NHS
Kernow
Clinical Commissioning Group

Cornwall and Isles of Scilly learning disability mortality review (LeDeR) annual report 2019

NHS
Kernow
Clinical Commissioning Group

Contents

NHS
Kernow
Clinical Commissioning Group

Executive summary

This report for Cornwall and the Isles of Scilly is the first report and covers the period 1 July 2017 to 31 December 2019. The purpose of the report is to share the findings and the learning from the reviews completed.

The learning disability mortality review (LeDeR) programme is a national project delivered by the University of Bristol and was introduced following the confidential enquiry into premature deaths of people with a learning disability (CIOPLD 2013). The enquiry had found that for every 1 person in the general population who dies from a cause of death amenable to good quality care, 3 people with learning disabilities will do so. The enquiry highlighted that people with learning disabilities tended to die 20 years younger than those without a learning disability. The LeDeR 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. The programme is led by the University of Bristol, and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England.

The NHS long-term plan confirms that the NHS will continue to fund the LeDeR programme. It stated: “Across the NHS, we will do more to ensure that all people with a learning disability, autism, or both can live happier, healthier, longer lives.” The plan went further in saying: “Action will be taken to tackle the causes of morbidity and preventable deaths in people with a learning disability and for autistic people” and “the whole NHS will improve its understanding of the needs of people with learning disabilities and autism and work together to improve their health and wellbeing”.

Cornwall and the Isles of Scilly has a combined population of 543,523 people. There are 2.890 people with a learning disability on the GP registers.

The LeDeR programme in Cornwall and the Isles of Scilly is led by NHS Kernow. The programme has a learning disability programme manager, supported by a project manager and a recently appointed interim local area contact.

Since the LeDeR programme commenced there have been 67 deaths reported between July 2017 and Dec 2019 to date. 15 of these deaths having been reviewed. There have been a number of challenges faced both nationally and locally sourcing reviewers with adequate capacity to undertake the work.

An additional £5 million was invested by NHS England and NHS Improvement (NHSE/I) in 2019/2020 to address the backlog of un-reviewed cases and increase the pace with which reviews are allocated and completed. Cornwall has been provided with £35k funding from NHSEI to fund reviewers on a zero hours contract.

Alongside this a backlog project run by North England Commissioning Support (NECS) has been allocated 23 of the Cornwall reviews to complete.

What is a LeDeR Review?

LeDeR reviews are not investigations of care but aim to develop learning and improve care.

The focus of the reviews is to:

- identify potentially avoidable factors that may have contributed to a person's death
- identify differences in health and social care delivery across England and ways of improving services to prevent early deaths of people with a learning disability
- develop plans of action that will guide necessary changes in health and social care services in to reduce premature deaths of people with a learning disability

For each death, there is an initial review. Someone who knew the person well, such as a family member, is invited to contribute their views. This is a fundamental part of the review. The reviewer will also look at relevant case notes relating to the person who has died and will make contact with relevant organisations/agencies to discuss cases and access notes if required. This involves the range of agencies that have been supporting the person who has died (e.g. health and social care staff).

The review looks at 3 levels of care:

1. Initial diagnosis and management of the condition.
2. Ongoing management of the condition from initial diagnosis to critical illness.
3. Management and care received during final illness.

Once a review is completed it is submitted to the local LeDeR review panel. This panel is chaired by the 1 appropriate person (LAC) with representation from health, social care, acute hospital, the community learning disabilities team, a person with a lived experience of learning disabilities, families and carers. The purpose of the panel is to:

- the panel review the quality and identify the learning and good practice from the review prior to submission to the LeDeR programme system
- feedback will be provided to the reviewer if necessary
- actions from the learning for each review will be allocated to the appropriate organisation/agency and logged on our learning into action log

NHS
Kernow
Clinical Commissioning Group

The LeDeR steering group

The LeDeR steering group has been in place since the commencement of the LeDeR programme in 2017.

Aims of the LeDeR steering group

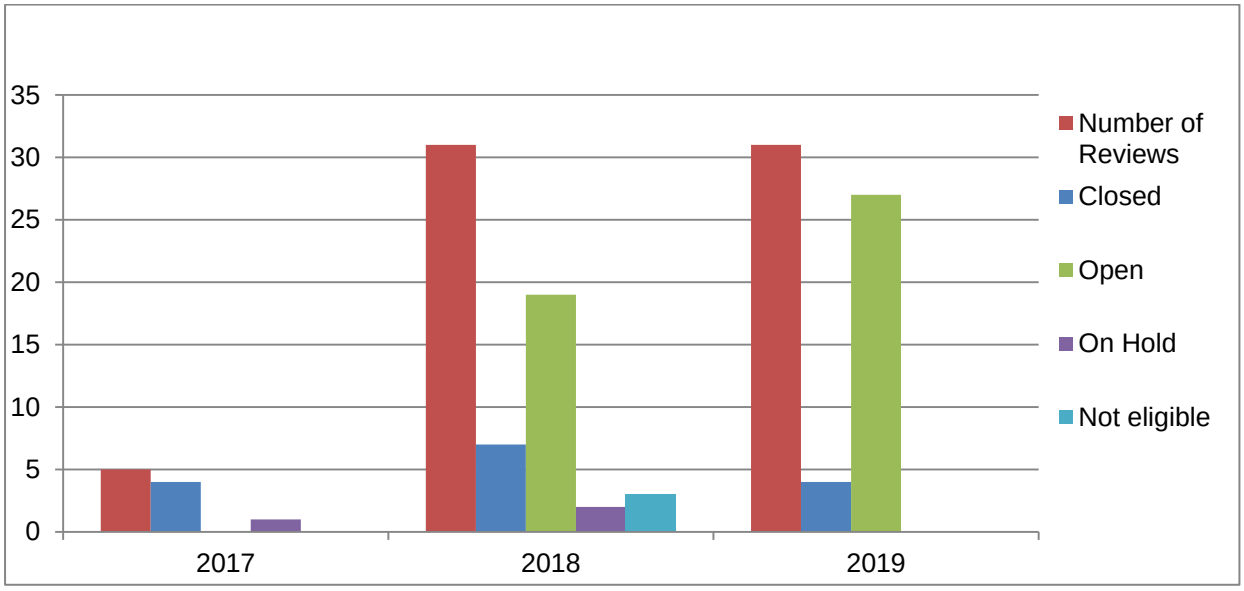
1. In partnership with stakeholders to ensure that at least 1 appropriate person (LAC) is recruited for each local area. The LAC will have oversight of the programme activities in the local area.
2. To work in partnership with the regional lead.
3. To guide the implementation of the programme of local reviews of deaths of people with learning disabilities.
4. To support the proportionate review of all deaths of people with learning disabilities in their area and more detailed reviews of those for whom it is indicated and those subject to a rolling programme of priority themed review.
5. To receive regular updates from the LAC about the progress and findings of reviews.
6. To help interpret and analyse the data submitted from local reviews, including areas of good practice in preventing premature mortality and areas where improvements in practice could be made.
7. To monitor the action plans that are developed as a result of the reviews of deaths and take or guide appropriate action as a result of such information.
8. To ensure agreed protocols are in place for information sharing, accessing case records and keeping content confidential and secure.
9. To share anonymised case reports pertaining to deaths or significant adverse events relating to people with learning disabilities for publication in the LeDeR programme repository in order to contribute to collective understanding of learning points and recommendations across case.

The steering group consists of representatives from a number of statutory and voluntary agencies working alongside key stakeholders including people with learning disabilities, families and carers.

The steering group reports to the Cornwall and Isles of Scilly Safeguarding Adults Board and the NHS Kernow learning disabilities and autism steering group.

Summary of LeDeR activity

Deaths notified in July 2017 to December 2019



- 2017:
  - Number of reviews: 5
  - Closed: 4
  - On hold: 1
- 2018:
  - Number of reviews: 31
  - Closed: 7
  - Open*: 19
  - On hold: 2
  - Not eligible: 3
- 2019:
  - Number of reviews: 31
  - Closed: 4
  - Open: 27

*Open includes –waiting to be allocated, with a reviewer and part of back log project

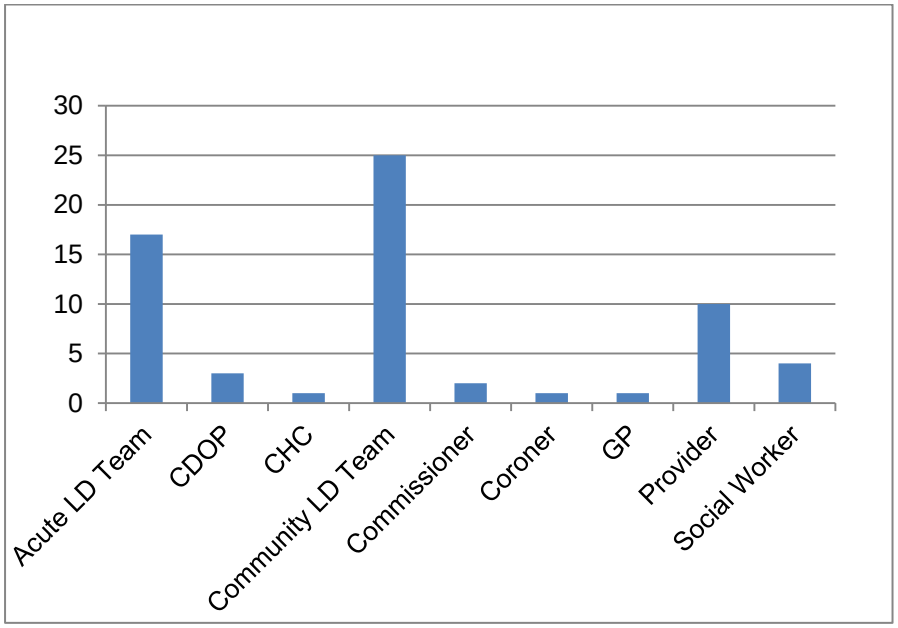
The total number of deaths reported from the start of the LeDeR programme from July 2017 to December 2019 is 67, of which:

- 15 reviews have been completed
- 3 reviews are on hold due to a child death review being held in the first instance
- 3 notifications are not eligible because in the initial stages it was established there was no learning disability
- 46 are currently open and being reviewed

- 12 of these are currently allocated to a local reviewer
- 23 are part of the backlog project
- 11 are waiting for allocation

Of the 15 completed reviews, pneumonia was identified as the primary cause of death on the majority of death certificates. Other causes of death included those which were cardiac related and cancer related.

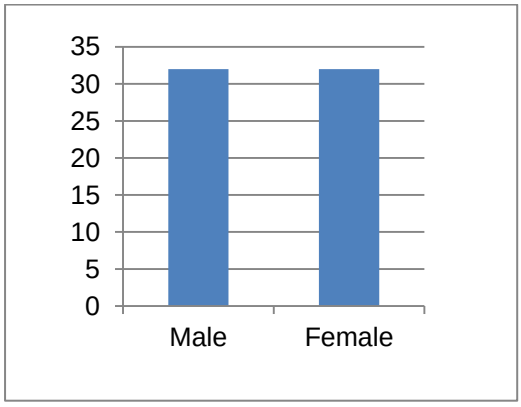
Source of death notification



- Acute learning disabilities team: 17
- CDOP: 3
- CHC: 1
- Community learning disabilities team: 25
- Commissioner: 2
- Coroner: 1
- GP: 1
- Provider: 10
- Social worker: 4

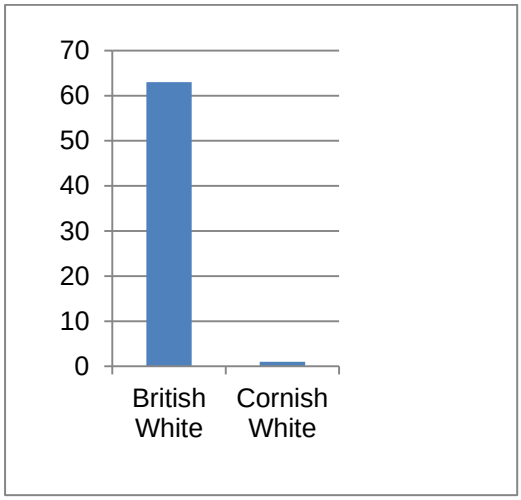
There were a total of 64 people eligible for an LeDeR review during this period with an equal proportion of males and females

Gender



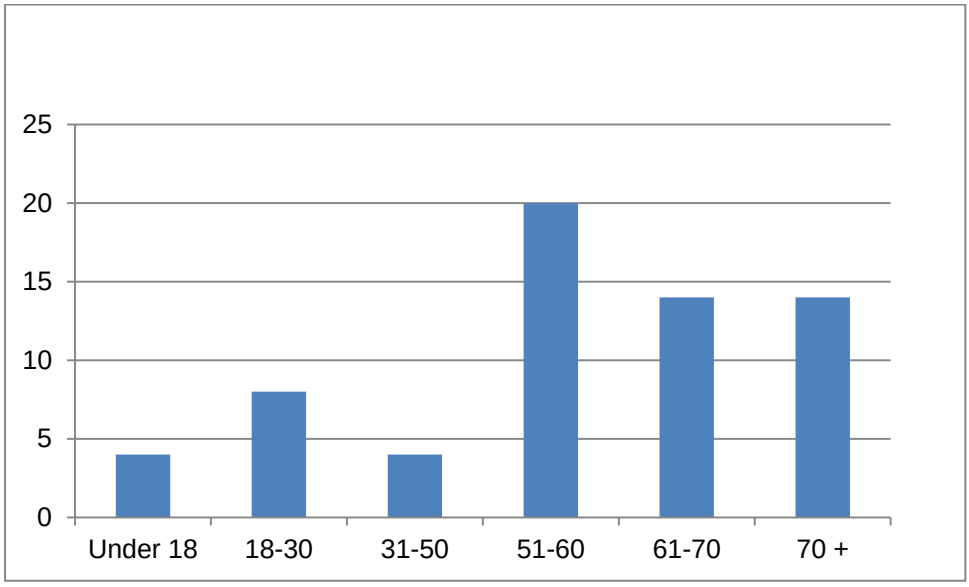
- Male: 32
- Female: 32

Ethnicity



- British white: 63
- Cornish white: 1

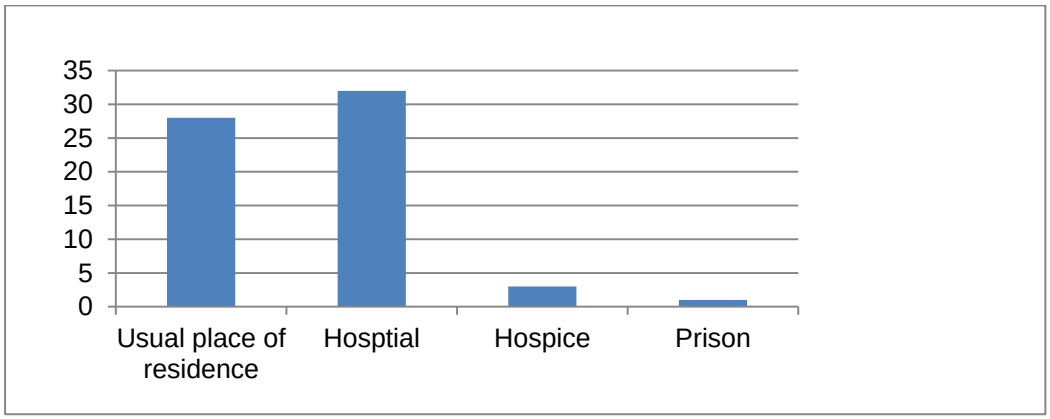
Ages of individuals at time of death



- Under 18: 4
- 18-30: 8
- 31-50: 4
- 51-60: 20
- 61-70: 14
- 70+: 14

Average age of death total: 55
Average age of death adults: 58
Average age of death children: 15.5

Where people died

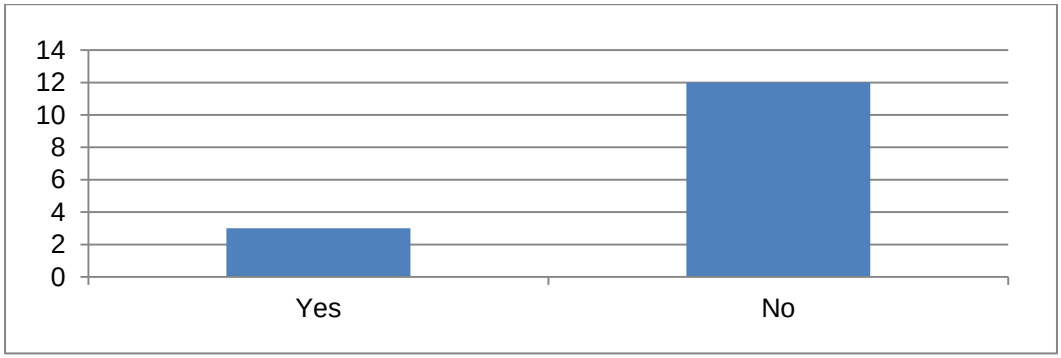


- Usual place of residence: 28
- Hospital: 32
- Hospice: 3

- Prison: 1

A total of 32 people in the cases reported were noted to have passed away in 1 of the acute hospitals serving the population of Cornwall (1 of which is sited in Devon), however the number of individuals who died in their usual place of residence was lower at 28. The 3 people who died in the hospice were all under the age of 18.

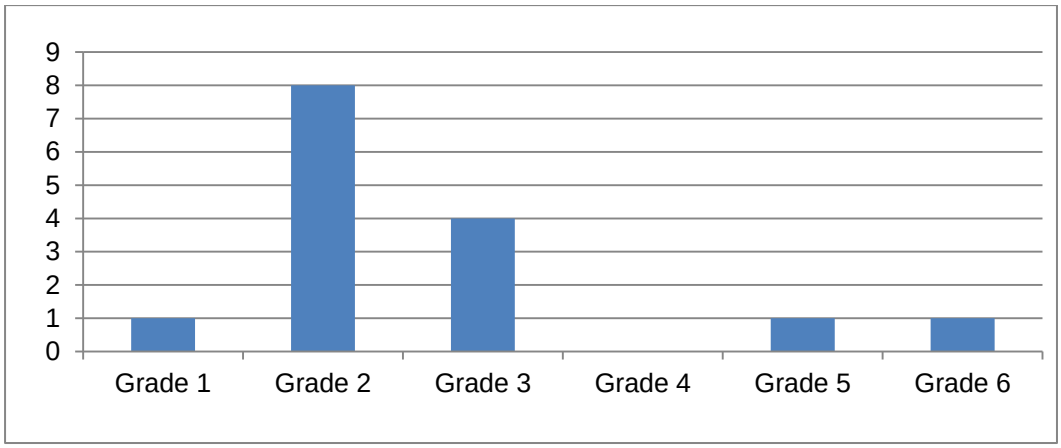
Coroner referrals



- Yes: 3
- No: 12

Of 15 completed reviews, 3 have been referred to the Office of the Coroner.

Grading of care received prior to death



- Grade 1: 1
- Grade 2: 8
- Grade 3: 4
- Grade 4: 0
- Grade 5: 1
- Grade 6: 1

Classification of grading

1. This was excellent care (it exceeded expected good practice).
2. This was good care (it met expected good practice in all areas).
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).
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.
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.
6. Care fell far short of expected good practice and this contributed to the cause of death.

Indicators of the quality of care provided

The majority of our reviews graded the quality of care provided at 2. However, 2 reviews showed a significant concern around the quality and timeliness of care and scored 5 and 6.

Although the quality of care scorings are an indicator, we have reviewed each case through the local LeDeR panel to assure both the quality of the review and the learning to be taken forward into recommendations for change.

1 case has required a multi-agency review which resulted in a number of recommendations regarding primary care interface and accessibility of professional input. The key recommendations from the review were:

- a clear system of care provider feedback direct to social care commissioners of increasing/changing needs is required
- a yearly review or relying on the client having contact with social worker is not sufficient
- further training for all workers regarding capacity and consent / sharing information / receiving information, which will include the care provider, primary care, social work and acute hospitals
- every person with a learning disability to have a shared, accessible, clear and easily updatable plan which states their needs and reasonable adjustments required
- improvement of primary care access for individuals with a learning disability
- a plan to be shared with primary care commissioning, which will focus on making reasonable adjustments to facilitate communication between patients and their GP practice, IT system recording and the use of lifelines
- development of a shared care record for all people with a learning disability receiving services in the community, accessible to all professionals and the individual themselves

The remaining case that was scored as unsatisfactory has been subject to review by the local acute hospital. As a result of the review, the acute hospital (Royal Cornwall Hospitals NHS Trust (RCHT)) co-produced a short film about the need for individuals with learning disabilities to be treated equitably and fairly. The individual's mother co-produced the film with the hospital.

As the care pathway over the preceding years for the individual in question was complex and involved other episodes of poor practice and discrimination, NHS Kernow has commissioned a local, parent led organisation to work with the individual's parent to produce a more in-depth film about his involvement with health services and how things can be improved. When completed, this will be presented to the CCG governing body and published on our website.

Focus on deaths of children

There have been 4 deaths of children/young people under the age of 18 reported.

All child deaths follow statutory review processes, including child death overview panel (CDOP) prior to review by LeDeR panel

The 4 deaths are yet to be reviewed by our local LeDeR panel. These will be reviewed in quarter 3 2020.

Recommendations for service improvement

The following list of recommendations is a headline summary of those made by local reviewers and providers of care and has been ratified by the LeDeR steering group. The LeDeR steering group maintains a learning onto action log for specific recommendations for individual cases.

1. **Treatment escalation plans (TEPs)**: Training for hospital staff in the application of TEPs. A local audit of TEPs applied at RCHT. Communication with primary care and care homes regarding the correct and lawful application of TEPs.
2. **Emergency department (ED) pathways**: Modification of ED IT systems to ensure triage is completed for all individuals without exception. Development of an ED pathway specifically for individuals with learning disabilities.
3. **Early identification of people with learning disabilites admitted to acute hospital**: Improvement of electronic flagging.
4. **Pain recognition**: Training and awareness for hospital staff in recognising pain in patients who cannot communicate, using accredited observational pain tools.
5. **Nutrition for patients with a learning disability/autism**: Engaging with dietetics and speech and language (SALT) in hospital and community to develop care pathways for patients when they are reluctant or refuse to eat or drink in hospital.
6. **Hospital staff training**: Information about welfare deputyship to be included in mandatory learning disability training for all staff.

Actions taken between 2017 and 2019 in response to mortality review

As a result of LeDeR mortality reviews and other local learning disability mortality review processes, the following developments have been implemented in our local area:

All individuals with a learning disability receiving secondary specialist care receive a check to ensure that the annual health check and flu vaccination have been offered.

RCHT, the local acute hospital, has implemented a series of processes to ensure all individuals are triaged appropriately in ED. A pack has been produced for front line professionals in ED. An ED flowchart for people with learning disabilities has been implemented.

Training for health professionals on the implementation of TEPs for people without capacity has been implemented. An audit has been carried out on all TEPs applied to individuals with learning disabilities and recommendations have been recorded.

A trial of the “bedside folder” for carers of people with learning disabilities has been commenced. This includes an introduction to the ward, a hospital passport and communication sheet.

An acute hospital checklist has been introduced for named health professionals to ensure all reasonable adjustments are being made and the correct referrals processes are in place.

Project funding from NHSE/I has been secured to co-produce 2 patient stories from a family perspective for use in communicating the importance of listening to relatives about their loved ones.

Conclusions and recommendations

The LeDeR programme has made a slow start with regards to the rate of reviews undertaken. NHS Kernow has, with the support of NHSE/I, recruited to the LAC role to give dedicated time to the programme, ensure timeliness of reviews and ensure that the learning from every individual’s death informs better practice in all of our health and social care services

Every LeDeR review completed is now presented to a panel consisting of people with lived experience, including family members, and professional leads from our health providers. This ensures that learning from deaths can be quickly transformed into action in our primary, secondary and specialist care providers, alongside health and social care commissioners.

The panel provides a safeguard against submitting reviews to LeDeR that have only had scrutiny from 2 clinicians and ensures that a focus from individuals who have experienced the health and social care system is brought to the process.

Our local LeDeR process has benefitted from membership of acute care colleagues at both the steering group and review panel. The structured judgement review process within acute hospitals, as well as the thematic review carried out by RCHT has resulted in clear and measurable actions within our acute sector.

The involvement of family members of the deceased individuals in our LeDeR programme is essential and we wish to build on their current involvement over the coming year. We will be working with NHSE/I to complete a film involving 2 bereaved parents to describe the story of their loved ones, to examine the positive and negative aspects of their care and to ensure that the importance of equitable, fair and safe treatment for people with learning disabilities is understood and championed at a senior leadership level.

The themes that are dominant in the reviews of deaths in people with learning disabilities, whilst based on low numbers of reviews, include:

1. Insufficient communication between health professionals and families in both community and hospital settings.
2. Delayed escalation in emergency care.
3. Poor practice in the application of TEPs and the Mental Capacity Act.

All 3 of these themes are being addressed through the learning into action grid and through local action plans in the acute and primary care sectors.

Recommendations for the LeDeR programme

The LeDeR programme has been slow to complete reviews and has encountered difficulty in finding a model of reviewing that can meet the demand in our area. The following recommendations are to support the recovery and development of the local LeDeR programme in 2020 to 2021.

1. LeDeR programme to become compliant with NHSEI specifications for the timely completion of reviews by December 2020.
2. Ensure that all LeDeR reviewers receive close leadership and management support to increase consistency and quality of LeDeR reviews.
3. Consolidate and expand the involvement of people with a lived experience of learning disabilities into our LeDeR panels and oversight.
4. Produce a quarterly newsletter summarising actions and issues for individuals with a lived experience and for the health and social care community.
5. Adopt the recommendations made in the national LeDeR annual report by December 2020 through local action planning.