Independent Review into Thomas Oliver McGowan's LeDeR Process

Phase two

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Abbreviations and acronyms

BNSSG	Bristol, North Somerset and South Gloucestershire
CCG	Clinical commissioning group
CEO	Chief executive officer
CIPOLD	Confidential inquiry into the premature mortality of people with a learning disability
ED	Emergency department
ICS	Integrated care system
ICU	Intensive care unit
LeDeR	Learning Disabilities Mortality Review
LAC	Local area contact
MAR	Multi-agency review
NBT	North Bristol Trust
RCA	Root cause analysis
STOMP	Stopping Over Medication of People with a Learning Disability, Autism or Both

Executive summary and recommendations

This summary presents the headlines from an in-depth and detailed review of the previous Oliver McGowan's Learning Disabilities Mortality Review (LeDeR) process. The panel undertaking this review was independent.

1 Thomas Oliver McGowan (known as Oliver) died on 11 November 2016. He was 18 years old. At the time of his death, Oliver was an inpatient at North Bristol NHS Trust.

2 Oliver's death first came to the attention of NHS England in May 2017 via an email from his mother, Paula McGowan, to the NHS England lead for the STOMP (Stopping Overmedication of People with a Learning Disability, Autism or Both) initiative. This triggered correspondence between NHS England and South Gloucestershire CCG, which resulted in the CCG commissioning a LeDeR process for Oliver.

3 In June 2017, the deputy director of nursing at South Gloucestershire CCG (Ms D) nominated (to the director of nursing at the CCG) a new member of staff (Ms A) to be lead reviewer for Oliver's LeDeR. Ms D also nominated a second reviewer (Ms G) and arranged LeDeR training for both of them.

Ms A was still on induction at this point and had not undertaken any LeDeR reviews before starting in post. Moreover, Ms A was not afforded enough dedicated time to complete Oliver's LeDeR. Due to these combined factors, she was not suitably prepared to complete this complex process. The panel feels this was unacceptable.

4 The lead reviewer (Ms A) believed that the supervision and support she received was inadequate. As a consequence, she felt overwhelmed by both the size and complexity of the task. The panel concludes that directing a new member of staff, with no experience of LeDeR, to undertake such a potentially difficult review, with a full portfolio, was highly inappropriate.

5 The LeDeR review for Oliver was commissioned at a time of significant organisational restructuring. Three CCGs (Bristol, North Somerset and South Gloucestershire) were merging into one, to become Bristol, North Somerset and South Gloucestershire (BNSSG) CCG.

In addition, the South West Region was the last region to formally adopt and implement the LeDeR process. As a result, the CCG did not have the necessary governance structures and process in place to adequately oversee and complete this LeDeR review. Consequently, the CCGs governance of Oliver's LeDeR was clearly lacking. The panel believes that this, combined with the 'light touch' of the previous CCG director of nursing (Ms B), was detrimental both to its process and outcome.

6 Following an in-depth review of all the evidence by the panel, it is evident that a LeDeR review was not, at that point, the most appropriate mechanism by which to review Oliver's death. Oliver was a healthy teenager who died of a relatively rare condition, known as neuroleptic malignancy syndrome (NMS).

Throughout the complaints, safeguarding and root cause analysis (RCA) process, Oliver' parents have consistently voiced their dissatisfaction with the care and treatment he received. RCA notwithstanding, the panel is of the view that the initial response to Oliver's death should not have been the instigation of an LeDeR but an independent serious investigation.

7 Ms A commenced the LeDeR review for Oliver in June 2017, even though at that point local LeDeR structures had not been fully established and there was no local area contact (LAC) in post to support her. As a result, she had to rely heavily on the LeDeR team at Bristol University. It is the role of the LAC to act as the link between the LeDeR programme team, the local steering group and lead reviewers.

8 In undertaking this complex review (Ms A) received assistance from a second reviewer (Ms G) and a small amount of administration support. The LeDeR review took 17 months to complete and was not uploaded on the LeDeR portal until November 2018. This unacceptably prolonged time span was due, in part, to the lead reviewer having to complete the review while doing her day job and receiving little support from the CCG.

The delay in completion was further compounded by difficulty obtaining medical notes. The notes should not, however, need to be chased. It is the responsibility of each organisation that all notes should be made available to the lead reviewer in a timely manner.

9 Fortunately, Oliver's family had been extremely helpful and were able to provide copious documents to Ms A relating to Oliver's care that they had obtained. While helpful, this added to the volume of documentation to examine.

10 When the LAC was appointed (in December 2017), she supported Ms A in the LeDeR process. The LAC had completed more than 40 LeDeRs and was able to offer advice to Ms A in terms of the assessment and grading of the care Oliver received to determine the need for, and subsequently arrange, a multi-agency review (MAR).

However, the panel notes that Ms A and Ms G interviewed only the family and the community team as part of the LeDeR process. This was not queried by the LAC despite the Bristol University guidance being clear that it should not be a 'tabletop exercise'. It would have been beneficial for the LAC to have been more proactive in her relationship with the lead reviewer. The panel is clear that it would not have completed Oliver's LeDeR without interviewing significant numbers of people.

11 In April 2018, the coroner's inquest into Oliver's death concluded, with no recommendations.

12 An independent chair was arranged for the multi-agency review meeting, which was held in June 2018. However, there was no training for chairs and as a result they were not as prepared as they could have been. Also, while they were experienced in chairing meetings, they had no previous experience of either LeDeR or the MAR process.

13 The course of the MAR meeting itself was observed to be complex. All people interviewed believed that the MAR meeting went as well as it could have, that is was well chaired, and that the providers were heard at the meeting. However, attendees communicated that the meeting proved stressful for a number of participants, with some attendees observing others to be defensive in their reporting and actions.

The MAR membership were not experienced in the process, so they did not know what to expect. As a consequence, the process lacked the necessary safeguards and assurances.

14 It is recorded that Oliver's parents were invited only to the first two hours of the meeting despite the LeDeR documentation advocating that families should be central to the process (although they were represented by an advocate from Mencap throughout). The

panel believes that not inviting the family to be present for the whole meeting was poor practice.

15 In the previous LeDeR paperwork, Question 8 (now Question 9 in the new version R05) asks the MAR meeting process to consider whether a death was potentially avoidable. There is a requirement to 'tick the box' or not, depending on the finding. The LeDeR process indicates that the full MAR membership should partake in this discussion, which includes participating organisations and stakeholders. However, on this occasion, the decision was made by four panel members: the chair, the LAC and the reviewers (Ms A and Ms G).

The panel believes that little consideration had being given to ascertain how these members were going to answer this question and the question was not asked of the whole MAR membership. Therefore, limited discussion took place with the four panel members and it appeared the question may have been ticked without due discussion and process as to how to answer it.

16 It is concerning that neither the chair, the LAC, Ms A or Ms G had any prior experience of attending a MAR meeting. This gave rise to these four individuals effectively making the determination that Oliver's death should be recorded as potentially avoidable at the end of the meeting after all other participants had left. The fact that some people at the MAR reported feeling uncomfortable answering the question (and tried not to answer it) is surprising to the panel.

17 The determination at the MAR panel that Oliver's death was potentially avoidable precipitated multiple correspondences with those individuals concerned with the LeDeR review within NHS Bristol, North Somerset and South Gloucestershire CCG and their solicitors. Consequently, after further discussion with the MAR chair, the LAC and the lead reviewer (Ms A), the box was unticked and left blank.

18 The delays and difficulties in completing the LeDeR process for Oliver was characterised by poor governance contributed to by poor leadership, reorganisation, changes in personnel and lack of oversight by the CCG executive team.

19 The lead reviewer (Ms A) stated in her panel interview that during the time she was undertaking this LeDeR she had felt bullied, overworked and overly stressed by the demands placed on her by the various correspondences with solicitors and her line

management. The fact that Ms A believed she was isolated and unsupported during this review illustrates evident failures in the CCG assurance and management processes at the time.

20 The LeDeR report for Oliver was uploaded onto the Bristol University LeDeR archive in November 2018.

21 The panel has reviewed an action plan that was developed after Oliver's LeDeR. This action plan seemed comprehensive, having begun in May 2019 – six months after the LeDeR had been uploaded on to the Bristol portal. However, 21 months later, these actions are still not all complete. The CCG has overhauled the LeDeR process to ensure LeDeR is appropriately undertaken and that learning is taken on board from Oliver's review.

22 The CCG should have made a concerted effort to understand the issues from the perspective of the family and to understand how difficult this whole process was, and continues to be, for them.

23 Oliver's death deeply affected many people – most of all, his family.

The panel has made a number of recommendations, set out below, to ensure that:

- the CCG takes its leadership responsibilities seriously
- the national LeDeR processes are more robust
- learning is taken forward nationally and not continually repeated.

	Recommendations	Action
1	Reporting a person's death to the LeDeR programme should be mandatory, with the responsibility placed on clinical commissioning groups (CCGs) to ensure this happens in their locality.	Department of Health and Social Care
2	Clear guidance should be produced to enable CCGs to effectively 'triage' individual deaths, to ensure that the most appropriate governance methodology is used to review them (based on circumstances and complexity).	National LeDeR programme team

3	All those who are new to the role of lead reviewer, or local area contact (LAC), must be allocated a 'buddy' who is experienced in the LeDeR process.	CCGs
4	There should be clear guidance on the roles of buddy and second reviewers.	National LeDeR programme team
5	Dedicated time and administrative support must be given to reviewers and LACs to undertake complex LeDeRs.	CCGs
6	There must be a transparent process for LeDeR in each locality, with robust governance and appropriate resources to ensure that each review is properly monitored in terms of procedure and outcomes.	CCGs
7	Governance of LeDeR should be appropriately embedded into emerging new structures, such as sustainability and transformation partnerships (STPs) and integrated care systems (ICSs), from the onset.	NHS England
8	Additional guidance should be produced that supports and advises LeDeR reviewers and LACs in situations where there are local disputes regarding the process or outcome of a LeDeR. This must include an independent escalation procedure to be used where there is a difficulty or impasse that cannot be resolved locally.	National LeDeR programme team
9	The LAC and the lead reviewer should confirm at the onset of the LeDeR process how much support is needed and what it should look like. Guidance for reviewers should emphasise that when undertaking a LeDeR, there is an onus on a team responsibility to complete the process to the required standards, rather than it falling to an individual (the lead reviewer, in this case).	LACs and lead reviewers
10	Each CCG must identify an executive lead to be responsible for the LeDeR programme and for ensuring that the board has full sight of progress.	CCGs
11	Experienced reviewers should be used when circumstances are intricate or challenging. The national LeDeR team should hold a national database of such reviewers to aid this process.	National LeDeR programme team

12	The CCG executive lead for LeDeR will ensure that LeDeRs are completed in a timely and correct manner and will intervene where problems are escalated, such as the inability to obtain critical information from the relevant agencies.	CCGs
13	When a multi-agency review (MAR) is indicated, it is important that the correct process and outcomes are achieved. It is therefore expected that where the reviewer and the LAC have no previous experience of a MAR, they will seek support from a 'buddy' who does.	LeDeR reviewers and LACs
14	One of the requirements for a MAR is determined by an initial scoring system of 1–6, with a score of 6 indicating that 'care fell short of current best practice in one or more significant areas resulting in the potential for or actual adverse impact on the person'. Currently, this scoring is not carried forward into the main report. It is recommended that there is a review of this scoring process and that the initial score is retained as a record in the main report.	National LeDeR programme team
15	In regard to the MAR meeting itself, it is recommended that there is action taken to:	
	• ensure that families are central to the process, are offered full sight of all documents, and are invited to attend all or part of the meeting as they wish	CCG
	• review the purpose of the MAR with specific reference to the function of Question 8 (now Question 9 in version R05) and, should this question be retained, provide clear guidance for MAR participants; also, to think through whether this question should be asked in confidence if it is a particularly difficult situation	National LeDeR programme team
	• provide specific guidance and training for MAR chairs delivered by the national LeDeR team and families to include key topics such as the Mental Health Act, Mental Capacity Act and best interest decision making	National LeDeR programme team
	• maintain a national list of experienced, trained people who could be called on to chair complex or contentious MARs.	National LeDeR programme team

16	There should be a review of the LeDeR methodology against similar processes, such as child death reviews, in order to garner the learning and include any improvements as appropriate.	National LeDeR programme team
17	A system process chart should be developed to enable reviewers to ensure they are undertaking the review correctly. This should include standard templates and a self-assessment tool that reviewers can use, to ensure consistency across the country.	National LeDeR programme team
18	There should be an assurance process with regard to providing regular, appropriately documented supervision for individual LeDeR reviewers.	CCGs
19	The LeDeR guidance must make explicit (to all parties) that it is completely acceptable for LeDeR reviews, where appropriate, to arrive at differing conclusions to other reviews or inquests. This is on condition that they have the evidence to support this determination and that the LeDeR itself was subject to correct governance processes.	National LeDeR programme team
20	Appropriate support should be available to reviewers, along with strong governance, to ensure that all LeDeR recommendations are robust and actioned in a timely manner, and that lessons learnt are shared nationally.	CCGs
21	Each CCG must formally undertake and document and review its own systems and processes against the learnings and recommendations arising from Oliver's re-review.	CCGs and ICSs
	This review and the accompanying action plan must be submitted to, and monitored by, the local integrated care system (ICS), giving feedback to the national LeDeR team around progress. The panel wishes for a senior, single point of contact from NHS England and NHS Improvement to ensure all actions are taken and progress monitored.	NHS England and NHS Improvement

1 Introduction

1.1 In 2019, NHS England and Improvement commissioned an independent panel to review Thomas Oliver McGowan's (Oliver) previous Learning Disabilities Mortality Review (LeDeR). The rationale for the review related to what had been described as a number of inconsistencies in the local quality assurance processes for LeDeR, and specifically some of the draft reports for Oliver's LeDeR review that were sent to the family via the Freedom of Information Act in 2018.

1.2 Additionally, Oliver's family had expressed their anxiety about a perceived lack of transparency within previous reports and processes. This report forms the second part of a two-stage process – the first being to review and complete Oliver's LeDeR.

1.3 The following objectives are cited from the terms of reference supporting the independent review:

> *It is also intended (Phase 2) will support a broader review of the LeDeR process by the following means:*
>
> *a) Determine whether in Oliver's case, the local LeDeR process and subsequent quality assurance followed national LeDeR guidance (Bristol University LeDeR Programme Guidance and associated resources);*
>
> *b) Identify any shortcomings in the LeDeR process highlighted by Oliver's case;*
>
> *c) Make recommendations as to how any such shortcomings may be remedied in future LeDeR reviews;*
>
> *d) Make recommendations about areas of local process, subsequent quality assurance and/or national guidance that would benefit from further work.*
>
> Source: Terms of Reference for Independent Review 2019–20

The Learning Disabilities Mortality Review

1.4 The LeDeR programme, established in 2015 to be used across England, aims to drive improvement in the quality of health and social care service delivery for people with learning disabilities. It does this by looking at why people with learning disabilities typically die much earlier than average, by reviewing the deaths of people

with a learning disability aged four years and over who have been notified to the programme.

The programme builds on the recommendations from the following reports:

- *The Confidential Inquiry into the Premature Mortality of People with a Learning Disability* (CIPOLD 2013)
- *Independent review of deaths of people with a Learning Disability or Mental Health problem in contact with Southern Health NHS Foundation Trust April 2011 to March 2015* (NHS England 2015)
- *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* (National Quality Board 2017).

1.5 The non-statutory LeDeR reviews of deaths are carried out to identify good, effective practice, as well as areas where improvements to the provision of care could be made. The completed reviews are first considered locally, and subsequently analysed and themed for reporting at a national level. The reports account key learning, highlighting potentially avoidable contributory factors leading to deaths.

Together, this should enable good practice to be integrated into systems and widely shared. Where there are recommendations for improvements to be made, these are expected to be fulfilled both at the national and local levels.

1.6 In June 2015, Bristol University was awarded the contract to establish and organise the rollout of the LeDeR programme on a national level. They held consultations to guide initial development followed by conducting two pilot sites – one in Wessex and one in North East region – and then across all regions. There followed a gradual rollout across the then four NHS England regions (currently seven). As part of the rollout, local areas had to employ, recruit and train reviewers, put local area contacts (LACs) in place and set up a LeDeR steering group before they could go 'live'.

December 2017 was the target date for the programme to go live nationally, but South Gloucestershire CCG began to set up their processes on 25 January 2018 as the CCG were going through a restructure and wanted to wait until this was complete. Before the restructure was complete (1 April 2018) an interim arrangement, with an integrated structure for nursing and quality from September

2017, took hold. LeDeRs are given to the CCG where the deceased person's GP is placed – which, in Oliver's case, was South Gloucestershire. South Gloucestershire was the last area to adopt the LeDeR programme nationally.

Mortality rates for people with learning disabilities

1.7 The latest LeDeR annual report (2018)[1] states that the median age of death for people with learning disabilities who are over four years of age is 59.

1.8 There is a 23-year disparity between the age of death of males with a learning disability compared to those without a learning disability. For women, this gap is 27 years. This is a substantial difference, which highlights the importance of the LeDeR programme and for people to truly learn from preventable deaths.

About this review

1.9 In consideration of this report, it is important to recognise that the basis of the review has been made retrospectively, with most of the information being almost three years old at the time of the review.

1.10 Most of the staff interviewed have now left or are in new roles. Some of the roles have had more than one staff member during the LeDeR process (some roles have had three different staff in the role for the period). To be clear, this report looks at the period 2017–2019.

For phase two of the review, the panel interviewed 16 people. These individuals were deemed crucial to the process and governance of Oliver's initial LeDeR:

- lead reviewer (Ms A), South Gloucestershire CCG; 1 April 2018, Bristol, North Somerset South Gloucestershire CCG (BNSSG)
- local area contact (LAC), NHS Gloucestershire CCG
- chief executive, clinical commissioning group (BNSSG)
- director of nursing, South Gloucestershire CCG; interim director of nursing and quality (1 September 2017), BNSSG CCG; director of nursing and quality, BNSSG (1 April 2018 – left December 2018) (Ms B)
- chair of the multi-agency review – medical director, NHS England South West (CH)
- former head of learning disabilities and mental health, NHS England (Until July 2017) (Ms J)

- former head of learning disabilities and mental health, NHS England (July 2017 until October 2018) (Mr K)
- lead for Oliver's safeguarding investigation, North Bristol Trust (Ms C)
- LeDeR programme lead, University of Bristol
- deputy nurse director, South Gloucestershire CCG (left End August 2017) (Ms D)
- quality assurance and improvement lead nurse, Bristol CCG; interim associate director of nursing, BNSSG CCG (September 2017); deputy director of nursing, BNSSG CCG from 1 April 2018 (Ms L)
- interim director of nursing North Bristol Trust (Ms E)
- head of quality Bristol CCG (September 2017); interim deputy director of nursing for BNSSG CCG; associate director of quality BNSSG CCG (April 2018) (Ms F)
- second reviewer, South Gloucestershire CCG (Ms G)
- former regional coordinator, LeDeR, NHS England South West (Mr H)
- family advocate, Mencap.

The majority of these individuals were seen face to face, with some contacted by telephone, by email or virtually. The opinion and narrative of the interviewees are used in the body of the report and shown in italics.

1.11 The panel has reviewed an extensive number of emails from the clinical commissioning group (CCG) along with a detailed scrutiny of policies and guidelines from the main LeDeR programme from 2017. Some of the above staff's views or intentions have been taken from directly from their email correspondence and are also included in the report and italicised.

1.12 The panel has also held 11 formal panel meetings. The independent chair completed eLearning in order to undertake a LeDeR review. To ensure due candour, regular contact has taken place with Oliver's family in order to try and ensure that they have felt meaningfully engaged in the overall process.

2 Oliver's LeDeR process

2.1 Oliver died in November 2016. A series of investigations and reviews took place after his death, as shown below.

Investigations and reviews timeline

21 November 2016	Email from the family to safeguarding lead raises serious concerns asking for a thorough and impartial investigation of the family's concerns
3 February 2017	Trust internal root cause analysis completed
9 March 2017	Review of root cause analysis (internal, with external clinicians)
June 2017	LeDeR review commissioned
5 September 2017	Formal letter from the family to the trust asking for complaints procedure to be formally engaged
27 November 2017	Trust internal safeguarding investigation completed
16 December 2017	Formal response re family complaint letter
14 November 2018	LeDeR complete and uploaded to the LeDeR system

Oliver's LeDeR

2.2 On 20 May 2017, the NHS England lead for STOMP (Stopping Over-Medication of People with Learning Disability, Autism or Both) received an email from Oliver's mother wanting to share her son's story to support the STOMP programme.

2.3 On 22 May 2017 the previous head of mental health and learning disabilities (Ms J) from the then NHS England was copied into the email. The head of mental health and learning disabilities (Ms J) emailed to the programme manager of Transforming Care at NHS England South asking what review would take place around Oliver's death:

> *Can you let me know what sort of review you will be looking for in this case? It will get picked up by LeDeR as a matter of course but will you be looking for a Serious Untoward Incident review, or a Serious Case Review under safeguarding?*

2.4 On 23 and 24 May 2017, email conversation ensued from the NHS England regional coordinator (Mr H) for LeDeR stating that:

> *[The] LeDeR process did not replace other statutory processes such as safeguarding and they should go ahead as usual and appropriate to those investigation processes*.

The then South West Transforming Care Assurance Manager NHS England stated:

> *I have spoken to South Gloucestershire CCG who are very aware of the case. I am informed that an SI [a serious investigation] has been raised in relation to NBT so there should be something on the SEIS [the Strategic Executive Information System].*

2.5 On 7 June 2017, in emails, the director of nursing for South Gloucestershire CCG (Ms B) asked Ms G (who was to become the second reviewer for LeDeR) and the deputy director of nursing (Ms D) to review Oliver's case. On 7 June 2017, an email from Ms D (deputy director of nursing) to Ms B (director of nursing CCG) stated:

> *I have reviewed the information we have available and concluded that a review under the LeDeR review framework is the most appropriate next steps… [Ms A and Ms G] are both attending the LeDeR reviewer training next week so we propose that if it is acceptable to the LeDeR lead we nominate [Ms A] to lead the review with [Ms G] providing the LD expertise.*

The lead reviewer Ms A, has since stated:

> *Ms G was not a clinician and could not have possibly provided learning disability expertise.*

2.6 During interview, Ms G (second reviewer) stated that she attended the LeDeR training (week of 12 June 2017) as part of her role with Ms A (lead reviewer) and the NHS England regional coordinator (Mr H) asked them both if they would review a historical case (which was Oliver's).

2.7 Instigating a LeDeR was not a given in Oliver's case, as he died before the LeDeR process was entirely rolled out across England. When Mr H (NHS England regional lead for LeDeR) was interviewed he stated:

Oliver's death was out of scope, as were other deaths that were notified to the programme. Normally, out-of-scope deaths were not reviewed.

It had also been agreed by NHS England and Bristol University that areas should not start the LeDeR review programme until all the processes were in place, with a national deadline of December 2017. This included recruiting and training reviewers, having trained local area contacts (LACs) and a local steering group. Retrospective deaths were not to be included.

2.8 South Gloucestershire CCG reviewed and agreed that the LeDeR process was the best course of action. Mr H (former NHS England regional coordinator) stated that he raised his concerns about Oliver having a LeDeR review at that point in time with colleagues but was told by the Bristol University programme lead that:

… if there was learning to come out of the review then it was ok to go ahead.

South Gloucestershire CCG had not rolled out the national LeDeR programme. This was in part due to the CCG amalgamating with two other CCGs in a restructure that completed on 1 April 2018. The CCG had not undertaken any LeDeR reviews in its area and at that point did not have the necessary LeDeR governance systems in place, such as a local steering group, support process or quality assurance mechanisms. All the LeDeR processes are an important part of LeDeR[2].

Mr H stated:

The message I received was that she [Ms B, former director of nursing] had enough meetings and wasn't going to set up another steering group at the CCG.

2.9 Thus, Oliver became South Gloucestershire CCG's first LeDeR review. The person nominated as the lead reviewer (Ms A) had just started working at the CCG (June 2017) and Ms A stated to the panel that on her first day in her new role, at an organisation where she had not previously worked, she was given Oliver's LeDeR to complete by her line manager, the deputy nurse director (Ms D). Ms D refutes this, stating that Ms A received Oliver's LeDeR after her training and induction was complete.

2.10 The director of nursing (Ms B) stated during the panel interview that the lead reviewer was:

> *… the best person to undertake this review, she was new, didn't know the area so could be independent and she had a mental health background*.

The national LeDeR guidance[3] states the LACs should help allocate cases to local reviewers.

2.11 The second reviewer (Ms G) stated the LeDeR process was:

> *… fledgling, no steering group or reference group and we had both just finished our training. This was the first LeDeR in the area.*

She *added:*

> *I remember speaking about it with… who shared her concerns around organisational liabilities and [Ms A] was very concerned as she had undergone a lot of SUI [serious untoward incidents] in her previous roles… One of my reasons for coming into the NHS is to focus on inequalities. I definitely felt it was the right thing to do for Oliver and the family.*

2.12 However, South Gloucestershire CCG did not have a LAC in place at this time. The guidance[4] also states that the local steering group should guide the implementation of the programme, monitor action plans from reviewers, nominate LACs and take appropriate action as a result of the information obtained. In this instance, South Gloucestershire did not have a local steering group in process until much later (at the end of Oliver's LeDeR process, in 2018).

2.13 As Ms A had never undertaken a LeDeR review before, she completed the LeDeR training with Ms G the second reviewer (June 2017). Ms A believed that she was not briefed properly about Oliver's case and therefore did not understand the complexities surrounding Oliver's death. Prior to commencement in post, she had not heard about Oliver's death.

2.14 Ms A stated that she believed her line manager (Ms D, the deputy nurse director) also did not understand LeDeR, and that Ms A did not receive supervision while at

the CCG. Ms A reported that she was not given any dedicated time to lead Oliver's review from her duties of her role.

Ms D, when interviewed, stated that she only managed Ms A for six weeks then left in August 2017 to take up another role elsewhere. Ms A had three line managers during her tenure: Ms D until August 2017, Ms L until April 2018, then Ms F until Ms A left in December 2018.

2.15 During those six weeks, Ms D did meet with Ms A but this was in relation to her induction. Subsequently, both Ms L and Ms F stated that although they line managed Ms A, Ms A reported to Ms B for Oliver's LeDeR. Ms L stated to the panel that it was agreed that Ms B would be the link for Ms A for Oliver's LeDeR.

Ms B contests the view of the lead reviewer (Ms A), stating that Ms A's line managers regularly met with her and supported her throughout. Ms L did state to the panel:

> *I did meet [Ms A] at least monthly, each meeting was documented I sent it to her the notes to change accordingly, it was then filed electronically and sent to HR for her file*.

However, they never spoke about Oliver's LeDeR in any detail, as Ms L stated that Ms B was supporting Ms A in this regard. Ms L also stated to the panel that she did make adjustments for Ms A (the lead reviewer) as she was worried about her workload. During Ms L's tenure she stated that the mental health component of Ms A's work was given to Ms F and Ms L took over the quality portfolio for North Bristol Trust to give her more space, but her other duties (which were significant) remained.

2.16 At the beginning of the process, Ms A (lead reviewer) told the panel that she used the University of Bristol contact for much of her support, to ensure she understood the process properly.

2.17 However, Ms A did have three people to support her:

- the second reviewer (Ms G), who left just before the main report was complete
- some time from an administrator, which stopped halfway through the review (when a reorganisation of the three CCGs was taking place)

- a LAC from Gloucestershire CCG, who was brought in to support Ms A in December 2017 because Ms A was also the LAC for her area and could not undertake both roles. Ms A wanted to stay as the lead reviewer and thus a different LAC was drafted in who had experience of the LeDeR process. This meant that there was not a different LAC for some six months after the start of the LeDeR process for Oliver (between June 2017 and December 2017).

Mr H (regional LeDeR coordinator) stated:

Ms A's role was certainly exceptional in these circumstances.

2.18 The LAC, who was from Gloucestershire CCG and in a joint health and social care post, was also part of the LeDeR pilot, which had pre-established processes. She was brought in to support South Gloucestershire, which was new to LeDeR. The LAC stated she had completed 40 LeDeR reviews before undertaking Oliver's. The panel is unclear who brought the LAC into Oliver's LeDeR, due to conflicting accounts.

2.19 Both the LAC and Ms A told the panel they were given Oliver's LeDeR in addition to their full-time jobs.

Panel comments

2.20 After Oliver's death, a series of reviews and investigations took place. The family raised initial serious concern with the trust, which gave a brief response, stating that the internal root cause analysis (RCA) investigation and subsequent internal safeguarding investigation would answer their concerns.

Following Oliver's death, the RCA was undertaken and took around three months to complete (February 2017). The panel feels this was acceptable as it was within the parameters stated in NHS England guidance for completion of serious untoward incident (SUI) investigations. However, the panel was told that a further RCA investigation was undertaken with external and internal clinicians because the first RCA did not answer all the family's questions.

2.21 The external review took one month to complete (March 2017), which the panel again believes was acceptable, but the safeguarding investigation was not completed until nine months (November 2017) after the initial root cause analysis. The panel believes

this was too long a period to learn any meaningful lessons between accepted processes.

The LeDeR was then commissioned seven months after Oliver's death, which appears extremely protracted, but suggests that governance arrangements were confused as there was a lack of clarity around instigating a LeDeR for Oliver in the first instance.

2.22 It is the panel's opinion that if one independent serious investigation – with a clearly defined scope – had been commissioned soon after Oliver's death, this would have facilitated the gathering of more robust and timely information and supported learning from Oliver's death. The LeDeR process could have used this to good effect, enabling any further potential learnings to be put into place with immediate effect.

2.23 The protracted period of time from Oliver's death to the conclusions of the investigations and the instigation of the LeDeR process would have led to a number of vulnerabilities in the process, such as accuracy of people's recall of events. In the case of Oliver's death, there was also the surrounding media attention, which may have created bias (conscious or not) when remembering events.

2.24 The panel fundamentally agrees that LeDeR was not the appropriate process from which to meet the family's request for a:

> *… thorough and impartial investigation.*

LeDeR is not designed to be an investigation process but a learning review, which seeks to attach no blame and is meant to facilitate learning, generate recommendations and garner good practice, while tracking actions.

2.25 In hindsight, the panel believes that an independent serious investigation, by someone with suitable experience and expertise external to the local system, should have been commissioned – with clear terms of reference, agreed by the family with a deadline. NHS England guidance is clear that an independent investigation is advised under a number of circumstances, including:

> … *where the commissioner(s) or provider(s) or the patient/family feel that the nature of the potential causes of an incident warrant*

independent scrutiny in order to ensure lessons are identified and acted upon in a robust, open and transparent manner.[4]

2.26 From the evidence reviewed, the rationale for the CCG to complete a LeDeR was unclear when there could have been other alternatives, as described above, that would have been more appropriate before a LeDeR was conducted. Ms B had executive responsibility for the LeDeR process at the CCG. It is the panel's view that she was not sufficiently actively engaged with the LeDeR process, and that it would have been prudent of her to ensure close supervision and guidance to the lead reviewer.

Given this was the first LeDeR that the CCG had undertaken, the panel believes the CCG should have been more directly involved – especially given the complex set of circumstances and the fact a new member of staff, with no prior experience of LeDeR, had been directed to undertake the review.

2.27 As Oliver was a fit and healthy 18-year-old teenager who had died from neuroleptic malignant syndrome (NMS), an initial review of this case should have signalled that this was unusual or rare clinical circumstance. This therefore should have led to a formal review of his death using the most appropriate governance process, such as a serious incident review process, with an appropriate independent lead to coordinate the investigation.

2.28 The panel concludes that directing a new member of staff with no experience of LeDeR to undertake such a potentially complex review, while still subject to induction, was extremely short sighted. The lead reviewer could, of course, have refused to accept the LeDeR review.

2.29 The lead reviewer stated she was subject to her induction when she was given this LeDeR and was not afforded dedicated time to complete this complex process. The panel feels that although adjustments were made at different stages of Oliver's LeDeR, these were insufficient. This is unacceptable.

2.30 The CCG governance of Oliver's LeDeR was clearly lacking. The panel believes that this and the 'light touch' of the director of nursing (Ms B) was detrimental both to its process and its outcome.

2.31 The LAC was not in place until six months into Oliver's LeDeR process. This meant that the lead reviewer (Ms A) was additionally in the difficult situation of conducting the LeDeR without someone more expert to provide, and to call on for, guidance and supervision.

	Recommendations	Action
1	Reporting a person's death to the LeDeR programme should be mandatory, with the responsibility placed on clinical commissioning groups (CCGs) to ensure this happens in their locality.	Department of Health and Social Care
2	Clear guidance should be produced to enable CCGs to effectively 'triage' individual deaths, to ensure the most appropriate governance methodology is used to review them (based on circumstances and complexity).	National LeDeR programme team
3	All those who are new to the role of lead reviewer, or local area contact (LAC), must be allocated a 'buddy' who is experienced in the LeDeR process.	CCGs
4	There should be clear guidance on the role of buddy and second reviewers.	National LeDeR programme team
5	Dedicated time and administrative support must be given to reviewers and LACs to undertake complex LeDeRs.	CCGs
6	There must be a transparent process for LeDeR in each locality, with robust governance and appropriate resources to ensure that each review is properly monitored in terms of procedure and outcomes.	CCGs
7	Governance of LeDeR should be appropriately embedded into emerging new structures, such as sustainability and transformation partnerships (STPs) and integrated care systems (ICSs), from the onset.	NHS England

3 Oliver's LeDeR process: timeline

The timeline below sets out key milestones in Oliver's LeDeR process. The narrative in the subsequent sections explains these key milestones in detail.

11 November 2016	**Oliver's death**
21 November 2016	Family email to safeguarding lead with serious concerns
26 May 2017	Email correspondence from NHS England South asking for summary of actions to date and whether South Gloucestershire CCG is planning independent review
27 November 2017	Trust internal safeguarding investigation
3 February 2017	Trust internal root cause analysis
9 March 2017	Review of root cause analysis (internal with external clinicians)
June 2017	Oliver's LeDeR review commences
5 June 2017	Director of nursing at CCG requests Oliver's RCA, Strategic Executive Information System report and 72-hour report
5 September 2017	Family submits formal complaint to the trust
November–December 2017	Pre-LeDeR report complete
11 December 2017	First email asking for solicitor's contact details from lead reviewer
16 December 2017	Complaint response from trust to family
8 March 2018	Oliver's LeDeR briefing paper sent by lead reviewer to director of nursing
3 April 2018	Briefing paper tabled at Bristol, North Somerset and South Gloucestershire CCG closed session board meeting
8 April 2018	Chair of multi-agency review commissioned

16 April 2018	Coroner's inquest starts
20 April 2018	Coroner's inquest concludes with no recommendations
14 May 2018	Multi-agency review invitations sent
14 June 2018	Multi-agency review takes place
2 September 2018	Draft minutes of multi-agency review sent to chair
4 September 2018	Email from solicitor to lead reviewer asking for a call concerning Question 8 (was Oliver's death potentially avoidable)
4 September 2018	Email from regional coordinator (NHS England) to LeDeR lead, Bristol University and head of nursing, NHS England asking if Question 8 can be removed
4 September 2018	Urgent call about the report (Question 8) – chair, lead reviewer and LAC. Panel agrees to untick Question 8 and put in narrative
8 September 2018	Manager asked lead reviewer asked to ensure report is run past solicitors
9 November 2018	Local area coordinator quality assures report
14 November 2018	LeDeR report uploaded onto Bristol University system and archived
18 November 2018	Family submits Freedom of Information request to obtain all five versions of LeDeR report

4 Evidence gathering

4.1 In preparation for the review, Ms A was handed a file of Oliver's notes by her line manager (Ms D). After reading through the notes, Ms A noted that a lot of information was missing, so attempted to obtain all records that were pertinent to Oliver's review.

4.2 Ms A stated she was not afforded dedicated time to complete the review and that she had to use evenings and weekends to read the large amount of information made available to her. During this time, she kept in contact with the family who, she noted, were very generous with their time. The family sent Ms A extensive information that they had obtained. The family acknowledged this to be the case.

4.3 At this juncture, Ms A believed that the LeDeR process was not robust enough and felt it should cease. She wanted the CCG to explain to the family in person that LeDeR would not meet their expectations as this was a learning and recommendations review, rather than an investigation into responsibilities and potential failings.

4.4 However, this did not happen, and Ms A was told to continue with the process. Ms B (director of nursing) stated at interview:

> *[I] didn't really think through the different options open to me and was unsure what options were open to the CCG. NHSE advised me to go through the LeDeR process.*

Due to the passage of time, Ms B could not recall with whom she had had conversations at NHS England. She did, however, state that when it came to Oliver's LeDeR:

> *… NHSE did have quite a central role.*

4.5 The LAC stated during interview that she acknowledged that the LeDeR process was:

> *… probably not the right route for this case and should have been more of an investigation eg safeguarding adults review… the family were pushed down this route by the CCG after a poor outcome from the*

coroner… It would never give them the full outcome that they wanted… they wanted someone held accountable as well as helping to prevent others going through similar experiences to Oliver.

4.6 Ms G, the second reviewer, stated*:*

I feel an enormous amount of sympathy for the family. In hindsight LeDeR was not the right process at that time, it was a fledgling process we were all learning as we went along.

4.7 The deputy nurse director at the CCG (Ms D) stated that she did not recall a discussion around whether the LeDeR was the right process for this review. She said she remembers:

… a discussion with Ms B about whether Oliver's death should go through the children death review process. I was clear that it was not the appropriate review as Oliver was 18 years and that a LeDeR review may be appropriate.

Ms B stated the lead reviewer (Ms A) did not escalate concerns to her line manager. However, Ms A stated that she did in fact escalate, both to her line manager (Ms D) and the director of nursing (Ms B). The panel believes that escalation would have been the desirable course of action in order to pause the LeDeR.

4.8 The previous director of nursing (Ms B) stated that NHS England had asked her to ensure that Oliver's death went through the LeDeR process. She said that she:

… *wanted to give the family something as they were clearly very distressed and complaints had not given them what they wanted… They deserved to have some learnings coming out of the process and because LeDeR was about recommendations and learnings and not blame I felt it was the right thing to do at the time.*

However, emails seen by the panel do not show that NHS England asked for Oliver to go through a LeDeR, and that in fact NHS England emailed Ms B asking what type of independent investigatory process was going to be followed (see page 17). The second reviewer (Ms G) stated that she and the lead reviewer (Ms A) were asked to take on a historical LeDeR case (Oliver's) by the NHS England regional lead (Mr H). Mr H did not state this at interview.

4.9 Ms A believed she was:

> *drowning in information.*

She had agreed with the family to look at the last year of Oliver's life and as a result she read all of Oliver's medical notes, which consisted of a number of volumes: In addition, there were:

- GP notes
- three separate sets of admission medical and nursing notes from Bristol Children's Hospital
- admission notes from London National Hospital for Epilepsy
- admission notes from Ashdown Unit Avon and Wiltshire Mental Health Partnership NHS Trust
- final admission medical and nursing notes from Southmead Hospital Bristol
- community learning disability team notes from Sirona Care and Health (the community learning disabilities team).

4.10 The LAC thought the reviewer was:

> *… doing an excellent job of the review, she was keeping in close touch with the parents, hospitals, college – she was doing a much more detailed review than I had seen previously from initial reviews, the amount of notes etc that she read was more than what was expected of LeDeR.*

Both the LAC and Ms A attended at least one NHS England regional meeting to gain support from their peers. The second reviewer did not attend any support-group meetings.

4.11 Ms A interviewed the family and Sirona but did not interview anyone else as she thought that this was not the usual process of the LeDeR review. Ms G, the second reviewer, stated:

> *Interviews were not held as there were other statutory processes happening concurrently. It was a paper tabletop exercise.*

4.12 Bristol University stated in an email exchange with the panel that:

any reviewer can interview any person that it is deemed necessary for the LeDeR review… it should not be a tabletop exercise.

4.13 On 27 November 2017, the second reviewer (Ms G – support to the lead reviewer) emailed the family stating that she was looking at the report to be in:

draft by early 2018 with a view to then convene a Multi-Agency Review.

Oliver's death received significant local and national media attention. On 17 August 2017, email trails show that the lead reviewer was briefing the head of mental health and learning disabilities at NHS England (Mr K). The brief was an overview of what the lead reviewer had achieved to date. There were no concerns raised at this point. Mr K replied:

I am much assured by your approach and progress. Let's keep in touch as I have offered by phone today. I will in turn keep you aware of any issues that are flagged nationally on this via ministerial interest.

Panel comments

4.14 The panel agree that it is difficult to ascertain the amount of support the lead reviewer did, or did not, receive. What is clear is that her first direct line manager (Ms D) was involved for only six weeks. The lead reviewer was then handed over to Ms L, the then the interim associate director of quality BNSSG. From 1 April 2018, the lead reviewer was then transferred to Ms F the associate director of quality (BNSSG).

Although Ms A had three line managers, the CEO stated that Ms A continued to be supported by Ms B for the LeDeR work throughout this period of time, as did the other two line managers for Ms A. During the panel interview, Ms B stated that Ms D was the lead reviewer's line manager and assumed Ms D was giving the lead reviewer one-to-one supervision.

Either way, within these six weeks of actual line management, the lead reviewer (Ms A) was still only just starting the LeDeR review when Ms D left. Having a line manager who was not responsible for Ms A's full portfolio may have led to confusion as to who was supporting Ms A with what.

The panel concludes that the lead reviewer did not receive the necessary supervision whilst undertaking Oliver's LeDeR. This should have been the responsibility of the

executive lead (the director of nursing) – either to do directly, or to ensure she was getting the support from her direct line manager.

4.15 The panel also notes that it would have been beneficial for the LAC to have been more proactive in her relationship with the lead reviewer. The fact that the lead reviewer (Ms A) only interviewed limited parties in connection with Oliver's death (because she believed going beyond this not to be part of the LeDeR process) should have been rectified by the more experienced LAC guiding her through the LeDeR process.

The panel is clear that it would not have completed Oliver's LeDeR without interviewing significant numbers of people. This was a complex, multi-agency LeDeR and, as such, it warranted confident and experienced leadership.

4.16 However, root cause analysis notwithstanding, the panel is of the view that the initial response to Oliver's death should not have been the instigation of a LeDeR but an independent serious investigation. Not applying the appropriate level of governance and support at the outset resulted in a protracted and, at times, fragmented approach to the review.

4.17 The panel believes that having so much information to work through must have been difficult for Ms A while simultaneously working in a new full-time role. The lack of dedicated administration time and of a clear remit directly impacted on her ability to effectively deliver the review. The panel does believe that the lead reviewer, for whatever reason (perhaps because of how new she was in the role), was unable to have her escalations taken seriously.

	Recommendations	Action
8	Additional guidance should be produced that supports and advises LeDeR reviewers and LACs in situations where there are local disputes regarding the process or outcome of a LeDeR. This must include an independent escalation procedure to be used where there is a difficulty or impasse that cannot be resolved locally.	National LeDeR programme team

9	The LAC and the lead reviewer should confirm at the onset of the LeDeR process how much support is needed and what this should look like. Guidance for reviewers should emphasise that when undertaking a LeDeR, there is an onus on team responsibility to complete the process to the required standards, rather than it falling to an individual (the lead reviewer, in this case).	LACs and lead reviewers
10	Each CCG must identify an executive lead to be responsible for the LeDeR programme and for ensuring that the board has full sight of progress.	CCGs
11	Experienced reviewers should be used when circumstances are intricate or challenging. The national LeDeR team should hold a national database of such reviewers to aid this process.	National LeDeR programme team

5 Timeline and initial report

5.1 Ms A and Ms G developed the timeline following the established LeDeR process. This took many months, as some medical notes were not forthcoming. Ms A was still developing the timeline right up until the first draft of the main report (in May 2018), adding more pieces of information when the notes came through to her. Ms A focused on the last year of Oliver's life, as requested by the family.

5.2 The initial report took five-to-six months to prepare. This was not a draft of the final report, but a pre-report created as part of the LeDeR process. LeDeR guidance states the initial review should take up to two weeks but can take longer if required. The initial report includes a score for care received by the person, on a scale of 1–6. The initial report uploaded on to the LeDeR portal gave a score of 6, which meant that:

> … *care fell short of current best practice in one or more significant areas resulting in the potential for or actual adverse impact on the person*.

The LAC agreed with this, as she believed there were:

> … *a number of missed opportunities.*

5.3 The pre-report scoring is designed to help the reviewer decide whether a multi-agency review (MAR) should take place. The scoring is not taken forward to the main report. Ms A stated that it was very apparent early on that this review would need a MAR. The LAC stated that, although she had completed around 40 LeDeRs, Oliver's was the first MAR she had required.

5.4 Emails on 6 March 2018 from the second reviewer (Ms G) to Ms A state that:

> … *[an] updated version of the recommendations with the attachment of the learnings and the pen picture [were] to be agreed at the multi-agency review*.

5.5 An email from Ms B (director of nursing) to Ms A on 6 March 2018 asked for a briefing around Oliver's LeDeR and potential associated media activity:

> *We need to brief [the CCG CEO]. I have a 1 to 1 with her next week so it would be helpful to have something before then.*

A short briefing was given outlining what had happened to date and the media interest around Oliver's death. This briefing was tabled at the board meeting in April 2018.

5.6 The LAC emailed Ms A on 19 March with a proforma to ensure all areas of process had been captured for the MAR meeting.

Panel comments

5.7 The panel concludes that the length of time that it took to complete the initial report was too long. This may have been due partly to the lead reviewer having to chase notes. Dedicated administration time may have helped the process. The notes should not, however, have had to be chased. It is the responsibility of each organisation to ensure that all notes are made available for review in a timely manner and should be a priority task for organisations to complete.

The panel concludes that because LeDeR is not mandated, people may not prioritise the importance of LeDeR over many other tasks. The priority status given to LeDeR reviews, alongside other professional duties, needs to be addressed by the Department of Health and Social Care.

5.8 The panel believes that it was appropriate for the reviewer to go back as far as one year for this LeDeR.

5.9 Having the experienced LAC onboard at the MAR stage was helpful, but she had not completed a MAR before. The panel believes that a MAR was known to be necessary early in the process, and therefore the LAC should have had experience of a MAR to support the lead reviewer. As the LAC was not introduced into the review for six months, there would have been time to ensure that the LAC had the required MAR experience.

	Recommendations	Action
12	The CCG executive lead for LeDeR will ensure that LeDeRs are completed in a timely and correct manner and will intervene where	CCGs

	problems are escalated, such as the inability to obtain critical information from the relevant agencies.	
13	When a multi-agency review (MAR) is indicated, it is important that the correct process and outcomes are achieved. It is therefore expected that where the reviewer and the LAC have no previous experience of a MAR, that they will seek support from a 'buddy' who does.	LeDeR reviewers and LACs
14	One of the requirements for a MAR is determined by an initial scoring system of 1–6, with a score of 6 indicating that 'care fell short of current best practice in one or more significant areas resulting in the potential for or actual adverse impact on the person'. Currently, this scoring is not carried forward into the main report. It is recommended that there is a review of this scoring process and that the initial score is retained as a record in the main report.	National LeDeR programme team

6 The multi-agency review

6.1 According to the LeDeR process guidance in the predetermined scoring scale, a score of 6 highlights that the reviewer should consider a multi-agency review (MAR). This would ordinarily result in the lead reviewer organising and chairing the MAR, but in this instance the LAC (Ms B) stated that, due to the complexity of the review:

> *[It] was felt to be not appropriate.*

Ms B believed that an impartial independent chair should be sought, in part to give the family confidence in the process. Ms G (the second reviewer) stated that a paper went to the CCG board updating them about Oliver's LeDeR. The lead reviewer (Ms A) stated that a paper was written (in April 2018) but could not confirm whether Ms B had submitted this.

The paper seen by the panel factually states progress made with no concerns raised to that point in time. The minutes from the board papers do not indicate a paper being submitted but a verbal update given. The second reviewer thought the CEO was present at the board meeting:

> *The board were having issues with North Bristol Trust namely the root cause analysis and the fact it had to be repeated [the second RCA, with independent clinicians].*

The board apparently agreed that an independent chair would be a good idea for the MAR:

> *It was pretty obvious that we were going to have a MAR… We waited for the coroner's verdict before we set the MAR in place.*

6.2 Thus, a panel was organised to oversee the MAR and Ms A supported the organising and administration of the meeting. The MAR panel consisted of an independent chair, the two reviewers, the LAC and another member who, due to family bereavement, did not attend the meeting.

6.3 Ms A began the process of coordinating the MAR. The LAC stated that Ms A did not ask for any support, and as such the LAC felt that the MAR was all in hand so did not

offer any additional assistance. The LAC went to the MAR meeting but was not involved in organising it.

6.4 The medical director for NHS England South West (chair) was approached by the deputy director of nursing NHS South West on 8 April 2018, some 10 months after the LeDeR process had begun, to see if she would assume the role of chair. The email explaining to the potential chair of the circumstances stated:

> *He [Oliver] walked in to ITU, was intubated, given antipsychotic drugs and died. He was allergic to antipsychotics drugs. The staff knew this and made a conscious decision to administer. The family are not happy.*

6.5 The medical director (NHS England South West) had never undertaken a LeDeR before but was used to leading independent reviews and had a background in general practice and public health. The chair conducted her own research to ensure that she understood LeDeR but was not offered any LeDeR training.

6.6 Ms A stated at interview she developed terms of reference for the MAR, but later discovered that there was a prescribed set of terms of reference as part of the LeDeR pack. Via email, both reviewers agreed that because it was late in the process and the two sets of terms of reference were similar, their own terms of reference should be used. In fact, the LeDeR process does not include terms of reference for a MAR, as the Bristol University lead for LeDeR stated:

> *There were no national Terms of Reference for the MAR meetings – we provided advice and guidance only… because the programme was not mandatory we were not in a position to tell local areas what to do and how to do it.*

6.7 Correspondence took place between the chair and Ms A, both by email and telephone, to confirm that everything was in place for the MAR meeting. The chair was also sent the outcome of Oliver's inquest (which was completed on 20 April 2018) before the MAR took place.

6.8 The MAR was set for 14 June 2018 and accepted. Organisational practices were in place, including Webex facilities being established for the family to join the meeting by video (they had moved to Australia). Invitations were sent to each organisation

(rather than to individuals), asking them to field the most appropriate people to the meeting. Terms of reference, timeline and agenda were disseminated.

6.9 The agenda was set by Ms A. The LAC stated:

> *… there is no detailed guidance on the format of the agenda for a MAR, so it had been agreed locally.*

They decided to have the family present for the first two hours of the meeting but only with the MAR panel, not with the whole MAR membership. Oliver's parents joined by video link and they discussed the terms of reference:

- *To agree that the pen picture was accurate*
- *Identify potentially avoidable factors that may have contributed to Oliver's death*
- *Identify and agree good practice, learning points, and any subsequent recommendation*
- *Develop an action plan.*

6.10 The family recalls that they were told a draft of the report would be shared with them and the rest of the members of the MAR meeting before the final report was published.

6.11 The family members were supportive of this process and read out their inquest testimony. They also highlighted several areas they wanted to explore:

- *Reasonable adjustments*
- *The fact that information (his hospital passport and crisis management plan should he attend Emergency Department (ED) in future) was not passed on to ED as promised*
- *The administration of anti-psychotic medication when Oliver and the family had told them they did not want this*
- *Lack of a multi-disciplinary team working in any of the hospitals*
- *The transition of children to adult services.*

6.12 The family members then outlined their views regarding each episode of care when Oliver had been admitted over the past year. The family left the video conference after two hours and the LeDeR panel decided the following points would be reviewed at the subsequent provider part of the MAR:

- *Police scaring Oliver and their use of physical restraint*
- *That his hospital passport was passed to A&E and was not shared within the hospital*
- *Reasonable adjustments were not put into place for Oliver particularly around autism and behaviour escalation*
- *Questioning why the best interests meeting was not held with a multidisciplinary agency*
- *The need to train medical staff to better deal with patients with autism and LD*
- *Temperature management in ICU*
- *Open wound cause and how it was treated (with a photo provided by the family)*
- *Multi-Disciplinary Team Meetings*
- *Creating a transition process between providers*
- *Service delivery.*

6.13 The organisations below attended from 11am. The family had an advocate from Mencap present for the whole meeting.

Position	**Organisation**
Family advocate	Mencap
Head of nursing	North Bristol Trust
Head of patient experience	North Bristol Trust
Matron, paediatric surgery	University Hospital Bristol – Bristol Children's Hospital
Matron, learning difficulties	University Hospital Bristol – Bristol Children's Hospital
Senior nurse manager, neuropsychiatry inpatient unit	National Hospital Neurology N
Senior OT (MH) and LD champion	National Hospital Neurology N
Service manager for learning disability services	Avondale Wiltshire Mental Health Partnership NHS Trust – Ashdown Unit
Lead community nurse	Sirona Care and Health

Head of learning disability services	Sirona Care and Health

6.14 The chair outlined the terms of reference, focusing on learning, highlighting good and potentially avoidable contributory factors within the complete report, sharing of the action plan.

6.15 The pen portrait was agreed and stood with no amendments. The timeline was discussed with only five comments made and was subsequently agreed by all parties. Each organisation was given time to go through its issues and air its views. Learning points were discussed, as was the sharing of good practice. The initial report stated they had not identified any good practice.

6.16 The MAR minutes indicate that the MAR went through the following questions:
'Are meeting members surprised that the person had died at this time from this cause?' (All stated 'Yes.')
'Was the death potentially avoidable?' (All stated 'Yes.')

This indicates that the full MAR membership discussed this as well as the above question and all agreed with the affirmative. However, this has not been evidenced with subsequent interviews.

There was some confusion as to whether Question 8 was discussed with the whole group. The family advocate who attended on behalf of the family stated:

> *… that actual question was not asked of the whole group however there was so much discussion and talk of contributing factors that it was just obvious that it was potentially avoidable. I realised the chair had not specifically asked this question but felt it had been talked about at the meeting enough for it to be very clear… I went away from the meeting expecting to see Question 8 ticked as a yes.*

6.17 The LAC, the chair, and Ms A stated that they did not ask this question of the whole group. The second reviewer (Ms G) stated:

> *We would have gone through it as a main question, NBT [North Bristol Trust] said the coroner stated it wasn't, others felt it was*.

Some members of the MAR group who were interviewed stated that they did not discuss this.

6.18 After all the providers had spoken, they left the room. The panel means were then left to go through the LeDeR template, which Ms A had already completed, to confirm they concurred. At this point, the LeDeR panel members stated they discussed the following, reaching a conclusion in each case:

- Were you surprised at Oliver's death? ('Yes')
- Is there learning? ('Yes')
- Was Oliver's death potentially avoidable? ('Yes').

6.19 Discussion took place around the learnings and recommendations, but the chair stated that the questions – and specifically, Question 8 (was Oliver's death potentially avoidable) – were not debated with the MAR panel members. She believed that:

> … *very little relevant conversation was had [between the MAR panel members].*

6.20 The second reviewer (Ms G) stated:

> *The panel went through the documentation. It was not a lengthy discussion, but all panel members felt Oliver's death was potentially avoidable.*

When asked by the interviewer specifically why the MAR panel felt this, the second reviewer stated:

> *The plan agreed with the parents to use soft cuffs whilst coming off sedation, was not enacted. There were two copies of NBT notes, one where the family had got copies of the notes directly after Oliver's death and the other notes that were directly issued by NBT. These were different.*

Ms G was sure she read a plan to use soft cuffs when Oliver's sedation was being lightened and that is why soft cuffs were put in Oliver's cabinet. Ms G thought the family were told this verbally:

NBT did not write much down and their notes were minimal which was problematic.

When questioned further about this, Ms G stated she was sure she had read something about using soft cuffs, but was equally sure that soft cuffs were never used with Oliver during his admission:

The rationale for using antipsychotics was not fully documented, some people felt it might be useful to him but the family were clear that it was not and had videos and pictures of what happened to him when he received antipsychotics in the past…

I didn't meet Dr xxxx. It was unclear why they used a different way of bringing him out of sedation when they knew about the antipsychotics.

6.21 During their interviews, the chair, LAC and Ms A all stated that all the boxes were ticked 'Yes', the timeline and pen picture agreed, recommendations discussed, and further actions agreed upon. The chair told the panel that it was agreed the draft report would be ready by early July and the final report would be complete by the end of July 2018.

6.22 At interview, Ms A stated that she was very uneasy about answering the question 'Was Oliver's death potentially avoidable?' as she believed that the question should not be part of LeDeR. She said that she spoke to the LeDeR lead from Bristol University and the NHS England regional coordinator (Mr H), to see if the question could be taken out. They ultimately decided to tick the box and agreed that Oliver's death was potentially avoidable.

Ms A stated she did not discuss the question with the whole MAR group as she did not think that doing so was part of the LeDeR process.

6.23 The LAC said that the guidance was unclear around who should make the decision on the question of whether Oliver's death was potentially avoidable, which she described as:

… *the contentious Question 8.*

She could not remember why the whole group did not discuss this. She stated that she knew that most panel members felt uneasy about having to answer, that question and she remembers the LeDeR panel having a lengthy discussion around it. The LAC stated that they ticked 'Yes' but asked the lead reviewer to go away and seek advice in relation to the coroner's outcome.

6.24 LeDeR guidance states that the MAR members should all discuss all aspects of the LeDeR template and complete it together.

6.25 The chair, the LAC, and Ms A all stated that the minutes of the MAR were an accurate reflection of the group's discussion.

6.26 All the members of the provider group who were interviewed were under the impression that they would receive copies of the minutes and the draft report.

6.27 All people interviewed believed that the MAR meeting went as well as it could have, was well chaired, and that the providers were heard at the meeting. In their panel interviews Ms A, Ms G, chair, LAC, and head of service at the community learning disability team all said they believed that most providers reflected on their practice but that the London Hospital staff team appeared to be very defensive during the meeting, as did NBT.

Ms G stated:

> *Bristol Children were one of the organisations to state that they had changed their process directly as a result of working with Oliver – they had ensured that there was a lead clinician going forward as Oliver had several and no one took over all responsibility looking at him in the round…*
>
> *[The] London team were very defensive, we asked the team to contribute their learning from working with Oliver and Oliver in the London hospital had had a horrendous experience but this was not accepted by the London team, they said he was wrong for them rather than them doing wrong for him…*
>
> *NBT focused on the verdict of the coroner – we never really understood the restraint measures… medication soft cuffs, there was a lot of unanswered questions.*

The Mencap advocate stated:

> *It felt like the answer to Question 8 had been covered in the difficult discussion we had already had.*
>
> *I can only speak for myself… that it did not feel a good idea to go over everything again and for everyone to be asked individually if the death was avoidable.*

Panel comments

6.28 The panel believes that it was the right decision to have an independent chair. This would ensure effective facilitation and a level of objectivity. The course of the MAR meeting itself was observed to be complex. All people interviewed believed that the MAR meeting went as well as it could have, was well chaired and that the providers were heard at the meeting. However, as there was no training open to them, the panel does not believe the chair was as well prepared as she could have been.

In the case of this MAR, there was a lead reviewer, a second reviewer, a chair and the LAC, who had never been part of a MAR before. As a result, the process lacked the necessary safeguards and assurances and highlighted some of the difference to national practice. This may have had a detrimental effect on the MAR meeting.

6.29 The panel believes that the LAC was too distanced from the process and should have ensured that the lead reviewer knew what was to be planned. However, the panel also believes that the lead reviewer should have used her LAC to better effect, in order to ensure that she (the lead reviewer) was undertaking it correctly. The LAC's inexperience with a MAR did not help this situation.

6.30 The administration of the MAR seemed generally sound. However, inviting to send the most appropriate person meant that the reviewer missed the opportunity to ensure that key individuals that worked with Oliver were present, as well as senior staff. The panel believes that not giving the family the option of being present for the full meeting was a missed opportunity and poor practice.

6.31 The LeDeR panel and the family had a pre-meeting before the larger provider meeting, meaning that the LeDeR panel members were privy to discussions that the rest of the MAR members were not. This put the majority at a disadvantage. The LeDeR guidance states:

Invite all individuals/agencies… efforts should be made to include the family member who is familiar with the individual [at the MAR].

It is the panel's belief that the family should have been central to the full MAR and been given the opportunity to be present for the full meeting. This would have ensured the family felt engaged and would have enabled the MAR members to have discussions with the family, to understand each other's viewpoints. Unfortunately, very few people in the MAR knew Oliver.

6.32 The fact that the MAR members agreed the timeline with minor amendments during the meeting was of concern to the panel. The timeline (although long and spanning a year) did still have gaps that led the reader to wonder what had happened. The panel's view is that the MAR members were not experienced in the LeDeR process and therefore did not know what to expect, or what the best example of an excellent timeline should look like.

6.33 However, the panel acknowledges that this timeline was far more detailed than is usual for LeDeR timelines, referencing many medical notes and covered a period of more than 12 months.

6.34 The main concern for the panel is the discussion around the question 'Was Oliver's death potentially avoidable?' The fact that some people felt uncomfortable answering this question (and tried not to answer it) is surprising to the panel. The question is part of the LeDeR process and therefore needs to be answered. The LeDeR guidance states:

The focus of the meeting (MAR) is to identify avoidable contributory factors to the person's death and any learning points and actions… The meeting may not be able to reach agreement on issues such as whether a person's death was potentially avoidable. In this case, the discussions should be noted.

It is clear from the guidance that all MAR members should have taken part in these discussions, with the question being directly asked of the full MAR membership not just the four panel members. The panel notes an apparent lack of discussion among the four MAR panel members around this question.

The panel believes that, although there was much discussion at the MAR meeting itself about contributory factors, Question 8 was not specifically asked of the rest of the MAR members. It has been suggested that the reason Question 8 was not asked during the MAR meeting itself was because of the strength of the defensiveness of some of the hospital representatives. Indeed, the family advocate stated that they tried to:

> … *shut the discussion down*.

This meant that a level of confusion entered the discussion that could have been avoided. Had the chair specifically asked the MAR members if they felt Oliver's death was potentially avoidable, this would have given everyone an opportunity to have their views heard – specifically around Question 8. If the meeting did not feel a safe space in which to have that discussion, the chair could have asked everyone the question in confidence.

The interview panel also believes that the MAR panel members did not give enough attention to how they should go about answering this question. If they had done so, perhaps they would have had more evidence to keep the 'Yes' box ticked. They certainly would have had a record of the decisions from the whole MAR meeting, which would have provided evidence for the discussion.

	Recommendations	Action
15	In regard to the MAR meeting itself, it is recommended that there is action taken to:	
	• ensure that families are central to the process, are offered full sight of all documents, and invited to attend all or part of the meeting as they wish	CCG
	• review the purpose of the MAR with specific reference to the function of Question 8 (now Question 9 in version R05) and, should this question be retained, provide clear guidance for MAR participants; also, to think through whether this question should be asked in confidence if it is a particularly difficult situation.	National LeDeR programme team
	• provide specific guidance and training for MAR chairs delivered by the national LeDeR team and families to include key topics such as	National LeDeR programme team

	the Mental Health Act, Mental Capacity Act and best interest decision making • maintain a national list of experienced, trained people who could be called upon to chair complex, or contentious MARs.	National LeDeR programme team
16	There should be a review of the LeDeR methodology against similar processes, such as child death reviews, in order to garner the learning and include any improvements as appropriate.	National LeDeR programme team
17	A system process chart should be developed to enable reviewers to ensure they are undertaking the review correctly. This should include standard templates and a self-assessment tool that reviewers can use, to ensure consistency across the country.	National LeDeR programme team

7 The LeDeR report

7.1 After the MAR meeting, the providers were told to liaise with Ms A if there were any alterations, learnings or best practice that they had previously not discussed during the MAR. By this point, the second reviewer (Ms G) had left the organisation (June 2018).

7.2 The promised report date (end of July 2018) was not met. The chair emailed Ms A several times asking for a copy of the draft minutes and the draft LeDeR report. The chair was told that the family had sent more information to Ms A and that she was having to factor this into her thinking.

The chair stated to the lead reviewer that she was getting anxious that nothing had been sent out to any of the MAR participants. She was then informed by Ms A that the minutes were for internal use only and would not be sent to the participants or the family. When Ms A was asked why she was under the impression that the minutes were for internal use only, she said she believed this was the LeDeR process.

7.3 The LeDeR guidance makes no reference to whether minutes should be taken or disseminated to the MAR group. The following is a chronology developed from emails and interviews:

8 August An email was sent from the interim director of nursing and quality North Bristol Trust to Ms B (director of nursing CCG) asking why the report was delayed and when it would be ready. Ms B stated it was complete and copied Ms A into the reply. Ms A then replied to both, stating that there were significant delays, about which she had spoken to Ms B.

15 August Ms A told Ms B that proceedings were being delayed by:

> *the sheer complexity [and] volume of information and an extremely challenging MAR.*

Ms A added that this was not helped by the fact that:

> *… resources [were] reduced to just me and [it was] not my only work, [I]… struggled to get the MAR transcribed as the new admin role doesn't*

work with me. [We are therefore] looking at mid-September for the draft report.

16 August Ms B sent an email to Ms A instructing her to prioritise the report and have it completed within two weeks.

20 August Ms A emailed the administrator trying to get the minutes completed. The administrator stated she was doing this when she could, and that she was finishing it during her current annual leave.

31 August The draft documents from the MAR meeting, minutes and report were sent to the director of nursing (Ms B) and the CCG's associate director of quality (Ms F).

7.4 In her interview, Ms A stated she knew that by answering 'yes' to Oliver's death being potentially avoidable:

… it could become extremely difficult.

7.5 Ms A did not feel that Ms B fully understood the LeDeR process and said Ms B asked her to take the report to the legal team for their views.

7.6 At this point, Ms A told the panel she had felt under enormous pressure, saying:

I was on speed dial to the legal team, I was speaking to them so much.

[The legal team] made it very clear that if the box remained ticked that she would be putting North Bristol Trust and the CCG in the firing line.

Following advice from the legal team and Ms B, Ms A was advised to organise a call with the chair of the MAR regarding Question 8 (was Oliver's death potentially avoidable) and its potential ramifications. Ms A stated to the panel that Ms B told her to use the telephone for these discussions and not to record the detail. Ms B refutes this version of events.

7.7 Ms A stated to the panel that she believed she was bullied and was instructed by Ms B to untick Question 8 as Ms B said the CCG's CEO was pressuring Ms B to untick the question. Ms A also stated she was not sure if this was accurate. She wrote regular reviews for Ms B to give to the CEO of the CCG:

… to pass upwards.

Ms A said it became apparent that the CEO was not kept up to date on the situation. She said Ms B told her it was felt the family would use the report to 'go for' North Bristol Trust, and said:

We cannot allow this in the public domain.

Ms B refutes this version of events.

7.8 In late August, Ms B made the CCG's CEO aware of the draft report and the issues of ticking Question 8. In her interview, the CEO stated that she advised Ms B to talk to the legal team to understand the consequences of the LeDeR panel ticking 'yes' when the coroner had stated that there were no recommendations.

The CEO was unclear whether a LeDeR could contradict a coroner's verdict as her knowledge of LeDeR at that point was minimal. She told the panel she was still unclear about this, as the national guidance appeared ambiguous and legal advice given was not conclusive.

2 September The draft MAR minutes were sent to the chair and were promptly sent back with track changes. The chair also asked for the LAC to have input into these edits, and to have a say where they would be distributed. As far as the chair was concerned, the minutes were not changed. The LAC saw a copy of the minutes that she believed that the chair had signed off.

3 September An email was sent from the CCG legal team to Ms A asking for her to contact them, about the:

… *non statutory process which has indicated different results from a statutory process… lets discuss*.

7.9 An 'urgent call to discuss the report' was then organised with the chair of the MAR and the LAC. Ms A said:

We have taken some advice and need to discuss [it] with you as a matter of urgency.

7.10 A call was set up on 4 September 2018. An email, sent from the chair to Ms A after the call, stated:

> *I think it is important to distinguish that this is a review and not an investigation therefore I do not feel as chair I am prepared to say whether it was avoidable or not. We should just focus on the learning*.

The LAC said that she was happy for Question 8 to remain unticked as she felt the narrative version would have been better. She stated she would have preferred the LeDeR panel to write the narrative to explain why certain questions had not been answered.

7.11 Mr H (the regional coordinator for LeDeR) stated:

> *Xxxx did ask for some advice around the Question 8 and the coroners response and the MAR review panel being at odds with each other.*

Mr H said this was the first time he had heard of this happening, adding:

> *I checked this out with the then Head of Learning Disabilities and Mental Health NHSE [Mr K] and the programme lead at Bristol University. The latter stated they could not take the question out but for the [LeDeR] panel to put their reasoning why in the box provided.*

7.12 As a result of this, Question 8 was unticked from 'Yes' and left blank. Ms A told the interviewer:

> *I did what I was told, I had no one to talk to, I was forced to compromise my values, I am proud to be a nurse, I feel very ashamed by this and I will have to live with it*.

The interviewer asked what would have happened if she had not done this. Ms A replied:

> *I would have been sacked, no doubt about it, they never said this, but I knew*.

Ms B refutes this statement, stating:

> *No disciplinary process was instigated or ever discussed*.

Ms B also told the panel that she did not agree with the chair's decision to untick Question 8 and that there should have been a narrative attached agreed on by the panel.

7.13 The LAC stated that she was:

> *… aware there was pressure on the reviewer by senior CCG management but not until afterwards did she realise how much pressure she was under to amend the paper work… It is not in my remit to get involved in the politics of the CCG.*

7.14 Ms A then unticked Question 8 and told the panel that Ms B instructed her, by telephone, to copy and paste from the final summing up from the coroner's verdict. Ms B stated that she did not ask Ms A to do this. Ms A then said she had a call with the chair to ascertain if she was happy with this. Ms A stated that the chair was. The chair refutes this version of events, stating:

> *I discussed the Question 8 with Ms A on 4 September, agreed that a narrative could go into the box, in principle… I did not have a further conversation with Ms A or see the content of the narrative until I received the final report on 23 October. I was not aware that there was any plan to use the coroner's verdict.*

7.15 The document was then edited accordingly. The panel has reviewed the coroner's summing position and that of the LeDeR text. They are not identical but the LeDeR text appears to draw heavily on the coroner's summing position.

4 September The chair emailed Ms A to say she was unhappy with the recommendations, some of which were vague. These were not changed.

7.16 The same day, Ms A sent an email to the CCG's associate director of nursing and quality (Ms F) and Ms B, stating:

> xxxx *is asking to see a copy of the report prior to a discussion with NHSE*.

Ms A asked for advice, and subsequently attached the draft report with text reading that it was nearly complete, saying:

I have taken all appropriate advice, as suggested.

7.17 Later that day, an email exchange from the regional south coordinator of LeDeR (Mr H) to the head of mental health and learning disabilities, NHS England (Mr K) and the lead for LeDeR Bristol University asked if they could remove Question 8 as it contradicted the coroner's verdict:

> *Question 8 which was in variance to the coroner's response that the death was avoidable. The consequences of this have been very challenging for all involved (family and staff) and I have been asked to raise this with you to see if it were possible to modify or remove it. It would be helpful to agree how best to manage this in future.*

Mr H stated that this email was in response to the national LeDeR programme rather than Oliver's LeDeR.

The panel has not seen any response to this email. Mr H stated:

> *There was no email response to this – I had a telephone conversation with the University of Bristol and the national NHS Lead. The discussions were about how legal and clinical professionals had different concepts/definitions of terms such as 'avoidable' and 'preventable', so there could be different responses on this*.

7.18 At 11pm on 4 September, the associate director of quality (Ms F) sent an email with all individuals' names redacted (including that of the recipient) stating:

> *I spoke to xxxx before she left and she had spoken to xxxx who has changed the panel's view (as the chair) and reworded section 8. Xxxx stated she has chosen the option of panel cannot reach a unanimous decision, but I have just noticed this is not 'checked' in the document. The words read a lot better.*

6 September An email from Ms B asked Ms A to check the report with legal team to be on the safe side.

6 September An email from Mr K to Ms A said:

Thank you for writing the report… have the family seen the report yet or when are they going to see it. I don't think they have seen it yet but just want to check that.

7 September A briefing paper was sent to the head of mental health and learning disabilities NHS England (Mr K) from Ms A. The report did not indicate an issues or concerns with Question 8 and the coroner's findings but, along with a list of the recommendations, did highlight:

… care fell short of current best practice in one or more significant areas resulting in the potential for, or actual, adverse impact on the person.

12 September The legal team emailed Ms A, saying:

The fact that the conclusions of the report appear to conflict with those of the coroner is irrelevant, occasionally such reviews do reach a different conclusion from that of an inquest.

It then goes on to advise how Ms A needed to strengthen statements of fact.

3 October An email from Ms A to the second reviewer said how she:

… *received very detailed advice from solicitors*.

It continued:

[The] post MAR report looks very different to perhaps how it was imagined at the start of the process.

3 October A follow-up email from Ms A added that:

The MAR will need to be approved by the legal team; CCG then sent to panel prior to its upload [referring to the LeDeR process of uploading the review onto the portal].

10 October The second reviewer replied to Ms A, saying:

… section 8 check box [was] missing [even though the] panel said 'yes'.

The second reviewer added:

Think section 8 needs a definite tick.

17 October Ms F sent an email to Ms A, stating:

The issue for me is the Question 8 in the report… it has not been answered in terms of checking one of the boxes… this may be because of advice from the solicitors, but I would imagine this will be challenged… We need to stress the need for a very quick response to this due to 22 [House of Commons] deadline.

17 October The CCG's deputy director of nursing (Ms L) emailed Ms B, saying:

[Ms A] was advised by the legal team to take anything that looked as blame out of the report.

17 October Ms A sent an email to the deputy director of nursing (Ms L) and the director of nursing (Ms B) telling them that:

I have endeavoured to remove anything that seems to indicate any sort of 'blame'.

17 October A briefing written by lead reviewer for the CCG's CEO provided a a list of the recommendations, highlighting that the care fell short of:

… current best practice in one or more significant areas resulting in the potential for, or actual, adverse impact on the person.

17 October Ms A sought advice from the regional coordinator south LeDeR (Mr H), saying:

[The] family have asked to see MAR prior to upload so they may make comment.

Ms A was not keen to share it with the family, and a reply from the coordinator showed that they agreed that sharing the MAR was not appropriate.

17 October An email from Mr K (head of mental health and nursing, NHS England) to Ms A said:

I would imagine family have been consulted upon as part of the process… it would be sensible to talk to them about the findings with senior support and awareness.

Mr K left post the following day.

18 October An email from Ms A to the director of nursing (Ms B) and associate director of nursing and quality (Ms F) and deputy director of nursing (Ms L) said that:

the question [was Oliver's death potentially avoidable?] is really not appropriate for what is supposed to be a review rather than a statutory investigation… I think it should be removed as [the chair] is of the mind that it should be left blank because it is not acceptable to contradict the coroners findings.

18 October–22 October Ms A wrote various emails to the solicitors requesting them to review the LeDeR document:

… the second, which is related is whether the [LeDeR] panel are able to form a view on appropriateness of the administration of Olanzapine if one issue in this case is that Olanzapine should not have been given, the family or the Trust may have questions if this is not dealt with.

On the one hand the family will expect an explanation of whether it should have been given at all; on the other, the Trust staff will presumably rely on the coroners finding as confirmation that the administration was reasonable.

23 October Ms A attached the draft document to an email. Ms A stated that the report went to the legal team, came back several times for Ms B to sign off, and was uploaded onto the LeDeR portal. By this time, Ms A stated:

The final report did not reflect my views.

31 October The report was uploaded for normal QA LeDeR process on the last day of October.

6 November Ms A asked Bristol University for advice as the family wanted to see the report.

7 November The regional coordinator (Mr H) emailed Ms A, saying:

> *I am hoping for some news on a steering group and firming up of local governance (LeDeR)*.

9 November The LAC emailed Ms A saying that she had reviewed the report and submitted it to the national programme.

9 November was the official date of the report being uploaded into the official LeDeR system. Question 8 was left blank with a narrative around the coroner's verdict. The family had not seen the report.

28 November A meeting took place with Ms B, the CEO of the CCG and NHS England's clinical lead (and lead for STOMP). From extracts in Ms B's notebook the panel could ascertain that there were many questions surrounding Oliver's LeDeR that were discussed, including:

> *Who owned the report?*
>
> *Who took responsibility?*
>
> *Are we at the right stage for implementation plan?*
>
> *Role of LeDeR review different to coroners?*

It was reported that the family and the national team did not feel the report was complete around Question 8. The clinical lead for NHS England said she was getting legal advice around quality assurance, the status of the report and guidance on process. Notes made by Ms B record that there had never previously been a coroners' verdict before a LeDeR panel's responsibility to complete Question 8.

6 December The same individuals had another meeting. In Ms B's notebooks, the following was discussed*:*

> *Coroner clear death not avoidable – number of contributing factors that were avoidable. System should have worked more closely together… report is not good. Legal advice – they are different processes therefore do not have to line up.*

7 December Again, the same set of individuals had another meeting – this, time discussing:

… having an independent reviewer to finish Oliver's LeDeR and to have scope of next steps drawn together… FOI request from the family… family feel report does not reflect the MAR… additional clearer guidance around the LeDeR review should be the outcome.

13 December The CCG's deputy head of external communications emailed the chair of the MAR, asking:

Can I ask why the independent review felt it could not go against the outcomes of the coroners court or the coroner's findings? If it is independent, is it not supposed to have its own findings?

13 December The chair replied to the deputy head of external communications:

I think all I can say is that on the day we considered evidence from the family and from representatives of the Trusts who provided care for Oliver during the final year of his life. The purpose of the LeDeR review is to consider if there is any learning and not to apportion blame. We did not consider any previous investigations into his death but were aware of the coroner's verdict.

13 December The deputy head of external communications then emailed the chair asking:

Does this response look ok?

The review panel was fully independent, and their findings are entirely their own. The review panel considered from previous investigations into Oliver's death, including the coroner's inquest, but these did not determine the outcomes of the review.

This media statement was amended further until both the chair and deputy head of external communications were in agreement on the following wording:

The review panel is an independent process that aims to identify learning and improve care of people with learning disabilities. The panel was aware of the coroner's inquest and considered a range of evidence in formulating the responses set out in its report.

7.19 Ms A left the CCG of her own accord, stating:

I could never work there again.

7.20 The LAC stated that after the MAR there were lots of:

… fingers in pies.

The report was checked by lots of people, including the CCG's legal team and senior management team. The LAC noted that in other cases:

… we would not expect solicitors to change the report. Ms A was under pressure to change the wording, she did change it.

The LAC felt uncomfortable about this.

7.21 Ms G (the second reviewer) stated she was not privy to all the changes that the lead reviewer made and the unticking of Question 8. She said:

There were definitely concerns around organisational liabilities, [she] told me that [the solicitors] had told her to change Question 8 and untick it… if you are legally told to do something and you don't do it… [she] would have had limited influence in this decision.

… I did not anticipate that [the solicitors] would ask to untick the question, the CCG would have looked at [the solicitor's] advice, there were lots of staff changes which meant people were not as aware as they should have been.

7.22 When the panel interviewed Ms B, her views were different to that of Ms A. Ms B said:

I was not concerned by the [LeDeR] panel ticking Question 8 but felt it should have narrative included and not just ticked.

She stated on more than one occasion that it was not up to her whether Question 8 was ticked or not, as she was not part of the panel. She did know that Oliver's LeDeR stated something different to the coroner's verdict so asked Ms A to seek legal advice.

Ms B said she thought that the report should be about learning, hence sought advice from their solicitors. Ms B said that she left Ms A to deal with the solicitors but remembers seeing the comments back from the solicitors, of which there were many – mainly around the language of the report.

Ms B said she did not ask Ms A to untick Question 8; they spoke about it and she had asked Ms A to talk it through with the panel. She also said she did not tell Ms A what to write as the narrative descriptor. Ms B said that she felt the CCG would not interfere with the decision if the question were to remain ticked, but she wanted everybody to understand the risk and impact of ticking it.

7.23 Ms B stated she had regular one-to-ones updating the CEO, and then subsequently updated the board. She said she wrote two board papers. At one of these board meetings the CEO asked the medical directors to review Oliver's case. Ms B sent the final LeDeR report to the CEO and updated her verbally on a regular basis.

7.24 When the interviewer asked Ms B what she felt the LeDeR panel ought to have done, she stated that:

> *The [LeDeR] panel should have kept Question 8 ticked and put a narrative as well*.

She stated she saw the final report and felt unable to change it as she was not a member of the LeDeR panel and the solicitors had been advising Ms A. Ms B claimed that the review:

> … *was not my remit… whatever the [LeDeR] panel published they had to ensure the report did not apportion blame as this was not what LeDeR was, Question 8 could be ticked but a narrative should be put in place also.*

7.25 At her interview, the CEO of the CCG stated that Ms B was:

> … *very concerned that the [LeDeR] panel had stated Oliver's death was potentially avoidable [when] the coroner's verdict had stated there was no recommendations or anything people could have done*.

The CEO told the panel that Ms B had told her that they could not contradict the coroners' view. Ms B refutes this version of events, stating:

I did not know myself if you could go against the coroners decision so I would not have stated this.

The CEO was uncertain, so discussed it with NHS England and ultimately the CCG's legal team. The CEO was led to believe that the coroners' report came out at the same time as the panel's deliberations. As a result, she did not have that knowledge to hand the MAR meeting was being conducted. In fact, the coroner's report came out two months before the MAR.

7.26 The CEO said she advised Ms B that it was the chair's responsibility to make any decisions and that she must own the decision as it was her report. The CEO said she did not instruct Ms B to take 'yes' out of Question 8 and to add text but asked her to discuss it with the chair.

As far as the CEO was aware, Ms B did have a discussion by telephone and agreed to take out the 'yes' to Question 8 and insert text explaining why it was left blank. Ms B stated she did not have a discussion with the chair about this topic.

7.27 The CEO was led to believe that the chair wrote the new text to be inserted and agreed with Ms A for this to be done. The CEO remembers a discussion with the chair, explaining:

She agreed to a narrative response only as if she were to stand up in a court of law. She could not defend the decision to go against the coroner's verdict as the LeDeR process was different and there to learn from things that could have been done differently through recommendations… learning rather than anything else.

The chair told the panel that this discussion took place in December 2018 after the LeDeR was uploaded.

7.28 It took 17 months for Oliver's LeDeR to be ready to upload onto the LeDeR IT platform. Ms B stated she did not monitor how long the report had taken to complete; she had been informed that there was a lot of information and that Ms A wanted to do a thorough job. She was not updated on the timelines for the report. In retrospect, she stated that the review took far too long.

7.29 When the panel interviewer asked Ms A why the report took so long, she said:

> *It was on top of my day job, though after I came under the management of the associate director of quality [Ms F] I was able to relieve normal work in order for me to concentrate on its completion. I think it was extremely apparent by this stage (and the fact that I was leaving) that the review had done an inordinate amount of damage to me, and really it just had to be finished.*
>
> *I was uncomfortable with the Question 8 and I procrastinated about it as I didn't want to answer it, I knew there would be issues with it, there was a lot of discussion and it took a long time. The family were pressing me to tick the box, but they didn't make me say it was potentially avoidable I did that myself because I believed it.*

7.30 The second reviewer stated:

> *I do still believe that Oliver's death was potentially avoidable because they are still unanswered questions… [a] very frightened young man who didn't want to be ill… a negative interaction with the police on his admission to ED… no detailed notes… [It was] really hard to understand the decision making process. [There were] always going to be questions about that.*

Panel comments

7.31 The length of time that it took for the LeDeR report to be completed was unacceptable. The panel believes that effective governance should have been present: for instance, Ms A's line manager for the LeDeR process (Ms B) should have monitored the time it was taking to complete the review. This would have highlighted what Ms A needed and whether they had adequate time and resources to complete the review in a timely fashion.

The fact that at any one time Ms A had one line manager plus a second line manager to support the LeDeR was confusing, and potentially led to the view that each manager felt the other was providing Ms A's support.

The panel believes that the lead reviewer (Ms A) should not have been left to make some of the judgements on her own – for instance, the legal team advice and the

question of how to address Question 8. The executive lead for LeDeR and Ms A's line manager for Oliver's LeDeR should have taken more accountability for this review.

Ms L stated to the panel:

> *I should have insisted Ms A hand over all of her work and take time off to manage her personal issues including seeking someone else to undertake the LeDeR. I accepted her reasoning that she wanted to maintain working and that she was able to manage the work, a decision with hindsight I now regret.*

7.32 The CCG should have made a concerted effort to understand the issues from the perspective of the family, to feel how difficult this whole process was, and continues to be, for them. The CCG should have ensured that those staff leading Oliver's LeDeR had the right experience and knowledge, were appropriately supervised, and had the ability to address or recommend actions in this complex case.

7.33 Based on the documentation reviewed and the interviews conducted, the panel's view is that staff have tended not to take accountability for their actions – stating either that it was not their remit, or that they felt they could not change things.

From the standpoint of professional accountability, the panel concludes that this is wholly unacceptable. The panel believes that those staff involved in this LeDeR process should reflect on the overarching outcome and impact of the collective decisions that were made.

7.34 The panel has considered the account of some senior staff that they believed they could not contradict the coroner's verdict. The panel is concerned as to why they would have that view as there is no clear evidence to back up this opinion. The LeDeR is an independent process. Lead reviewers consider other reviews and reports that have been written but they do not have to agree with them if they have good evidence to say otherwise.

This LeDeR considered the last year of Oliver's life so had the benefit of seeing the case in much wider context than the coroner's process and a greater understanding

of how Oliver presented. Therefore, different conclusions could have been drawn, with appropriate evidence to support a different decision.

7.35 The panel unanimously agrees that there was no robust mechanism in place to decide whether the question 'Was Oliver's death potentially avoidable?' should have been answered or not and what, then, should have been done about making a decision on the question. The panel believes that the MAR panel felt compromised and unsupported in answering Question 8.

Instead of having a clear rationale about how to answer the question with the full MAR membership, they had much discussion with the MAR membership around the topic and contributing factors rather than asking the question specifically. Ultimately, choosing not to formally include the whole MAR membership in the discussion around the question put them in a very difficult position.

7.36 The solicitor supporting the CCG stated that the LeDeR panel could disagree and the independent panel could not find evidence as to why this advice was not taken.

The panel believes that the LeDeR panel felt compromised in answering the question as they felt unsupported. Instead of deliberating and answering the question with the whole MAR membership, as per the LeDeR process, they put themselves in a very difficult position. The panel also believed Ms A when she stated that she prevaricated and did not want to finish it. However, if she was so unhappy with what she was being told to do, she could have used the local whistleblowing policy.

Ultimately, however, it is the CCG that must responsibility for the poor decisions in regard to not asking the full MAR to answer Question 8; the small panel of four doing so with what appears like little discussion between them, and then, after much discussion with the solicitors, agreeing to untick the question.

The inaction from Ms A's line manager should also be a cause for concern to the CCG. The director of nursing (Ms B) appears not to have afforded the necessary priority to this LeDeR review and therefore was unable to give guidance and leadership at this crucial time for the review. The panel believes this to be a serious omission by Ms B.

7.37 The panel believes that, given the evident focus on Oliver's death, the CEO of the CCG should have had a greater oversight of the issues arising and the decision making that followed – especially as this was the organisation's first experience of LeDeR. The CEO should have also had this matter brought to her attention as part of her induction when she was brought in to amalgamate the three CCGs.

7.38 The panel believes that too much attention and energy was expended deliberating on whether Question 8 should be answered or not, rather than how to answer it. The recommendations needed more thought and were not as robust as they could have been in order for the system to learn from Oliver's death – which is the overarching objective of the LeDeR process.

	Recommendations	Action
18	There should be an assurance process with regard to providing regular, appropriately documented supervision for individual LeDeR reviewers.	CCGs
19	The LeDeR guidance must make explicit (for all parties) that it is completely acceptable for LeDeR reviews, where appropriate, to arrive at differing conclusions to other reviews or inquests. This is on condition that they have the evidence to support this determination and that the LeDeR itself was subject to correct governance processes.	National LeDeR programme team
20	Appropriate support should be available to reviewers, along with strong governance, to ensure that all LeDeR recommendations are robust and actioned in a timely manner, and that lessons learnt are shared nationally.	CCGs

8 Governance of the LeDeR

8.1 Ms B was responsible for the LeDeR programme for the South Gloucestershire CCG. At the time that Oliver's LeDeR came to the CCG, the organisation did not have an established LeDeR process and was behind the timeline of the national programme due to a reorganisation. Ms B told the panel:

> *South Gloucestershire CCG was a small organisation and about to undergo a reorganisation… I was unclear at the time who 'owned' the LeDeR process and felt the CCG was commissioning the LeDeR, and NHSE was responsible for the programme…*
>
> *There was no governance arrangements locally, these were provided by NHSE regionally… It was not easy to understand who owned the process, I did feel responsibility but was difficult to understand.*

Ms B accepted that her understanding of the LeDeR process at the time was limited, and she was unaware of what training or expertise her own team had regarding the LeDeR programme.

8.2 Ms B stated she did not directly line manage the reviewer; she was kept informed by the reviewer's line managers. She could not remember receiving written briefings from the reviewer, saying:

> *There may have been [briefings].*

However, emails clearly show that Ms A wrote a board briefing for Ms B, and that Ms B had received this and passed it up to the board. This was tabled as 'verbal feedback only', discussed in the private part of the board. The briefing that the panel saw was from 3 April 2018 – before the MAR took place. The panel acknowledges that since Oliver's LeDeR took place Ms B has retired and many of the intricacies of events will be difficult to recall.

8.3 When asked by the panel whether Ms B felt removed from the LeDeR process she answered:

> *Yes, it was not deliberate, just how it worked out at the time.*

8.4 When the panel asked how Ms B supported Ms A, she stated:

Most of the support given to [the lead reviewer]… was verbal. Our desks were close to each other.

Ms B told the panel she had several discussions with Ms A, but:

I did not give [Ms A] any formal support as I assumed her line manager was [providing it] at the time.

Ms A had three direct line managers. The last two stated that Ms B was still responsible for the LeDeR with Ms A. Ms B suggested that, in hindsight, she had not given the reviewer enough formal support throughout this process.

8.5 Ms B said she met regularly with the CEO of the CCG and briefed the board on the LeDeR. She stated that the briefings were given verbally to the CEO. She could not recall if the discussions around the LeDeR were part of the closed board discussions. Neither could she recall whether they were documented.

8.6 The chair of the panel has had access to the CEO's notebooks, in which she keeps all her records of her one-to-one supervisions. There were 11 one-to-one meetings recorded between the CEO and Ms B. Only the last one, on 2 October 2018, mentioned LeDeR and it is unclear if this was a generic discussion around LeDeR in general or relating specifically to Oliver's case. There was nothing visible that related specifically to Oliver.

8.7 The CCG CEO said that she had been appointed from the South East area to ensure that the then three CCGs were stabilised and then merged into one organisation (BNSSG). This required a full organisational restructure. At the time, there were many issues as two of the three CCGs were in special measures. The CEO stated she had no knowledge at that point of LeDeR and was not aware that a LeDeR was going on in her patch until the issue of Question 8 (whether Oliver's death was potentially avoidable) was raised with her in August 2018.

However, the panel has seen the paper written for the board from April 2018. Even if this were a verbal update, people present and the minutes indicate that Oliver's LeDeR was discussed. However, no concerns were raised at that point in time. The CEO stated that when she knew about the issues of Oliver's LeDeR she took a more direct oversight.

8.8 Ms B reported that she knew the LeDeR was a non-statutory process looking at learning rather than fault but was unclear whether LeDeR could contradict the coroner's conclusions. She believed the guidance from LeDeR was unclear and asked her team to seek advice from a number of sources, including NHS England – regionally and nationally.

When no response was received, she then asked that the case go through the CCGs legal advisors. This was not seen as an unusual thing to do as the CCG regularly requested advice from their legal partners.

8.9 Ms B was responsible for LeDeR. The CEO stated that:

> … *as a senior nurse, I expected Ms B to raise important issues with her*.

However, the CEO did say several times during the interview that, as the CEO, she was ultimately responsible.

8.10 The CEO told the panel that she did not receive any written reports from Ms A. She realised subsequently that they had been written but had not received them. She felt that Ms B did not keep her abreast of the situation until much later into the process. The CEO told the panel she confronted Ms B, telling her that she would have expected her to keep her fully up to date. Ms B said that she had spoken verbally to the CEO about the case in her one-to-ones, raising it at a governing body meeting. The CEO does not remember either. She stated:

> *It certainly was not escalated at the time at the level that would have been appropriate to Oliver's case or the issues involved*.

Ms B, however, stated to the panel that she updated the CEO on several occasions.

8.11 The CEO said that Ms A's line management was transferred to the associate director of quality (Ms F – who was present, with the CEO, at the panel interview) from 1 April 2018, in order to alleviate the stress that she was clearly under.

Ms L told the panel:

> *During the six months leading to April 2018, the team discussed the new portfolio management for the senior quality team. It was agreed that Ms F would take the mental health and learning disability (including LeDeR)*

portfolio… Ms A indicated that she would like to maintain the mental health LD portfolio. We agreed this and Ms A changed line management to Ms F on 1 April 2018.

However, neither the CEO nor the associate director of quality (Ms F) knew the extent of the pressure that Ms A felt. Both stated that Ms A did start to receive supervision but by then she was working out her notice while finalising the report.

8.12 The CEO said that she did not see the LeDeR report until it was complete and uploaded on the LeDeR portal. The CEO was very clear that she would not have allowed the report to be uploaded as she felt the report was:

… poorly written [and that the recommendations were] not clear and… not as they should have been to maximise change.

The CEO did acknowledge that the report format could have made this difficult, but nevertheless she would have wanted to see improvements before completion even though the LAC and NHS England regional lead had signed it off.

Ms B told the panel that NHS England had changed the national LeDeR process just before Oliver's report was due to be signed off. Previously, the local team signed the report off before it went to NHS England to sign off. This was changed and NHS England would not sign off the LeDeRs going forward. Ms B stated she asked on more than one occasion for NHS England to read Oliver's LeDeR before she uploaded it but was told that this was no longer the correct process.

8.13 The CEO told the panel that she believed that the LeDeR process was the wrong route to take in relation to Oliver. She said that she had been led to understand that South Gloucestershire CCG had not wanted to progress through LeDeR but that NHS England had insisted. The panel has not seen proof to ascertain why Oliver's case was put through a LeDeR at that point in time.

8.14 The CEO believed that the CCG would have been better placed to undertake a formal independent investigation and said she would have instigated this, given the opportunity.

Panel comments

8.15 The panel believes that the governance arrangements were inadequate, there was no systematic monitoring and there was a lack of knowledge regarding the LeDeR process in a number of key individuals. Evidence seen indicates that internal communication was poor, with the use of verbal rather than written information at key times.

A systematic lack of any meaningful senior oversight was apparent from within the CCG, and upwards to the regional process. The panel is unable to resolve why this would be the case with such a complex LeDeR.

8.16 As stated, the fact that the LeDeR systems were not in place for this particular CCG did not help – but then the time taken to set up the systems had been extremely slow. The regional steering group had only just materialised once Oliver's LeDeR had been completed, creating further governance risks.

8.17 The fact that Ms A believed herself to be isolated and unsupported throughout the process could illustrate failures in the CCG assurance and management processes at the time.

Culture is not fixed: it is constantly changing, affected by a number of factors, including leadership. This report focuses on decisions and events that occurred more than four years ago. Therefore, it is not possible, (nor within the scope of this report) to make detailed reference or recommendations to the culture of the commissioning or provider organisations concerned. However, it acknowledges that that the culture of an organisation shapes the quality of care it delivers, the behaviour of staff and its overall performance.

	Recommendations	Action
21	Each CCG must formally undertake and document and review its own systems and processes against the learnings and recommendations arising from Oliver's re-review.	CCGs and ICSs
	This review and the accompanying action plan must be submitted to, and monitored by, the local integrated care system (ICS), giving feedback to the national LeDeR team around progress. The panel	NHS England and NHS Improvement

wishes for a senior, single point of contact from NHS England and NHS Improvement to ensure all actions are taken and progress monitored

9 Learning

9.1 The CEO of the CCG stated that NHS England told her that it had withdrawn the report and that she was to stop whatever the CCG was doing in relation to this case, as a new review was being commissioned.

9.2 The panel has reviewed the system-wide action plan developed six months after Oliver's LeDeR was uploaded onto the Bristol portal. The action plan included the main recommendations from the LeDeR review – in summary:

- **Training** Learning disabilities and autism, Mental Capacity Act, consent and best interest
- **Transition** Development of a pathway for young people with learning disabilities and autism into adulthood including sharing of documentation
- **Intervention** for people with learning disabilities and autism, looking at NICE guidance for people with challenging behaviour, including family issues
- **Hospital passport** Ensuring every area is using the same document, with training, and that it is uploaded onto IT systems
- **Multi-disciplinary team** Ensuring everyone works together for care planning with people with complex needs
- **Reasonable adjustments** Having better understanding of what reasonable adjustments might comprise for people with learning disabilities and autism and promoting these.

9.3 The panel notes that not all actions have been achieved, with the latest update being August 2020. It is now 23 months since Oliver's LeDeR was uploaded. The panel also notes that the action plan provided was not SMART and looks more like a CCG monitoring tool for system-wide actions. There is no discussion about the outcomes that have changed due to the actions that have been completed.

9.4 The CCG has overhauled the LeDeR process to ensure LeDeR is appropriately undertaken and learning is taken onboard from Oliver's review. The panel has seen action plans and reports dated from January 2020 that indicate significant progress on the structure, governance and leadership of the LeDeR process.

10 Conclusions

10.1 The panel concludes that, from the outset, Oliver's LeDeR was mismanaged, poorly monitored and allowed to progress without due rigour or any independent oversight.

10.2 The lack of knowledge around LeDeR systems and process meant that ultimately, Oliver's LeDeR did not accurately nor appropriately adhere to accepted process. LeDeR is designed to allow for reflection in order for the health and care system to learn, and where necessary, enact improvements.

10.3 Although the action plan is a system-wide plan – and approach that is to be recommended – the fact that it is not complete after 23 months is a source of concern for the panel. The action plan must be complete with a sense of urgency and outcomes for people with learning disabilities and autism and their families reviewed, to ascertain how effective the changes have been.

10.4 Many people have been significantly affected by Oliver's death – most of all, his family. It is intended that the Department of Health and Social Care and NHS England and NHS Improvement will critically consider the conclusions of this independent review. This should be done to ensure that correct governance processes are used when commencing the initial review of any relevant death. This will determine required actions (statutory and non-statutory) in order to make sure an appropriate and thorough investigation process (where required) is concluded before LeDeR is implemented.

All necessary steps must be taken to ensure that LeDeR becomes robustly embedded nationally, so that health and social care services can effectively tackle the pressing and widespread issue of premature deaths of people with learning disabilities. This is the mission LeDeR was established to achieve.

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[1] University of Bristol Norah Fry Research Centre (2018). The Learning Disability Mortality Review – Annual Report 2018. Available at: www.hqip.org.uk/resource/the-learning-disabilities-mortality-review-annual-report-2018

[2] University of Bristol Norah Fry Research Centre (2017). Learning Disability Mortality Review Local Reviewers Information pack

[3] University of Bristol Norah Fry Research Centre (2017). Learning Disability Mortality Review Local Reviewers Information Pack

[4] NHS England (2015) *Serious Incident Framework*. Available at: www.england.nhs.uk/patient-safety/serious-incident-framework