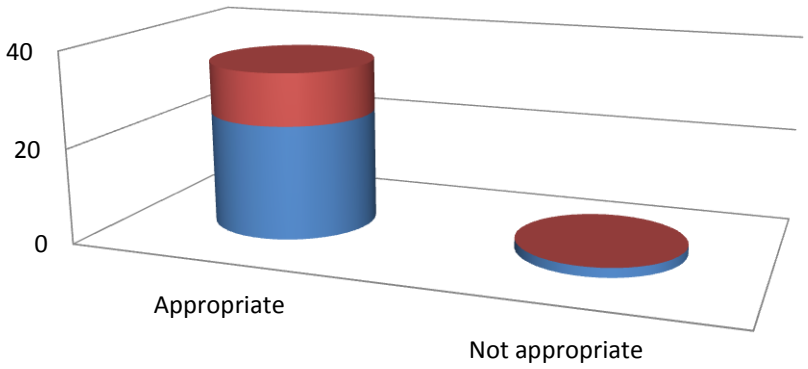
Grading of Care in Adult Cases	2019/20	2020/21
1 = Excellent Care	0	4 (10%)
2 = Good care	8 (57%)	15 (41%)
3 = Satisfactory Care	4 (29%)	12 (33%)
4 = Care fell short of expected good practice but did not contribute to the cause of death.	2 (14%)	4 (10%)
5 = Care fell short of expected good practice and had the potential to contribute to the cause of death	0	2 (5%)
6 = Care fell short of expected good practice and this contributed to the cause of death.	0	0
The child Review was not graded as it was a CDOP review		

There were also 4 reviews which were graded as excellent care and it is important that the learning from these is shared to promote good practice.

The sister of a person who has died told the reviewer that the early work and input from Psychiatrists, including medication management over the years, was significant in establishing a level of stability and quality of life for that person.

Feedback from the brother of a person who died, praised the leadership skills of the team manager in ensuring the staff team were supported during the last days of the person's life, which enabled the staff team to deliver care above and beyond their core duty. Provider care was well supported by the District Nursing Team and Community LD Team.

- ❑ DNACPR numbers and comments re appropriateness



	Appropriate	Not appropriate
No DNACPR	11	0
DNACPR in place	24	2

It is positive to note that the majority of DNACPR decisions were appropriate and that the documentation and decision making was clearly evidenced.

Analysis of the reviews shows that where people were felt to be generally well, a DNACPR was not agreed; there was no blanket decision making and the majority of the DNACPR conversations and decisions were completed in a person centred way.

The two identified as not appropriate were categorised as such because the decision was taken without consultation with the person, their advocate or people who knew them well and there was no capacity or best interest process documented.

- Role of cancer screening

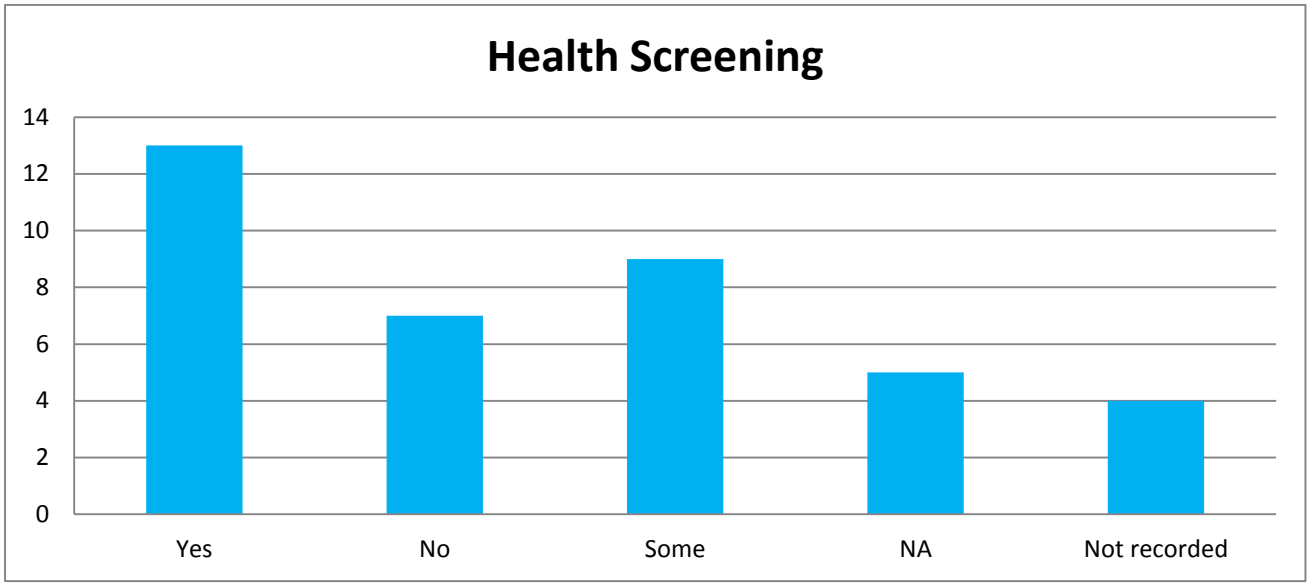
Unfortunately data for cancer screening in LD is not currently available for 2020/21.

National data from 2019/20 is available for cervical smear tests, with 33.6% of eligible patients with a learning disability having had an adequate smear test. The percentage of eligible patients without a learning disability who had an adequate smear test percentage points over the same period was 71.8%. This shows a significant disparity in access for people with a learning disability.

The next chart shows the percentages of people with a diagnosis of cancer nationally and while diagnostic rates are lower for those with a learning disability, the evidence suggests that this may be in relation to reduced uptake of cancer screening.

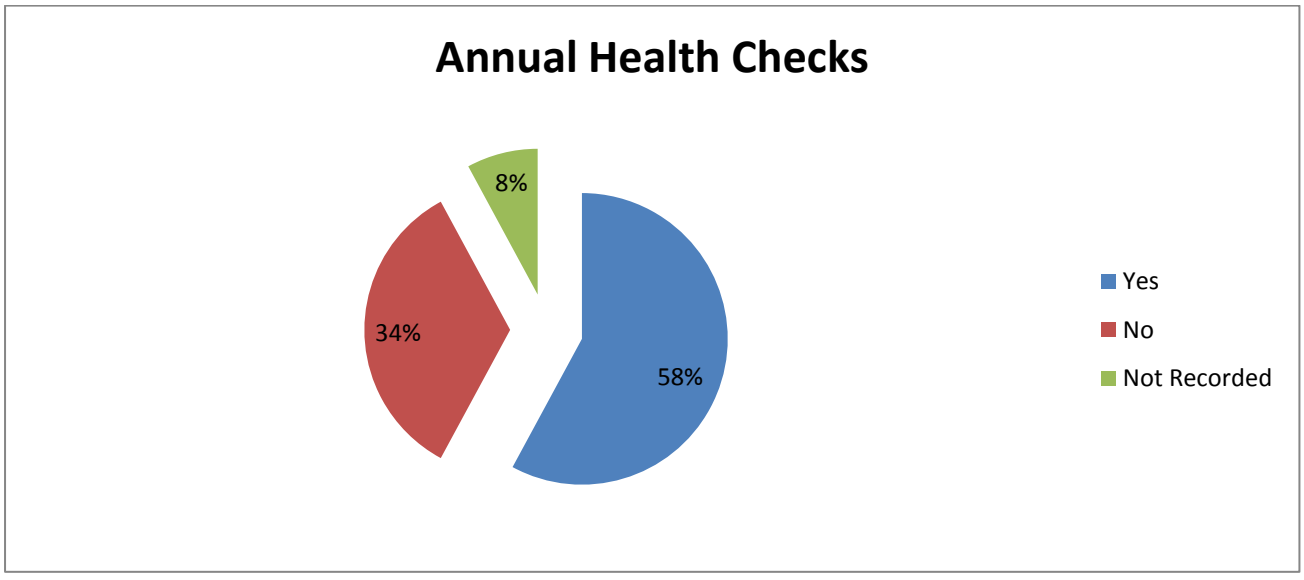
- Health Screening

Data from Stockport LeDeR reviews in 2020/21 shows performance for gender and age appropriate health screening for people with a learning disability. This shows that 55% of people either had all or some health screening, noting that not all those with a learning disability who died were part of cohorts who would be eligible for health screening (NA).



❑ Annual Health Checks

In 58% of reviews, it was recorded that appropriate annual health checks took place in primary care in 2020/21.



Of the 34% (13) of cases where an annual health check did not take place, 6 of these offered no rationale for why this did not happen and often health checks had not taken place in the preceding years.

The remaining 7 reviews in this cohort offered supporting information as to why there had not been an annual health check:

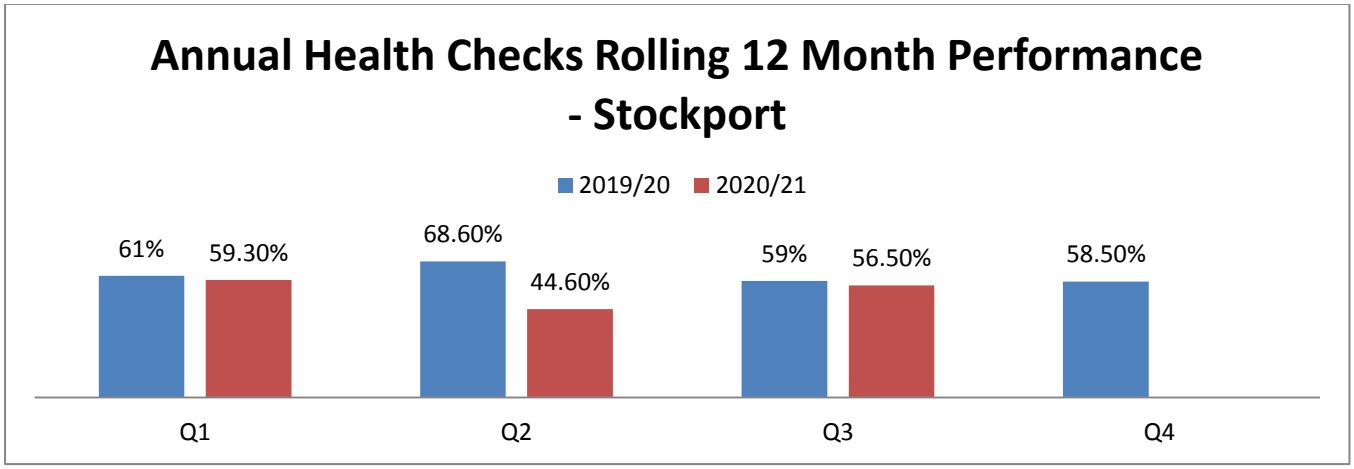
- The annual health check was postponed during the early stages of Covid; this was in line with a national pause on LD annual health checks in primary care during the initial

pandemic response. It is of note that in all these cases, an annual health check had been scheduled, however the individuals sadly died before these appointments could take place;

- Annual health checks were offered, however the person declined or refused these. In these cases the person was assessed as having the capacity to make this decision;
- The person was not on the Practice LD register;
- The person was admitted to hospital prior to the annual health check;
- An annual health check was not formally recorded; however there was clear evidence that the components of this were integrated into their general care.

A review highlighted that the person declined to attend the GP practice for annual health checks; they were scared of hospitals and clinics, and became incredibly distressed at the thought of attending. In response to this need the Practice arranged for all the person's annual health checks to be completed at their usual place of residence.

The chart below shows the performance for Stockport, for the total number of patients aged 14 years or over in the last two financial years (on Practice agreed learning disabilities registers) that have received a learning disability health check by the GP practice in the last 12 months. The data broadly matches the performance data captured in the LeDeR reviews. Data for Q4 2020/21 will not be made available from NHS Digital until July 2021 so cannot be included.



Summary of Local Learning from Reviews

Mental Capacity Act & Supporting Decision Making 	There continues to be notable variance in the application of the Mental Capacity Act for people with a learning disability. Reviews show that while there are references in notes to say capacity has been assessed and considered, formal documentation is often not completed. **Recommendation**: Services should provide assurance that staff are familiar with MCA and BI paperwork and that it is completed appropriately. Over the last year, MCA pocket guides have been made available on our acute hospital wards and there has been a multi-agency MCA audit and learning workshop led by the Safeguarding Adult Partnership Board. MCA pocket guides have additionally been developed for use by all safeguarding partner agencies, and this has included distribution to local GP practices to support the application of the process. The pandemic and the vaccination programme have given the opportunity to develop and deliver some focussed learning sessions for staff across the system about MCA and Best Interests. Attendees have included managers and staff from Learning Disability supported accommodation services, social care, nursing and care homes, and Continuing Health Care nursing staff. It is also clear through safeguarding assurance processes that practice in relation to MCA and Best Interests is improving. Reviewers have noted some excellent evidence of working with the individual and their family to support decision making in both primary and secondary care. One review noted that where people are assessed to have capacity yet make unwise decisions, this makes it difficult for services to intervene without coming into conflict with the person's human rights. **Recommendation**: Services should consider collating how many people fall into this group, and develop a specific engagement pathway/service to promote access to services.

Annual Health Checks 	There is a Directed Enhanced Service with the CCG and GP Practices to deliver the annual health checks for Stockport residents who are living with a learning disability. Completion of annual health checks is included as a quality marker in the Impact & Investment fund targets and is also one of the "must do's" in the £150m support fund for general practice announced in early December 2020. This allows for practice delivery in this area to be audited and benchmarked. A letter was sent out to the Stockport Primary Care Network clinical leads by NHS England/Improvement, to remind them about staying focussed on annual health checks for people with a learning disability during the pressures of the pandemic. **Recommendation**: Promotion of annual health checks should continue to be a focus for improvement in 2021/22, with a clear project plan to support this.
Learning Disability support and expertise 	A theme from the reviews completed in 2020/21 is the need for specialist LD support and expertise within the Acute Trust. This is recorded as a failure to make reasonable adjustments for those with a learning disability, who may need additional support whilst in a hospital setting. **Recommendation**: A learning disability liaison nurse role should be established within the Acute hospital setting. Reviews have identified some challenges in people receiving the right level of care and support from statutory services. There are references to capacity issues within the Community LD Team and difficulties with appropriate allocation which would best meet the person's needs. **Recommendation**: Adult Social Care & Learning Disability Community Service to review referral and allocation process.

Health Screening

There was a theme throughout reviews that people were not always offered age or gender appropriate screening and that when appointments were missed, these were not followed up. It is acknowledged that there needs to be additional consideration to ensure that people with a learning disability have access to health screening and are given the relevant information to understand this.

Recommendation	All individuals with a learning disability should receive accessible information in relation to health appointments and health screening.
Recommendation	Promotion of appropriate health screening should to be a focus for improvement in 2021/22, with a clear project plan to support this.

This has been a challenging year and staff have committed to ensuring that people with a learning disability, have access to the same health screening and vaccination programmes as the general population. Some Pennine LD staff trained in administration of flu and Covid vaccine for hard to reach patients to support this.

Medication issues

Reviews of medication, most notably anti-psychotic psychiatric medicines, do not routinely take place. It is important to ensure that medication is reviewed regularly to stop over use of psychotropic medication in people with learning disabilities.

Recommendation	CCGs should ensure that guidelines on stopping the over use of psychotropic medication in people with a learning disability and/or autism are implemented.

One review noted that while care staff were aware of what medication the person was prescribed, there was a lack of understanding around expectations and plans around medication management.

Recommendation	Additional training should be offered to care staff on understanding medication management and care plans.

In one case, the person's dementia was reviewed by the Learning Disability team and GP but there was no evidence that they were prescribed medication to slow cognitive decline. It is recognised as

	important to ensure care is equitable to that offered to a person without a learning disability. **Recommendation** → GPs should consider parity with the general population in prescribing medications to slow down cognitive decline.
Communication 	Cross agency communication especially when transferring between services, continues to be identified as an issue in reviews. A family member requested that this area is highlighted as a priority and stated that continuity of care is vital to people who have a learning disability and complex needs. Where service provision is changed, it is important that staff receive a detailed handover, including a pen portrait of the person and that care is designed to meet their needs. In this case, continuity of care suffered as the new care team was made up of non-permanent staff. **Recommendation** → Providers are able to evidence how continuity will be maintained, and that they understand the importance of continuity to clients and their families. It is noted that residential care staff are not always made aware of any changes or information which would change care plans. One review concluded that there had been a significant impact on the person's quality of life, as there were delays in the content of a clinical letter being considered as part of the treatment plan. **Recommendation** → Service managers need to establish a clear process for ensuring recommendations and information in clinical letters is communicated to care staff. There are also examples of good practice – in one case the reviewer noted that there was effective and extensive multi-disciplinary liaison between the care team, family and health professionals which had a positive impact on the person's experience of care.

Carer Support

An emerging theme in 2020/21 are the needs of family members as carers.

Where people with a learning disability were being supported to live at home with their families, it is clear that they are receiving high quality care and treatment from agencies.

In all reviews where family were identified as the main source of support for the person who died, it is noted that there was no carer's assessment offered or recorded. In only one of the reviews was it documented that a GP considered carer needs when completing an annual review. The legal responsibility for completing a carer's assessment within the context of the Care Act (2014) sits with the Local Authority, and is accessed by a referral to Adult Social Care.

Recommendation

Where families are the main source of support, they should be offered a formal carer assessment as standard.

Analysis of the reviews indicates that often family carers were elderly or in poor health and in addition to the support that they could have needed or been offered had there been an assessment. It is also important to ensure that future planning for when they are no longer able to fulfil the role is in place.

Recommendation

Services need to work with people and their families to plan and prepare for any changes in carer ability.

Nutritional needs and oral care

There is evidence in reviews that staff and carers do not always recognise the need to refer to SALT, where the individual does not have a safe swallow or there are concerns relating to eating and drinking.

Recommendation

There must be a clear referral pathway and criteria for referral to SALT.

It is apparent that care staff are not always treating people with dignity when they are eating and drinking and at risk of dysphagia or choking. One reviewer noted that carers were seen to be rushing a person with their meal.

	Recommendation: Carers should receive skills training in respect of dignity when supporting someone to eat and drink. There is also evidence that where a Community Learning Disability Nurse is involved with the person's care, their nutritional and feeding needs are regularly reviewed and managed more effectively. There are examples of the LD Nursing Team providing additional support and training to care staff which is highlighted as good practice. To support effective care, the Community Learning Disability Team has shared Dysphagia lists with GPs to identify people who are at risk of aspirational pneumonia.
Constipation 	It is apparent that in most cases, where a person has constipation, that medication is the first consideration to manage this. There is an evident lack of working with people to advise and educate on lifestyle and dietary reasons for constipation and in four reviews this was identified as a key concern and area for improvement. Recommendation: The reliance on medication to treat constipation should be minimised, and health promotion considered as a preventative option . Reviewers highlighted that where people were identified as prone to constipation, in most cases bowel movements were monitored daily using the Bristol Stool Chart. This is identified as good practice; however it is clear that not all care staff understand how to interpret bowel output and when it might be necessary to seek GP advice or input. Recommendation: Care staff should receive additional training on Bristol stool chart as an assessment tool to recognise potential constipation/faecal overload.
Health Passports 	In 2019/20 there was a focus for our health partners to ensure that health passports were person centred and available in hospital records. A spot check by the Local Area Contact when completing rapid reviews shows that where health passports are available they are

	person centred and that a copy is kept in the hospital records. There is excellent evidence of health passports being developed with people and their families and that these followed people through the system and are available to hospital staff. The theme emerging from the reviews in this year is the implementation and use of the information in the passports by medical staff. **Recommendation**: Training should be provided to medical staff to support their understanding of health passports and their importance in the health care setting.
End of Life Care 	In the 2019/20 LeDeR Annual Report, one of the areas cited as positive practice was the development of a specific LD End of Life pathway. The pathway has yet to be implemented in Stockport and it is acknowledged that the pressures on staff working within a pandemic situation have had an impact on the development of the pathway. It is clear that the need to embed the pathway in practice is a priority for 2021/22, as this continued to be an area of focus in reviews during 2020/21. There were occasions when the previous wishes of people were not taken into consideration and they were conveyed to hospital at the end of their life. The role of advanced decision making and supporting people to die in the place of their choice should not be underestimated in the context of quality of care. One example is a person who had previously been clear that they did not wish to be taken to hospital. However when their health deteriorated care staff and the GP practice arranged for a hospital admission. Had there been effective end of life planning and a record of preferences, this would have supported clinical decision making. **Recommendation**: Where possible, professionals involved in a person's care should record their preferences for end of life care at an early opportunity.
Care & Nursing Homes	During 2020/21 LeDeR reviews have highlighted three key areas for nursing and care home learning, with a focus on those homes that are not commissioned specifically to provide support for people with a learning disability.

It has been noted that not all care and nursing homes were aware of LeDeR and had not been made aware of learning and recommendations which may have improved practice.

Recommendation — Care and nursing homes would benefit from additional training on dementia awareness in LD.

The Local Area Contact has attended a Care Home Forum to share information about LeDeR and some of the learning from reviews.

Recommendation — Care and nursing homes would benefit from understanding the LeDeR programme.

Recommendation — Care homes should have 'grab sheets' for carers to take with people to appointments, so that any relevant information can be communicated even if the carer does not know the person well.

The Local Area Contact delivered a LeDeR case study to the Care Home Forum to support learning into practice. This was well received and provided the opportunity for a 'quick win' for improving the experience of people living with a learning disability when attending scheduled or emergency health appointments by implementing a really simple reasonable adjustment:

Background

- A person with a learning disability who lived in a nursing home was supported to attend a GP appointment
- The carer who supported the person did not know them well, and did not have access to information relevant to their care needs

Review

- The review identified that because the carer did not know the person well or have access to the relevant information, an opportunity to identify a physical health need was missed
- The review identified that the nursing home did not make reasonable adjustments to support the person with their appointment

Learning

- Where possible, someone who knows the person should support them to attend appointments
- Care and nursing homes should develop 'grab sheets' so that all relevant information can be communicated at appointments

Next Steps and Priorities for 2021/2022

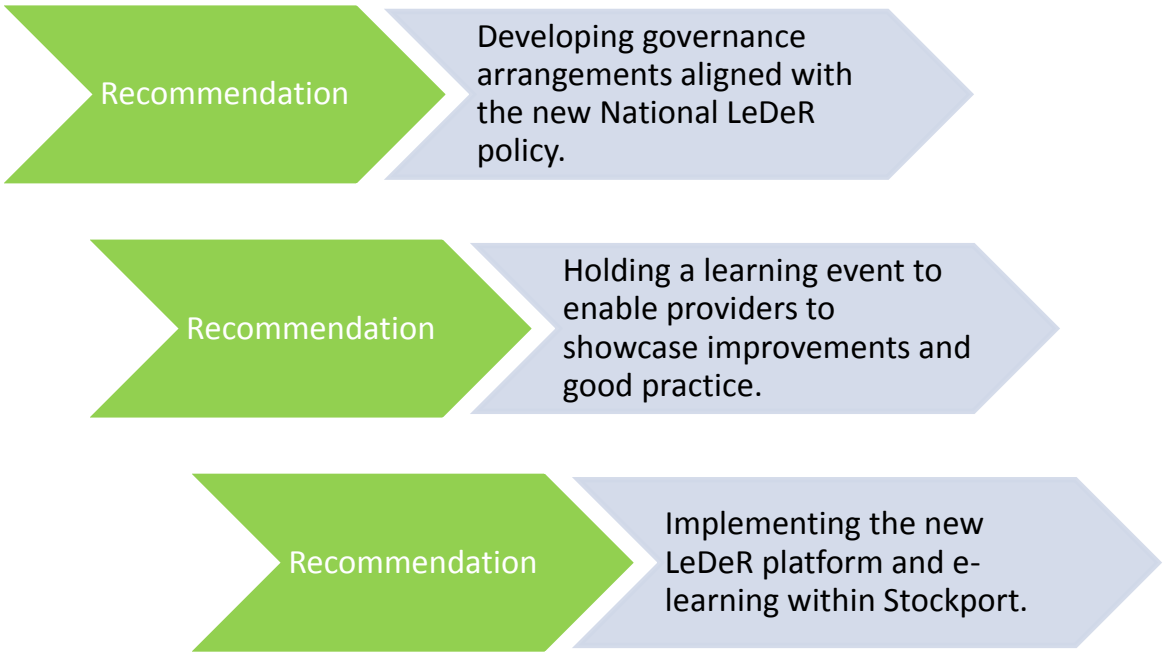
It is requested that the Steering Group endorse the recommendations from this report and develop an action and implementation plan for 2021/22 with appropriate monitoring and feedback mechanisms to support learning across the system.

Delivering against the recommendations in this report will require engagement across the system and strong leadership within organisations to support learning and provide assurance of implementation and improvements.

Areas of focus will be:

- Embedding MCA and Best Interests into core practice
- A continued focus on uptake of annual health checks
- Securing expertise across the system
- A continued focus on the uptake of health screening
- Parity in medication management
- Improving inter-agency communication
- Carer assessment and support
- Improved nutrition and oral care
- Effective management of constipation
- Embedding use of health passports within medical teams
- Establishing the End of Life pathway
- Continuing to support care and nursing homes to deliver appropriate and effective care

In addition to the recommendations from reviews, the following actions are also recommended:



Appendix 1: LeDeR Process in Stockport 2020/21