



Learning Disabilities Mortality Review (LeDeR) Programme

Learning from LeDeR pilot sites



The Learning Disabilities Mortality Review (LeDeR) Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP), on behalf of NHS England.

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1.0 Executive Summary

The Learning Disabilities Mortality Review (LeDeR) Programme aims to make improvements to the lives of people with learning disabilities. It supports local areas in England to review the deaths of people with learning disabilities aged 4 years and over, to clarify any potentially modifiable factors associated with a person's death, and ensure that these are not repeated elsewhere.

Each of the four NHS England regions of England established a pilot site for the programme in 2016. The pilot sites were as follows:

- NHS England North – Cumbria & North East
- NHS England Midlands & East – Leicestershire, Leicester City & Rutland
- NHS England South – Wessex, Gloucester & Oxford
- NHS England London – Lambeth, Richmond, Kingston, Camden, Islington & Tower Hamlets

The lessons learnt from the pilot sites have been shared at learning and sharing events in each region. This report aims to supplement those events by collating the combined learning from the pilot sites to assist those establishing the LeDeR programme in their area.

Core points to note from the LeDeR pilot sites:

1. Steering groups

- When establishing a steering group, use local existing mechanisms where possible.
- Seek the correct membership early on, but don't stop progress in seeking perfection.
- Pay attention to including primary care, coroner's office and social service membership.
- Pay attention to family and paid carer representation.
- Agree a strategy to get providers engaged.
- Find and utilise LeDeR champions.

2. Programme governance

- Ensure strong governance and decision making is in place at steering group level.
- Ensure any steering group has a consistent presence of an effective Chair.
- Ensure governance arrangements are sustainable and robust.
- It would assist local areas to have a detailed delivery plan to work from, highlighting key milestones and deliverables.
- It is essential to engage key senior leads who can help remove project obstacles as necessary.

3. Roles and responsibilities

- Local Area Contacts (LACs) have pivotal roles within the local LeDeR process. Sufficient, and sufficiently skilled and committed LACs are crucial.
- It helps for potential reviewers to be screened before they attend training, to ensure that they have sufficient information about the reviewer role, are committed to undertaking reviews, and have senior level support.
- The allocation of a review soon after the completion of training can help reviewers to apply their training, keep motivation levels high and ensure that reviews are completed in a timely way.
- Reviewers require support structures to be in place, led by LACs.
- Consider additional bereavement training for reviewers if possible.

4. Training

- Establish a rolling training plan, with longer term plans for in-house delivery of training.
- Ensure LACs are appointed and trained before reviewers. Try and ensure LACs attend reviewer training.
- Use anonymised case studies in training to aid understanding.
- Cover the LeDeR quality assurance process as an essential part of training.
- Consider the use of a CPD points system for those attending training.

5. Communication

- Communicate early, often and at a national and local level.
- Communication needs to be reviewed regularly and preferably owned by a steering group member.

6. Reviews of deaths

- Make sure all of those involved in the programme are aware of the LeDeR principles and process and revisit these regularly.
- The upper age limit of 74 has now been removed.
- Allocate reviews in a timely way via LACs.
- Ensure reviewers have sufficient dedicated time required to complete their reviews.
- Remember that part of the review is about speaking to people that knew the person with learning disabilities best. This would usually be a family member, but may in some circumstances be a paid carer.
- Note the 'top tips' for completing a full multi-agency review.
- Monitor the flow of reviews regularly through the LeDeR system, especially length of time a review is taking.

7. Confidentiality and privacy

- Utilise CAG S251 in the early days of setting up a steering group, but ensure a data sharing agreement is an agenda item, until agreed by all parties.
- Remind staff involved in the LeDeR programme of their information governance responsibilities and how these apply to the LeDeR process.

8. Funding & Resources

- One of the biggest issues the pilot sites have faced, and arguably the biggest risk to a national roll-out, is the lack of funding for the LeDeR process and reviews.
- All pilot sites believed that the work needs to be established on a mandatory footing.

9. Support

- All steering groups have identified that the LeDeR process works better when reviewers have on-going support and / or supervision as they progress with the work.
- There is no similar support for LACs and this needs further work.
- National support through the LeDeR team in Bristol was thought to be excellent yet unobtrusive.

10. Culture

- The programme has required a cultural shift for a lot of professionals – commonly referred to by the pilot sites as the need to change hearts and minds. However, few people have questioned

why the LeDeR programme is needed. They just question how it can be delivered given existing time and funding constraints.

11. Programme outcomes

- Systems still need to be established that will provide evidence about the effectiveness of mortality reviews in improving health and social care services for people with learning disabilities.

12. Learning and sharing events

- Regional learning and sharing events have been helpful; at least one area is considering an annual event.

13. The legacy of LeDeR

- Over the longer term, the natural 'home' for the LeDeR programme needs to be confirmed.

2.0 Background

The LeDeR Programme is delivered by the Norah Fry Centre for Disability Studies, at the University of Bristol. It is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. Work on the LeDeR programme commenced in June 2015 for an initial three-year period.

A key part of the LeDeR Programme is to support local areas to review the deaths of people with learning disabilities. The Programme has developed and is rolling out a review process for the deaths of people with learning disabilities. The programme is helping to promote and implement the new review process and provide support to local areas to take forward the lessons learned in the reviews, to make improvements to service provision. The LeDeR programme also collates and shares the anonymised information about the deaths of people with learning disabilities so that common themes, learning points and recommendations can be identified and taken forward into policy and practice improvements.

The geographical 'footprint' for the roll-out of reviews of deaths in the NHS England architecture, comprises of four regions: North, Midlands & East, South and London. The regions cover healthcare commissioning and delivery across their geographies. The regions work closely with clinical commissioning groups (CCGs), local authorities, health and wellbeing boards and GP practices.

To ensure a national rollout was as effective as possible, one pilot site was established in each NHS England region. The pilot sites were in:

- NHS England North – Cumbria & North East
- NHS England Midlands & East – Leicestershire, Leicester City & Rutland
- NHS England South – Wessex, Gloucester & Oxford
- NHS England London – Lambeth, Richmond, Kingston, Camden, Islington & Tower Hamlets

The lessons learnt from the pilot sites have been shared at learning and sharing events in each region. This report aims to supplement those events by collating the combined learning from the pilot sites to assist those establishing the LeDeR programme in their area. It would be helpful for this report to be considered alongside the new national Guidance on Learning from Deaths (National Quality Board 2017).

Contributions to this report were captured via:

1. Face to face meetings with senior staff at pilot sites, such as regional LeDeR leads, Chairs of LeDeR steering groups at pilot sites, regional coordinators and Local Area Contacts.
2. Pilot site learning and sharing events:
 - a. North – July 2016
 - b. Midlands & East – November 2016
 - c. South – February 2017
3. Discussions at various governance steering groups for the LeDeR programme, such as the National Operational Steering Group or LeDeR Steering Group.
4. Views of the LeDeR programme team, based at University of Bristol.

The report is structured into the following sections:

- | | |
|--------------------------------|---------------------------------------|
| 1. Steering groups | 8. Funding and resources |
| 2. Programme governance | 9. Support |
| 3. Roles and responsibilities | 10. Culture |
| 4. Training | 11. Programme outcomes |
| 5. Communication | 12. Learning and sharing events |
| 6. Reviews of deaths | 13. The legacy of the LeDeR programme |
| 7. Confidentiality and privacy | |

3.0 Learning and Reflections

3.1 Steering groups

3.1.1 Set-up

One of the first tasks in establishing the LeDeR mortality review programme has been for the pilot sites to establish a steering group to guide the roll-out of reviews and provide a governance function at the correct level.

What was important from the outset was to use existing mechanisms and processes for the LeDeR programme work, rather than create new and different systems. Different areas had different starting points, networks and processes, and took different approaches to establishing a steering group: for example, some used existing multi-agency fora, or sub-groups of existing fora; others established new groupings. What is important to recognise is that providing the same end-point is reached, there will inevitably be a degree of local variation in how it is reached.

LeDeR pilot steering groups achieved quicker, earlier success if they utilised existing governance structures. This was because structures such as Transforming Care Partnerships (TCP), Safeguarding Boards, or learning disability networks already had engagement from the right membership required for multi-agency delivery of the LeDeR programme. This also helped with the limited staff time commitments available at senior level. However, in using existing groups for LeDeR steering groups, care was needed to ensure that the other responsibilities of the group didn't spill over into the LeDeR work, and that LeDeR wasn't de-prioritised.

3.1.2 Membership

Establishing a steering group has generally been a developmental, evolving, iterative process and many of the pilot sites have amended membership of their steering groups over time. What has been important has been to ensure that there is representation and willingness to engage by all relevant sectors, and that those attending are of a sufficient level of seniority to take forward

recommendations arising from mortality reviews. The use of champions or those with an enthusiasm towards the programme are also useful to engage early.

Initial steering group membership seems to have been good in most pilots. One area did note that they felt initially the steering group membership was too big; people were enthused and it was therefore a good opportunity to get more people involved, but this, on occasions, led to slower decision-making.

The most commonly reported gaps in steering group membership were of representatives from local authorities, families and self-advocacy organisations, the Child Death Review Process, and the Coroner's service. There was a risk raised about primary care and social care's capacity to be involved in the LeDeR programme fully, particularly given the current constraints in social care and the need to focus on meeting statutory duties. This still hasn't been fully addressed and needs further work.

Retention of steering group members has been an issue for some pilot sites. On reflection, they felt that a clearer message at the outset would have been helpful, that included the remit, the requirements and the likely time commitment of the role. One steering group is currently considering ways of making meetings more interactive, for example running them as workshops or problem solving sessions to retain interest and commitment. Some have utilised conference calls occasionally to reduce travel time.

3.1.3 Family engagement

Family member representation at the steering group level was felt to be particularly valuable as it brings interesting insights and a different lens; a combination of family members and family carer support workers at each steering group was also thought to be potentially helpful. The National Valuing Families Forum (NVFF) had a list of regional contacts for involving families in national level work who could be contacted for advice about identifying a local family member to attend steering group meetings, and could provide more general advice about family involvement. From 1st April, the NVFF will no longer receive central funding so its future engagement may change. One family member reported feeling more comfortable being a member of a steering group in an adjacent area to their home, thus avoiding working alongside professionals with whom they had potentially been in a more personal relationship.

Avoiding the tokenistic representation of families and people with learning disabilities was highlighted as being important, as was the representation of families who were well networked in to other families and not solely drawing on their own thoughts and experiences. One area has involved advocacy agencies from the outset, and these have encouraged and supported people with learning disabilities to attend meetings and work together outside of meetings.

3.1.4 Regularity

In the initial stages of the programme, the pilot sites tended to hold steering group meetings every month, but as the programme became more established some sites reduced the frequency to bi-monthly. Most early-adopter and rollout sites have established steering group meetings on a bi-monthly basis.

3.1.5 Managing Expectations

Some of the challenges the steering groups have faced, have been in relation to managing expectations, addressing concerns and worries and the group getting overly-focused on one issue (whilst missing opportunities to make progress in other areas). Key concerns and worries have been:

- The sharing of patient identifiable information across agencies for mortality reviews. Section 251 approval for the programme and the completion of local data sharing agreements have largely resolved this.
- Calculating the number of reviews likely to be required in the area and the corresponding number of reviewers needing training. The Bristol team has now provided a model for local areas to calculate the likely number of reviews each year and number of reviewers requiring training.

3.1.6 Change champions

It has been noted that some Trusts are already carrying out mortality reviews for people with learning disabilities. This will increase with the introduction of the national framework for Learning from Deaths. Steering groups in these areas have found it helpful to identify 'champions' to link with, who share a commitment to the LeDeR programme and can prove useful for accessing information and "spreading the word".

3.1.7 Time required

Not all the work in establishing the programme has been completed in steering group time. A considerable investment has been made by programme coordinators and some steering group members to supplement the work, including attending meetings with other agencies or networks, to share information about the programme. One pilot site estimated that they required one day a week for administrative support plus a full-time coordinator to establish the programme. As the programme developed, this time commitment has been reduced.

3.1.8 Support

The LeDeR programme team has provided a range of support for steering groups, including templates for terms of reference, data sharing agreements and other supporting documents. This was noted to be particularly useful. The LeDeR programme team has also attended many steering group meetings to provide guidance and help respond to queries or concerns. It was noted that such face-to-face attendance helped to overcome issues which could otherwise have been more prolonged. Maintaining such a presence, even beyond the initial stages of steering group set-up has been felt to be helpful.

3.1.9 Key points in relation to steering groups

Key points in relation to steering groups are:

- When establishing a steering group, use local existing mechanisms where possible.
- Seek the correct membership early on, but don't stop progress in seeking perfection.
- Pay attention to primary care, Coroner and social service membership.
- Agree a strategy to get providers engaged.
- Pay attention to family and paid carer representation.
- Find and utilise LeDeR champions.

3.2 Programme governance

3.2.1 Making best use of existing and relevant governance arrangements

Establishing clear, robust and sustainable governance arrangements for the programme has been vital to provide legitimacy for the work and to ensure that any learning and recommendations arising from mortality reviews is appropriately taken forward into service improvements.

Establishing governance arrangements for the programme has been generally time-consuming in the pilot sites, as the multi-agency nature of the reviews requires the work to sit across traditional organisational boundaries. The LeDeR programme does not direct an area about the governance arrangements required for the programme, but clear guidance is available from NHS England.

Safeguarding Adult Boards have been identified as having a key role in the governance of reviews at local level. Although not all deaths of people with learning disabilities raise safeguarding concerns, and not all deaths of people with learning disabilities should be regarded as safeguarding issues, close working with Safeguarding Adult Boards has been found to be important.

Safeguarding Adults Boards operate in multi-agency partnerships, and have the infrastructure upon which the LeDeR reviews are based. They are also well-placed to ensure that follow up on necessary actions is taken as required. In some areas, the findings of mortality reviews are being reported to the Learning and Improvement sub-group of the Board, with updates being provided to the Board at regular intervals. In one area, the Safeguarding Adult Board is testing out a process in which they have oversight of completed initial reviews and provide a view about whether the case should progress to full multi-agency review or not. Another area is considering the extent to which they should be involved in the conduct of a full multi-agency review.

At regional level, the agencies with a role in the governance of the programme are Quality Surveillance Groups. These have a statutory function, and have senior level multi-agency composition. In one area, the Quality Surveillance Group has requested from each member an update about the LeDeR mortality reviews and their findings to be reported twice a year.

Some people have commented on a lack of national NHS England presence in the initial stages of the pilot programme, and that this has made establishing governance structures more difficult. This has now been overcome with the establishment of the national operational steering group, and the appointment of four LeDeR regional coordinator posts.

3.2.2 Clear lines of accountability and decision making

Where pilot groups have progressed well, each group was found to have a strong decision-making process. This was largely due to the consistent presence of an experienced Chairperson of the steering group, who could strike a fine balance between achieving consensus but at the same time ensuring actions are allocated and progress made.

Some steering groups requested a checklist of items for steering groups to work through to ensure that progress can be audited and to understand when the set-up of a steering group moves from pilot status to 'business as usual'. NHS England regional coordinators plans have been useful in this regard.

3.2.3 Planning

Some steering groups in the pilot areas were led by a top level skeletal, national project plan, but felt that it would have been helpful to have, additionally, had a local plan to work from, to ensure clarity with regards to specific milestones to work towards. This has now been rectified.

In addition, some pilot sites have requested the LeDeR team should hold a risk log, which could look at risks generated nationally and locally, and the responses to these. This has been implemented.

3.2.4 Key points in relation to programme governance

- Ensure strong governance and decision making is in place at steering group level.
- Ensure any steering group has a consistent presence of an effective Chair.
- Ensure governance arrangements are sustainable and robust.
- It would assist local areas to have a detailed delivery plan to work from, highlighting key milestones and deliverables.
- It is essential to engage key senior leads who can help remove project obstacles as necessary.

3.3 Roles and responsibilities

3.3.1 Local Area Contacts

Local Area Contacts (LACs) act as the link between the LeDeR programme team, the local steering group and local reviewers. They play a pivotal role in ensuring a smooth review process and in working with their steering groups to understand and take forward recommendations from reviews. The LeDeR team provides a draft role description and person specification for the post.

Areas have taken very different approaches to the number of LACs required. Some have established one per NHS sub-region and others one per CCG. Providing the LeDeR processes and principles can be adhered to, and reviews are of a consistent quality, then it has been left to steering groups to decide the number of LACs required.

Identifying LACs with the capacity and skills for the role has been challenging for some steering groups, and early pilot sites reflected that it would have been helpful to have had a better understanding of the time commitment, grade and professional role of potential LACs.

Different areas have taken different approaches to recruiting LACs. Some have invited nominations from interested personnel, whilst others have allocated the role to an individual. The latter approach has risks as well as benefits: it can ensure that there is a senior named person responsible for the role, but it may also leave the person lacking in the skills, knowledge and enthusiasm that is required to undertake the work. Some areas have considered appointing recently retired health or social care professionals as a LAC (or reviewer), but this has not been taken forward due to concerns that it would not meet information governance requirements.

It was felt that it is more helpful to have a LAC in place before recruiting reviewers, so that the LAC can then be available to identify and attend the training for reviewers. This helps engagement, a partnership approach to reviews, support and confidence for reviewers, and allows for clarity of the quality assurance process.

3.3.2 Reviewers

Generally, it was felt that it was easier to identify reviewers through established networks than to identify LACs, and that many reviewers were self-selecting. One pilot site stressed the importance of using already established networks for this, so that reviewers didn't feel isolated in their role and already knew others undertaking reviews of deaths. There was concern, however, that over time it would be more challenging to recruit new reviewers if senior managers considered that leading a review was too time-consuming for a member of their staff. In some areas, this was particularly applicable to social care staff. Some areas have instigated time and motion studies with regard to time commitments for reviewers.

The LeDeR programme gives a very strong steer about the mortality reviews being independent of those providing care for the person who has died. In practice, there are differing approaches being taken for this which are largely being determined by local structures and preferences:

- Buddying an existing member of staff with an independent reviewer. Buddying reviewers across boundaries, so a reviewer will conduct reviews in a neighbouring area to them.
- Establishing an independent pool of mortality reviewers for the area.
- Asking CCGs to contribute a small amount of funding to pay for dedicated mortality reviewers in their local area.

The LeDeR programme provides steering groups with a draft role description and person specification for the reviewer post, however some pilot sites have identified additional key qualities required by reviewers to be:

- The confidence to pick up the phone and talk to families and other agencies.

- The ability to think holistically and strategically outside the boundaries of one's own area of expertise.
- A degree of emotional resilience given that being a reviewer can be challenging emotionally, and potential reviewers need to be prepared for this.
- A few sites mentioned the need to look at specialisms within the pool of reviewers and recruit a diverse range if possible, to be able to provide expertise about specific issues.

Retention of reviewers has been helped by the establishments of reviewers' groups which provide a safe space for reviewers to discuss their work and support each other. This has been very well-received and some draft terms of reference have now been developed for interested areas.

3.3.3 Key points in relation to roles and responsibilities

- Local Area Contacts have pivotal roles within the local LeDeR process. Sufficient, and sufficiently skilled and committed LACs are crucial.
- Potential reviewers to be screened before training, to ensure that they have sufficient information about the reviewer role, are committed to undertaking reviews, and have senior level support.
- The allocation of a review soon after the completion of training can help reviewers to apply their training, keep motivation levels high and ensure that reviews are completed in a timely way.
- Reviewers require support structures to be in place, led by LACs.
- Consider additional bereavement training for reviewers if possible.

3.4 Training

3.4.1 LAC Training

At the pilot stage, no specific training was provided to the LACs, but this was quickly identified as being a significant omission. A separate training day for LACs has now been developed, and a specific focus for this training is what good quality reviews look like and how to support reviewers to achieve this. Training for LACs precedes training for reviewers with the expectation that a LAC would then be present at reviewer training to provide a local context for the work, and for the LAC to meet and get to know the local reviewers in their area.

3.4.2 Reviewer training

Some useful reflections have been made about the content of the training for local reviewers, and these have now fed into a formalised training strategy and a refreshed training programme being delivered by the LeDeR team. It is acknowledged that releasing staff to attend training can be difficult, so maximum use needs to be made of their time and that there is a need to move towards a more sustainable way of delivering training using 'train the trainer' and blended learning approaches.

In relation to the content of the reviewers' training, four key improvements have been proposed:

- The increased use of case studies, to help participants to better understand what is expected of them as a reviewer.
- Demonstration of the secure web-based platform, rather than waste time supporting attendees to access it individually.
- Developing the confidence of reviewers to approach and talk with recently bereaved families.
- A greater focus on the emotional connection with the work for participants.

3.4.3 Timeliness of training

Timeliness of delivering training is important, in order that there is not a significant time lag between a reviewer receiving training and them starting to review a death. This has been identified as an issue contributing to drop-out of reviewers.

In all pilot and early adopter sites there have been people who have attended the reviewers' training but who didn't go on to undertake any mortality reviews – and this has been a significant waste of resources. Key learning in this respect is that:

- Potential reviewers should already have some understanding of the process and what is expected in conducting a review prior to attending the training.
- The LeDeR programme is providing resources to NHS England regional coordinators to support information sharing sessions for those interested in finding out more about the programme so that they can make a more informed decision as to whether they will go on to be a reviewer.
- It is important to invite to the training potential reviewers who already have an agreement from their line manager about taking on the role.
- Formal screening a potential reviewer prior to training could be helpful.
- Once training has been completed, the early allocation of a review to a reviewer would be helpful. If a review isn't allocated immediately, the reviewer should be encouraged to support another reviewer with their review.
- The LAC should contact new reviewers and maintain contact with them.

It was felt important for steering groups to establish a rolling training plan, in conjunction with trainers from the LeDeR team in Bristol, to ensure that there are always future training dates scheduled and that the correct numbers of reviewers and LACs are maintained.

3.4.4 Other training

Early in pilot site roll-outs, some sites found it essential to offer and run LeDeR information sharing sessions. This has subsequently been formalised for all areas to utilise if need be.

Other pilot sites have provided bereavement training for reviewers to aid their engagement with bereaved families, and have required supplementary guidance for reviewers about what to do if other mortality investigation processes are being followed, e.g. if there is a criminal investigation of the death or a death has been referred to a Coroner. Guidance about this is now available on the LeDeR website.

3.4.5 Training developments

Some pilot sites asked the LeDeR team to look into whether Continuing Professional Development (CPD) points could be awarded for attendance at LAC or reviewer training, in order to recognise the training undertaken and increasing engagement with the programme from certain sectors. This is currently being considered by the LeDeR team.

Another demand has been to consider the use of new technology, such as webinars, for the delivery of training. This is currently being investigated. The LeDeR team are already in the process of developing train the trainer and e-learning approaches using richer visual formats such as video clips.

3.4.5 Key points in relation to training

- Establish a rolling training plan, with longer term plans for in-house delivery of training.
- Ensure LACs are appointed and trained before reviewers. Try and ensure LACs attend reviewer training sessions.
- Use anonymised case studies in training to aid understanding.
- Cover the LeDeR quality assurance process as an essential part of training.

- Consider the use of a CPD points system for those attending training.

3.5 Communication

3.5.1 National

Good, regular communication, at all levels, is key to the success of the implementation of the LeDeR programme. The most successful steering groups are those that have communications at the heart of everything they do. Initially, communication was localised, prior to the development of a national communications strategy, which some have felt could have been formulated sooner than it was. It is widely felt that a communications plan and its progress should be an agenda item at most steering group meetings.

Key learning in relation to national level communication has been the need for communication to be disseminated via recognised channels such as NHS Gateway or through established networks such as ADASS. Confusion has arisen with some communication being distributed directly by the programme team under the guise of the University of Bristol, in the early days.

The relatively disparate geographical distribution of the pilot sites has required caution in communicating widely about the programme to a wide audience, because of concerns that deaths in non-pilot site areas would be notified to the programme and then not be reviewed. As the implementation process has progressed, this concern is becoming redundant.

The LeDeR programme website provides a ready source of information about the programme and acts as a first port of call and reference point for steering groups, LACs and reviewers, as well as a wider audience. Some people have felt that the website should be better publicised and could be easier to navigate. The LeDeR team is currently reviewing and updating the website.

3.5.2 Local

Pilot sites all agreed that a local communications plan agreed by the steering group is essential. Establishing the programme locally was felt to require changing some 'hearts and minds' and good communication about the purpose, process and outcomes of the mortality reviews was felt to be vital. All pilot sites have noted the need for communications to happen multiple times, at all levels, to ensure that the message is received. One steering group member commented that steering groups need to 'live and breathe communications' as part of their work, and could helpfully set up a communications work stream.

Some of the key learning about successful communication at local steering group level is as follows:

- The involvement of a well-informed communication lead at steering group level would be helpful in order to optimise communication about the programme at regional level. In particular, they could help share information with existing networks and beyond, scan NHS England, LeDeR and other relevant websites for updates, and facilitate information about the programme being shared in the weekly CCG Bulletin and other relevant publications.
- It is important that steering groups know who the local/regional stakeholders are and how best to communicate with them. A regional communication strategy that identifies relevant stakeholders and the key messages that they require is essential.
- The LeDeR programme provides briefing papers and templates to support local communication messages. Messages that were felt to require strengthening were that the reviews of deaths are prospective and not retrospective, and that they are reviews not investigations.
- Communication needs to be available in a range of different styles and formats. One steering group has adopted 'easy-read' agendas and documentation to assist with the engagement and involvement of a broad range of people in meetings and discussions.

3.5.3 Key points in relation to communication

- Communicate early, often and at a national and local level.
- Communication needs to be reviewed regularly and preferably owned by a steering group member.

3.6 Reviews of deaths

3.6.1 Notification process

Generally the notification system was felt by all to work well, and that notifying a death was not burdensome for pilot sites. Once the wider roll-out of the programme takes place, more work needs to be done to publicise the need to notify deaths, and the process by which to do so. In addition, there was general acknowledgement that after the national roll-out has been completed, it would be useful to review the notification process and make it more efficient and streamlined where possible.

Most problems with the notification process have been in relation to a lack of clarity about the date from which deaths should be notified to the programme, how deaths occurring before that date should be reviewed, and aligning existing regional or local processes with the LeDeR methodology.

3.6.2 Conducting an initial review

All deaths of people with learning disabilities are notified to the LeDeR programme, but only those aged 4-74 years were reviewed in the pilot sites. There has been some confusion and questioning about the upper age limit, and why those aged 75 years and over should be excluded from review. Some areas chose to review all deaths of people with learning disabilities aged 4+ on the understanding that opportunities for improvements in services for older people should not be missed. As such and to align with the new national Learning from Deaths programme, the upper age limit for the LeDeR programme has been removed.

The capacity of reviewers to undertake a holistic, good quality review has been identified as being a significant issue in many areas. Many reviewers do not have dedicated time to undertake reviews and so snatch short periods of time, when possible, to complete the review. What reviewers have said would be more helpful, would be dedicated time and the capacity to focus on the review without getting pulled away from it, by other competing priorities. That said, the pilot sites have generally understood the need to balance local practicality and flexibility with the need to get quality and comparable data for reviews.

The time taken to conduct a review seems to vary widely. Some reviews appear to be completed fairly quickly, whereas others take more time, especially if information is required from a range of agencies. One pilot site felt that they would like the review process to be quicker, leaner and smarter, for example by linking in more with other mortality review processes, whilst retaining confidence that the decision about whether the death required a full multi-agency review was not compromised.

There have been some concerns about the legal basis on which agencies are expected to share patient identifiable information. This has largely been overcome by communication to those who would be expected to share patient identifiable information (GPs, Health and Social care providers) being accompanied by confirmation of CAG S251 approval.

All reviews must be multi-agency in approach – including at initial review stage. Some areas have been referring to initial reviews as single agency reviews, which is incorrect. As part of the initial review process one site noted it may be useful to check and access information about any complaints that have been lodged with respect to the deceased person – paying attention to the diversity of different service systems and locations that the complaints may be lodged in.

Concerns have been raised about what reviews may uncover. Advice offered by pilot sites to alleviate concerns is:

- To use the review process to explain not blame.
- Other systems exist for detailed investigation, such as when serious incidents are identified or professional negligence is suspected.
- Often it is system changes that are identified as being needed rather than any individual failing.
- All completed reviews are anonymised prior to collating findings across a region.

One site has been inviting people with learning disabilities who knew the deceased person well to contribute to a holistic pen portrait of the person who has died, by using photographs and/or objects associated with the person to encourage discussion about the person, what they were like, and what they meant to them. They, and others, have reiterated the need for appropriate, on-going bereavement support for those who knew the person well, including friends, peers, and colleagues, and that the reviewer needs to be able to signpost to appropriate local resources as required.

In general, there has been a lack of confidence on the part of reviewers about grading the quality of care received by the deceased person. In order to address this, many areas are now doing this jointly between local reviewer and the LAC.

3.6.3 Conducting a multi-agency review

More anxiety has been expressed about conducting a full multi-agency review, than has been expressed about any other part of the review process. Some of the concern seems to be related to the perceived time required to coordinate the meeting in the absence of administrative support, and the potential attendance at the meeting by family members when reviewers have little experience of this.

A few issues have arisen regarding the availability or ease of availability of case notes for reviewers. What has worked well has been when there are more formalised communications from the steering group or LAC to the relevant authorities requesting access to notes. The LeDeR team have now created a template letter that can be used to request access to notes.

‘Top tips’ for conducting multi-agency review meetings include:

- Being clear about who the essential participants must be, and trying to maximise their attendance. This can be facilitated by allowing plenty of advance notice of the meeting, holding the meeting in a place accessible to key attendees, and providing refreshments if possible.
- Allowing plenty of time for the meeting so that it is not unduly rushed – approximately an hour seems to be required.
- Being clear about what the meeting needs to cover and being prepared with an agenda.
- Distributing papers prior to the meeting so that attendees are prepared.
- Ideally having a minute-taker – recognising that it is difficult to chair a meeting and take minutes.
- Providing support to family members who want to attend the meeting, and offering input in preparation of the meeting and afterwards.

3.6.4 Involvement of families in reviews of deaths

One of the core values of the LeDeR programme is the ongoing contribution of people with learning disabilities and their families in all aspects of the work. This is considered to be central to the development and delivery of the programme. As well as being involved at advisory and steering group levels, our expectation is that families are centrally involved in the review of their relative’s

death where this is appropriate (i.e. when families have been in regular contact with a deceased person). Reviewers need to be able to respond to the needs of families in order for their involvement to be meaningful, by being flexible about times and places for discussions with families, and having access to translators as necessary.

Some professionals have expressed concern about the best time to approach families to let them know about the mortality reviews and to seek their input. Most pilot sites have confirmed the importance of discussing the review with families as soon as possible. Feedback from reviewers is that it is helpful to explain to families that this is part of a national initiative to review all deaths of people with learning disabilities in order to contribute to service improvements in general, not that there are necessarily any particular concerns about the death of their relative.

3.6.5 Timeliness of reviews

There has been some consternation about the length of time that it has taken to allocate deaths of people with learning disabilities to reviewers, and for reviewers to complete their review. A significant time lag between a person's death and when it is reviewed can make the review process more challenging, because notes may be recalled, personnel move on, and the memory of the sequence of events leading to the person's death is likely to fade. Timeliness in conducting the review is therefore important and processes need to be in place to review this regularly.

3.6.6 Key points in relation to reviewing deaths

- Make sure all of those involved in the programme are aware of the LeDeR principles and process and revisit these regularly.
- The upper age limit of 74 has now been removed.
- Allocate reviews in a timely way via LACs.
- Ensure reviewers have sufficient dedicated time required to complete their reviews.
- Remember that part of the review is about speaking to people that knew the person with learning disabilities well. This would usually be a family member, but may in some circumstances be a paid carer.
- Note the 'top tips' for completing a full multi-agency review.
- Monitor the flow of reviews regularly through the LeDeR system, especially length of time a review is taking.

3.7 Confidentiality and privacy

3.7.1 Confidentiality Advisory Group (CAG) S251

Section 60 of the Health and Social Care Act 2001 as re-enacted by Section 251 of the NHS Act 2006 allows the Secretary of State for Health to make regulations to set aside the common law duty of confidentiality for defined medical purposes.

Section 251 (or commonly referred to as CAG S251) came about because it was recognised that there were essential activities of the NHS, that required the use of identifiable patient information – but, because patient consent had not been obtained to use people's personal and confidential information for these other purposes, there was no secure basis in law for these uses.

CAG S251 was established to enable the common law duty of confidentiality to be overridden to enable disclosure of confidential patient information for medical purposes, where it was not possible to use anonymised information and where seeking consent was not practical, having regard to the cost and technology available.

There have been challenges in establishing acceptable systems within which to share patient information in the LeDeR programme. Prior to CAG S251 approval being received, and whilst local data sharing agreements were being developed, the first reviews undertaken in the main pilot site

tended to be in-house mortality reviews. The pilot site therefore lost ground in establishing the inter-agency and cross-boundary approaches required by LeDeR. Subsequent pilot and early adopter sites were advantaged because data sharing barriers and challenges were, by and large, resolved by the time they started establishing the programme in their area.

Some pilot site feedback has been that whilst CAG S251 approval has been essential to make progress, it took a long time to obtain and should have been applied for earlier. However this would have been impossible whilst the secure web-based platform was still being developed. There is also some anxiety about what will happen when the current CAG S251 approval expires, and the time frame in which an extension should be requested.

Most steering groups have local data sharing agreements to supplement CAG S251 approval. A template for such an agreement has been developed and shared by the LeDeR team. However, some data sharing agreements still need to be ratified and signed off by the local Caldicott Guardian. Every steering group is recommended to ensure that they have a cross-agency data sharing agreement and relevant governance in place whilst moving in to the future.

Any confusion regarding information governance has best been dealt with face to face, with support from the local Information Governance lead.

Information Governance training needs to be reinforced for all LACs and reviewers. One suggestion was to seek assurance from LACs and reviewers that they had undertaken their own Trust or organisation's information governance training as part of their induction to the reviewer role.

3.7.2 Key points in relation to confidentiality and privacy

- Utilise CAG S251 in the early days of setting up a steering group, but ensure a data sharing agreement is an agenda item, until agreed by all parties.
- Remind staff involved in the LeDeR programme of their information governance responsibilities and how these applies to the LeDeR process.

3.8 Funding and resourcing

3.8.1 Resources to implement LeDeR

With little additional resource for the pilot sites, funding the work from existing resources has been perceived to be a challenge. In some areas, some funding has been identified at CCG level to part-fund administration or other support costs for LeDeR, but these have been the exception rather than the rule.

In particular, pressures have been faced in the coordination of the work stream as a whole, and in the time spent by reviewers, away from their usual job role, in conducting each review.

3.8.2 Utilising existing review mechanisms

Some pilot sites have identified problems because of the different footing for Care and Treatment Reviews (which are perceived to be mandatory and attach a sum of money to each review) and LeDeR mortality reviews (which are perceived to be optional with no additional funding attached). Some tensions in the system have been identified when both types of reviews are required – with the perception that Care and Treatment reviews are prioritised over LeDeR mortality reviews.

3.8.3 Can the NHS afford not to implement LeDeR?

In the wider context it's a balance between the time investment in conducting reviews, and the resulting benefits from sharing best practice, improving services for people with learning disabilities and the prevention of early deaths from potentially avoidable causes.

One of the biggest risks with the LeDeR programme has been the perceived underinvestment for conducting reviews of deaths, and the fact that such reviews are not mandatory. All of the pilot sites believe that this important work needs to be established on a mandatory footing, especially in light of the fact that the Child Death Overview Process is mandatory - it was noted by some, that many people with learning disabilities are more vulnerable than children.

There is a clear argument, that in not establishing an early warning system such as the LeDeR programme (and addressing relevant issues), repeated harm and suffering may be caused to others, which is costlier than preventing the issue in the first place. At the launch of the national programme for 'Learning from Deaths' on 21st March 2017 Jeremy Hunt, Secretary of State for Health, argued that the NHS cannot afford not to implement the reforms (and therefore LeDeR).

3.8.4 Funding and resources

- One of the biggest issue pilot sites have faced, and arguably the biggest risk to a national roll-out, is the lack of funding for the LeDeR process and reviews.
- All of the pilot sites believe that the work needs to be established on a mandatory footing.

3.9 Support for the programme activities

3.9.1 Support for reviewers

All steering groups have identified that the LeDeR process works better when reviewers have ongoing support and / or supervision as they progress with the work. Such support has been provided in a range of ways.

- Some local areas have established peer support 'network' sessions for local reviewers, chaired by LACs, which provide an opportunity for them to discuss the work in a reflective and non-judgemental forum, and to support each other. The sessions tend to be bi-monthly, with some attached to the end of steering group meetings. The peer support sessions form a confidential safe space where attendees can speak freely (or choose not to speak at all). They are not usually minuted, apart from a record being kept of significant actions that have been agreed.
- Some local areas are providing reviewers with the opportunity to 'buddy' with another reviewer. In some cases this is specifically to link reviewers with different professional backgrounds and so support them to consider the circumstances leading to death from different perspectives. In other cases this is to engage reviewers in shared decision-making within the review process.

There is a strong feeling that there is no need to 'reinvent the wheel' and local areas are generally happy to share any resources they have developed (or are developing) with other areas. The route for sharing these resources is likely to be via the Regional Coordinators, and a central repository for such resources has been recommended.

3.9.2 Support for Local Area Contacts

Certain pilot sites have mooted whether linking up LACs, either nationally or locally, would be beneficial in terms of providing a forum for them to support each other, learn from one another and share best practice. The LeDeR team are considering what options are available to support this.

3.9.3 Central support structures

The appointment of four LeDeR Regional Coordinators who started work in early 2017 will accelerate roll-out of the LeDeR programme. Most people have felt that these appointments would have been beneficial from the outset and would have accelerated the progress of the programme.

All felt that the support from the LeDeR team in Bristol had been excellent. Its success lay in the flexibility of approach, supporting areas to take the work forward as they see fit, whilst adhering to LeDeR processes and principles.

3.9.4 Key points in relation to support

- All steering groups have identified that the LeDeR process works better when reviewers have ongoing support and / or supervision as they progress with the work.
- There is no similar support for LACs and this needs further work.
- National support through the LeDeR team in Bristol has been considered to be excellent yet unobtrusive.

3.10 Culture

In some respects, the programme has required a cultural shift for many professionals – commonly referred to by the pilot sites as the need to ‘change hearts and minds’. Inevitably this takes time, through the sharing of information and evidence, and providing explanations about the need for, and the potential benefits, of the work.

LeDeR effectively makes use of cross-agency working, when many staff are already under significant pressure. The cultural fit between health and social care personnel has been raised as a potential challenge, but has been easily overcome by getting people together. Few people have questioned why the LeDeR programme is needed. They just question how it can be delivered given existing time and funding constraints.

3.10.1 Key points in relation to culture

- The programme has required a cultural shift for a lot of professionals – commonly referred to by the pilot sites as the need to ‘change hearts and minds’.

3.11 Programme outcomes

3.11.1 Measuring outcomes

Most pilots are now mature in status and are turning their attention to completed reviews, actions emanating from them and taking forward the actions into service improvements. It’s clear that this is an essential part of the LeDeR programme. All pilot sites acknowledge that the real outcome of the LeDeR process is not the number of high quality reviews completed but the service improvements, shared learning and ultimately the reduction in premature deaths of people with learning disabilities that should ensue. As such the LeDeR team, including Regional Coordinators, are ensuring that this is on the agenda of all steering groups, when appropriate.

At present there does not exist a clear structure that will ensure that the actions identified in any review as being required are appropriately followed up, other than at steering group level. What is needed is a national reporting structure that can capture this information and evidence the effectiveness of mortality reviews in improving services.

A number of regional workshops will be delivered in June and July 2017 to share learning from the USA about how their mortality reviews have led to service improvements, and to establish systems in England that will provide evidence about the effectiveness of mortality reviews.

3.11.2 Reporting

The LeDeR team are currently providing weekly, monthly and quarterly reports about programme activities for regional coordinators. In response to requests from steering groups, quarterly reports for steering groups are being trialled. The programme provides a higher level annual report for NHS

England and wider public dissemination. In future, annual reporting of progress will be direct to the Secretary of State for Health by NHS England.

3.11.3 Key points in relation to programme outcomes

- Systems still need to be established that will provide evidence about the effectiveness of mortality reviews in improving health and social care services for people with learning disabilities.

4.0 Learning and sharing events

Learning and sharing events are being held at the end of each regional pilot, prior to wider roll-out of the programme. To date, three such events have been held. Generally they have both been perceived to be useful in sharing the region's progress with undertaking mortality reviews. One area is considering running an annual event to share the findings from the reviews and reflect on resulting actions taken and their impact.

Feedback about the learning and sharing events is as below:

- A key factor in the success of the event is to have a positive ambience – with presenters open to questions, sharing learning, being honest about challenges and successes, and being positive with a 'can do' approach. Speakers who are inspiring, have a recognised status, and engaging delivery style also contribute to this.
- It is crucial to have the involvement of family members at the event, preferably with a family member speaking about the importance of the work and how families can be involved in it.
- Comprehensive advertising and administering of the event is essential to make it run smoothly. Pre-reading prior to the event may be helpful so that the material is familiar to attendees and questions would be appropriately pitched.
- The presentations must be focused on the LeDeR methodology and approach – it is confusing if other approaches are presented without any reference to what would need to be changed to fit within a "LeDeR model" of working.
- There could be some coverage of the key aims and elements of the LeDeR programme over the next three years – an "elevator pitch" that everyone could keep in mind and share with colleagues who asked about the day and / or the LeDeR programme.
- Where possible time should be allocated to the practical nature of setting up the programme and how to overcome difficulties.

4.1 Key points in relation to learning and sharing events

- Regional learning and sharing events have been helpful; at least one area is considering an annual event.

5.0 The legacy of the LeDeR programme

Over the longer term, the natural 'home' for the LeDeR programme needs to be confirmed. Although many areas have linked the work to Transforming Care Partnership Boards, some consider that the work should be more closely aligned with other mortality review programmes. It is likely that the LeDeR programme will require oversight by a national body, to ensure security and continuation of the secure web-based platform that supports reviews of deaths, and collation of information at national level in relation to reducing premature deaths of people with learning disabilities.

5.1 Key points in relation to the legacy of LeDeR

- Over the longer term, the natural 'home' for the LeDeR programme needs to be confirmed.

6.0 For further information

For further information about the LeDeR programme please see the website at www.bristol.ac.uk/sps/leder.

You can also contact the LeDeR team at: leder-team@bristol.ac.uk or phone 0117 3310686.

References:

National Quality Board (2017) National Guidance on Learning from Deaths. A Framework for NHS Trusts and NHS Foundation Trusts on Identifying, Reporting, Investigating and Learning from Deaths in Care. <https://www.england.nhs.uk/wp-content/uploads/2017/03/nqb-national-guidance-learning-from-deaths.pdf>