Thomas Oliver McGowan's
LeDeR Process Review - October 2020

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Chair on behalf of Oliver's Independent Panel for NHSE&I

This is an **Easy Read Version** about the review and the **recommendations** that were made.

The meaning of some of the words used in this report:

Recommendation is advice to improve things and make things better.

LeDeR means The Learning Disability Mortality Review Programme.

LeDeR looks at why some people with learning disabilities can die much younger and makes recommendations to try and stop this.

STOMP

Means to stop giving too much of a type of medicine to people with a learning disability and/or autism.

Clinical Commissioning Group (CCG) arranges health services for their local area.

Neuroleptic malignancy syndrome (NMS)

This is something that can happen when a person is given anti-psychotic medicines. This is rare.

Independent Serious Review (ISR)

This is another way to look into how a death happened.

Coroner

A person who looks into why a person died if people are not sure about this.

Chair of meeting is a person who leads the meeting

Multi-Agency Review known as a **MAR,** this is when lots of organisations get involved in a meeting to discuss the persons death

Local Area Contact or LAC

Each area of England has a person called a Local Area Contact (LAC). It is their job to make sure that in their area deaths of people with a learning disability that the LeDeR programme is told about are reviewed.

Main report

2016

Thomas Oliver McGowan, who was known as Oliver, died in a hospital at North Bristol NHS Trust on the 11th November 2016.

Oliver was 18 years old.

In May 2017, Oliver's mum sent an email about his death to the NHS England lead person from **STOMP.**

NHS
South Gloucestershire
Clinical Commissioning Group

South Gloucestershire **CCG (Clinical Commissioning Group)** then started a LeDeR process for Oliver.

Two of the staff didn't have any experience of LeDeR reviews and had other work to do as well as the review.

The Panel said this was not good as a review can get very complicated.

The person who was leading the review did not have the right support. The panel said that this had made doing the review a harder job for them.

Oliver died of **neuroleptic malignancy syndrome (NMS).**

This happened because he was given Olanzapine anti-psychotic medicines.

Oliver and Oliver's family said they did not want Oliver to be given these medicines. Oliver's parents

regularly said that they were not happy with the care and treatment that he received.

His death should have been looked into by an **Independent Serious Review (ISR)**.

The LeDeR review took 17 months to finish. This took a long time because the lead reviewer had other work to do at the same time.

There were also some problems getting the medical notes. Oliver's family were very helpful in providing lots of documents for the review.

In December 2017 the **Local Area Contact (LAC)** started to help with the review. They had experience of completing lots of reviews.

2018

In April 2018 the **Coroner's Inquest** was finished

No recommendations were made.

They arranged for a **Multi-Agency Review** meeting known as a **MAR.**

The panel said that there should have been lots of other people interviewed about Oliver's death.

2018

The Multi- Agency Review (MAR) meeting was held in June 2018.

The chair didn't have any experience of being involved in LeDeR or a MAR process

The people that were interviewed at the MAR meeting said that it went well.

Oliver's parents were only invited to the first 2 hours of the meeting, but families should be more involved in the whole process if they want to.

Question 8 asked was Oliver's death potentially avoidable. This question is asked in LeDeR so that we can understand if deaths could have been prevented.

Question 8?

Yes

At the beginning the answer to this question was yes, but later on it was taken out and the question wasn't answered.

Question 8?

___

They did not say if his death was potentially avoidable or not.

This is because the CCG did not understand how to do a LeDeR review and thought they had to say the same thing as the Coroner, who said there were no recommendations.

This meant the LeDeR process for Oliver did not work well. (thumbs down)

The panel have looked at an action plan that was done after Oliver's LeDeR.

The action plan was started in May 2019.

Some of the actions have still to be completed.

The CCG have learnt from Oliver's review and have made changes to the LeDeR process to make things better.

The CCG should have seen the issues for Oliver's family. This is a difficult time for them.

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

The panel have made some recommendations about things that will make the process better.

This will help the CCG to make sure that the LeDeR process is a better one.

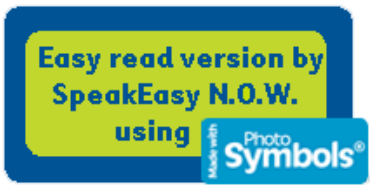
	Recommendations - what should happen	Who should do this
1	If somebody dies the CCG should be required to do a LeDeR. At the moment they are not. When a death is reported to LeDeR the local CCG should be responsible.	Department of Health & Social Care Department of Health & Social Care
2	There needs to be clear information about the LeDeR process and what is the best way to review a death.	National LeDeR Programme Team Learning Disabilities Mortality Review (LeDeR) Programme

3	Staff who are new Lead Reviewers or are new Local Area Contacts should work with someone who has experience. This is known as a 'buddy'.	CCGs
4	There should be good and clear guidance on the job that a 'buddy' does.	National LeDeR Programme Team
5	Reviewers and Local Area Contacts need to have the time to do their job and also have some admin support.	CCGs
6	There must be a good clear process for LeDeR in each area.	CCGs
7	The LeDeR process should be set into new arrangements like Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICS) from the start.	NHSE
8	There needs to be guidance for reviewers and LAC's when there is a problem with the local LeDeR process.	National LeDeR Programme Team

9	The LAC and the lead reviewer should say how much support is needed at the start of the LeDeR process. The process is a team task not just one person.	LACs & Lead Reviewers.
10	There needs to be a senior lead person for the LeDeR process in each CCG area who report actions to the board.	CCGs.
11	When there is a complicated LeDeR review there needs to be experienced reviewers to do the job. There needs to be a list of all the experienced reviewers who can do this.	National LeDeR Programme Team
12	The senior leads for LeDeR need to make sure that the process is finished in good time and in the right way. They will also get involved if there are problems such as getting all the information.	CCGs
13	When the Reviewer and the LAC do not have much experience of a MAR, they will get support from a 'buddy' who does.	LeDeR Reviewers and LACs.
14	There is a scoring system to check if a MAR is needed. This needs to be looked at again and the score needs to be written in the main report.	National LeDeR Programme Team

15	If there is a MAR in place, then these are the things which needs to happen: • Make sure that families are involved in the process and the meetings and that they can see all the documents • Think about why the MAR is needed and if we need to ask question number 9 (this used to be question 8). This question should be asked in confidence if it is a difficult situation. • Make sure that MAR chairs have information and training by the National LeDeR team and families. • Keep a list of experienced, trained people who could Chair difficult MAR's	National LeDeR Programme Team
16	The LeDeR approach should be looked at against processes like Child Death Reviews, so that we can learn and improve things.	National LeDeR Programme Team
17	A process chart needs to be in place and the same documents used by everyone in the country.	National LeDeR Programme Team

18	There should regular support for the reviewers and it should be documented.	CCGs
19	The LeDeR guidance must say that there may be different results from other reviews or inquests.	National LeDeR Programme Team
20	There needs to be proper support for reviewers and good systems so that recommendations are done in good time and lessons are learnt across the country.	CCGs
21	Each CCG must look at their own systems and processes and learn from Oliver's re-review. This review and the action plan must be sent to and monitored by the local Integrated Care System (ICS) who will give feedback to the National LeDeR team. The panel want a senior single point of contact from NHSEI to make sure that all actions are taken and progress is monitored	CCG & ICS NHSEI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