
Learning from 17/18 reviews

Oxfordshire Vulnerable Adults Death Review Process

Annual Report for 2017/18

Oxfordshire Vulnerable Adults Death Review Process (LeDeR)

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1.0 Introduction from the Vulnerable Adults Mortality (VAM) Chair

The annual report of the Oxfordshire Vulnerable Adult Mortality steering group's work during 2017-2018 sets out the work carried out during 2017-2018. The report discusses activity, functions, processes and analysis. It reviews the recommendations from the retrospective Mortality Review in Oxfordshire report (2015-16) and makes recommendations for 2018-2019.

It has been established that people with a Learning Disability die younger than the population as a whole. There has been an increasing median age at death over time (from 53 to 57 years from 2008-2011) but there is 'little evidence of any closing of the gap in age-standardised mortality rates or life expectancy between people with learning disabilities and the general population' (Emerson et al. 2014 p.94).

The University of Bristol's Norah Fry Research Centre led by Dr Pauline Heslop had identified that there was approximately a 16-20 year disparity between age of death for people with learning disabilities and the population as a whole¹. Their review identified that almost three times as many people with LD die of causes which could be avoided through good quality healthcare as do the population as a whole.

The Learning Disability Mortality Review Programme (also known as LeDeR) was established to drive improvement in the quality of health and social care service delivery for people with learning disabilities (LD) by looking at why people with learning disabilities typically die much earlier than average. The Oxfordshire VAM steering group have worked hard to ensure they incorporate this methodology into its review processes over the past 12 months. On May 4th 2018 the first annual report was published and this report will include information from this national picture².

The VAM steering group is made up of representatives from the agencies that make up the Oxfordshire Safeguarding Adults Board membership. The representation from agencies and professionals is consistently good. I am grateful for the commitment of all those who are involved in this process by attending panel meetings and contributing to the analysis of cases.

This year has seen continued commitment to ensure effective communication and good working relationships. The panel has supported a review process that critically reviews and seeks to identify any local issues and learning. It is through this scrutiny and constructive challenge that we will continue to jointly work to improve services across Oxfordshire.

Sula Wiltshire, VAM Chair

Director of Quality and Lead Nurse

¹ (<https://www.hqip.org.uk/resource/confidential-enquiry-into-deaths-of-people-with-learning-disabilities-cipold-2013/#.WvFs0O8vy00>)

² <https://www.hqip.org.uk/resource/the-learning-disabilities-mortality-review-annual-report-2017/#.WvFwJu8vy00>

Oxfordshire Clinical Commissioning Group

2.0 Background

Since the 1990s, there have been a number of reports and case studies which have consistently highlighted that, in England, people with learning disabilities die younger than people without learning disabilities. The Confidential Inquiry of 2010-2013 into premature deaths of people with learning disabilities (CIPOLD) reported that for every one person in the general population who died from a cause of death amenable to good quality care, three people with learning disabilities would do so. Overall, people with learning disabilities currently have a life expectancy at least 15 to 20 years shorter than other people. This is unequivocal evidence that demands additional scrutiny be placed on the deaths of people with learning disabilities across all settings. This is managed by The Learning Disabilities Mortality Review (LeDeR) programme, commissioned by Healthcare Quality Improvement Partnership (HQUIP) for NHS England. The programme receives notification of all deaths of people with learning disabilities, and supports local areas to conduct standardised, independent reviews following the deaths of people with learning disabilities aged over 4 years of age. These are conducted by trained reviewers. The purpose of the local reviews of death is to identify any potentially avoidable factors that may have contributed to the person's death and to develop plans of action that individually or in combination, will guide necessary changes in health and social care services, in order to reduce premature deaths of people with learning disabilities.

In 2016 Oxfordshire introduced a 'Vulnerable Adults Mortality' Subgroup of the Oxfordshire Adult Safeguarding Board. This followed a retrospective review that formed part of Oxfordshire CCG's response to the report by Mazars³. This review looks at the deaths of all people within Oxfordshire's commissioning responsibility⁴ with a learning disability who died between 1 April 2011 and 31 March 2015, and highlighted key learning points. The themes identified of this retrospective review (2015-2016) were:

1. Excellent care coordination is essential and is a central part of care planning.
2. Services should work in partnership with families and carers.
3. Annual health checks have been established as good practice for a number of years. However, in Oxfordshire, the number of people with learning disabilities receiving an annual health check is low. A regular comprehensive health check would help to detect health issues early. Work on full implementation of health checks is ongoing through the Transforming Care Programme.
4. High skilled workforce is essential for learning disabilities care. The development of a workforce plan is a key part of the TCP
5. Knowledge and correct application of the Mental Capacity Act should be promoted. All employers should ensure that their staff are competent in this area. In particular, providers should ensure their support staff have a good level of health literacy

³ <https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2015/12/mazars-rep.pdf>

⁴ There are complex rules around 'responsible commissioner'. Some of the people we reviewed were Oxfordshire patients who had not lived in Oxfordshire for decades.

6. There needs to be a robust quality assurance process to ensure that providers are delivering care to a high standard. Where quality falls below the expected standard there needs to be a clear process for addressing this.
7. Mainstream services should make reasonable adjustments to ensure equality of outcome.
8. The quality of care provided to people who are placed out of Oxfordshire should be equal to that provided in county. An enhanced level of scrutiny of out of area placements is necessary.

This subgroup is following the LeDeR (learning disabilities mortality review programme) methodology to ensure that all deaths are reviewed in a consistent manner. The group has widened the LeDeR system remit to include reviewing the death of anyone with a significant vulnerability that has caused the professionals to be concerned about some aspect of care or treatment. Neither the CIPOLD report, nor the LeDeR process define a Learning Disability. As such the VAM steering group has chosen not to define it, or what is meant by a 'vulnerable adult'. Rather professionals should use their judgement and if they believe that an individual's vulnerability contributed to their death they should make a referral to VAM.

3.0 Process

The administration of the Oxfordshire Vulnerable Adults Mortality Process and the role of the Local Area Contact (LAC) is hosted by Oxfordshire Clinical Commissioning Group (OCCG) and is chaired by the Director of Quality and Lead Nurse from Oxfordshire Clinical Commissioning Group.

The standardised review process is detailed in appendix 1.

Anyone involved in the care of the patient can complete a notification using the online form <http://www.bristol.ac.uk/sps/leder/notify-a-death/>. The case is then allocated to the correct locality (via the LAC) for allocation of a reviewer. In Oxfordshire the team then request information from the GP, and any known providers to provide a baseline of information for the reviewer.

The reviewer then discusses the circumstances leading up to the person's death with someone who knew them well (including family members wherever possible), and scrutinising at least one set of relevant case notes. Taking a cross-agency approach, the reviewer develops a pen portrait of the individual and a comprehensive timeline of the circumstances leading to their death, identifies any best practice or potential areas of concern, and makes a decision, in conjunction with others if necessary, about whether a multi-agency review is indicated.

When a death of a person with learning disabilities occurs, mandatory review processes (such as Safeguarding Adult Reviews and Structured Judgement Reviews) need to take precedence. LeDeR Reviewers need to ensure that a coordinated approach is taken to the review of the death in order to minimise duplication and bring in the learning disabilities expertise (Appendix 1).

The process includes the reviewer speaking to a family member to gather their perspective on the patient's death. The level of detail gathered varies significantly depending on the family preferences, but many have spoken positively of the value of being asked, although some have declined to comment.

For children aged 4+ the Child Death Review Process will run concurrently with the LeDeR process, using one set of information.

4.0 National Report

On 4th May 2018 the first annual report from the Learning Disabilities Mortality Review (LeDeR) programme was published. It was reported that from 1st July 2016 to 30th November 2017, 1,311 deaths were notified to the LeDeR programme. There are 39 steering groups across England. 103 reviews had been completed and approved by the LeDeR quality assurance group.

Key information about the people with learning disabilities whose deaths were notified to the LeDeR programme in Oxfordshire includes:

- Just over half (57%) of the deaths were of males
- Most people (96%) were single
- Most people (93%) were of White ethnic background
- Just over a quarter (27%) had mild learning disabilities; 33% had moderate learning disabilities; 29% severe learning disabilities; and 11% profound or multiple learning disabilities.
- Approximately one in ten (9%) usually lived alone
- Approximately one in ten (9%) had been in an out-of-area placement

The report identifies that the proportion of people with learning disabilities who died in hospital was greater (64%) than the proportion of hospital deaths in the general population (47%). The median age at death of people with learning disabilities (aged 4 years and over) was 58 years (range 4-97 years). Almost a third of the deaths (31%) had an underlying cause related to diseases of the respiratory system and was more commonly identified as the underlying cause for those aged between 25 and 44. The second most common category of deaths was of diseases of the circulatory system (16%). These were distributed across all age groups, but were more common in the oldest.

Most of the learning to-date echoes that of previous reports of deaths of people with learning disabilities. Reviewers indicated that in 13 (13%) the person's health had been adversely affected by one or more of the following: delays in care or treatment; gaps in service provision; organisational dysfunction; or neglect or abuse. From the 103 completed reviews, there were 189 learning points or recommendations identified. In each review that identified one or more learning points, the average number of learning points and/or recommendations was 2.8. Thirty-six reviews (35%) did not identify any learning. The most commonly reported

learning and recommendations were made in relation to the need for: a) Inter-agency collaboration and communication b) Awareness of the needs of people with learning disabilities c) The understanding and application of the Mental Capacity Act (MCA).

National recommendations made based on completed local reviews of deaths in 2016-2017 are as follows:

1. Strengthen collaboration and information sharing, and effective communication, between different care providers or agencies.
2. Push forward the electronic integration (with appropriate security controls) of health and social care records to ensure that agencies can communicate effectively, and share relevant information in a timely way.
3. Health Action Plans, developed as part of the Learning Disabilities Annual Health Check should be shared with relevant health and social care agencies involved in supporting the person (either with consent or following the appropriate Mental Capacity Act decision-making process).
4. All people with learning disabilities with two or more long-term conditions (related to either physical or mental health) should have a local, named health care coordinator.
5. Providers should clearly identify people requiring the provision of reasonable adjustments, record the adjustments that are required, and regularly audit their provision.
6. Mandatory learning disability awareness training should be provided to all staff, and be delivered in conjunction with people with learning disabilities and their families.
7. There should be a national focus on pneumonia and sepsis in people with learning disabilities, to raise awareness about their prevention, identification and early treatment.
8. Local services must strengthen their governance in relation to adherence to the Mental Capacity Act, and provide training and audit of compliance 'on the ground' so that professionals fully appreciate the requirements of the Act in relation to their own role.
9. A strategic approach is required nationally for the training of those conducting mortality reviews or investigations, with a core module about the principles of undertaking reviews or investigations, and additional tailored modules for the different mortality review or investigation methodologies.

The future focus of the LeDeR programme will be to move beyond 'learning' into 'action' to support improved service provision for meeting the health and care needs of people with learning disabilities and their families.

5.0 Local Activity

In 2017/18, 29 deaths of adults with learning disabilities were reported to the Oxfordshire VAM team, along with 9 deaths which were carried over from 16/17. The information on each person's death is collected and collated using the LeDeR system. In addition, the deaths of 2 children age 4+ who had learning disabilities, were also considered as part of the

LeDeR system, with both processes running concurrently, using one set of data. These deaths are reviewed at the Child Death Overview Processes panel.

The Oxfordshire VAM Steering group met on 5 separate occasions in 2017-18 to review the deaths of vulnerable adults. The deaths of 17 adults whose usual residence was in Oxfordshire were reviewed. These reviews included 9 adults that had been carried over, due to alternative investigations which prevented earlier completion.

Where other processes need to be completed, for example criminal investigations and proceedings, Coroner's investigations, or individual internal agency reviews, there can be a gap of several months between a death and that death being reviewed by the panel. The VAM Steering group cannot review the death until all other processes have been completed, as the review would not be comprehensive.

Not all of the adult deaths occurring in 2017-18 have been reviewed by the VAM Steering Group, 21 cases have been carried over to the 2018-19 year.

Outstanding cases are discussed weekly by the LeDeR administration team and the Local Area Contact, to ensure that data collection and information sharing is up to date and progressing. Assurance is also sought to confirm any immediate learning and actions are being undertaken by practitioners and organisations. A summary of all activity, including information requests and current progress is presented at each panel meeting to ensure the panel has clear oversight of the issues causing delays.

The recent rate of notifications is resulting in a growing backlog. There are currently a significant number of cases waiting to be allocated to a reviewer for review. The LeDeR system requires a trained reviewer to complete each individual review and the capacity of the current group of reviewers has presented a challenge. There are ongoing discussions with key organisations to identify further reviewers and support their capacity. In addition, the interplay with other review processes can cause delays eg. structured judgement reviews (which are required to be completed within 3 months) (see appendix 1).

Deaths from 16/17 carried forward	Number of death notifications 17/18	Number of cases reviewed 17/18		Outstanding 17/18 cases awaiting reviews
		From 16/17	From 17/18	
8	29	9	8	21

6.0 Learning from 17/18 reviews

The 17 cases that have been reviewed and closed were analysed against age, gender and geographical area (see appendix 4). From this data there is a wide spread across all categories and no areas of concerns highlighted. Of the 17, over 50% were aged 60+.

6.1 Cause of death:

An understanding of the cause of death helps inform the judgement of whether all appropriate care had been accessible to the patient and identify any potential modifiable factors.

- In 6 (35.3%) cases the certified cause of death was pneumonia. This is higher than expected and consistent with data identified in the national data. Only in 1 case had it been felt that a swallow assessment that should have been undertaken had not been. There was no evidence that this had contributed to the patient's death.
- In 4 (23.5%) cases the patient had died of a Myocardial Infarction. All but 1 of these patients were in their 80s, where heart disease is to be expected. There was 1 case of a 46 year old gentleman who died of a myocardial infarction and he did not have a history of a cardiac condition. The review did not identify any concerns about his treatment
- 5 (29%) patients died of cancer. In all cases the patients had accessed appropriate care and treatment. One case was investigated under the serious incident process.
- There were 2 (12%) cases that had just transitioned from children's to adult services. Both cases had underlying neurodegenerative conditions and had exceeded their expected life expectancy.
- There were 2 (12%) patients whose cause of death was documented as sepsis. In both cases this was after long term co-morbidities.

6.2 Themes

- Only 5 (29%) cases had documented pre-existing Do Not Resuscitate. All of these had been completed in a timely manner, but two did have a note that there was no evidence of any consultation about the decision.
- 4 (23.%) cases noted lack of coordinated care. These included comments by the carers that they felt that health care professionals showed a lack of respect of the information and knowledge they had about the patient. The reviews did not find any evidence that this had contributed to any of the deaths.
- Only 1 (6%) case had a documented Mental Capacity Assessment (MCA) but only 1 other case had evidence of a poor assessment and it was suggested that MCAs are happening, but are not being clearly documented.
- In relation to the care of the patients who died of pneumonia, challenges in accessing swallow assessments were highlighted in 2 (12%) cases. In neither case was this felt to have contributed to the patient's death. There was no record of access to chest physiotherapy, or if there had been any delay in diagnosis and treatment.
- Good care was recorded in 8 (47%) cases.
 - 1 patient had a low BMI which was thoroughly documented and had evidence of a thorough nutritional review and dietetic support.

- Several cases had evidence of good communication with families, joint working to support the patient in their chosen place of care.
- The 2 (12%) cases that had transitioned from children's to adult services both noted that transition had been complicated and delayed, although this had not directly impacted on end of life care.

7.0 Comparison of themes from Oxfordshire retrospective review and Vulnerable Adults Mortality 17/18 themes.

As this is the first annual report of VAM, and as there is currently no national data available, the themes from the Oxfordshire retrospective review have been used to compare the 17/18 data.

Oxfordshire retrospective review	National report	VAM
Excellent care coordination is essential and is a central part of care planning	<p>1. Strengthen collaboration and information sharing, and effective communication, between different care providers or agencies.</p> <p>2. Push forward the electronic integration (with appropriate security controls) of health and social care records to ensure that agencies can communicate effectively, and share relevant information in a timely way.</p> <p>4. All people with learning disabilities with two or more long-term conditions (related to either physical or mental health) should have a local, named health care coordinator.</p>	Poor communication was mentioned in 20% of cases.
Services should work in partnership with families and carers.		There were good and bad examples of services working in partnership with families and carers.
The number of people with learning disabilities receiving an annual health check is low.	3. Health Action Plans, developed as part of the Learning Disabilities Annual Health Check should be shared with relevant health and social care agencies involved in supporting the person (either with consent or following the appropriate Mental Capacity Act decision-making process).	The VAM review process has not formally been recording whether or not the cases reviewed had had access to annual health checks. This has now been added to the standard GP letter.

High skilled workforce is essential for learning disabilities care	6. Mandatory learning disability awareness training should be provided to all staff, and be delivered in conjunction with people with learning disabilities and their families.	There were no comments in any of the cases of a lack of a skilled workforce.
Knowledge and correct application of the Mental Capacity Act should be promoted.	8. Local services must strengthen their governance in relation to adherence to the Mental Capacity Act, and provide training and audit of compliance 'on the ground' so that professionals fully appreciate the requirements of the Act in relation to their own role	There was poor documentation of mental capacity assessments restricting understanding of completion by the reviewers.
There needs to be a robust quality assurance process to ensure that providers are delivering care to a high standard. Where quality falls below the expected standard there needs to be a clear process for addressing this.		The VAM review process, now using the LeDeR system, provides a robust quality assurance process. There are capacity issues in relation to reviewers. NHS trust mortality reviews are contributing to this.
Mainstream services should make reasonable adjustments to ensure equality of outcome.	5. Providers should clearly identify people requiring the provision of reasonable adjustments, record the adjustments that are required, and regularly audit their provision.	There was no evidence that there had not been reasonable adjustments made, but only one case specifically demonstrated that this had been done for the patient involved.
The quality of care provided to people who are placed out of Oxfordshire should be equal to that provided in county. An enhanced level of scrutiny of out of area placements is necessary.		The VAM process does not specifically monitor this. One case reviewed was of an Oxfordshire patient placed out of county.

8.0 Recommendations for 18/19

There is a need for a raised awareness of the value of the knowledge held by carers (formal and informal). It is suggested that non family carers are acknowledged as 'support workers' to formalise the importance of their role and that all health care providers are reminded of the wealth of knowledge of the patient/ service user that these individuals hold.

Lack of clear evidence of Mental Capacity Assessments and Do Not Attempt Cardio Pulmonary Resuscitation is disappointing; Reviewers will be alerted to these issues so that a more detailed examination of case notes and discussion with professionals involved with the cases can be conducted. This will provide a clearer understanding of whether this is due to poor documentation, or whether these assessments and planning are not happening. This resonates with the national report findings which suggests that local services must strengthen their governance in relation to adherence to the Mental Capacity Act, and provide training and audit of compliance 'on the ground' so that professionals fully appreciate the requirements of the Act in relation to their own role.

Some gaps have been identified in information currently analysed by the VAM review process. To date there has not been a check of whether or not the patients had had access to annual health checks. This will be added to the letter routinely sent to the patients' GP. Additionally, there has not been any formal monitoring of out of county placements although this is recorded (see appendix 4).

There is a significant backlog of cases awaiting review and a need for an increased capacity of reviewers, particularly from the acute trust. In addition current reviewers have identified a lack of confidence in their understanding of the process. A workshop was arranged for May 2018 to bring the reviewers together and share learning and support, but poor uptake of this session has caused it to be postponed. This will be raised with service managers to highlight the importance of attendance at a future event.

Transition is a national priority area and the 2 cases in Oxfordshire who were in transition to adult services both families reflected how challenging the process had been. Oxfordshire County Council appointed a project manager in 2017 to co-produce a 'moving into adulthood' social care pathway that will provide a better experience for young people and their families. This project is due to report in Summer 2018 and the plan is to then integrate with the Oxford Health pathways. Oxford Health have recently made changes to how this is managed in Oxfordshire and this will be monitored closely by the VAM steering group.

The number of cases who died of pneumonia remains higher than in the general population. This was highlighted in the national report and in local data. Further work is needed to address this disparity.

9.0 Conclusion

The first year full of the Vulnerable Adult Mortality process has been identified as a well-established process. There have been challenges with use of the LeDeR system, and capacity of reviewers to complete the work. In addition, other statutory processes such as structured judgement reviews (which are required to be completed within 3 months) create

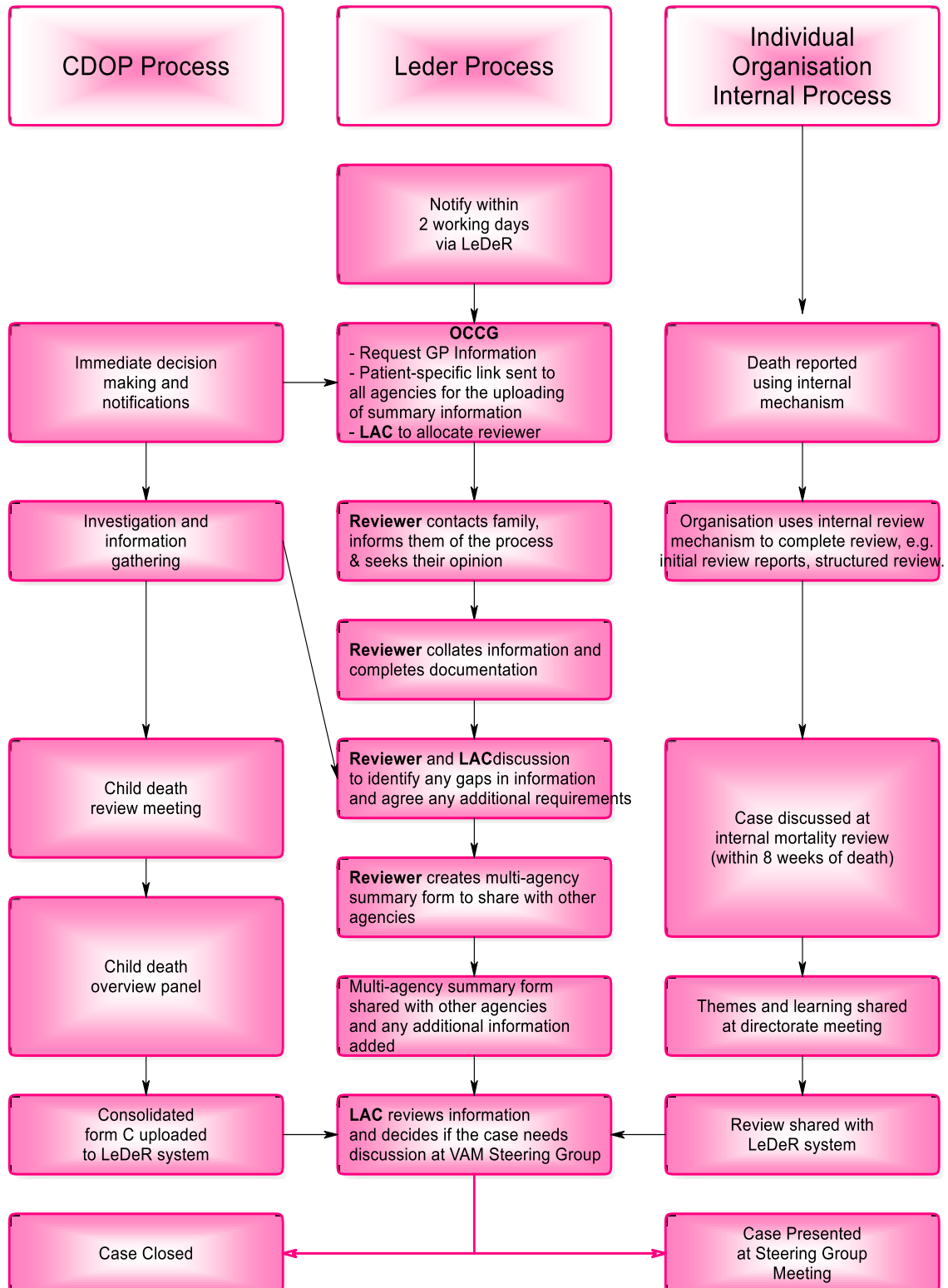
an unavoidable delay in the VAM/LeDeR review timescales. This has been raised with NHS England as part of their review of the LeDeR process.

There is evidence of some progress against the themes from the Oxfordshire retrospective review, but also evidence that further work is needed.

The learning from the VAM steering group echoes many areas that the National report has highlighted and during 2018/19. The level of understanding and awareness about care and support for individuals with learning disabilities has improved. Over this year we have developed better partnership, which will facilitate joint learning and promote more coordinated care for the individuals. Ensuring that mental capacity assessments are completed in a timely manner will need commitment from all agencies.

Appendix 1

Notification of an Oxfordshire death of an adult (18+) (or child age 4+ with a learning disability)



Appendix 2

VAM Membership 2017-18

Name	Position	Agency
Sula Wiltshire	Chair: Director of Quality and Lead Nurse	Oxfordshire Clinical Commissioning Group
Alison Chapman	Designated Nurse, Safeguarding	Oxfordshire Clinical Commissioning Group
Karen Brombley	Nurse Consultant	Helen & Douglas House Hospice
Pauline Burke	VAM and Safeguarding Officer	Oxfordshire Clinical Commissioning Group
Helen Ward	Deputy Director of Quality	Oxfordshire Clinical Commissioning Group
Steve Turner	OSAB Business Manager	Oxfordshire Safeguarding Adults Board
Diane Dillon	Board Support Officer	Oxfordshire Safeguarding Adults Board
Stephanie Ross	Learning Disability Liaison Nurse	Oxford University Hospitals NHS Trust
Sandhya Chundhur	Clinical Outcomes Manager	Oxford University Hospitals NHS Trust
Robyn Noonan	Service Manager North	Oxfordshire County Council
Melanie Pearce	Service Manager Safeguarding Service	Oxfordshire County Council
Chris Ingram	Chief Executive	Style Acre
Matt Bick	Detective Inspector	TVP
Moira Gilroy	Safeguarding Adults Manager	Oxford Health NHS Trust

Ruth Rees	Oxfordshire Coroner's Service Manager	Coroners Officer
Sarah Ledingham	Named GP for Safeguarding	Oxfordshire Clinical Commissioning Group
Kirsten Prance	Team Manager North Learning Disability Team and Oxfordshire Intensive support team	Oxford Health NHS Trust
Jane Kershaw	Head of Quality Governance	Oxford Health NHS Trust
Robert Tunmore	South of England Regional Co-ordinator	NHS England

Appendix 3

Findings from the Oxfordshire retrospective review in relation to the Mazars categories

The two Oxfordshire learning events did not follow the categories set out by Mazars. The areas of focus were instead developed from looking at the cases and identifying themes.

The Oxfordshire cases have been considered in relation to the Mazars finding and the findings are set out below.

A) The quality, timing and follow up of dysphagia assessments

We did not find that referrals for dysphagia assessments were delayed. We did, however, find that a high number of people with learning disabilities had gastric and/or respiratory causes of death. It is not clear at this stage how much of this morbidity would be amenable to better quality healthcare. Further research is required in this area.

B) The level of support provided by hospital liaison services and the challenges faced in acute liaison

Acute liaison was not identified as a lack in Oxfordshire. In fact the liaison service at the Oxford University Hospitals trust is consistently identified as excellent by services users, their families and carers.

c) The decision-making process for PEG insertion

It was not clear from the evidence that there were adverse decisions in this respect.

d) The hydration and nourishment of service users refusing to eat

Again, while not an uncommon issue we did not find that this was a problematic area in Oxfordshire. We did find that nutrition in social care settings was an area identified for improvement particularly where people had a high level of independence.

It was agreed that it is important to balance quality of life, individual choice and managing risk when it comes to supporting individuals with nutrition.

e) Delays in decision-making for treatment - including primary care, decisions by care staff and responses in A&E and on wards.

None found

f) The inclusion of carers and families in investigations

The cases which we looked into were those which had not previously been investigated. This meant that the deaths had not, for the most part, been identified as 'incidents' and there was no investigation with which the families could become involved.

What we did find was a number of families who had unresolved issues. There may have been historic complaints, or families who did not find that the complaints were investigated to

their satisfaction. Families often report a 'battle' with services. In more than one case an historic experience of a person with and LD being in a poor social care setting meant that the family became very wary about any changes to provision in the future. This was a particular challenge when there need to be changes as families are scared of losing what has been so hard fought for.

g) Waiting times for therapy services and community nursing.

Waiting times were not identified as a significant issue by our multi-disciplinary process. However, there was a suggestion that people were not being referred to services when they should have been. This could be as a result of a lack of understanding that a specialist opinion was required, or it could be due to a perceived lack of availability of services.

h) Identification of early warning signs of deterioration through behavioural change

The late identification of health need was clearly identified and is discussed above. This included health need which could have been identified through behavioural change and health needs apparent from other symptoms.

i) Arrangements for attending appointments and seeing healthcare professionals

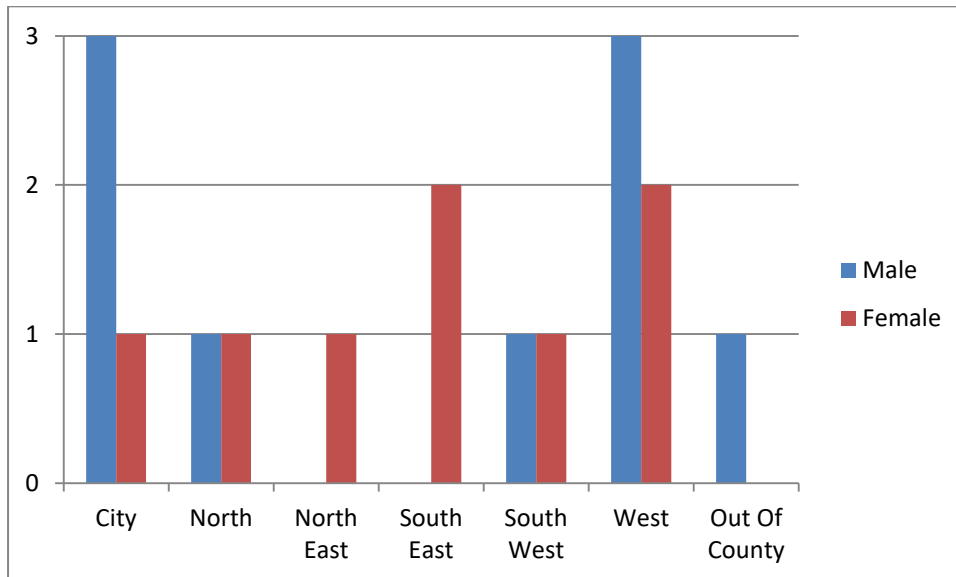
We did not find evidence that appointments were missed. However, we did find evidence that people did not have the right level of skill to support them at appointments. We also found that this sometimes resulted in actions not being followed up on in a timely way.

j) Reporting and acting on safeguarding concerns

There was a lot of evidence of safeguarding concerns being raised and responded to. Safeguarding information was a useful source of information on problems which had been encountered with care. We did not find evidence that concerns raised were not acted upon.

Appendix 4: Data

a: Geographical location by GP localities



b: age and gender

Age	4-10yrs	11-17yrs	18 - 25	25-39	40s	50s	60s	70s	80s	Total
Number of cases		1	2		3	2	4	1	4	16
Male		1	1		2		3		2	8
Female			1		1	2	1	1	2	8

