OSAB
Oxfordshire Safeguarding Adults Board

NHS
Oxfordshire
Clinical Commissioning Group

Learning from 19/20 reviews

Oxfordshire Vulnerable Adults Death Review Process

Annual Report for 2019/20

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1.0 Introduction from the Vulnerable Adults Mortality (VAM) Chair

This year has been my first year as Chair and it is a privilege to present the annual report. This report of the Oxfordshire Vulnerable Adult Mortality steering group (VAM) sets out the work carried out during 2019-2020. The report discusses activity, functions, processes and analysis of identified themes. It reviews the recommendations from 2018-2019's annual report and makes recommendations for 2020-2021.

The VAM steering group is made up of representatives from the agencies which 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.

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 LD, by looking at why people with LD typically die much younger than average. The Oxfordshire VAM steering group have worked hard to ensure they incorporate this methodology into its review processes over the past 3 years. This work is supported and driven by NHS England and it is being incorporated into contractual requirements for all health services in 2020-2021. It is also anticipated that this will be part of partnership work stream within any Integrated Care Partnership (ICP)

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.

At the time of writing the country is on lock down as a result of the COVID -19 pandemic. Whilst not within the scope of this report I felt it was important to highlight that additional monitoring and review processes have been implemented and a full statement of findings can be found on the OSAB webpage (https://www.osab.co.uk/wp-content/uploads/LeDeR-comms-statement-v4.pdf).

Alison Chapman, VAM Chair

Designated Nurse and Safeguarding Lead

Oxfordshire Clinical Commissioning Group

1.0 Background

In 2016, Oxfordshire introduced a Vulnerable Adults Mortality steering group (VAM), which is a subgroup of the Oxfordshire Adult Safeguarding Board.

This VAM 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, which has caused the professionals to be concerned about some aspect of care or treatment. Neither the confidential inquiry of 2010-2013 into premature deaths of people with learning disabilities (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.

The administration of the Oxfordshire Vulnerable Adults Mortality Process is hosted by Oxfordshire Clinical Commissioning Group (OCCG) and is chaired by the Designated Nurse and Safeguarding Lead, who is also the Local Area Contact (LAC) for Oxfordshire.

When the death of a person with learning disabilities occurs, mandatory review processes (such as Safeguarding Adult Reviews and Structured Judgement Reviews) need to take precedence. The LeDeR process aims 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. For children aged 4+ the Child Death Review Process (CDOP) will run concurrently with the LeDeR process, using the CDOP reports. This process is also hosted by OCCG.

OCCG has introduced an information gathering stage prior to assigning the review to a reviewer. This has improved efficient maintaining a robust and effective process. It has been possible using this process to triage cases and to improve the timeliness of completion. Reviewers have been able to use their clinical expertise to focus on family involvement and analysis of care and treatment.

2.0 Activity 2019/2020

2.1 Data

In 2019/20, 35 deaths of adults with learning disabilities were reported to the Oxfordshire VAM team (compared with 40 in 18/19). In addition, the deaths of 5 children age 4+ who had learning disabilities, were also notified as part of the LeDeR system, and were reviewed within the Child Death Review Process, with both processes running concurrently, using one set of data. These deaths are reviewed at the Child Death Overview Panel, with LeDeR expertise and support present on the panel. There are 8 open cases dating back to 2018, which are being managed by a Clinical Support Unit (CSU), funded by NHSE as part of a national review support programme.

The Oxfordshire VAM Steering group met on 3 separate occasions in 2019-20, to review the deaths of vulnerable adults. The deaths of 35 adults, whose usual residence was in Oxfordshire, were reviewed.

At the end of 2019-2020, excluding the 8 cases being managed by the CSU, there were 18 open cases. This is less than half the number at the end of 2018/19 (37). This significant progress is a result of additional project money from NHSE which has enabled some additional capacity within the OCCG, and the amended information gathering process described above. There is now a performance requirement monitored by NHS E/I to complete all reviews within 6 months of notification. At the end of March 2020 there were 7 cases that were over 6 months and remained open. All but one of these was completed in April. The remaining case is being delayed by other statutory processes.

Appendix 2 demonstrates Oxon's performance is significantly higher than both the SE and Nationally and confirms that 75% of cases have been completed and closed. 19 cases are in progress and 5 have yet to be commenced.

Open 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.

2.2 Analysis

2.2.1 Cause of death

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

- In 12 (34%) of cases, the certified cause of death was pneumonia compared with 14 (66%) cases in 17/18. The incidence in the whole population is 12% (Office of National Statistics, 2018). Whilst the incidence of pneumonia remains higher than the national average the number has reduced. It is not yet possible to assume this is a sustained improvement as a result of the changes made from VAM recommendations, but reviews this year have shown that all individuals had evidence of timely swallow assessments and had feeding plans in place. Two cases highlighted poor communication about changes in care plans, following a change in the individual's condition.

- 8 (23%) patients died of cancer (compared with two (10%) in 17/18. This is a higher number. In all cases the patients had accessed appropriate care and treatment, but there was lack of documented age appropriate cancer screening.

- There were 6 (17%) patients whose cause of death was documented as myocardial infarctions.

2.2.2 Age at time of death

The average age of the 35 cases reviewed by VAM was 71 (compared to 55 years of age in 2018/19). This is a positive improvement, but VAM will continue to monitor this to be assured it is a consistent trend.

2.2.3 Themes

As a result of previous work in all areas of services, the themes that are being seen are moving to a more proactive approach.

A number of deaths were associated with the consequences of lifestyle choices. Obesity and constipation were the two significant examples of this. Analysis of the care these individuals received suggests that further work is needed to ensure that individuals with learning disabilities have access to information that they can understand and use. Anecdotal evidence shows that in promoting an individual's choice over their diet, if not balanced with good advice about healthy eating, may have contributed to obesity. Similarly, promoting an individual's independence in self-care and toileting, whilst not equipping them with an understanding of what a 'normal' bowel habit is, has been a factor in a number of cases where significant chronic constipation has contributed to an individual's death.

A quarter of all deaths were from cancer. Whilst all individuals had access to appropriate treatment once diagnosed, it is unclear whether they had been able to access health screening as any other individual would. OCCG has developed an enhanced project to improve the information available to anyone with a learning disability, and to promote reasonable adjustments in the way testing can be accessed. For example, if an individual is not able to tolerate a mammogram, an ultrasound scan can be offered. Clinical teams are working closely to build knowledge and expertise around supporting health screening within this population.

3.0 Update on recommendations from 19/20

Appendix 3 contains the full action plan and associated updates.

Of note, considerable work has been undertaken by Oxford Health Foundation Trust (OHFT) and Oxford University Hospital Trust to better understand the challenges of coordinated end of life care and to develop cross organisational systems to improve this essential area of care planning. Ensuring all updated care plans are shared between everyone caring for the individual has also progressed, but remains an ongoing piece of work.

4.0 Recommendations for 20/21

I. A number of deaths were associated with the consequences of lifestyle choices where it appeared that the individuals did not have access to information that they could understand and use. Learning Disability teams will lead a piece of work developing lifestyle information for individuals and those supporting them. This will be shared at an Oxfordshire-wide learning event.

II. There was a lack of evidence that individuals had been able to access the same health screening as others in Oxfordshire. A project to enhance the information available to anyone with a learning disability, and to promote reasonable adjustments in the way testing can be accessed is being undertaken. The impact of this will be monitored by commissioners to ensure all individuals have equal access to health screening.

5.0 Conclusion

The third year of the Vulnerable Adult Mortality process has further embedded the process. There is evidence of strong multi-agency working at all levels to support this process, which facilitates the quality of the overview the panel can take. The capacity of reviewers to complete the work has significantly improved as a result of the information gathering now conducted by OCCG, and is reflected in the improved performance to complete good quality reviews in a more timely manner.

Locally organisations and services have been active partners in the process. This has resulted in the quality of evidence provided improving. As a result, reviewers have had access to better information in order to identify good practice and learning points, which in turn is influencing positive system changes.

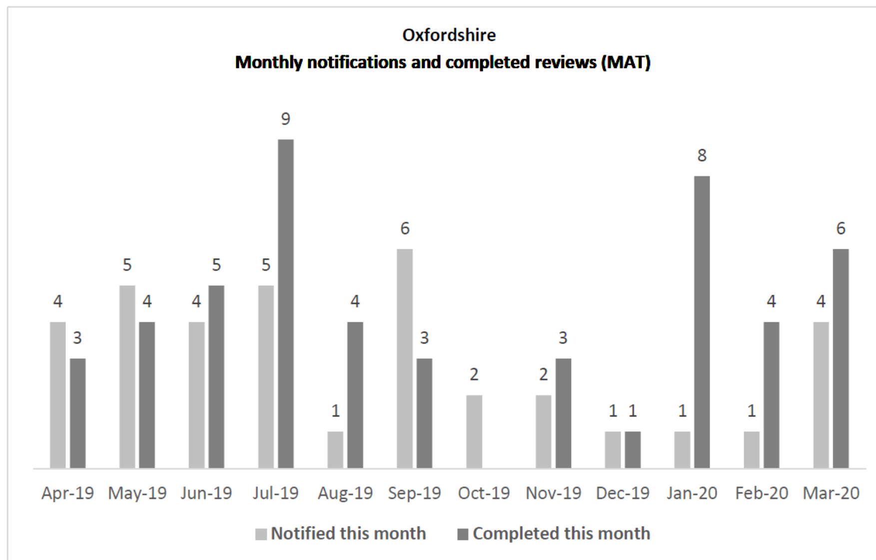
The level of understanding and awareness about care and support for individuals with learning disabilities has improved, and there are key multi-agency areas of work in progress. Over this year, we have developed better partnerships, which will facilitate joint learning and promote more coordinated care for the individuals.

Appendix 1

VAM Membership 2019-20

Name	Position	Agency
Alison Chapman	Chair: Head of Safeguarding and Designated Nurse	Oxfordshire Clinical Commissioning Group
Karen Brombley	Designated Nurse LAC and, Safeguarding in complex care	Oxfordshire Clinical Commissioning Group
Pauline Burke	VAM and Safeguarding Officer	Oxfordshire Clinical Commissioning Group
Steve Turner	OSAB Business Manager	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
Chris Ingram	Chief Executive	Style Acre
Matt Bick	Detective Inspector	TVP
Kirsten Prance	North Learning Disability Team and Oxfordshire Intensive support team	Oxford Health NHS Trust
Jane Kershaw	Head of Quality Governance	Oxford Health NHS Trust
Gail Hanrahan	Programme Manager	Oxfordshire Family Support Network

Appendix 2: Data from LeDeR system (19/20)



Progress: Oxfordshire compared to regional and national data (adult deaths)

	Oxon.		South East		England	
Status of in scope reviews at quarter end	No.	%	No.	%	No.	%
Reviews not yet allocated to a reviewer	5	5%	265	22%	1187	16%
Allocated - review in progress	18	18%	475	40%	2162	29%
Review complete, with LAC for approval	1	1%	48	4%	230	3%
Reviews completed this quarter	18	18%	68	6%	863	12%
Reviews completed previously	56	57%	339	28%	2949	40%
Total reviews	98	100%	1195	100%	7391	100%

<table>
<tr><th colspan="3">Appendix 3: VAM Annual Report 2018/19 Action Log</th></tr>
<tr><th>Recommendation</th><th>Action from Annual report and additional Actions from VAM panel</th><th>Timescales and updates</th></tr>
<tr><td>1. Multiagency work is needed to improve the use of EOLC plans as care planning at the end of life can affect the quality of the experience and whether or not the individual is supported to die in the place of their choice. Whilst there is evidence of where the individuals die, and that there are a higher number of hospital deaths than average, we do not know where the individuals would have wanted to die, as this information is not being sought, or recorded.</td><td>a. OHFT and OUH are working together to map a process that will support the identification of people with LD who are at the end of life. The aim is that this will enable proactive case management, including how and where clients would like to be supported at the end of their lives.
b. Ongoing work is needed to enable support workers to advocate for the individuals in their care. This will aim to increase the number of End of Life care plans and the skills of the support workers to be able and confident to care for them in their normal place of residence.
c. OCCG to share this learning with End of Life Collaborative Health Needs Project, including a consideration of the introduction of the national RESPECT document.
d. OUH to audit all LD deaths to identify barriers and leavers to LD patients receiving appropriate palliative care within OUH.(completed)
e. OH LDT team to develop local networks with support workers (completed)</td><td>Work undertaken by OHFT specialist LD services to reduce the number of avoidable deaths in the LD population.

Process agreed between OUHFT and OHFT LD liaison nurses that ensures that any person known to services with complex health presentation has a completed comprehensive nursing assessment and that information from this and a hospital passport is shared.

OUHFT LD Liaison nurses update the OHFT LDT's on admissions and discharges formally weekly and as required during the week. This is to facilitate Joint co-ordination and planning for those people open to the LDT's. OUHFT Liaison Nurses review those people with frequent admissions to ensure the appropriate management plans are in place

Clients with complex health needs are fully case co-ordinated via the LD specialist teams to support with a reduction in diagnostic overshadowing and also to support with navigation of the health system.</td></tr>
</table>

		OHFT have improved access to end of life care planning for those with complex presentations to support with the most clinical effective care and to try and reduce the % of people dying in hospital.
2. Providers are developing improved systems for sharing of care plans in a timely manner, ensuring that these are available to family members and all members of the team supporting the individual. The impact of these changes will be monitored via VAM and LeDeR reviews.	All agencies to implement.	Analysis of cases 19/20 showed an improvement – difficulties were mentioned in only 2 cases
3. Further work is needed to enable support workers to respond to the changing needs of the individuals in their care and to empower them to have the confidence to challenge medical professionals when appropriate.	OCCG, OCC and OHFT Learning Disability Team to develop a. Developing a toolkit of resources for the workforce, b. Improving their access to training in key areas. c. Encouraging the development of local networks, so that the teams know who they can call on to assist them.	OHFT LD team have developed a suite of resources
4. Pneumonia was the most common cause of death. In all but 2 of the cases, there were comprehensive swallow assessments and feeding plans in place and that the reviewers	a. Although the infective cause is rarely identified, it was identified that where an individual had a needle phobia alternative arrangements to improve access to flu immunisations were not made. There is guidance from Public Health England that	a. Completed May 19 (Disseminated to primary care Aug 19)

could not identify any failure in care that had contributed to the individual's death. Further work is needed to understand why this continues to be higher than for the rest of the population	individuals with Learning Disabilities should be offered all reasonable adjustments, including being offered a nasal spray[1]. This guidance will be shared with Primary Care in this year's flu awareness information. b. OCCG to liaise with LeDeR National team	

[1] https://www.gov.uk/government/publications/flu-vaccinations-for-people-with-learning-disabilities/flu-vaccinations-supporting-people-with-learning-disabilities