Ipswich & East Suffolk Clinical Commissioning Group
West Suffolk Clinical Commissioning Group

Suffolk Learning Disability Mortality Review (LeDeR) Programme Annual Report – 2018/2019

Introduction

The aim of this annual report is to provide an update on progress of the LeDeR Programme in Suffolk during 2018/2019.

The key issues the report considers are:

- The Governance for the LeDeR Programme and where the learning is progressed and monitored.
- Planning in place to address backlog of LeDeR Reviews in Suffolk.
- The LeDeR Learning from Suffolk Reviews and how this is being progressed across multi-agency services in Suffolk.

The report is intended to detail assurances with regards to how the Suffolk LeDeR Review learning is being identified and how local learning is influencing change and improvements in quality of health and social care for people with learning disabilities in Suffolk. This is inclusive of improvements in care that will help reduce incidence of earlier deaths and improve the statistics of life expectancy of this population.

The work described in this report is intended to drive forward work streams to improve the quality of, and access to, health and social care provision for people who have a learning disability and reduce incidence of earlier preventable deaths.

In Suffolk since August 2018, in addition to having a Local Area Contact Role, we have employed a Named Nurse for Safeguarding Adults with responsibility for LeDeR Review Coordination, 12.5 hours per week and a business administrator, 18.75 hours per week since June 2019. The responsibility of these two roles is to support the implementation of the LeDeR Programme in Suffolk.

LeDeR Programme Governance

The Suffolk LeDeR programme continues to maintain good engagement from multi-agency services into its local steering group meetings.

During 2018/2019, the steering group concentrated on development of a communications strategy to improve multi-agency understanding on what the programme is about and how to make a notification following the death of an individual with a learning disability.

2018/2019 saw an increase to 34 notifications received for review, as opposed to 9 notifications received in the previous year, 2017/2018.

Year	April	May	June	July	August	September	October	November	December	January	February	March	Total
17/18	0	0	0	0	1	0	0	0	2	2	3	1	9
18/19	0	6	0	3	4	1	2	3	2	5	1	7	34

However, this number still falls short of the NHSE/NHSI statistics prediction of 40 to 50 deaths across Suffolk in any one year.

The Steering Group is now looking to explore local demographics to identify if this lower number of deaths is reflective of a positive outcome of how well we are looking after people with a learning disability, or is reflective of a need to further improve understanding of the programme aims and increase the number notifications. This information will inform where, across the county, there is a need to target further LeDeR communications.

To support the process of notification a number of awareness raising processes have been put in place across provider services including residential and support services, hospitals and primary care. Additionally, an alert has been placed on the Primary Care Recording System, when registering a death, which prompts the surgery to make a notification. Notifications are being received from across the full range of services, with the majority being made in a timely way, within 1 week of date of death. 3 notifications were made over 1 month after the date of death.

The Steering Group continues to ensure awareness and understanding of LeDeR is shared across all our local multi-agency services. The Clinical Commissioning Group LeDeR Coordinator and LeDeR Local Area Contact frequently provide LeDeR Training sessions across health, social care, police and the University of Suffolk. They have also presented at Regional Child Death Overview Panel Workshops.

The LeDeR Steering Group sits at an Executive level and is intended to lead on strategic oversight of the programme's progress in Suffolk.

The Steering Group identified there was a need for an additional Working Group. This Group was formed in October 2018, and continues to meet on a bi-monthly basis. The Group leads on taking forward the operational work required to progress the LeDeR learning across health and social care organisations.

Both LeDeR groups are made up of multi-agency organisation directors or practice leads from children's and adults' services across health, social care, police and coroners. Both meetings are also attended by Healthwatch, Suffolk Family Carers, Suffolk Parent and Carer Network and Local Advocacy Groups as well as the Learning Disability Partnership Board Chair.

A Suffolk LeDeR Engagement Group was planned to commence in autumn 2018. However, due to issues in finding a suitable and accessible venue, this group has not yet met. The first meeting for this group is now planned for early autumn 2019. A number of families, carers and people with a learning disability have expressed an interest in participating. A local Learning Disability Self Advocacy Group have been commissioned to facilitate production of easy read agendas, easy read themes from the redacted LeDeR Reviews and easy read/pictorial action plans for the group. The purpose of these meetings will be to empower people with a learning disability, and their families and carers, to meaningfully participate in the LeDeR Programme work, and, in particular, in the Steering Group work. This is to ensure their voice drives forward the local LeDeR learning and outcomes.

Suffolk LeDeR Reviews

The National LeDeR Annual Report identified that the East of England has the lowest performance in addressing backlogs of reviews and progressing local learning.

However, statistics indicate that Suffolk is performing well. In 2019, the National Programme requested sharing of our local governance structure, good practice and how learning is being progressed, with our regional peers. The LeDeR Lead and Named Coordinator have met with the National LeDeR Communications Team to share Suffolk good practice at a national level.

Bi-weekly regional East of England LeDeR teleconferences are also in progress and Suffolk continues to be proactive in sharing of good practice and learning from other areas within these meetings.

Suffolk monitor reviews which have not commenced or been completed within the NHSE 6 month trajectory from date of notification. As at 31st December 2018, there were two unassigned reviews which could have potentially been considered for the NHSE Backlog Project. This is significantly lower than other regional counties and potentially disqualifies Suffolk from receiving additional funding from NHSE later this year to support addressing significant backlogs of reviews waiting more than 6 months.

Each month, Suffolk continue to receive on average of two new LeDeR notifications for review.

Breakdown of reviews: Total 51 in September 2019

Year	Completed	%	Assigned/ in Progress	%	Unassigned	%	Total	%
17/18	6	66.6	3	33.3	0	0	9	20.9
18/19	14	41.2	8	23.5	12	35.3	34	79.1

To date, 40% of the local total of 51 reviews have now been completed and 12 are currently in progress (including 2019/20 data). One review required an additional multi-agency LeDeR Review to take place and one review led to the request for an organisation to take forward a Serious Incident Enquiry.

There is currently a backlog of 12 reviews from 2018/19 (plus 8 reviews from 2019/20). A Review Backlog Action Plan is in place. This plan intends to address the current backlog and also ensure continuing compliance 2019/2020 with NHSE trajectory for all reviews to be completed within 6 months of receiving notification.

Suffolk are trialling a panel approach to complete reviews. This includes having all case notes available to reviewers to complete the initial review, with the exception of meeting with families. The allocated reviewer will then meet with families external to this panel. Should further exploration of review be required as a result of further information from families, the review can be brought back to panel. So far this has proven to be a successful approach.

Delays in completion of reviews is greatly reduced by having dedicated time and access to notes.

Suffolk continue to have issues with delays with accessing Primary Care notes which have been returned to PCSE. As such a system has been put in place with Primary Care requesting notes are retained prior to returning to PCSE in order to allow time for upload.

Completed reviews are quality assured by the Suffolk LeDeR Coordinator and a member of the LeDeR Steering Group.

Redacted Reviews are also now uploaded to a secure area on the Safeguarding Adult Board website for access by the Steering Group.

Currently Suffolk has a total of 44 reviewers trained, this includes:

Clinical Commissioning Group Staff: 28
Norfolk and Suffolk NHS Foundation Trust Staff (NSFT): 4
Suffolk County Council staff: 9
Consultancy basis: 3

There has been a clear commitment made by the CCG Chief Nursing Officer that as part of their employment contract, all nurses employed by the CCG will train to become LeDeR Reviewer's and support the review process, with commitment from their managers. Suffolk County Council and NSFT have also made a clear commitment to the reviewer's panel to ensure a minimum of one staff member be available to support the panel process.

The LeDeR Coordinator holds a group e-learning session for new reviewers on a monthly basis and also holds bi-monthly action learning sets in order to provide updates and any further support to reviewers. E-Learning Bereavement Training has been sourced and is available to reviewers. A resource pack has also been developed to support reviewers with the review process which includes other local resources in addition to those provided by the LeDeR Programme Support Team.

Local LeDeR Learning and Action Planning

The LeDeR Coordinator draws the recommendations and themes from the completed redacted reviews for the Steering Group to review and discuss. Including a review of age at date of death, cause of death, thematic review and recommendations.

Local LeDeR Reviews have identified a number of themes and trends:

- Sepsis is a named contributor in cause of death

Primary Care Liaison Nurses, West Suffolk Hospital and Ipswich Hospital LD Liaison Nurses are participating in local sepsis work streams in our local hospitals and community healthcare.

- Care Coordination is lacking, particularly with regards to day to day physical healthcare needs

The Transforming Care Board is leading on work streams to look at care coordination and skills for carers in understanding and facilitating day to day physical healthcare. For example; accredited core skills training for carers, supported living and care home contracts detailing facilitation for annual health checks.

- Lack of practitioner understanding of learning disability

The Transforming Care Board are leading on dissemination of mandatory and standardised learning disability core skills framework training for all practitioners and carers working in health and social care services.

- People having not accessed regular annual health checks or cancer screenings

ACE Anglia were commissioned by the CCGs and NSFT to develop a number of easy read materials to support people with a learning disability to access and have quality health checks. Primary Care Liaison Nurses work with providers and people with a learning disability to put in place appropriate reasonable adjustments and encourage people to access their annual health checks and cancer screenings. Provider contracts detail they must facilitate annual health checks and provide relevant health information with the individual to support quality of these. Additionally, ACE Anglia have developed a Peer Educator Network to raise awareness around annual health checks in the learning disabilities community.

- Lack of sharing of health information when people move to new social care provider/accommodation or on discharge from hospital

Primary Care/Hospitals reviewing health passports. Discussions with Care Homes Quality Team with regards to introducing the Red Bag Scheme for supported living settings and people with a learning disability residing in care settings.

- Lack of reasonable adjustments to access hospital care and support whilst staying in hospital

Reasonable adjustment information and toolkits have been developed and are now available for Primary Care and hospital staff to support them in putting in place reasonable adjustments for individuals.

- Quality of, or lack of mental capacity assessments and best interests' decision making

Ipswich Hospital and West Suffolk Hospital now complete regular audits on quality of capacity assessing and best interests' decision making, particularly targeting capacity assessing for vulnerable groups. Discussions in progress with CCG Primary Care Team with regards to CCG audits and support to improve quality of capacity assessing with GPs. Funding commissioned from NHSE for MCA/Best Interest Decision Making for Primary Care event to be organised for later this year. Adult Social Care MCA/DOLS Team completing audit on capacity assessing across social care.

- Access to mental health services

NSFT Consultant Learning Disabilities Nurse is taking forward the LeDeR learning identified issues in accessing appropriate mental health services and further developing the Greenlight Toolkit work.

The next step, 2019/2020, is to consider how, locally, we track improved performance and monitor if outcomes are improved. Next year, the LeDeR Steering Group will be planning how to analyse local demographics and data and evidence , for example; if numbers of deaths decrease next year from sepsis and aspiration pneumonia, whether we are seeing less people dying in hospital.

2019 /2020 Workstreams

2018/2019, the LeDeR Local Area Contact continued to submit quarterly reports to NHSE for assurances on local progress of the LeDeR Programme. However, the national programme has requested that from June 2019, all LeDeR learning and actions be part of Transforming Care Board Action Plans and monitored by NHSE/NHSI through their reporting.

This year, identified learning in our local reviews has further evidenced work already in progress to improve services for people with a learning disability in Suffolk.

LeDeR is now integral to the NHS 10 Year Plan, published 2019. This plan aims to work towards improving multi-agency working together and joint commissioning. The LeDeR Programme in Suffolk is a good example of multi-agency already working well together and progressing learning across multi-agency Suffolk services.

Next year, we expect to see that LeDeR learning will be the driving force behind changing and developing better health and social care services for people with a learning disability across Suffolk.

The LeDeR Programme goals for 2019/2020

- All reviews in Suffolk to be completed within 6 months of notification.
- Meaningful engagement of people with a learning disability, their families and carers in the LeDeR Programme work.
- Continued good quality of reviews to identify local learning.
- Progression of identified learning in a timely manner.
- Numbers of notifications to improve in line with national statistical expectations.
- Continuing multi-agency senior leader/director engagement in LeDeR Steering Groups.
- Increasing numbers of multi-agency reviewers.
- To track improved performance and monitor if outcomes are improved.
- To analyse local demographics and data and evidence, for example; if numbers of deaths decrease next year from sepsis and aspiration pneumonia, less people dying in hospital.

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Designated Nurse Safeguarding Adults and LeDeR Lead/ Local Area Contact Lead.

Date: August 2019