

NHS South Sefton CCG & NHS Southport and Formby CCG Learning Disability Mortality Review (LeDeR)

Annual Report 2019-2020

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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 first 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), and is authored by the Local Area Contact for the CCGs. The report provides a background in relation to the introduction of the LeDeR programme in 2015 and the CCG's engagement of the programme.

The purpose of the report is to provide the CCGs and key partners with; an update on the key priorities for the LeDeR programme, an overview of the cases that have been registered on the LeDeR platform since 2017 (when all CCGs signed up to the programme), details of the cases registered on the platform in 2019-20 and the CCGs performance against NHS England measures. The report covers the period from 1st April 2019 to 31st March 2020.

In year there were 27 people with a confirmed learning disability registered on the LeDeR platform in year, which presents an increase from the previous year (21). In Q1 2020-21 there have been 10 cases registered on the platform which represents an increase in year. This increase is likely to be associated with the coronavirus pandemic (COVID) associated deaths, and an increased awareness of the LeDeR programme across adult social care relating to the COVID period. The increased numbers are likely to have an impact on performance in 2020-21 which is outside of this reporting period.

In 2018-19 NHS England (NHS E) introduced a set of key performance indicators for CCGs to report against during 2019-20. These include; governance requirements with key roles and responsibilities across CCGs, networking with NHS E/I Cheshire and Merseyside (NHSE/I C&M) LeDeR Steering Group. They also set out performance indicators for the expected completion of LeDeR reviews at the point of being registered on the platform.

Currently the Local Area Contact (LAC) role is sitting with the Assistant Chief Nurse with the Deputy LAC role sitting with the Designated Safeguarding Adult Manager. This arrangement has been in place since 2017, when the CCGs were required to support the programme. The CCG LAC and Deputy LAC had been represented at the NHS E/I C&M LeDeR Steering Group in year.

During 2019-20 the CCGs have reported non-compliance in relation to the performance set by NHS E for LeDeR reviews to be allocated within 3 months, and



completed within 6 months. The performance in year was 0 for South Sefton CCG and 15.3% for Southport and Formby CCG. This can be attributed to the limited LeDeR reviewer resource across both CCG areas.

In 2019-20 the CCGs were successful in a bid from NHS E North for non-recurrent funding to support performance and sustainability. The CCGs were successful in securing £37K; this funding was transferred across to Mersey Care NHS Foundation Trust (Mersey Care), who has employed Band 7 practitioners to undertake LeDeR reviews. The CCGs are expecting a business case to be submitted to the CCG to support LeDeR reviews in the longer term. It is anticipated the CCG will be able to report in line with NHS E requirements as we move into 2021-22 with the necessary resources in place. Against current target and trajectory all NHS E North specified LeDeR cases will be completed by the end of December 2020.

Systems and processes have been in place to support the quality assurances of LeDeR reviews across the CCGs, with recommendations and learning being reported internally and via the NHS E/I LeDeR Steering Group. More work is required to ensure the reviews, recommendations and learning are considered across health and social care, and this will be a key priority for 2020-21. An action plan has been developed based on the learning from 2019-20 to support the development of LeDeR for the CCGs (Appendix 2). The action plan and progress will be monitored at the CCGs Joint Quality and Performance Committee.

2 Background and Introduction

The Learning Disability Mortality Review (LeDeR) programme is the first national programme of its kind, 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 out to all CCG areas in 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 delivery of the programme requires working across health, social care, primary and secondary care, generic and specialist services. The reviews are multi-agency in nature and don't currently sit within existing single systems. However there is a requirement to consider other single or multi-agency processes and how the reviews interface with this. The programme was established at a time of increased scrutiny of avoidable deaths in general, and deaths of people with a learning disability in particular, with a focus on learning lessons and making changes.

The objectives set out of 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 4 to 74 years (inclusive) who are registered with a GP in England at the time of death. Whilst there is a national ceiling applied to the age range, all deaths from the age of 4 years and above are subject to a LeDeR review for the CCGs. This allows for all learning including best practice to be captured and not to discriminate a review based upon an individual's age. Reviews are carried out irrespective of cause or place of death. Deaths for children and young people age of 4 years to 17 years are conducted by the Child Death Overview Panel (CDOP). CDOP is fully linked into the LeDeR programme.

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)
- This started before adult hood, with a lasting effect on development.

The CCGs have fully committed to support the LeDeR programme since 2017. The CCGs have a designated Local Area Contact (LAC) in place. This role and function is undertaken by the Assistant Chief Nurse, whilst the Deputy LAC role and function are carried out by the Designated Safeguarding Adult Manager. During 2020/21 which is outside of this reporting year, the LAC for Sefton CCGs, is also covering the role and function across NHS Liverpool CCG (Liverpool CCG).

The LAC has developed networks across the Sefton area to ensure that from a health perspective all NHS providers and GP practices support the LeDeR programme, with learning being taken back through to respective organisations. NHS organisations are also 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 CCG governing body that organisations are signed up to, and supporting the LeDeR programme. Although further work is in train to streamline the processes.

3. Governance and Accountability Arrangements

NHS E has set out a purpose statement of expected requirements for CCGs for every CCG 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 the CCG Governing Body. During 2019/20 the CCGs have in place an interim Chief Nurse The role and function being covered by the Director of Quality and Outcomes from Liverpool CCG, with the Chief Nurse for the Sefton CCGs undertaking a secondment opportunity. The role of the LAC is a delegated function sitting with the Assistant Chief Nurse. The Deputy LAC covered by the Designated Safeguarding Adult Manager.

To support assurance to the Governing Body, the CCGs receive regular updates via the safeguarding quarterly reports, and individual papers to the Joint Quality and Performance Committee (JQPC) as a subgroup of the board. Papers have also been submitted to Leadership Team and Senior Management Team.

In 2018-19 NHS England made changes to the process for quality assuring reviews before formal submission to University of Bristol. This had previously been the responsibility of University of Bristol, but has since transferred across to CCGs. In year to support the governance arrangements the CCGs have quality assured LeDeR reviews as part of the CCGs Performance, Quality Independent Report Panel (PQIRP). The panel was set up to manage reports from areas outside of serious incidents with oversight from; CCGs quality team and lead commissioners. There have been challenges with the engagement from the CCG LD commissioning team in year. However LeDeR reviews should be considered within the context of health and social care. Further work is required to support the quality assurance by health and social care, which is a key priority for 2020-21.



A key priority for 2020-21 will be to develop the CCGs LeDeR action plan to further support the LeDeR governance arrangements that need to be in place. This will enable system learning and to drive improvements in service delivery across health and social care for people with a learning disability. It is anticipated the action plan will be monitored at the JQPC, with networks into the CCGs Joint Operational Group (JOG) and the North Mersey LeDeR Steering Group. The JOG reports through to the Primary Care in Common Committee (PCiCC) which in turns reports to the CCGs Governing Bodies. It is important to note the North Mersey LeDeR Steering Group was set up outside of this reporting period.

4. Learning Disability Deaths South Sefton CCG and Southport and Formby CCG 2019-20

During 2019-20 29 deaths were notified with 2 removed from the platform as they were confirmed not to have a learning disability diagnosis. This was a slight increase from the previous year. The numbers are representative of deaths that have been notified to the Bristol team as opposed to deaths of people with a learning disability across Sefton as a whole. The number is likely to be higher due to under reporting. While in essence the numbers have increased since 2017/18, more work needs to be undertaken across health and social care to raise the profile of the LeDeR programme, to ensure all relevant deaths are registered and, where eligible, receive a review.

The majority of deaths were notified by either NHS Trusts; Southport and Ormskirk Hospitals NHS Trust, Liverpool University Hospitals NHS Foundation Trust (or previously CQC registered organisations), Mersey Care NHS Foundation Trust. However in year notifications have been made by NWAS and the independent care provider where the person lived at the time they died. In a previous reporting year (2017-18), one case had been registered by People First Sefton, a third sector organisation working across Sefton. This would suggest there is a greater awareness of the LeDeR programme across health providers and commissioners as a whole.

In year there have been no cases which have been subject to parallel processes that have directly impacted on the delay of the review taking place, and or delay for the review being complete. Parallel processes are taken into consideration by NHS E, with acknowledgement they may not be completed within the six month timescale.

From the data that is available on the system and at the time of writing this annual report, of the 27 cases, two cases were completed and submitted to Bristol within the required 6 month timescale, both were Southport and Formby CCG (SFCCG) residents. These cases were expedited, as part of the 2020-21 COVID rapid reviews, which is outside of the reporting period for this annual report. One review was completed within 3 months and one within 4 months. No deaths registered on the system in year were associated with the COVID pandemic



Table 1. LeDeR cases per annum 2016 – 2020

Financial Year	South Sefton CCG Number of cases on the LeDeR platform	Southport & Formby CCG Number of cases on the LeDeR platform	Total Number
2016 – 2017 (Jan – March)	1	3	4
2017 – 2018	5	14	19
2018 – 2019	11	10	22
2019 – 2020	14	13	27

Table 2 below demonstrates the total number of reviews on the system for Sefton CCGs and the current status of these reviews including those for 2020-21 which is outside of this reporting period. Given the numbers as of month 5 for 2020-21, it is likely the numbers reported will be greater than those reported in previous years.

Table 2. Status of LeDeR Reviews 2017 - 2020

CCG Area	Status of Reviews	2016-17	2017-18	2018-19	2019 - 2020	2020 to date
	Total Number	1	7	10	14	4
South Sefton CCG	No. completed and submitted to Bristol	1	5	4	1	4
	No. allocated to a LeDeR reviewer	0	2	6	13	0
	No. awaiting to be allocated to a LeDeR reviewer	0	0	0	0	0
	Total Number	2	15	11	13	6
Southport and Formby CCG	No. completed and submitted to Bristol	2	15	5	2	4
	No. allocated to a LeDeR reviewer	0	0	6	11	1
	No. awaiting to be allocated to a LeDeR reviewer	0	0	0	0	1

At the time of writing this report, 37 cases are allocated to a LeDeR reviewer (19 SSCCG, 18 SFCCG), with one case waiting to be allocated. The case waiting to be allocated is within the designated 3 months allocation period as set by NHS E/I C&M.

Of the overall cohort on the system (82) forty eight were men (58.5%) and thirty four women (41.5%), showing a very slightly greater number of deaths associated with men than women.

The majority of deaths were for those in the over 50 year age group (66), with fourteen under the age of 50 years. The youngest death was a young lady who was 18 years of age. It is relevant to note LeDeR only applies to those who are 4 years of age and over. All deaths for those who are between 4 years to 17 years of age are



reviewed as part of the Child Death Overview Panel (CDOP), there have been no deaths registered for children and young people below the age of 18 years for either CCG. All deaths within the age range 18 years to 30 years were young people who had complex learning and physical disabilities, two of whom would have had special education and disability needs (SEND). Further work is needed to ensure the Designated Clinical Officer for SEND is sighted on the deaths for children and young people aged 4 to 25 years to support system learning.

For the total cohort registered on the system (86) the cause of death has been confirmed by the medical certificate cause of death (MCCD) for 50 individuals (Table 4). The remaining cases are in progress and MCCD is yet to be confirmed. The majority of deaths were attributed to pneumonia which accounted for 27 (50) which accounts for 54% of deaths. This number increases when considering section 1b) of the MCCD which would include 3 additional case accounting for 30 (50) and 60% of cause of death relating to respiratory failure and infection / pneumonia. There were 2 cases which were specifically attributed to COVID 19 (outside of this reporting year). The person who had an empyema also had lung cancer, however this was not included on the MCCD. It is not possible to provide a detailed report of all the causes of death as there is no reporting system currently in place for the CCG. Further work is needed to support the CCG to develop systems to provide reports including themes relating to cause of death. This will be a key priority for 2020-21.

Table 3. Age profile 2017 - 2020

Age Range	Number of People
4 – 17 years	0
18 – 30 years	4
31 – 50 years	10
51 – 75 years	57
Over 75 years	11

Where the death was attributed to sepsis the reasons were noted on the MCCD attributed to;

- Pneumonia (3)
- UTI (1)
- Peritonitis (1)



Table 4. Cause of death as registered on section 1a) of the MCCD 2019 - 2020

System	Cause of death on section 1a) of the MCCD	Number of People	Total Number by system
Respiratory	Respiratory Failure	3	27
	Aspirational Pneumonia	10	
	Broncho-pneumonia	5	
	Hospital Acquired Pneumonia	3	
	Lower Respiratory Tract Infection	2	
	Chest Infection	1	
	Coronavirus 19	2	
	Empyema lung fistula	1	
	Sepsis	4	4
Cardiac	Multi-organ Failure	5	11
	Renal Failure	1	
	Myocardial Infarction	2	
	Heart Failure	2	
	Pulmonary oedema	1	
	Alzheimer's Disease	2	2
	Epileptic seizure	2	2
	Intracranial haemorrhage	1	1
	Small bowel obstruction	1	1
	Cancer of the bowel	1	1
	Not ascertained (coroner)	1	1
	Total Number	50	

Deaths from pneumonia and aspiration pneumonia continue to be the highest cause of deaths nationally as well as locally (LeDeR annual report 2019). In May 2019 LeDeR made a recommendation to the Department of Health and Social Care (DHSC) to support the recognition and deterioration as early signs of illness in people with learning disabilities and to minimise the risks of pneumonia and aspirational pneumonia. A focus for 2020-21 for NHS E is the triangulation of initiatives across health and social care in the identification and prevention of aspirational pneumonia and pneumonia. This action will be best placed to be monitored as part of the newly formed North Mersey LeDeR Steering Group which was set up in 2020-21 outside of this reporting year. The North Mersey LeDeR Steering Group will report through to the CCG Joint Quality and Performance Committee.

Whilst the current LAC has developed a tracker which includes the cause of death on the MCCD, the CCG currently does not have in place a system for reporting against cause of death. This will need to be considered as a key priority for 2020-21.



5. Recommendations from LeDeR Reviews

5.1 LeDeR Quality Assurance Mechanisms

The LeDeR programme has a key focus on learning from reviews and service improvement. Up until 2018-19 all completed LeDeR reviews were required to be proof read by the LAC and then submitted to the University of Bristol for external review and sign off. During 2018-19 the process was reviewed with the responsibility for quality assurance of reviews transferred across to CCGs. From 2019-20 there has been a requirement for CCGs to convene their own LeDeR panels for formal sign off and submission.

This presented an opportunity for the CCGs to develop internal systems and processes to consider LeDeR reviews and capture the learning to inform service improvement. During 2019-20 the LAC set up a panel known as the PQIRP where completed reviews are submitted for sign off and capture the learning.

Whilst this has supported the internal review and sign off, there have been difficulties encountered in oversight and attendance from CCG commissioners. However there is a recognition LeDeR reviews require oversight across the partnership including social care. To strengthen the process a North Mersey LeDeR Multi-Agency Panel has been convened with engagement across the partnership including; Sefton Metropolitan Council (Sefton MBC), NHS Organisations, and Designated Nurse Safeguarding Adults. This has taken place outside of this reporting year in 2020-21. As there is currently a shared resource of the LAC role and function across Liverpool and Sefton for the reporting year of 2020-21 the multi-agency panel has been convened across the North Mersey area. The governance arrangements for the panel will be a key priority for 2020-21.

A number of trends and themes from completed LeDeR reviews have been captured as part of the minutes from PQIRP, although the CCG does not have in place a robust process for reporting against themes arising from LeDeR reviews. There is a current reliance on the manual count by the LAC. The development of a reporting system will be a key priority for 2020-21. The trends and themes noted have been highlighted in table 5 below. Further work is required to support the themes from LeDeR reviews to feed into organisational action plans to support the improvement of services for people with a learning disability.

Whilst the themes noted for primary care include a lack of evidence of the LD annual health check, a number of these reviews are retrospective dating from 2017 and 2018. This pre-dates any changes the CCG may have in place as part of the local quality contract and the current arrangements to improve the access to an LD annual health check.



Table. 5 Trends and Themes from LeDeR reviews

Themes From LeDeR Reviews	Primary Care	Acute Trust	Community Provider	Local Authority	MLCSU
Reasonable adjustments and best interest decisions to be evident with the GP records to support the increased uptake of the LD annual check and health promotion including; cancer screening programmes and vaccination and immunisation programmes.	√				
Health action plans following the annual LD health check to be available in the GP records	√				
Dementia screening to be provided to people with Down Syndrome as part of the annual health check	√				
NHS acute providers to ensure LD flag is added to the patient record on admission to hospital to support reasonable adjustments to be considered with input from the Trust LD liaison service		√			
DNA CPR decisions should evidence application of the MCA and best interest decision making with family and or carers.	√	√	√		
Enable the discharge from hospital to an appropriate place of care to meet the person's needs in a timely manner			√	√	
Safeguarding adult referral to be submitted irrespective of funding route to support the needs of the individual			√		√
Application to be considered for Court of Protection where there are concerns in relation to the next of kin / person who has lasting power of attorney is not acting in the person's best interests irrespective of funding route			√		√
Local authority to take account that individuals will have an entitlement for social care services irrespective of funding route				√	

The CCGs took over the role of lead commissioner for general practices services from NHS England C&M from April 2019. Prior to this the performance against learning disability annual health checks would have been with the NHS E C&M area team. Whilst the CCG does have data for years prior to April 2019, the CCGs are only able to report against performance from April 2019 (Table 6). Since April 2019 practices can choose to deliver this element via a Direct Enhanced Service (DES), or access the support to deliver this on their behalf via the GP Federation. Learning Disability registers have been validated in year to ensure accuracy of those patients who should receive an annual health check. Additionally the learning disability health check has been prioritised via the CCGs local quality contract (LQC) to ensure that



practice performance is on track, the local medical council (LMC) is engaged and supportive of this piece of work. The data would support an increased uptake year on year, however the COVID pandemic is likely to have a negative impact for 2020-21 with a number of people with a learning disability needing to shield due to co-morbidities.

Table 6. Sefton CCGs Performance Learning Disability Annual Health Check

CCG Area	2017 - 2018	2018 - 19	2019 -20
South Sefton CCG	83	203	293
Southport and Formby CCG	173	380	398

Plans are in place with community providers to support the uptake of health checks by supporting a pre-health check questionnaire and explaining what would be involved to prepare people for a full health check. It is anticipated this will increase uptake.

The recommendations for primary care from LeDeR are reported through to the Joint Operational Group (JOG) as a sub-group of the Primary Care in Common Committee (PCiCC). The PCiCC reports directly through to the CCGs governing bodies. LeDeR is a standing item at JOG.

A key priority for 2020-21 will be to enable the recommendations and learning from LeDeR reviews to feed into the CCG primary care commissioning arrangements.

6. Engagement with the Learning Disability Community

6.1 The CCGs work in partnership with Sefton MBC to engage with the learning disability community across Sefton. The CCG provide funding via the Better Care Funding to People First Sefton a 3rd sector self-advocacy organisation as a mechanism to support engagement and awareness raising with people with a learning disability. People First Sefton is the local branch of the Merseyside wide group who works as part of the Transforming Care Partnership Board (TCPB). The purpose of the group is to represent all people with a learning disability in Sefton.

They run the monthly 'Get Involved Group' to talk about issues for people with learning disabilities such as; health, housing, day services, hate crime and relationships. They are represented at the CCGs Experience and Patient Engagement Group, and support key pieces of work at an NHS E/I C&M level.



The organisation submits quarterly reports to Sefton MBC and CCGs on the activity, outputs including case studies. Examples of Sefton health specific focused areas supported in year are;

- **Community Champions Network** – Access to podiatry services, GP extra service, Southport and Ormskirk Hospitals (S&O) listening event,
- **Awareness Raising and Promotion**; taking responsibility for their own health and wellbeing – North West Borough’s physical health event, filming and interviews for NHS England STOMP programme, Cancer Red Flag symptoms & Look after your lungs presentations (six in year), Medicines management development session, NHS England Physical Health Event, Sefton sexual health services promotion, healthy eating awareness
- **Get Involved Group** – increasing access to annual health checks, S&O accessibility consultation, LeDeR funding increased access to health screening, annual health check, messages to support STOMP campaign.
- **Health Watch Sefton Steering Group** – ‘enter and view’ Accident and Emergency at S&O.
- **Health and Social Care Forum** – Personal Health Budgets
- **LeDeR Steering Group** – Cancer red flags awareness, findings from LeDeR reviews, David project (death and dying)
- **Consultation** – Annual health check consultation Mersey Care and CCGs Primary Care Team.
- **Patient Participation Group** – via Health Watch Sefton
- **Health Watch Sefton Consultation** - Changes to chemists and walk-in-centres.
- **NHS England newsletter Easy Read Consultation** – including health issues and LeDeR.

6.2 In year People First and the CCGs submitted a successful bid to NHS England North under ‘Learning into Action’ for £21K to support awareness raising and improve health outcomes for people with learning disability. The health focus outcomes included within the bid are the themes from LeDeR reviews across Sefton:

- Increased uptake of annual health check
- Increased uptake cancer screening programmes
- Increased uptake of vaccination and immunisations

The ‘Passport to Good Health’ programme is aimed at people with a learning disability and their carers to support attendance, reasonable adjustments and uptake. The Memorandum of Understanding (MOU) is in place with the reporting through to the CCG and NHS E/I C&M.

The programme is intended to run from April 2020 to March 2021, which is outside of this reporting period. Despite COVID period with members needing to be shielded, the programme has started, although there may be some risks that will need to be



considered within the remit of COVID requirements to maintain the safety of members and target audience as part of the road shows.

6.3 To support engagement with the Learning Disability Community, the annual report will be shared with People First Sefton, and explore how the CCGs can ensure the learning disability community can be involved in the production of the annual report for future years. People First have already confirmed their attendance at the North Mersey LeDeR Steering Group. This will be a key action for 2020-21.

7. Sefton CCGs LeDeR Performance

7.1 Compliance Against Governance and Accountability

Whilst the LeDeR programme is not a statutory role for CCGs, the programme has now been included in the contractual requirements for CCGs. The programme was established to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement initiatives. It was implemented at the time where there was a focus on the deaths of patients in the NHS, and the introduction of the national Learning from Deaths Framework in England (2017) NHS England have set a number of performance measures which CCGs are required to comply with;

- To have in place a Local Area Contact for LeDeR
- 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 on 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. 2019-20 is the first year CCGs are required to produce an annual.
- CCGs to have in place an action plan which is reviewed and updated on a quarterly basis, this is the first year the CCGs are required to produce an action plan.

As stated in the Governance Arrangements in section 3 of this report, NHS E 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 for the CCGs is carried out by the Assistant Chief Nurse, with the Deputy LAC sitting with the Designated Safeguarding Adult Manager. The CCGs have been compliant with having the necessary roles and functions in place to support the LeDeR programme in year.

NHS E have set out a standard to monitor CCGs engagement and representation at the local area NHS E LeDeR Steering Group. This includes;



- 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.

In 2019-20 there were six scheduled NHS E Cheshire and Merseyside LeDeR Steering Group meetings held, with attendance from Liverpool CCG for two out of the six meetings. Whilst this does provide the necessary compliance and assurance rating of for the CCGs, it is important to note engagement has taken place outside of the steering group. Non-attendance were as a result of unforeseen absence of the LAC in year, and competing priorities for the Deputy LAC. The CCG has actively contributed to the forums as part of wider learning across the Cheshire and Merseyside Area.

7.2 CCGs Performance within NHS E Timescales

During 2018-19 NHS E carried out a review of length of time it was taking to complete reviews up until the end of May 2019. It was reported the average number of months to complete a LeDeR review was determined as 9.5 months. This was on the expected timescale of completion of 6 months from the death being registered on the platform and the reviewing being completed and submitted to Bristol. The delay in completing reviews in turn means delays to identify potential learning from the deaths being incorporated into local systems.

NHS E have set out contractual requirements for all cases to be allocated to a reviewer within 3 months of notification, with subsequent completion of reviews within 6 months of the case being raised on the LeDeR platform. However those cases that are subject to parallel processes are exempt from the calculations, these include;

- Police Investigations
- Section 42 safeguarding adult enquiries
- Child Death Overview Panel
- Coronal process
- Serious incident reviews
- Complaints
- Cases subject to multi-agency reviews as part of local safeguarding children and adult arrangements.

Since January 2017 until end of March 2020, 71 notifications meeting LeDeR requirements have been raised on the LeDeR platform for the CCGs (31 x SSCCG, 40 x SFCCG). During this period the CCGs have remained below the expected performance as set by NHS England. The main reason for this are the ongoing challenges faced by the CCGs and NHS commissioned organisations supporting the programme within the existing financial envelope.



A number of actions have been taken by NHS E/I C&M and North region to support CCGs to meet the mandated performance, with additional funding.

- NHS E/I C&M have provided funding for a total of 34 cases. These were either outsourced to Farley Dweck solicitors and conducted by independent practitioners, or funding transferred across to Mersey Care to employ LeDeR reviewers. NHS E/I C&M are responsible for the performance monitoring of these cases with support of the LAC.
- NHS E North region have provided additional funding for unallocated cases where the person died before the end of October 2019. These cases have been outsourced to North of England Commissioning Support Unit (NECS). This accounts for 21 cases. NHS E North is responsible for the performance management.

Performance of progress against the NECS allocated cases has been negatively impacted by the COVID period, with a number of reviewers re-deployed as part of the government COVID legislation. During 2020-21 performance is a focus for NHS E with an expectation for CCGs to meet requirements for cases to be line with the 6 month timescale for completion, and a specified cohort of cases to be completed by the end of December 2020. Those cases allocated to NECS will be excluded from the CCGs management.

The CCGs have a LeDeR tracker in place which was developed by the LAC, to support the monitoring of cases in line with NHS England requirements. The tracker does not have a reporting functionality and is reliant on manual trawl/count. The CCGs currently do not have in place a system to support the reporting against NHS E expected compliance. This will be a key priority for 2020-21.

At the time of writing this report which is outside of this reporting period, a number of cases have been completed and either signed off or awaiting panel for approval (Appendix 1). There has been slight increase in the number of deaths raised on the Bristol platform year on year. In Q1 2020-21 nine cases have been registered on the system, which may lead to an overall increase in year which is outside of this reporting year. The increase in reporting is likely due to the increased scrutiny and focus on the LeDeR programme from NHS England an Association for Directors of Adult Social Services (ADASS) and the noted increased deaths of people with a learning disability as part of the COVID pandemic.

Overall performance has been below the expected standard with 100% compliance to allocate a case within 3 months to a LeDeR reviewer. In year performance was; 15.3 % for SSCCG and 30.7% for SFCCG. Completion of the reviewer within 6 months has also been below required 100% target. This was 0% for SSCCG and 15.3% for SFCCG. All cases up until the end of 2019 -20 have been allocated to a reviewer, being progressed or completed. The CCGs are expecting to be complaint with the NHS E expectations expectation by the end of Dec 2020.



Table 7. Sefton CCGs Compliance against NHS E LeDeR Measures 2019/20

Evidence against measure	Reporting	Assurance Rating	
		South Sefton	Southport & Formby
1. Named person with job title and contact details. Local Area Contact in place: Senior Quality and Safety Manager Deputy LAC in place: Deputy Director of Quality and Outcomes	Quarterly		
2. 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		
3. Mins of steering group meeting showing attendance at and participation in of named CCG representative Local Area Contact attended 2 out of the 6 meetings as evidenced in the minutes	Quarterly		
4. % notifications assigned within 3 months (target 100%) South Sefton CCG 15.3% Southport and Formby CCG 30.7%	Monthly		
5. % of notifications completed within 6 months (target 1005) South Sefton CCG 0% Southport and Formby CCG 15.3%	Monthly		
6. 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. Draft CCG action plan in place			
7. Actions within plans updated at least quarterly Updates to be provided at the Joint Quality and Performance Committee	Quarterly		

In year the CCGs submitted a joint successful bid with Mersey Care to NHS England for funding against the criteria 'Performance and Sustainability', and were successful in obtaining £37K non-recurrent funding. A MOU is in place with Mersey Care to employ a Band 7 practitioner to support the reviews. Recruitment has taken place with reviews being progressed. As part of the MOU, Mersey Care are expected to submit a business case to the CCGs to support long term sustainability of the programme. This was expected to be submitted in Q1 2020-21 which is outside of this reporting year. Delays have been incurred due to COVID with personnel re-deployed. This hasn't affected reviews being progressed and completed.

Table 7 above denotes the CCGs overall performance against the NHS E LeDeR measures for 2019-20. NHS E Measures for contractual compliance can be referred to in Appendix 3 of the document. The CCGs have reported below compliance



threshold both for allocating cases within three months and completion of reviews against the six months timescale. It is anticipated the CCGs position will improve with the current action plan and trajectory in place. The CCGs are anticipating reporting in-line with the required standards for cases raised on the platform from April 2021. Performance will be a key priority for 2020-21.

8. Sefton CCGs LeDeR Key Priorities for 2020-21

A number of key priorities have been identified as part of the 2019-20 annual review which will form the CCGs LeDeR action plan for 2020-21:

- 8.1 Engagement across the partnership: Whilst there is good engagement to support the LeDeR programme across health providers, more work is required to ensure there is engagement from Sefton MBC and third sector to support the voice of people with a learning disability including awareness raising, and as part of the overall LeDeR programme.
- 8.2 To develop the networks and relationships to involve the learning disability community across Sefton and enable representation at the North Mersey LeDeR Steering Group, including contribution to the annual report for 2020-21.
- 8.3 To develop a robust multi- agency quality assurance processes for completed reviews to support wider learning.
- 8.4 Recommendations and learning from LeDeR reviews are highlighted through internal the CCGs processes and via the NHS E C&M LeDeR Steering Group. More work is required to ensure the recommendations inform the commissioning of services and quality improvements by the CCG commissioners including primary care and Sefton MBC.
- 8.5 The CCGs to develop an action plan which is monitored at the Joint Quality and Performance Committee, to demonstrate progress against key areas identified in the annual report.
- 8.6 The CCGs to develop a system to support the reporting of LeDeR; performance; demographics, trends and themes, to provide assurance and inform commissioning arrangements; to Governing Body, NHS E/I C&M and NHS England.
- 8.7 The CCGs to consider additional resources to support the co-ordination of LeDeR programme across the CCGs area, including performance reporting.
- 8.8 The CCGs to improve attendance at the NHS E/I C&M LeDeR Steering Group, with exception reporting through to the Joint Quality and Performance Committee.



9 Conclusion

This annual report has provided an overview of the current case load registered on the LeDeR platform and has outlines the CCGs performance during 2019-20.

There has been a year on year increase of cases registered on the platform, which is likely to increase in 2020-21 due to; the impact of the COVID pandemic, and increased awareness of the programme across the partnership. This may affect performance for 2020-21.

The CCGs performance against NHS E measures have been below what has been expected. This has been as a result of limited capacity and resources to support the programme from when it was introduced. This has proved to be a challenge not only for the CCGs but for other CCGs locally, regionally and nationally. Whilst NHS England North, NHS E/I C&M have provided additional funding to support the programme, this is non recurrent from the Transforming Care Fund. The CCGs will need to review the capacity and resource to support the programme during 2020-21.

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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.



10 Abbreviations

ADASS	Association of Directors of Adult Social Care
CCG	Clinical Commissioning Group
CDOP	Child Death Overview Panel
COVID	Coronavirus 19
DES	Direct Enhanced Service
LAC	Local Area Contact
LeDeR	Learning Disability Mortality Review
LMC	Local Medical Council
MCCD	Medical Certificate Cause of Death
MLCSU	Midlands and Lancashire Commissioning Support Unit
MOU	Memorandum of understanding
NECS	North of England Commissioning Support Unity
NHS E	NHS England
NHS E/I	NHS England and Improvement
NHS E/I C&M	NHS England and Improvement Cheshire and Merseyside
SEND	Special Education Needs and Disabilities
SSECCG	NHS South Sefton Clinical Commissioning Group
SFCCG	NHS Southport and Formby Clinical Commissioning Group
STOMP	Stopping over medication of people with a learning disability



Appendix 1. South Sefton and Southport and Formby CCGs Performance against NHS E Completion of Reviews within Six months 2017 - 2020

NHS E Performance Measures by reporting period	South Sefton CCG	South Sefton % Compliance in Year	Southport & Formby CCG	Southport & Formby % Compliance in Year	Narrative
No. registered on LeDeR 16/17	1		2		
No. allocated within 3 months	0	0%	1	50%	
No. completed within 6 months	0	0%	0	0%	All cases were completed by Nov 2018
No. registered on LeDeR 17/18	5		14		
No. allocated within 3 months	3	60%	9	64.2%	
No. completed within 6 months	0		0		18 cases have been completed with 1 allocated as part of NHS E Backlog NECS for SSSCCG
No. registered on LeDeR 18/19	11		11		
No. allocated within 3 months	4	36.3%	3	27.2%	
No. completed within 6 months	1	9%	0	0%	10 cases have been completed with 12 cases allocated as part of NHS E backlog NECS (6 SSSCCG, 6 SFCCG)
No. registered on LeDeR 19/20	13		13		
No. allocated within 3 months	2	15.3%	4	30.7%	
No. completed within 6 months	0	0%	2	15.3%	2 cases have been completed with 7 cases allocated as part of NHS E backlog NECS. 9 allocated to Farley Dweck (TCP), 5 allocated



					to Mersey Care
Total Number LeDeR Cases Allocated and in progress	18		16		
Total Number Yet to be allocated	3		1		Expected trajectory to be received by MCT
Overall % Compliance allocated to a LeDeR within 3 months	30%		42.5%		
Overall % Compliance review completed within 6 months of registration	3.3%		5%		



Appendix 2. South Sefton CCG and Southport and Formby CCG LeDeR Action Plan 2020/21

Ref No.	Recommendation	Action	Evidence / Narrative	Responsible Person	Deadline	Progress Update	Rag Rating
1.	The CCGs to demonstrate engagement of the LeDeR programme across Sefton CCGs, health, social care, and 3 rd sector to support awareness raising and commitment to the LeDeR programme	Identify lead representatives across CCGs, NHS providers and Sefton MBC.	Key stakeholders across health, social care and 3 rd sector are represented at the North Mersey LeDeR Steering Group	Chair of North Mersey LeDeR Steering Group	Oct 2020	Key stakeholders have been identified across Sefton CCGs, Sefton MBC, NHS Providers and 3 rd sector	Completed Sept 2020
		Develop a LeDeR Forum to provide oversight of LeDeR across Sefton CCGs with ToR and governance arrangements in place.	North Mersey LeDeR Terms of Reference and Minutes	Chair of North Mersey LeDeR Steering Group	Dec 2020	North Mersey LeDeR Steering Group in place. Terms of reference in draft to be agreed.	
					Dec 2020	Chair and Administration to be confirmed	
					Sept 2020	Confirm the reporting requirements from the North LeDeR Steering Group through the CCGs JQPC	
					Sept 2020	Confirmation received from Sefton MBC LeDeR updates to be discussed at the Safeguarding and Governance Meeting. Paper presented on 16 th September 2020	Completed Sept 2020
2.	The CCG to have in place robust governance arrangements in place to support the quality assurance of LeDeR reviews.	To put in place multi-agency LeDeR panel with governance arrangements to report trends, themes,	Multi –agency panel meeting Terms of Reference. Minutes and reporting through to North Mersey	Local Area Contact	Oct 2020	North Mersey LeDeR Multi-agency panels meetings in place with representation from Sefton MBC and NHS providers.	Completed Sept 2020
					Oct 2020	Terms of Reference to be drafted and agreed.	



Ref No.	Recommendation	Action	Evidence / Narrative	Responsible Person	Deadline	Progress Update	Rag Rating
	To enable reporting against trends and themes to inform commissioning arrangements	recommendation and escalate risks / consideration of parallel processes.	LeDeR panel and CCGs Joint Quality and Performance Committee as a sub-group of the board including; recommendations, risks and key issues		Oct 2020	LeDeR quality assurance checklist in place to support consistency	Completed Aug 2020
Dec 2020					LeDeR reporting system to be developed to report against key recommendations, demographics, trends and themes		
Sept 2020					Minutes from the multi-agency panels to be submitted routinely to the North Mersey LeDeR Steering Group.		
3.	The CCGs in-conjunction with key partners to develop a forum to support the governance arrangements, develop a Sefton CCGs LeDeR overarching action plan to support the quality improvements based on recommendations and learning from LeDeR review. Ensure the relevant governance arrangements are in place to support reporting / escalation of risks through to LCCG governing body.	Develop a LeDeR Forum to provide oversight of LeDeR across Sefton MBC & CCGs with ToR and governance arrangements in place.	North Mersey LeDeR Steering Group in place with Terms of Reference and Minutes	Chair of North Mersey LeDeR Steering Group	Oct 2020	North Mersey LeDeR Steering Group in place. Initiated in July 2020 Terms of reference to be agreed 16.09.2020 Draft ToR tabled at the Sept meeting.	Completed July 2020
		Identify key stakeholders across health, social care and 3 rd sector to ensure the voice of people with a learning disability	Key partners identified from across the CCG, health, social care and 3 rd sector as represented on the Steering Group attendance tracker	Chair of North Mersey LeDeR Steering Group	Oct 2020	Key stakeholders have been identified across Sefton CCGs, Sefton MBC, and NHS Providers. Key representative for 3 rd sector and Sefton CCGs GP clinical lead to be identified	Completed Sept 2020
		Confirm the reporting mechanisms to support the governance arrangements for	Minutes and reporting through to North Mersey LeDeR panel and CCGs JQPC as a sub-group of the board including;	Chair of North Mersey LeDeR Steering Group	Oct 2020	Confirm the reporting requirements from the North LeDeR Steering Group through the CCGs JQPC to be discussed at the JQPC.	



Ref No.	Recommendation	Action	Evidence / Narrative	Responsible Person	Deadline	Progress Update	Rag Rating
		reporting through to CCGs Governing Body	recommendations, risks and key issues North Mersey LeDeR Steering Group overarching LeDeR action plan owned by partners of the steering group across health and social care. The progress of the action planning being monitored at the Steering Group	Chair of North Mersey LeDeR Steering Group	Sept 2020	16.09.2020 LeDeR paper submitted to Sefton MBC Safeguarding and Governance Group	Completed Sept 2020
				Chair of North Mersey LeDeR Steering Group	Dec 2020	Draft North Mersey LeDeR action plan tabled for discussion at the Steering Group in Sept for further development	
4.	The CCGs to have in place appropriate reporting mechanisms in place to enable the reporting against; Performance of LeDeR in-line with NHS England requirements Key demographics of people who have died Recommendation, learning, trends and themes to inform commissioning arrangements and improvements in quality	The CCGs to have a robust system with regular reports being presented at JQPC	Evidence of reports in the minutes of the North Mersey LeDeR Steering Group. Recommendations are evident in the overarching North Mersey LeDeR action plan Evidence of reports in the minutes of the CCGs JQPC	Local Area Contact	Dec 2020	CCG exploring the use of Ulysses as the reporting tool, to develop and set the reporting requirements. Further discussions to take place with the InSight Team in MLCSU	
				Chief Nurse	April 2021	Administrative capacity and resource to be identified in the longer term. NHS E has funded 1.0 WTE Band 5 LeDeR co-ordinator for 12 month fixed term contract. The post is in the process of being recruited to via Mersey Care. CCGs to consider ongoing resource on completion of the 12 month fixed term contract	



Ref No.	Recommendation	Action	Evidence / Narrative	Responsible Person	Deadline	Progress Update	Rag Rating
	of care and service delivery.						
5	CCGs to have in place the necessary resources to support the LeDeR programme across the Sefton area; LeDeR reviewers Administrative function	CCG to identify roles and responsibilities including in job descriptions	LeDeR reviewer capacity and resource to be in place to support LeDeR reviews To have in place a LeDeR process across the North Mersey area including expected timescale for delivery	Local Area Contact	April 2020	Mersey Care has in place a 0.7 WTE Band 7 reviewer for a 12 month fixed term contract. Practitioner is in place. NHS E funding.	Completed Jan 2020
		Develop the mechanisms to enable LeDeR reviews are completed in line with NHS England reporting requirements, including quality assurance.		Local Area Contact	March 21	Business case to be submitted to support sustainability – expected Q1 20/21 delayed due to COVID To be tabled at the Mersey Care CCQRM	
				Chief Nurse	March 21	CCGs administrative resource and capacity to be confirmed. Mitigation in place with the CCGs Quality Improvement Support Officer providing interim support	



Ref No.	Recommendation	Action	Evidence / Narrative	Responsible Person	Deadline	Progress Update	Rag Rating
				Local Area Contact	Nov 2020	Mitigation in place with a 1.0 WTE Band 5, 12 month fixed term contract for a North Mersey LeDeR co-ordinator funded by NHS E/I C&M. post in the process of being recruited to by Mersey Care	
				Local Area Contact	Sept 20	LeDeR pathway task and finish group in place with representation across NHS providers. As a sub-group of the North Mersey LeDeR Steering Group	In place from July 2020
			To have in place a LeDeR process across the North Mersey area including expected timescale for delivery	Local Area Contact	Dec 20	LeDeR pathway in draft further developments to be incorporated. To be agreed at the North Mersey LeDeR Steering Group	
6	The CCGs to further develop key networks and relationships with the Learning Disability Community across Sefton, to ensure the voice of people with Learning Disability are included	To identify and engage with key partners across the 3 rd sector	Learning Disability 3 rd sector membership at the North Mersey LeDeR Steering Group	Local Area Contact	Oct 2020	Engagement in place with People First Sefton who will be included on the membership for the North Mersey LeDeR Steering Group	Completed Sept 2020
			The voice of people with a learning disability is evidenced in the CCG LeDeR annual report for 2020/21	Local Area Contact	Sept 2020	Discussion taken place with LAC and People First Sefton; Co-ordinator and Development worker. The 2019- 20 annual report will be shared with the membership and discussions to take place input into annual report for 2020-21	Completed Sept 2020



Appendix 3 NHS England – CCG LeDeR Contractual Measures

Evidence required	Frequency of collection	Assurance Scoring Matrix		
		Red	Amber	Green
<ol style="list-style-type: none"> 1. Named person with job title and contact details. 2. Terms of reference for LeDeR steering group including name of organisation and details of representative. 3. Mins of steering group meeting¹ showing attendance at and participation in of named CCG representative² 	Quarterly	CCG meets one or fewer of the three criteria: <ol style="list-style-type: none"> 1. Named person. 2. Terms of reference give details of representative 3. Minutes of steering group showing attendance and participation. 	CCG meets two of the three criteria: <ol style="list-style-type: none"> 1. Named person. 2. Terms of reference give details of representative 3. Minutes of steering group showing attendance and participation 	CCG meets all three criteria: <ol style="list-style-type: none"> 1. Named person. 2. Terms of reference give details of representative 3. Minutes of steering group showing attendance and participation.
4. % notifications assigned within 3 months ³	Monthly	<60%	Amber: 60%- 100%	100%
5. % of notifications completed within 6 months ³	Monthly	<60%	Amber: 60%-90%	<=90%
<ol style="list-style-type: none"> 6. 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. 7. Actions within plans updated at least quarterly 	Quarterly	<ul style="list-style-type: none"> • CCG does not have an action plan or is a not signatory to its local LeDeR action plan • and actions have not been updated in last quarter. 	<ul style="list-style-type: none"> • Draft plan in development or awaiting sign off • or all CCGs in the steering group do not sign off on the action plan or actions not updated in last quarter 	<ul style="list-style-type: none"> • LeDeR action plan in place and approved by Executive Board of CCG • and actions updated at least quarterly

1 One set of minutes may be submitted on behalf of all member CCGs as long as these minutes show attendance by a representative of each member CCG.

2 This may be the executive lead for the CCG or named delegated representative.

3 As of 22/10/19 measures are indicative. These will be confirmed through regional assurance routes upon final approval



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