NHS
Surrey Heartlands
Clinical Commissioning Group

LeDeR (Learning Disability) Mortality Review

Annual Report Jan – Dec 2019

Surrey LeDeR Steering Group

Credits and Acknowledgements

With thanks to the Family members, Carers and our system partners for talking to us and providing information to help us undertake the reviews.

With thanks to Post 19 Enterprise Group for taking the time to meet with us to understand the LeDeR programme and producing such wonderful artwork.

With thanks to our LeDeR reviewers for completing the reviews

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1. Introduction

The LeDeR programme is the national programme which reviews the deaths of people with learning disabilities across the country. It was established in response to the recommendations made in the Confidential Inquiry into the Premature Deaths of People with Learning Disabilities (2013) with the aim of supporting local areas to review the deaths of people with learning disabilities, identify learning and identify areas of both good practice and where service improvement is required. The programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP) and is funded by NHS England. The University of Bristol is contracted to establish and develop the review process and evaluate the findings.

The most recent national LeDeR reports (2019) show that women with learning disabilities die on average 27 years sooner and men with learning disabilities die on average 22 years sooner, when compared to the general population. In addition to this they found that some of the deaths were avoidable through people being able to access good quality health care that acknowledges the persons learning disability and makes reasonable adjustments to the care process accordingly. The report also found that there was bias in the care of people with learning disabilities, resulting in unequal treatment.

The Surrey Heartlands CCG, Surrey Heath CCG and North East Hampshire and Farnham CCGs are committed to the implementation of the LeDeR programme and welcome the learning from local reviews to ensure that we can address any such bias. We will work to ensure that people with learning disabilities are able to access good quality care across Surrey. In addition to this we recognise that the findings from local reviews influence service improvement locally, regionally and nationally and welcome the opportunity to contribute to service improvement at all levels.

1.1 Background

The LeDeR programme was established in 2015. This was initially rolled out across pilot sites before being fully implemented across England in 2017. When the programme was initially adopted within Surrey there was a wealth of local interest in the programme however a lack of reviewer availability resulted in slow progress initially. Throughout 2019 we have invested in the LeDeR programme and look forward to the impact this will have on progressing our outstanding reviews and addressing the learning identified.

1.2 Review process

1.2.1 LeDeR Process

The LeDeR process is as follows:

- A notification of a death is completed by someone who knew the person that died. This can be anyone involved in the persons care and can be done via the LeDeR website https://www.bris.ac.uk/sps/leder/notification-system/ or phoning 0300 7774 774.

- The Local Area Contact within the Clinical Commissioning Group is notified of the death.
- The death is allocated to a local LeDeR Reviewer who will undertake the review.
- The reviewer will contact the family of the person who died to tell them about the programme and ask them if they would like to be part of the review.
- The reviewer will contact the relevant people who were involved within the individuals care.
- Some cases may need to go to a multi-agency meeting.
- The findings of the review are then reviewed through local LeDeR meetings where themes are considered and actions are agreed.
- In Surrey it is agreed that every review, other than those which are allocated to a dedicated LeDeR reviewer, will have both a lead reviewer and a buddy reviewer allocated to each case. This is to ensure a joint skill mix and ensure there is a shared allocation of tasks.

1.2.2 Key Individuals

Local Area Contacts (LAC)

Each CCG has a Local Area Contact. Their role is to allocate the reviews to a reviewer, monitor their progress, provide advice and support to reviewers and carry out quality assurance checks. In addition to this they provide advice and guidance to the steering group to ensure that appropriate action is taken to improve the care of people with learning disabilities and reduce premature mortality.

Role of the LeDeR Co-ordinator

The LeDeR Mortality Review Co-ordinator will support and monitor the LeDeR review process, provide training and support to reviewers and will ensure the dissemination of learning from reviews. In addition to this the co-ordinator will act as a resource to reviewers and provide clinical supervision to reviewers as required.

Reviewer

Reviewers complete the LeDeR reviews of the deaths of people with learning disabilities. In order to ensure a holistic review, they liaise with family members where possible, and any relevant friends, carers or professionals. They also access records relating to the person's health and social care. If the review highlights any concerns / areas that would benefit from further review, a multi-agency meeting will be arranged by the reviewer and actions will be agreed to address any issues highlighted.

Each provider will have a selection of trained reviewers within their area who will carry out reviews as requested.

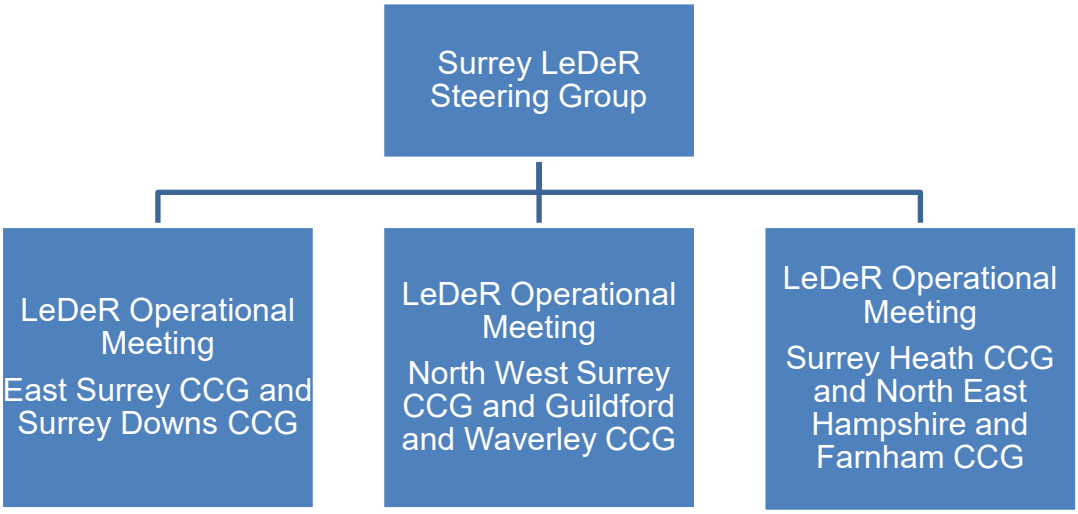
Buddy Reviewer

Buddy reviewers will be allocated as standard practice in the Surrey and North East Hampshire and Farnham CCGs to ensure distribution of workload and support for the reviewer. Their role will be the same as the reviewer however the reviewer will lead on the review.

1.2.3 Surrey LeDeR Steering Group

The Surrey LeDeR steering group was set up in September 2017 and since then has developed and evolved. In order to identify both Surrey wide and local themes, it was agreed that the group would introduce a second layer of meetings, these meeting are called Operational Groups.

After reviewing the outstanding reviews and the ongoing work required to progress the reviews, the LeDeR meeting structure was reviewed in December 2020. Please see the meeting structure below:



The steering group has membership from the following Clinical Commissioning Groups (CCG):

- East Surrey CCG (ES)
- Surrey Downs CCG (SD)
- North West Surrey CCG (NWS)
- Guildford and Waverly CCG (GW)
- Surrey Heath CCG (SH)
- North East Hampshire and Farnham CCG (NEHF)

These CCGs form part of the Surrey Mental Health and Learning Disability Collaborative. As a result, it was agreed that they would continue to be part of the Surrey steering group and annual reporting despite Surrey Heath CCG and North East Hampshire and Farnham CCGs moving into the Frimley Health and Care Integrated Care System.

Please note that East Surrey CCG, Surrey Downs CCG, North West Surrey CCG and Guildford and Waverley CCG merged to form Surrey Heartlands CCG on the 01/04/2020. The chair of the LeDeR steering group is the Deputy Director of Quality and Nursing within Surrey Heartlands CCG, previously the LAC for Surrey Downs CCG.

In addition to this, there is also representation from Commissioners, a family representative, Local Authority, Primary and Secondary healthcare, Health watch, Provider representatives and a Child death review process representative

The steering group reviews the themes identified from the reviews, which will have previously been discussed by members of the operational groups, identifies Surrey wide learning and themes, responds to recommendations to improve service provision and reduce the likelihood of premature mortality, identifies wider strategic actions, produces and monitors a Surrey Wide LeDeR action plan and identifies any process issues or challenges.

1.2.4 Operational Group

The operational group invites reviewers to present their completed review. The group will then respond to recommendations, identify a responsible person for each action, create a local LeDeR action plan, monitor completion of the action, share good practice, report themes into the Surrey LeDeR Steering Group and obtain feedback from reviewers on the review process identifying any good practice / challenges.

1.2.5 Reviewer Workshops

We host quarterly workshops in order to provide reviewers with Local and National LeDeR updates. In addition to this we invite specialists to deliver a training or information session and any relevant topics identified. Recent presentations have included: A session on aspiration pneumonia provided by a local Speech and language therapist and an End of Life in learning disabilities session provided by a Professor of Intellectual Disability & Palliative Care.

1.2.6 Local Developments

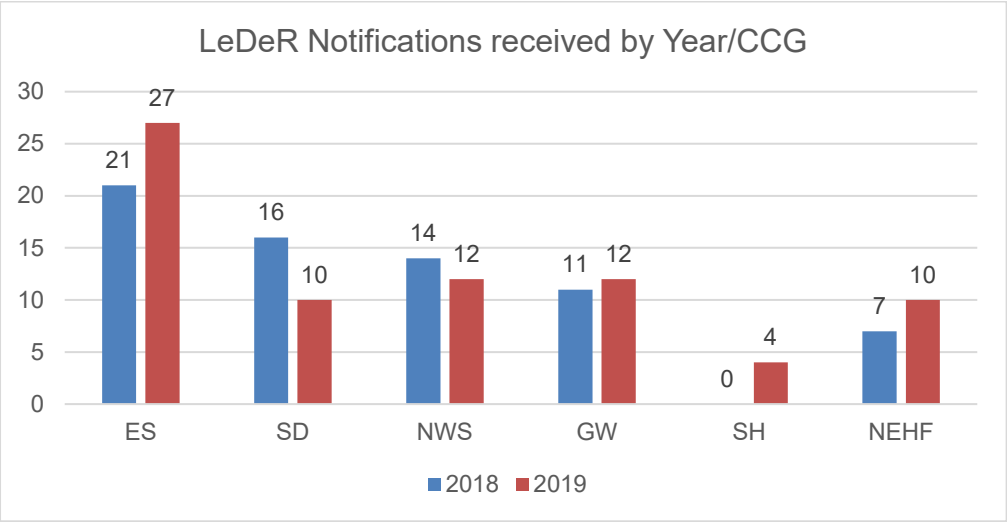
In 2019 the LeDeR steering group commissioned a local enterprise company to develop introductory cards which will be sent to the family members. The cards provide information on the LeDeR programme and extend an invitation to be part of the review process. The enterprise company employs and provides work experience opportunities for people with learning disabilities. They designed and printed the cards specifically for use by the LeDeR programme and have given permission for the images to be used within this report.

2. Deaths notified to LeDeR in 2019

2.1 Surrey Wide LeDeR Notifications

There were 75 notifications made to the LeDeR programme from the 1st January 2019 until the 31/12/2019. This is an increase of 6 from 2018. This slight increase may be due to the raised profile of the LeDeR programme and the requirement to notify the programme of any deaths. The notifications can be seen in Graph 1 below.

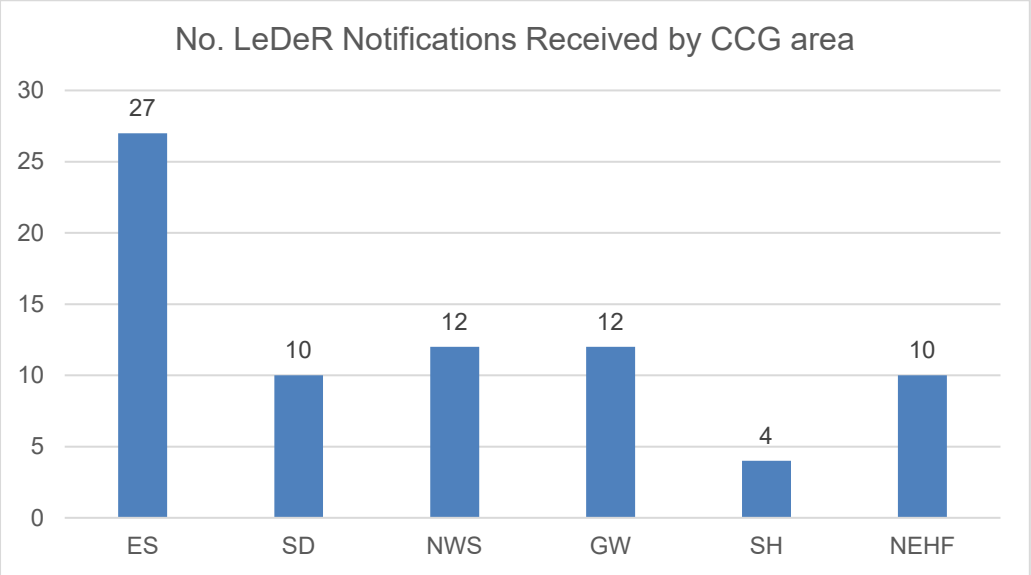
Graph 1.



2.2 Notifications via CCG Area

The total number of notifications for 2019 can be seen broken down by CCG area in graph 2 below. This shows that East Surrey CCG area have the highest number of death notifications. It is worth note however that East Surrey CCG also has the highest population of people with learning disabilities in Surrey.

Graph 2.

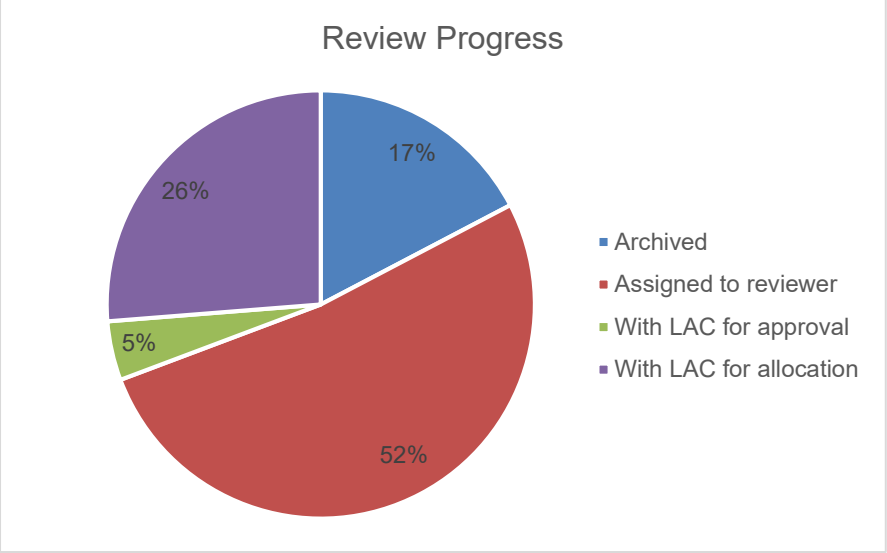


2.3 Review progress

Since the introduction of the LeDeR programme in 2017, there have been 157 notifications made until the 31st December 2019. Due to the large back log of reviews across the country, NHS England / Improvement have commissioned the North East Commissioning Support Unit (NECS) to undertake a selection of reviews. Surrey have 85 reviews being carried out by NECS. This leaves 72 reviews that were notified up until the end of December 2019 being carried out locally.

Of the 157 reviews, 26 reviews have been completed, 80 are currently assigned to a reviewer, 7 are submitted and awaiting quality assurance checks and 44 are yet to be allocated to a reviewer. This is demonstrated in the pie chart below.

Chart 1.



2.4 Action taken to ensure completion of review

The timeframes for undertaking reviews that have been set by NHS England / Improvement are;

- the review should be allocated to a reviewer within 3 months of the notification being received and
- the review should be completed within 6 months of the notification being received.

Since the programme began, reviewer availability has been a challenge. This has resulted in these timeframes not being met. The CCG Collaborative are committed to ensuring that the outstanding LeDeR reviews are completed by the 31st of December 2020 in line with national expectations.

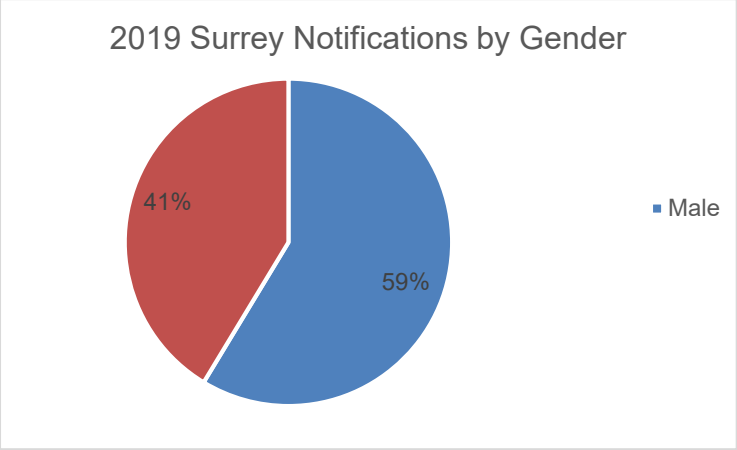
In order to ensure the programme is developed and reviews are progressed within the above timeframes, Surrey have employed a full-time LeDeR Co-ordinator on a permanent basis and some specialist reviewers working on a bank basis. In addition there are now a number of reviewers available from local providers across the system. We currently have 39 active reviewers.

3. About the people who died

3.1 Demographic Data

Of the 75 deaths reported to LeDeR in 2019, 31 were female and 44 were male. This is very similar to the national data, where 42% of the deaths reported are female and 58% are male.

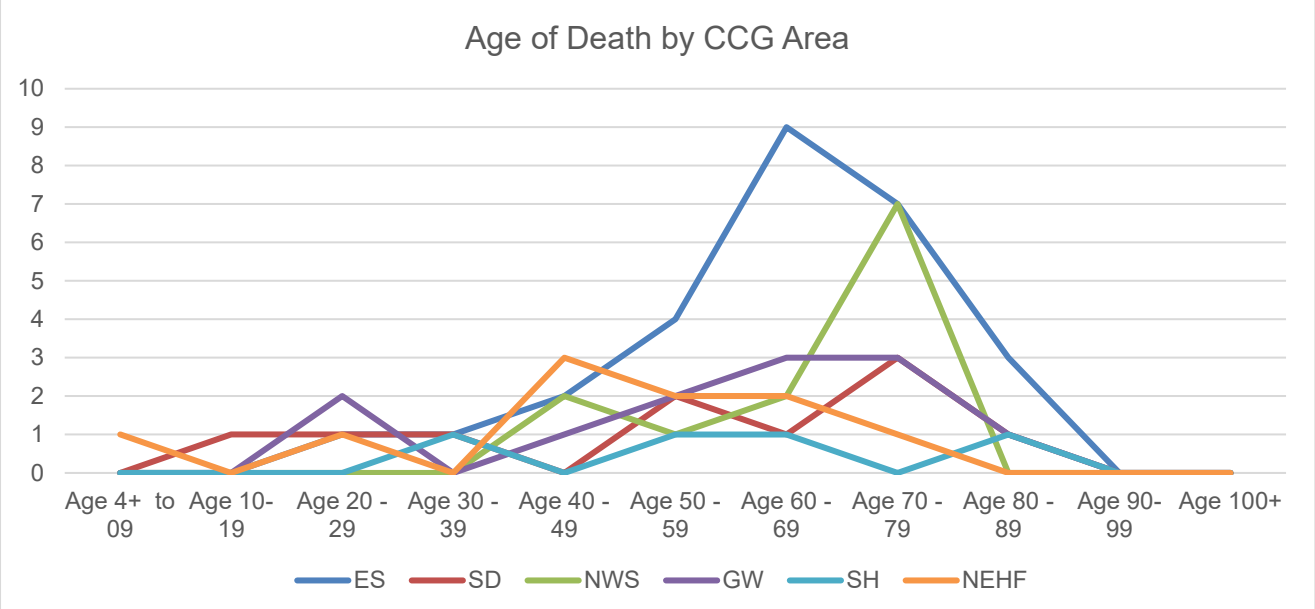
Chart 2.



3.2 Statistics

3.2.1 Age of death

Most of the people who died were between 70 and 79 years old when they died however there is a variance across the CCG areas in relation to the age of the individual. The graph below displays this in more details.

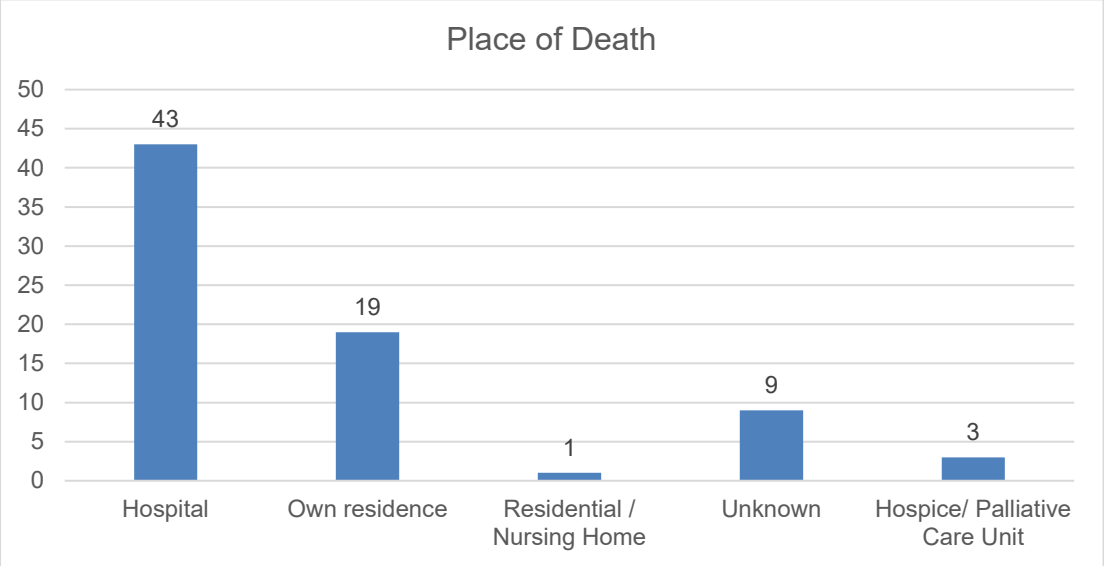


3.2.2 Level of Learning Disability

Of the 75 deaths that were reported to LeDeR in 2019, 20 of the reviews have been completed. Of those 20, 3 people had a mild learning disability, 7 people had a moderate learning disability, 8 people had a severe learning disability and 2 people had a profound learning disability.

3.2.3 Place of Death

43 of the individuals who died in 2019, died in a hospital environment and 19 died in their usual residence. 9 of the cases were reported as location unknown, these cases have not had the reviews carried out as yet. This information will be collected during the completion of the review.



3.2.4 Health Data

Existing health conditions were reviewed for all of the 20 completed reviews. Every individual had an existing health concern. The health conditions noted were as follows:

- Epilepsy noted on 4 occasions
- Constipation noted on 3 occasions
- Cerebral Palsy noted on 3 occasions
- Dysphagia noted on 2 occasions
- Repeated chest infections
- Dementia
- Phenylketonuria
- Gastro oesophageal reflux
- Prostate cancer
- Volvulus

- Hypertension
- Left Ventricular Impairment
- Neurofibromatosis

4. Assessment of quality of care provided

20 of the notifications received in 2019 have had their review completed. Please see the table below which indicates the grading of care broken down by CCG area. One case was a child death therefore this follows the Child Death review process and does not get graded in the same way as adult deaths.

Grading of care of all archived cases							
	ES	SD	NWS	GW	SH	NEHF	Total
1. This was excellent care (it exceeded expected good practice).	**0**	**0**	**0**	**0**	**0**	**0**	**0**
2. This was good care (it met expected good practice). Please identify in Q62 any features of care that current practice could learn from	**2**	**0**	**2**	**3**	**0**	**1**	**8**
3. This was satisfactory care (it fell short of expected good practice in some areas but this did not significantly impact on the person's wellbeing).	**2**	**1**	**0**	**1**	**0**	**1**	**5**
4. Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death.	**0**	**2**	**1**	**0**	**0**	**0**	**3**
5. Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death	**0**	**1**	**1**	**0**	**0**	**0**	**2**
6. Care fell far short of expected good practice and this contributed to the cause of death.	**0**	**1**	**0**	**0**	**0**	**0**	**1**

5. Multi-agency Review

5.1 Number of cases progressed to multi-agency review

2 of the 20 cases completed required a multi-agency review meeting to identify further learning. Recommendations from multi-agency reviews are included in the learning recommendations below.

6. Child Death Reviews

There were two child deaths reported to the LeDeR programme in 2019. One of these reviews has been completed. The second case is in the process of being reviewed through the child death review process.

The Surrey LeDeR steering group has representation from the child death review team. All of the nurses within their team have undertaken the LeDeR training so that they can amalgamate the two review processes when undertaking their reviews. The learning is presented through the operational and steering groups.

7. Evidence of Reasonable Adjustments

There was good evidence of reasonable adjustments being made which resulted in good care outcomes, Examples include:

Table 1.

Theme	Reasonable adjustments detail
Additional support	Carer support in hospital, reported in 2 reviews.
	Open visiting, reported in 3 reviews.
	Referral to liaison nurse.
Communication of needs	Hospital passport in place. Carers actively encouraged to visit and share strategies for interaction.
Documentation of Reasonable Adjustments	Annual Health Check records that the carer must be present.
Home visits	GP carried out home visits.
Prioritisation	Seen as the first appointment in GP surgery due to difficulty waiting.
Equipment	Wheelchair brought in by home to aid posture / respiratory management.

Theme	Reasonable adjustments detail
	New orthotic shoes had been provided to support the individual whilst moving around at home and in and out of vehicles.
	Photos, lights and music brought into hospital to aid relaxation.
Multi professional approach	Frequent contact with community Learning Disability team and liaison nurse.
Service provision	Diabetic retinopathy unsuccessful therefore referred to hospital for further investigations as an outpatient.
	Phlebotomy- Emla cream and Diazepam medication used to support blood tests.
	Cat brought into hospice

8. Good Practice Examples

There were lots of examples of good practice happening locally which helped to improve patient experience.

Theme	Good Practice details
Communication	DISADAT (Pain assessment) tool used.
	Care Home notify the learning disability liaison services as standard when any of their residents are admitted.
	Patient was flagged as having a learning disability on the hospital electronic system.
	Regular best interest meetings to agree treatment plan.
	Residential home had a clear and detailed health action plan that was updated each year.
	Familiar staff supported their resident during hospital admission.
End of life care	Individual supported to die at home.
	Compassionate practice from teams -provided soothing music at XX's bedside.
	Training provided to care home staff on end of life care.
Medical care	Quick and efficient interventions to make the individual comfortable upon admission.

Theme	Good Practice details
	The ward doctor sought advice from multi-disciplinary colleagues and documented decision making process re: insertion of nasogastric tube.
	GP practice was responsive to the residential home staff concerns and saw the patient at home.
	STOMP review carried out.
	Good evidence of reasonable adjustments being made including LED lights and a pet cat being brought into the hospice.

9. Recommendations from reviewers

The learning and recommendations from the 20 reviews completed identified the following themes:

- Communication
- Annual Health Check
- Deprivation of Liberty Safeguards (DoLS)
- Mental Capacity Act (MCA)
- Reasonable adjustments
- LD Awareness Training
- Meeting medical needs
- Discharge from hospital
- Escalating concerns
- Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR)

The details of the recommendations are as follows:

Theme	Sub-Topic	Recommendation Details
Communication	Treatment plan	Consultant should write directly to family members and not rely on carers to pass on the message.
		Missed opportunity to gather feedback from the service user in an accessible way. (this would have informed how to support him with his health needs going forward)
		NOK details should be checked on admission to hospital.
	Learning Disability	Communication of the person's learning disability should have been available to the consultants in a

Theme	Sub-Topic	Recommendation Details
		timelier manner and should be easily accessible at outpatient clinics. Electronic systems should be developed to ensure access to essential clinical information. (Reported in 3 reviews)
		Patients with hospital passports should be highlighted at handover so that staff can familiarise themselves with them at the start of their shift.
	Follow up care	Hospital staff and GP must share and act upon communications so that the transition of information is comprehensive and actioned.
	Carers	Carers should be viewed as partners in care. (Reported in 2 reviews)
		Hospitals should have a carers policy in place which proposes a meeting is held on admission between the nurse in charge and the residential home manager to agree roles and responsibilities, hours of support, communication etc.
Annual Health Check	Availability and quality of health check	Full health assessment should be completed annually and should use standardised process and include all health data. (Reported in 4 reviews)
		Practices should notify the CCG if they are going to be unable to undertake the AHC in order to explore alternative arrangements.
		Home staff should monitor whether all patients have been offered an annual health check and health action plan and should escalate to the GP practice if they have been missed.
	Screening	The GP to routinely review and discuss access to cancer screening during the Annual Health Assessment which needs to then inform and be documented in the Health Action Plan.
Deprivation of Liberty Safeguards (DoLS)	Training	Further DoLS training in acute hospitals, recommended in 2 reviews
	Outcome	The local authority should provide updates on the process of DoLS applications. Reported in 5 reviews.
Mental Capacity Act (MCA)	Training	Further MCA training recommended in 4 reviews
	Documentation	Improved / Formal documentation of MCA assessments and decisions, recommended in 4 reviews.
	Care bundle	Consideration should be given as to the introduction of a MCA care bundle for the hospitals.
Reasonable adjustments	Communication	Easy read information should have been used to explain procedures and prepare the individual.
	Visiting hours	Open visiting should have been in place and carers should have been viewed as partners in care.
	Dentistry	No evidence of reasonable adjustments being made for patient declining dental treatment.

Theme	Sub-Topic	Recommendation Details
LD Awareness Training		Staff training and support from the Learning Disability Nurse in the Acute setting in how to engage effectively with people with Learning disabilities and their carers / family.
		All hospital staff should be informed of the importance of hospital passports through Learning disability awareness training.
Meeting medical needs	Training	Carers would benefit from increasing knowledge, awareness and confidence in their monitoring and observations of a person's health and any signs of deterioration.
		Supported living care providers to embed routine health observations within Health Action Plans. Drawing on supporting literature such as the 'Stop-Look-Care' handbook
	Screening	Procedures need to be in place to ensure that GP practices and care providers are supporting individuals with a learning disability to access routine screening; within the legal framework of the Mental Capacity Act.
		Discussions should take place between professionals and family about how to ensure screening can be undertaken and any reasonable adjustments required.
		The principles of the Mental Capacity Act need to be applied together with evidence of best interest decision making; to consider less invasive measures (such as breast examination) to enable a proportionate degree of screening to take place. Reported in 4 reviews.
	Social care knowledge / skills	Care homes should ensure that they follow the Surrey Eating and drinking policy and are trained in dysphagia management.
	Pain management	Care home should complete pain assessment tools and share with acute hospitals. Reported in 2 reviews
	Palliative care	Anyone nearing end of life should be referred to palliative care services.
	Weight monitoring	Weight monitoring in care homes should be standard practice and should be followed up with the GP if there are any concerns.
	Psychiatric support	There should be clear advice on how to access psychiatric advice for people with learning disabilities whilst they are acute hospital inpatients.
	Stopping over medication of people with a learning disability,	Referral should be made to specialist services for STOMP review.

Theme	Sub-Topic	Recommendation Details
	autism or both (STOMP)	
Discharge from hospital	Assessment of complex cases	Discharge tools should have been utilised which take into account the complex health needs of the individual and their learning disability.
	Planning	A discharge planning meeting should take place prior to discharge for patients with complex health needs.
Escalating concerns	Acute	Care home staff should use hospital complaints procedures if they are unhappy with the standard of care being provided, reported in 2 reviews.
	Liaison	There should be clear communication of the cover arrangements when the learning disability liaison nurse is unavailable i.e. Community Team for People with Learning Disabilities.
	Safeguarding	There should be clear communication and documentation in relation to the safeguarding investigation and outcome of safeguarding enquires.
Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR)	Documentation	Respect forms should be fully completed with appropriate clinical reasoning, finding from 2 reviews.
	Training	Examples of both good and poor practice in relation to DNACPR completion should be provided in training.

10. Conclusions and Recommendations

This is the first annual report for the Surrey LeDeR programme. The Surrey LeDeR Steering Group recognise the importance of the LeDeR reviews and are committed to ensuring the reviews that remain outstanding are completed by December 2020. As highlighted above there have been many developments in 2019 which provides a strong foundation for improved performance in 2020 / 2021. The learning identified from the completed reviews will create an action plan and will inform our future priorities.

Our recommendations from this report are to:

- Raise awareness and improve compliance with the Mental Capacity Act.
- Improve compliance with annual health checks and ensure the benefits of these are understood by our local Primary Care Networks and Care Providers.
- Work with partner organisations to address access to screening and ensuring the principles of the Mental Capacity Act are applied in decision making.
- Focus on improved communication between services to provide information in relation to reasonable adjustments required in advance of appointments / attendance.
- Identify gaps in service provision and make recommendations to commissioners to address any gaps in services.

11. Future Steering Group Priorities

In addition to the above priorities, the steering group are keen to expand the attendance at both the steering group and the operational group, in particular we would like to increase the service user engagement, representation from primary care and the coroner service.

In order to put learning into practice, we aim to engage with and participate in existing provider groups to share identified themes and support mitigating actions.

We also will arrange a system wide Learning into Action event focusing on the principles and the application of the Mental Capacity Act and associated legislation.