NHS South Sefton CCG and NHS Southport and Formby CCG

Learning Disability Mortality Review (LeDeR)

Annual Report 2020/2021

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Contents Page

1. Executive Summary

The Learning Disability Mortality Review (to be referred to hereafter as LeDeR) programme requires all people with a diagnosis of a learning disability from the age of 4 years, to have a review into the circumstances of their death. The aims of the programme are:

- To identify key learning to support increased quality of care and service delivery for people with a learning disability.
- Prevent avoidable deaths of people with a learning disability.

This is the second Learning Disability Mortality Review (LeDeR) annual report that has been produced by NHS South Sefton CCG and NHS Southport and Formby CCG (to be referred to hereafter as CCGs) which has been authored by the Local Area Contact (LAC) for the CCGs. The LAC covers the role across both Liverpool and Sefton. The report provides an update on LeDeR for the CCGs from April 2020 to March 2021.

The purpose of the report is to provide the CCGs with an update; on LeDeR performance, key priorities and developments in year. This report covers the period from 1st April 2020 to 31st March 2021. Things to note within the report are:

1.1 In year there were 30 notifications to the LeDeR platform, in comparison to 24 notification from the previous period 2019 – 20. This represents a 25% increase from the previous year. Alongside the new cases in year, the CCG were required to clear the existing backlog of cases dating back to May 2018 (79) by 31 December 2020. The CCG were able to support closure of 74 (94.1%) of cases within timescale, with the LeDeR reviewer resource provided by NHS England Improvement Cheshire and Merseyside (NHS EI C&M).

1.2 Between March and June 2020, 11 cases were subject to rapid review as a direct request from NHS EI. To determine the impact of the COVID pandemic. To date there are have been 7 confirmed COVID related deaths, with 1 other death to be confirmed by the end of September 2021, when the full years LeDeR reviews will have been completed. This represents the highest cause of death for people with a learning disability across Sefton in year. The majority of people were living in a care setting, either a care home or supported living. The trends and themes from these reviews has fed into national learning and recommendations. This includes:

- Lack of clarity and access to COVID testing for residents and carers in residential and supported living placements
- Additional requirements for Infection and prevention control (IPC) standards and measures across independent care sector
- Implementation of shielding letters from GP’s for those people with an LD at risk
- Review of hospital discharge processes back to an independent care sector setting including COVID testing.
- Oxygen saturation monitors being rolled out across independent care setting (Primary Care Network).

- Introduction of the Restore 2 tool to identify deterioration in independent care setting (Primary Care Network)

1.3 LeDeR performance to complete LeDeR reviews within 6 months has improved significantly in year from 7.6% in 2019/20 to 100% in 2020/21. This has been despite the additional backlog of cases. LeDeR performance will continue to be monitored on a quarterly basis.

1.4 The CCGs have been compliant with the majority of the governance arrangements for the LeDeR programme. However, the LeDeR annual report was delayed due to the capacity of the LAC, who is also the CCGs interim Deputy Chief Nurse.

1.5 The governance arrangements for LeDeR have been strengthened in year with the implementation of the North Mersey LeDeR Task and Finish Group and the North Mersey LeDeR Multi-Agency Panel. Both have been led and implemented by the CCG. In year the LAC has successfully led and developed:

- co-production of the LeDeR local arrangements document to streamline the LeDeR process across the North Mersey Footprint, support improved communication and performance.
- Development of supportive materials to aid LeDeR reviewers
- Successful bid for a Band 5 LeDeR coordinator across the North Mersey footprint.
- Chaired the North Mersey Multi agency LeDeR panel.

1.6 In year there has been a transfer of the LeDeR system across from the University of Bristol to NHS EI. The system was paused at the beginning of March 2021, for the systems to transfer including the migration of data across. Systems and processes were put in place by the LAC to mitigate against the inability to access the system for the 3 months. The system came back on-line at the beginning of July 20201 which is outside of the reporting period.

1.7 An independent review on the LeDeR review for an 18year old young man, Thomas Oliver McGowan was published in October 2020. The review detailed key recommendations for: Department of Health and Social Care (DHSC), NHS EI, National LeDeR Programme Team, Integrated Care Systems (ICS) and CCGs. The recommendations were reviewed and added to the CCGs LeDeR action plan. The CCGs have been able to report compliance against the CCG recommendations within the review.

1.8 The national NHS EI LeDeR policy was published in May 2021. Whilst outside of this reporting period, the policy has made number of changes to the LeDeR programme. These changes have been incorporated into the CCGs 2021/22 action plan.

2 Background and Introduction

2.1 The Learning Disability Mortality Review (LeDeR) programme is the first national programme of its kind at aiming at making improvements to the lives of people with learning disabilities. The programme was established in June 2015 as part of a pilot, which is funded and run by NHS England (NHS E), with the support of the University of Bristol. The programme was subsequently extended to all CCG areas across England from January 2017. Reviews of deaths are 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. The programme was established at a time of increased scrutiny of avoidable deaths in general, and deaths of people with a learning disability, with a focus on learning lessons and making changes

LeDeR is directly linked to the Transforming Care Programme (TCP) and the C&M TCP plan “To reduce the health inequalities experienced by people with a learning disability and/ or autism”. Children, young people and adults with a learning disability and/or autism have the right to the same opportunities as anyone else to live satisfying and valued lives, and to be treated with dignity and respect. They should have a home within their community, be able to develop and maintain relationships, and get the support they need to live healthy, safe and rewarding lives.

The delivery of the programme requires a partnership approach across, health, social care, primary and secondary care, generic and specialist services. The reviews have tended to be multi-agency in nature, which don’t currently sit within existing single systems. However, the programme does take account of statutory and parallel processes. How LeDeR reviews interface with parallel processes, is determined on an individual basis, with the exception to Child Death Overview Panel (CDOP) which is the default mechanism for review of deaths for children and young people between the ages of 4 – 18 years.

The objective set out for the LeDeR programme are:

1. To influence practice change at individual, professional, clinician and allied health professional levels, such that it will contribute to improving service provision for people with learning disabilities and their families.
2. To influence change in policy and service provision at national level with Government, NHS England, Public Health England and the Local Government Association, such that it will contribute to improving service provision for people with learning disabilities and their families.
3. To support commissioning and service redesign by helping commissioners understand opportunities to improve service delivery, reduce variation and learn from best practice.
4. To encourage a move towards equality of treatment and parity of esteem for people with learning disabilities and help tackle the systemic contributors to the health and access inequalities they face.

The scope of the programme is to support reviews of deaths of people with a diagnosis of a learning disabilities aged from 4 years and over who are registered with a GP in England at the time of death.

The definition that is applied to the LeDeR programme is based on the definition within the 2001 white paper 'Valuing People'. This sets out that a learning disability includes the presence of;

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with
- A reduced ability to cope independently, impaired social functioning)
- Which started before adult hood, with a lasting effect on development.

2.2 There have been significant challenges during 2020/21 due to the Coronavirus 19 (COVID) pandemic. The pandemic has had a significant impact on vulnerable people, and health and social care services. People with a learning disability have been noted to be disproportionately affected from COVID and considered as a vulnerable group. The University of Bristol published a report in November 2020, following the review of 206 deaths between March and June 2020. It was noted that 80% of deaths were attributable to COVID. A third of those were living in a residential care homes, 50% had Down Syndrome and 25% living in supported living.

In November 2020, DHSC, with the support of the Chief Medical Officer for England, commissioned Public Health England (PHE) to review the available data on the deaths of people with learning disabilities in England during the COVID pandemic. The data was sourced from the LeDeR register and hospital dataset to establish the number of people with a learning disability who had died in England with confirmed of possible death from COVID 19 from 5th June 2020. The review looked at:

- deaths from COVID-19 of people with learning disabilities
- factors impacting the risk of death from COVID-19 of people with learning disabilities
- deaths in care settings of people with learning disabilities

It was estimated there had been 956 deaths nationally, accounting for under-reporting. Based on the deaths reported to LeDeR, the COVID-19 death rate for people with learning disabilities was 240 deaths per 100,000 adults with learning disabilities. This is 2.3 times the rate in the general population for the same period. However, after adjusting for under-reporting the estimated rate was 369 per 100,000 adults, which is 3.6 times the rate in the general population.

Age	COVID deaths among people with a learning disability were spread more widely than across the general adult population with the greatest age range of 55 – 64 years compared with over 75 years for the general population.
Gender	The death rate was higher for men than women by 1.4 – 1.6 which is slightly less for the general population
Ethnicity	There were three times the proportion of deaths for people with a learning disability from an Asian, Asian British group, or Black or

	Black British Group than the previous two years. The number of deaths of people with learning disabilities from all causes in 2020 for White groups was 1.9 times the number in the 2 previous years. For Asian or Asian British groups it was 4.5 times and for Black or Black British groups it was 4.4 times.
Care Setting	COVID accounted for 54% of deaths of adults with learning disabilities in residential care in the review period, slightly less than for people with learning disabilities generally, but still much more than in the general population. The rate of COVID-19 deaths for adults with learning disabilities in residential care was higher than the rates of COVID-19 deaths of adults with learning disabilities generally, estimated from LeDeR. It was 2.3 times the rate calculated from the actual LeDeR notifications and 1.5 times the estimated rate adjusting for under-notification. This difference is likely in part to reflect the greater age and disability in people in residential care.

2.3 The CCGs continue to support the LeDeR programme and have a designated LAC in place. The role and function of the Deputy LAC was allocated to the Designated Safeguarding Adult Manager (DSAM) in year. Going forward this will be the role of the CCGs Programme Manager for Quality and Performance, which is outside of this reporting period. Both the LAC and Deputy LAC provide the role and function across both Sefton and Liverpool, as a North Mersey approach.

The LAC has developed networks across both the Liverpool and Sefton area, to ensure that from a health perspective all NHS providers and GP practices support the LeDeR programme. Feedback mechanisms are in place with respective organisations and via the CCG lead commissioners and Quality Team. NHS organisations are required to consider the learning from all deaths, this is set out in the NHS contract and the National Guidance on the Learning Deaths (National Quality Board, March 2017).

Whilst NHS commissioned trusts have the structured judgement review (SJR) process in place to review the circumstances of deaths (this includes people with a learning disability), it isn't explicit that that the SJR needs to be in line with the LeDeR programme. The LAC has developed a set of reporting standards within the quality contract to support NHS organisations to deliver this specific element of learning from deaths and provide assurance to the CCGs governing body that organisations are signed up to, and supporting the LeDeR programme.

3. Governance and Accountability Arrangements

3.1 NHS EI have set out a purpose statement of expected requirements for CCGs to implement the LeDeR programme in their locality, working with local partners. Leadership is a critical tool for the successful delivery of the LeDeR programme and local leaders at all levels are required to drive the programme forward. Working with partners is the mechanism to ensure reviews are completed in a timely way and developing approaches to address learning arising from reviews.

CCGs are required to identify an executive lead who is the senior responsible officer for the delivery of the LeDeR programme. For the CCGs the senior responsible officer role and function sits with the Chief Nurse as a member of Governing Body. The role and function being delegated to the LAC, which has been provided by CCGs Deputy Chief Nurse.

The CCGs have received a quarterly LeDeR report to the Quality and Performance Committee. Highlighting the Sefton key issues and updates as part of the LeDeR programme.

The Deputy LAC role had been allocated to the DSAM. However, due to capacity issues in year, it has not been possible for the DSAM to fulfil the role and function. The role and function is now provided by the CCGs Programme Manager for Quality and Performance, which is outside of this reporting year. The LAC and Deputy LAC provide cover for the LeDeR programme across both Liverpool and Sefton. This model is likely to remain in place for 2021/22, when it is anticipated the management of LeDeR will transfer across to the Cheshire and Merseyside Integrated Care System (C&M ICS).

3.2 In year the LAC has established a North Mersey approach to LeDeR, with the implementation of the North Mersey LeDeR Task and Finish group and the North Mersey LeDeR multi agency panel, to strengthen the governance and reporting arrangements. Minutes and key issues from the North Mersey LeDeR multi agency panel are routinely submitted to the CCG Joint Quality and Performance Committee, as a sub-committee of Governing Body. The CCG's, GP Clinical Lead, Secondary Care Doctor, DASM were part of the core membership for the North Mersey LeDeR multi-agency panel.

3.2.1 The North Mersey LeDeR Task and Finish Group was implemented in year, with representation across the North Mersey NHS commissioned providers. This enabled the co-production of the North Mersey LeDeR Local Arrangements document. The document outlines expectations for all parties, including timescales, supporting LeDeR performance. Sefton Metropolitan Borough Council have been consulted and contributed to the document.

The North Mersey LeDeR Task and Finish Group, has been successful in a bid to NHS EI C&M for a Band 5 LeDeR Coordinator for a 12month fixed term contract. The functions include supporting information from NHS and General Practice to the reviewers, management of the LeDeR system, supporting CCG performance and providing administrative support to the LAC. There was agreement the post-holder to be hosted by Mersey Care. The post-holder commenced in post in February 2021, however, has since been re-called back to her substantive role due to capacity issues. Mersey Care are going out to recruit to the post for the remaining tenure of the fixed term contract, which is outside of this reporting year.

3.2.2 The LAC set up the North Mersey LeDeR Multi-Agency Panel in year. To enable all reviews to have oversight by health and social care partners.

Providing an opportunity to understand the trends and themes for LeDeR reviews across the North Mersey (Liverpool and Sefton) footprint. All reviews in year have been subject to oversight either as part of the North Mersey multi agency LeDeR panel, or at the NHS EI North LeDeR panel.

3.3 During 2020/21 there have been changes to the LeDeR programme following a national review, and the planned transfer of the LeDeR platform from the University of Bristol to NHS EI.

3.3.1 The LAC contributed to the review of the LeDeR programme led by the national team. A LeDeR policy has since been published in May 2021 which is outside of this reporting year outlining the key changes and requirements for LeDeR going forward. These include:

- The programme has been rebranded to “learning from lives and deaths: people with a learning disability and autistic people”. Whilst the programme now receives notifications for people with autism, further confirmation is awaiting from NHS EI when CCGs will be expected to progress these reviews
- Introduction of new classification of reviews; initial and focused. Only focused reviews will be required to be discussed at the LeDeR panels. Cases meeting the threshold focused review include; children and young people aged 4-18 years (CDOP), people with a diagnosis of autism, people from a black, asian and ethnic minority (BAME), and cases following an initial review would benefit from a more focused review.
- LeDeR panels to include representation from people with a learning disability and or family /carers
- Whilst the timescales for the completion remaining the same (100% compliance within 6 months), the timescale for a case being allocated within 3 months has been removed.
- ICS to have in place a 4 year LeDeR strategy, the draft to be in place by Sept 2021. The LeDeR strategy is being led by NHS EI C&M, with the LAC supporting the developments.

3.3.2 The NHS EI contract with the University of Bristol to manage the LeDeR platform was due to come to an end in May 2020, however due to COVID the contract was rolled over. The contract has now come to an end, with the LeDeR system now being managed by NHS EI. The Bristol system was paused at the beginning of March 2021, whilst the NHS EI system came online with migration of information to the new system. During this pause, it was not possible to access either system. The new system came on-line at the beginning of July 2021, however there are still issues which need to be resolved which is outside of this reporting period. Mitigation was put in place across the North Mersey footprint to prevent deterioration in CCG performance whilst it was not possible to access the system.

3.4 In October 2020, NHS E published the independent review of the Thomas Oliver McGowan’s Learning Disability Mortality Review (LeDeR) process (phase 2). This was the review of the LeDeR review for an 18year old young man who died as an

inpatient in North Bristol NHS Trust. The review identified key learning and recommendations to make improvement to the LeDeR process. 11 actions were applicable to the CCGs:

- All those who are new to the role of lead reviewer, or local area contact (LAC), must be allocated a 'buddy' who is experienced in the LeDeR process.
- Dedicated time and administrative support must be given to reviewers and LACs to undertake complex LeDeRs.
- There must be a transparent process for LeDeR in each locality, with robust governance and appropriate resources to ensure that each review is properly monitored in terms of procedure and outcomes.
- The LAC and the lead reviewer should confirm at the onset of the LeDeR process how much support is needed and what it should look like. Guidance for reviewers should emphasise that when undertaking a LeDeR, there is an onus on a team responsibility to complete the process to the required standards, rather than it falling to an individual (the lead reviewer, in this case).
- Each CCG must identify an executive lead to be responsible for the LeDeR programme and for ensuring that the board has full sight of progress.
- The CCG executive lead for LeDeR will ensure that LeDeRs are completed in a timely and correct manner and will intervene where problems are escalated, such as the inability to obtain critical information from the relevant agencies.
- When a multi-agency review (MAR) is indicated, it is important that the correct process and outcomes are achieved. It is therefore expected that where the reviewer and the LAC have no previous experience of a MAR, they will seek support from a 'buddy' who does
- In regard to the MAR meeting itself, it is recommended that there is action taken to: • ensure that families are central to the process, are offered full sight of all documents, and are invited to attend all or part of the meeting as they wish
- There should be an assurance process with regard to providing regular, appropriately documented supervision for individual LeDeR reviewers.
- Appropriate support should be available to reviewers, along with strong governance, to ensure that all LeDeR recommendations are robust and actioned in a timely manner, and that lessons learnt are shared nationally.
- Each CCG must formally undertake and document and review its own systems and processes against the learnings and recommendations arising from Oliver's re-review.

All recommendations were reviewed and added to the CCG LeDeR action plan in year. The CCG has been able to report compliance against the recommendations within the Thomas Oliver McGowan independent review. An update was provided to Quality and Performance Committee in Quarter 4.

4.0 Sefton Learning Disability Deaths 2020/1

4.1 During 2019-20 30 deaths were registered on the LeDeR platform. This represented a 25% increase from the previous year (24). Of these cases, 2 cases

were confirmed not to have a learning disability (LD) diagnosis, and 1 was a duplicate. Out of the 30 cases, 27 were eligible for a LeDeR review. One case comes under the remit of CDOP, as per process. CDOP reports are uploaded onto the system once completed. There is good communication between the CCG LAC and the Meseyside CDOP Manager.

There has been a small increase in people being registered in year which is likely as a result of:

- Increased awareness of LD deaths due to the COVID pandemic.
- Additional scrutiny by the Association Directors Adult Social Services (ADASS) due to COVID pandemic.
- Number of deaths directly related to COVID
- Awareness of the LeDeR programme across health, primary care and social care.

Financial Year	No. of cases on the LeDeR platform
2016 – 2017 (Jan – March)	0
2017 – 2018	11
2018 – 2019	29
2019 – 2020	24
2020 – 2021	30

4.2 During 2020/21 NHS EI, requested rapid reviews for all death registered on the platform between the 31 March 2020 – 30 May 2020, with all cases prioritised for a full review, outside of the standard 6 months schedule. This was to determine learning as part of the COVID pandemic. For Sefton CCGs this applied to 11 cases. 2 cases relating to the previous reporting year. All rapid reviews and full reviews were completed in timescale.

Of the 11 cases 4 deaths were directly related to COVID 19 being the cause of death, as documented on either part 1a) or part 1b) of the Medical Certificate Cause of Death (MCCD). The learning from these reviews was submitted to NHS EI C&M and fed through to the national learning. This will have contributed to the University of Bristol report published in November 2020.

In addition to the 4 COVID confirmed death, there were an additional 3 confirmed cases in year. Currently 25.9% of all deaths registered in year were COVID related. The number is likely to higher with 5 cases yet to receive a LeDeR review and 1 of these suggesting COVID as the cause of death. This would suggest that at least

29.6% of deaths are likely to be COVID related, this would also be in keeping with the national prevalence. It should be noted there will be a 6month delay in understanding the full extent and impact of COVID. This is due to cases registered on the system in March and April 2020, not due for completion until the end of August and September 2021 respectively. This will be reported in the Quarter 3 update to Quality and Performance Committee.

4.3 The key learning from the COVID related deaths as identified by the North Mersey LeDeR Panel in year, are set out below. All learning is reported through to LCCG, Liverpool City Council, NHS Providers and NHS EI C&M.

- Discharge from acute hospital without COVID testing back to care settings
- The need for robust discussions with families/carers in relation to Do Not Attempt Cardio-Pulmonary Resuscitation (DNA CPR) decision making.
- Strengthening COVID Infection Prevention Control (IPC) measures in care homes and supported living
- Improved access to COVID polymerase chain reaction (PCR) testing across care homes and supported living for both residents and care staff.
- Self-isolation letters required for people with an LD who are at higher risk of COVID, from Primary Care.
- The impact on self-isolation on mental health of people with a learning disability in a care setting. Not being able to access the community of see families/friends.
- The need for early identifying of deterioration of physical health across care homes and supported living.

4.4 Equality and Diversity

Under the Equality Act 2010, everyone in Britain is protected against discrimination under the nine protected characteristics. The breakdown against protected characteristics is limited within this report, due to the lack of robust reporting systems in place. Although reporting systems have started to be developed using Ulysses, this has yet to be fully resourced. The NHS E LeDeR system that was in place as developed by the University of Bristol, was also not able to provide meaningful data or reports. For the purposes of the 2020/21 it is only possible to report against three elements: Gender, Age and Ethnicity. This is via a manual trawl utilising the standalone spreadsheet developed by the LAC.

In 2020/21 the profile breakdown:

4.4.1 Gender: 13 men and 14 women. There was very little difference between deaths reported women compared with men.

4.4.2 Age Profile: Most deaths in year were those who were 26 years and over, with the exception of 1 death. The oldest death was for a lady who was 86 years of age, the cause of death is yet to be confirmed. However, this is not indicated to be a COVID related death.

Age Range deaths 2020/21

4 – 17 years	18 – 25 years	26 - 40 years	41 – 60 years	61 - 75 years	over 75 years
1	0	7	8	7	4

Of the 7 deaths were reported as COVID related (4 female, 3 male)

- 4 aged 50 years and over
- 1 aged 40 – 50 years of age
- 1 aged below 40 years of age

The youngest death related to COVID was for a 28year old female, and the oldest an 76year old female.

The age range for COVID related deaths 2020/21

4 – 17 years	18 – 25 years	26 - 40 years	41 – 60 years	61 - 75 years	over 75 years
0	0	2	2	2	1

4.4.3 Ethnicity: 100% of people were registered as white British. The Sefton data doesn't reflect significant disadvantages due to ethnicity. However, it has been identified the people from a BAME background are likely to be disproportionately affected by COVID.

4.5 Main causes of death on part 1a) of the MCCD:

Cardiac / Arterial related	Myocardial Infarction	1
	Multi organ failure	1
	cardiomyopathy	1
Renal	Acute renal failure	1
Hepatic	Fatty Liver	1
Neurological	Hypoxic brain injury	2
	Alzheimers	2
	Bowel	1
Respiratory	COVID 19	5
	Chest Infection	1
	Pneumonia	3
	Aspirational Pneumonia	2
Other	Natural cause	1
	Old age	1

Whilst the table represents what was documented as part 1a) of the MCCD, in many cases other causes were also documented on part 1b), 1c) and 2 of the MCCD. Down's Syndrome / Trisomy was documented on three MCCD's which were deemed appropriate under part 1b) of the MCCD and not as part 1a). It is accepted that learning disability on its own is not a cause of death. However, it can be a contributing factor to poor health and therefore should not be documented as part 1a) of the MCCD.

The most significant cause of death in year as on part 1a) of the MCCD related to the COVID pandemic. For two case COVID was documented on part b). However, the remaining cause of deaths compares similarly with the causes of deaths reported in the 2019/20 annual report, with a respiratory cause being the leading cause of death.

5.0 Recommendations from LeDeR Reviews

5.1 All LeDeR reviews in year have been submitted to review at a LeDeR panel. This was either the North Mersey LeDeR multi-agency panel, or the NHS EI North LeDeR panel. The NHS EI North LeDeR panel was utilised to support the 97 cases required to be closed by 31 December 2020.

Minutes from the North Mersey LeDeR multi-agency panel are reported through the CCGs Joint Performance and Quality Committee, as a sub-committee of the CCGs Governing Body. However, the LAC will escalate concerns from reviews through to the CCG Quality Team and Lead Commissioners as appropriate, outside of the North Mersey LeDeR multi-agency panel.

Learning, recommendations trends and themes from LeDeR reviews are also reported through to the NHS EI C&M LeDeR Steering Group. The LAC is a core member of the steering group, which reports through to the NHS EI C&M Transforming Care Board.

NHS Trusts are required to feed learning back through their own internal governance arrangements. The North Mersey LeDeR multi-agency panel has an action tracker in place to monitor progress and hold partners to account.

In year, the LAC has attended Sefton Safeguarding Adult Governance Meeting. To support the adult social care (ASC) understanding of the LeDeR programme, to streamline the information flow from (ASC), and to share learning and recommendations from the reviews. This was a particular response to the COVID pandemic.

The table below outlines the key learning points from LeDeR reviews in 2020/21. Learning and recommendations are fed back to respective organisations to support improvements in practice. They have also been included as part of the NHS EI C&M 4 year LeDeR strategy.

Primary Care	• Robust GP LD Registers • Access to Annual Health Check and Action plans (compliance, quality) • Not Brought policy (annual health check and health screening programmes) • Information available in Easy Read format • MCA – BI decisions (evidenced in GP records, DNA CPR) • Advanced Care Planning / End of Life (care plans not always in place as part of hospital avoidance) • Promotion of health eating and weight management • Closer attention SLT and risk of aspiration (recurrent chest infection)
NHS Trusts	• Not Brought policy • MCA / BI decisions end of life and DNA CPR • Hospital Discharge end of life pathway • The need for non-verbal pain tools

	• Diagnostic overshadowing • Hospital Flagging Systems • Variance gastro OGD pathway (multi agency LeDeR review) • Appropriate diagnosis LD as part of the MCCD
Local Authority Commissioned Providers	• Reporting death to LeDeR • Supporting people to attend: annual health checks, health screening programmes, health related appointments • The need for non-verbal pain tools • Diagnostic overshadowing • End of Life care plans • Completion of health passports • Promoting health eating and weight management • Referral to Community Learning Disability Team / Community services • Adherence to SLT care plan • Escalation to LA re: deterioration and appropriate placement • Recognition of deterioration • Delayed hospital discharge due to lack of available commissioned placement • COVID outbreaks and management • Impact of reduced services and support for carers (COVID impact) • Day Services response to emergency health related situations/actions.
COVID Related	• Discharge process from acute hospital and COVID testing • IPC in care homes and supported living • Access to PCR testing across care homes and supported living • Self isolation letters to those at risk from Primary Care • Impact on self isolation on mental health • Identifying deterioration (oxygen saturation, Restore 2 (PCN EHCP)

5.2 Learning Disability Annual Health Checks:

The NHS has provided a directly enhanced scheme (DES) to support GP practices to provide annual health checks, however practice participation is optional. In order to ensure equity in provision GP practices in Sefton have an arrangement via the Local Quality Contract (LQC). Practices can choose to deliver the LD health check to their own patient population, or the health check can be provided by South Sefton GP Federation. Throughout the pandemic a virtual LD health check has been offered.

There is no target in the DES for individual practices to achieve, however there is an expected CCGs target for 67 % of people with a learning disability aged 14

and over to have had an LD annual health check in year. This managed by the Primary Care Networks.

The Investment and impact fund (IIF) was introduced as part of the Primary Care Network (PCN) contract DES in October 2020/21. The LD health check DES is one of the IIF indicators for PCN's to achieve based on a lower threshold of 49% and a higher threshold of 80%. At the end of year 2020/21 South Sefton CCG achieved 61.3% and Southport and Formby 77.6%. Discussions were held with the LMC in November 2020, and practices with low uptake were contacted and asked to provide narrative as to their plans to carry out the annual health check. one practice at this stage asked the Federation to undertake the health checks, whilst others confirmed their intention to carry out in the last quarter.

The PCN lead will be holding discussions with PCNs to identify how improvements can be made to the uptake and provision of the LD annual health check. The LD annual health check data is submitted monthly to the CCGs and to the LD lead. This ensures an updated position is known and, if needed a remedial action plan can be put in place. There appears to be a trend for the annual health check to be completed towards year end which impacts on data through-out the year.

Quality Outcomes Framework (QOF) was income protected during 2020/21 due to COVID, although the Quality Performance Framework templates were still required to be completed and submitted. This is likely to be the position for 2021/22.

2020/21 Totals			
CCG Name	**Total Registered**	**Total Checked**	**Total % Checked**
South Sefton CCG	693	425	61.3%
Southport & Formby CCG	799	620	77.6%
Grand Total*	**1,492**	**1045**	**70.1%**

5.3 COVID vaccination programme:

Sefton CCGs have ensured that all people with a learning disability either living in the family home, or in a care setting have been prioritised and offered the COVID vaccination. The CCGs vaccination programme for people with a learning disability commenced in February 2020.

In March 2021 the CCGs were able to report that for South Sefton CCG that out of the 734 people with a learning disability on the GP registers, 678 were eligible for the COVID vaccination. Of these 509 had received their first dose (75%).

For Southport and Formby CCG of the 853 people with a learning disability, 789 were eligible to receive the COVID vaccination. Of these 635 have received their first dose (80%). The CCGs continue to deliver the 2nd dose as part of the vaccination programme.

The CCG continues to prioritise people with a learning disability. Vaccination is offered in the person's own home, and fast tracked at vaccination sites. Support from the Community LD Team is accessed where appropriate. The vaccination of vulnerable groups is discussed at the Sefton Vaccine Hesitancy Group.

5.4 GP Practices and DNA CPR:

DNA CPR for people who are on GP practice LD register is a QOF QI indicator, including peer review at PCN meetings for 2021/2022. There are no set compliance thresholds in year, with an expectation for a per review to be completed by year end.

Updates on performance on COVID vaccination, annual health checks, review of DNA CPR, implementation of Restore 2 and oxygen saturation monitors across care settings will be reported to the JQPC in Quarter 3.

6.0 Sefton LeDeR Performance:

6.1 Whilst the LeDeR programme is not a statutory role for CCGs, NHS EI have put in place contractual key performance indicators (KPI's) to monitor CCGs performance and compliance with the programme:

- CCGs to have in place a LAC and Deputy LAC.
- Membership and attendance at the NHSE/I area team LeDeR steering group.
- Expected timescale of allocating cases across to a LeDeR reviewer within three months of being registered of the platform.
- Expected timescale for the completion of LeDeR reviews within six months of being registered on the platform.
- CCGs to produce an Annual LeDeR report. This is the second annual report the CCGs will have received.
- CCGs to have in place an action plan which is reviewed and updated on a quarterly basis.

6.1.1 As stated in the Governance Arrangements in section 3 of this report, NHS EI have set out a requirement for CCGs to demonstrate leadership of the programme to be evidenced by a named person and job title, as the identified lead and deputy for LeDeR as a delegated function of the Chief Nurse.

The LAC role and function was transferred across the Deputy Chief Nurse for the Sefton CCGs in year. The Deputy LAC role and function remaining with the CCG DSAM. The Deputy LAC function has now been allocated to the Programme Manager for Quality and Performance which is outside of this reporting period. It is expected the North Mersey approach will continue throughout 2021/22, pending changes as part of the forth coming ICS in April 2022, when it is anticipated LeDeR management will transfer across to the ICS.

6.1.2 NHS EI have set out standards to monitor CCGs engagement and representation at the local area NHS E LeDeR Steering Group. These include:

- Named CCG Local Area Contact as part of the membership
- Terms of Reference for the LeDeR steering group include the CCG and details of the representative.
- Minutes of the steering group meeting show attendance and participation of the CCGs named representative.

The LAC is a core member of the NHS EI C&M LeDeR steering group and actively contributes to the development and learning from LeDeR, across the Cheshire and Merseyside Area. The LAC is now a core member of the NHS EI LeDeR strategy group which is outside of this reporting period.

6.1.3 In year CCGs were required to allocate reviews within 3 months, and closure within 6 months of being registered in the system.

In 2020/21 most cases were managed as per schedule. It should be noted that cases registered on the system in March and April 2021 will not be due to be closed until the end of August and September 2021, which is outside of this reporting period.

As of the end of July 2021, 100% of cases were allocated within the 3month timescale. As of the end of July 2021, 100% of cases were closed on the LeDeR system within the 6months timescale. It must be noted that 3 cases are subject to parallel process with are excluded from the performance management

- 1 case subject to CDOP and remains open on the system.
- 1 case is subject to Coroners process and remains open on the system.
- 1 case is subject to a serious incident review process and remains open on the system

The performance reporting has since been reviewed by NHS EI, who have removed the KPI for allocation within 3 months for 2021/2022. The timescale for completion within 6months remains in place.

6.2 Backlog Cases

In addition to the new cases registered in year, there were an additional 79 cases which remained open on the system from previous years 2018 – 2020. NHS EI mandated that all cases open on the system up to, and including 31 May 2020 were required to be closed on the system by 31 December 2020. This amounted to 86 reviews in total. As of 31 December 2020, 81 reviews had been completed (94.1%) with 5 remaining open. The reason for 5 remaining open were due to; statutory process, multiagency reviews, and a delay in information being provided. All cases have since been closed.

To enable compliance with NHS EI requirements, the CCG were able to access additional resource from NHS EI C&M. The reviews were either outsourced to North England Commissioning Support Unit (NECS), health professionals from Farley

Dweck solicitors, additional resource to Mersey Care for a band 7 for a 6months fixed term contract. This was in addition to the 1 whole time equivalent (WTE) band 7 12month fixed term contract, the CCGs had successfully made a bid to NHS EI C&M in 20219/20.

To support cases being reviewed and closed, additional North Mersey LeDeR Multi-agency panels were scheduled. Where the panels did not have capacity, cases were reviewed at the NHS E North LeDeR panels.

The CCG were able to report a significant improvement in compliance with NHS EI LeDeR reporting at the beginning of Q4 2020/21.

NHS E Performance Measures by reporting period	No. of Cases	Compliance against target in year	Narrative
No. registered and eligible for LeDeR 16/17	3	N/A	Programme commenced Jan 2017 1 case subject to multi-agency LeDeR
No. registered 17/18 and eligible for LeDeR	19		
No. allocated within 3 months (100%)	12	63.1%	
No. completed within 6 months (90%)	0	0%	
No. registered and eligible for LeDeR 18/19	22		
No. allocated within 3 months (100%)	7	31.8%	
No. completed within 6 months (90%)	1	4.5%	
No. registered and eligible for LeDeR 19/20	26		
No. allocated within 3 months (100%)	6	23%	
No. completed within 6 months (90%)	2	7.6%	
No. registered and eligible for LeDeR 20/21	30		
No. allocated within 3 months (100%)	27	100%	Compliant with target in year.
No. completed within 6 months (90%)	22 (5 cases still within timeframe)	100%	Complaint with target YTD. Full year compliance yet to be provided at the end of Sept 2021. Expected to be completed within timescale.

Compliance significantly improved during 2020/21, with zero cases missing the target for allocation within 3 months. The full year compliance data can only be confirmed once the remaining 5 cases have been completed. This is likely to be at the end of September 2021. Compliance has been challenged in year due to the significant numbers to be completed which included the 79 backlog cases.

To minimise the risk of the transfer over to the new LeDeR system with the Bristol system paused from March 2021. NHS EI have commissioned NECS to conduct the reviews raised on the system between March and July 2021. All cases have been allocated and are in progress, with expectation to be completed in timescale.

6.3 Overall CCG LeDeR Performance and Compliance

In year there has been significant improvements in the CCGs LeDeR performance overall in comparison to 2020/21. Where performance is below threshold, actions are being taken to improve performance. These will be included in the CCG LeDeR action plan for 2021/22.

Evidence against measure		Frequency of Reporting	Assurance Rating
Named person with job title and contact details	Local Area Contact provided by the Assistant Chief Nurse from Sefton CCGs	Quarterly	
	Deputy Local Area Contact in place	Quarterly	
Terms of reference for LeDeR steering group including name of organisation and details of representative	Local Area Contact included in the membership of the ToR	Quarterly	
Mins of steering group meeting showing attendance at and participation in of named CCG representative	Local Area Contact regulatory attendance	Quarterly	
% notifications assigned within 3 months (100%)	100%	Monthly	
% of notifications completed within 6 months (90%)	100% (YTD) full year data to be confirmed at the end of September 2021	Monthly	
LeDeR action plan including timescales for completion, action owners, actions, outcomes/ outputs, brief description of evidence. Steering Group level action plans must be clear about the actions for each member CCG.	CCG action plan in place for 2020/21	Quarterly	
Actions within plans updated at least quarterly		Quarterly	
LeDeR Annual Report to be published on CCG website by the end of June 2021	Annual report delayed by 2 months scheduled to be approved at the CCGs Governing Body in August 2021	Annually	

7.0 LeDeR Key Priorities and Developments 2021/22

In 2020/21 the CCGs LeDeR governance arrangements were reviewed to support NHS EI performance requirements. A CCG LeDeR action plan was developed to take account of the key priorities as set out as part of the 2019/20 annual report. The action plan was reviewed in year following the publication of the Oliver McGowen report, which was published in October 2020. Updates and progress against the action plan have been reported to the Quality and Performance Committee apart from Quarter 4 due to capacity issues for the LAC.

7.1 Successes in year:

- Development and implementation of the North Mersey LeDeR Task and Finish Group. A LeDeR local arrangement document and process has been developed which has been co-produced by health and social care partners. This has streamlined the LeDeR process across the North Mersey area, to support information flow and enable improvements in LeDeR performance.

Action 1: The LeDeR local arrangement document to be reviewed in line with the NHS E LeDeR policy published in May 2021.

- Development and implementation of the North Mersey Multi-agency panel. There is now consistent representation across the partnership from; NHS trusts, CCG GP clinical leads, CCG representation Designated Nurse Safeguarding Adults, Liverpool City Council. This brings appropriate challenge to the reviews presented and formation of key actions.

Action 2: The LeDeR Multi-agency panel to be reviewed in line with the NHS E LeDeR Policy.

- CCG LeDeR performance is now reporting in line with NHS EI contractual requirements.

- Successful bid to NHS EI C&M for LeDeR Co-ordinator to support the North Mersey LeDeR programme. The post holder commenced in post at the beginning of March 2021 for a 12month fixed term contract. The post being hosted by Mersey Care NHS Foundation Trust (Mersey Care). However due to capacity in Mersey Care) the post holder was re-called to the substantive role at the beginning of July 2021. Mersey Care are in the process of recruiting to the post for the remaining tenure of the fixed term contract.

Action 3: North Mersey LeDeR Co-ordinator to be recruited to for the remained of the 12 month fixed term contract.

- The CCGs LeDeR governance arrangements were reviewed in line with the recommendations within the Oliver McGowan report (Oct 2020) with the CCG reporting compliance. All additional requirements were put in place, and assurance provided from Mersey Care who host the CCGs commissioned LeDeR reviewer resource.

7.2 Actions which were included as part of the CCG LeDeR action plan which were not completed in year are:

- The development and implementation of the North Mersey LeDeR Steering Group. Following further discussion with partners and CCG colleagues, consideration was given for potential duplication. There was a recommendation for LeDeR to be integrated as part of the Liverpool Transforming Care Partnership (TCP). The LAC is yet to receive a formal invitation to the Liverpool TCP via the Programme Manager for Learning Disabilities and Mental Health.

- Robust reporting arrangements to be put in place. Whilst LeDeR reporting via Ulysses was being developed by the LeDeR co-ordinator, this has paused due to the post holder returning to her substantive post.
- Deputy Local Area Contact in place. Whilst the role and function has not been able to be provided in year, the role and function is in place provided by the Sefton CCGs. This is outside of this reporting period.
- The 4 Year LeDeR strategy and action plan will be developed and overseen by the C&M Integrated Care System (ICS). The LAC is part of these meetings which is outside of this reporting year.
- Annual report to be published on the CCG website including easy read version by the end of June 2021. There has been a delay for the annual report to be written and presented to Quality and Performance Committee, due to the capacity for the LAC.

A revised CCG LeDeR 2021/22 action plan will be put in place, which will be monitored as part of the quarterly reports to the CCG Quality and Performance Committee. LeDeR will then transfer across to the C&M ICS as of April 2022.

8 Conclusion

This annual report provides an overview of:

- LeDeR cases reported in year and the management of backlog cases.
- CCG LeDeR performance against NHS EI contractual measures.
- Trends and themes from LeDeR reviews, including specific learning resulting from COVID.
- CCG governance arrangements and actions to strengthen LeDeR governance.
- LeDeR developments in year
- Progress against the CCG LeDeR action plan

It must be noted there has been a significant increase in the number of people registered on the platform during 2020/21 which can be directly attributed to the COVID pandemic, and increased awareness of the programme across the partnership.

The CCG performance against NHS E contractual measures has significantly improved in year, with full compliance for eligible cases being completed within 6 months. The CCG will continue to monitor and report on LeDeR on a quarterly basis.

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On request this report can be provided in different formats, such as easy read. large print, audio or Braille versions and in other languages.

9.0 Abbreviations

ADASS	Association of Directors of Adult Social Care
BAME	Black Asian and Ethnic Minority
CCG	Clinical Commissioning Group
CDOP	Child Death Overview Panel
COVID	Coronavirus 19
DES	Directly Enhanced Scheme
DHSC	Department of Health and Social Care
DNA CPR	Do Not Attempt Cardio Pulmonary Resuscitation
GP	General Practitioner
ICS	Integrated Care System
KPI	Key Performance Indicator
LAC	Local Area Contact
LeDeR	Learning Disability Mortality Review
LQC	Local Quality Contract
LUHFT	Liverpool University Hospitals NHS Foundation Trust
MCCD	Medical Certificate Cause of Death
Mersey Care	Mersey Care NHS Foundation Trust
MLCSU	Midlands and Lancashire Commissioning Support Unit
NECS	North of England Commissioning Support Unit
NHS E	NHS England
NHS E/I	NHS England and Improvement
NHS E/I C&M	NHS England and Improvement Cheshire and Merseyside
PCN	Primary Care Network
PHE	Public Health England
QOF	Quality Outcomes Framework
Sefton CCGs	NHS South Sefton CCG and NHS Southport and Formby CCG
SJR	Structured Judgement Review
TCP	Transforming Care Partnership