

LeDeR Annual Report Oxfordshire

For the period 1st April 2020 – 31st March 2021

NHS England and NHS Improvement



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Introduction

- This is the Fourth Annual Report collating learning from the mortality reviews of those living with a learning disability using the learning disability death review (LeDeR) framework. This programme was commissioned and is overseen by NHS England. The review process is a strongly supported partnership activity in Oxfordshire, with membership from a wide range of organisations. This report presents the findings from the 61 case reviews undertaken in 2020-2021. The pandemic has created challenges and offered us opportunities. It has prompted different ways of working and closer working relationships.

Acknowledgements

- The Oxfordshire steering group and the review team has increased its activity this year. They have also overseen an additional initial review process to ensure all COVID-19 linked deaths were considered in a timely manner. This has been invaluable in ensuring a good level of understanding about issues and challenges, and has resulted in actions being agreed and put in place in a more timely manner.
- Oxfordshire Association of Care Providers (OACP) has been an extremely valuable partner, disseminating resource, information and advice as COVID-19 emerged over the past year. It has also been instrumental in providing a platform to promote learning in a virtual way, which has enabled learning from the mortality reviews to be shared in a timely manner.
- During the past year Oxfordshire Family Support Network (OxFSN) and My Life My Choice (MLMC) have been instrumental in continuing to raise issues, ask challenging questions and voice the concerns of those living with a learning disability. They have maintained close contact, and we have been able to offer feedback and assurance as a result of this. There have also been opportunities to share experiences through the learning events and activities.

Executive Summary



- This year has seen continued commitment to ensure effective communication and maintain good working relationships. The panel has supported a new rapid 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 for those living with a learning disability.
- Activity this year has been sustained and enhanced, using reviewers forced to work at home due to the pandemic. 41 notifications have been received and 61 case reviews have been completed, resulting an improvement in timeliness of review completion. 97% of reviews notified to Oxfordshire in 2020-21 were completed within the 6 monthly target set by NHS England. This report presents a summary of their findings.
- The average number of notifications of deaths per month in 2019-20 was less than 4 and this has remained consistent in 2020-21. This represents a variance to the nationally reported data that has suggested an increase in deaths among the learning disability community. Locally the data has been cross referenced to ensure no individual was missed from the review process. Whilst there has been no specific learning identified to account for this the steering group has acknowledged that there are a very high number of small supported living settings, more family like units, which may have been a factor. In 2021-2022 living environments may be a feature of some more detailed analysis.
- Learning from the LeDeR process has been a regular report component of the Learning Disability and Autism system wide group, that was set up as part of the COVID-19 reporting structures (bronze cell) and will be sustained to create a forum for ensuring providers and commissioners regularly review quality and effectiveness through a range of perspectives.
- Hospital admissions in 2020-21 have been a challenge for all. During the pandemic it was necessary to ensure that there were adjustments made to support those living with a learning disability requiring hospital care. The rapid reviews undertaken led to changed visiting arrangements for those requiring additional support, changes to communications with care providers and families and the development of COVID-19 passports.
- Learning has been shared in webinars, through a series called “ Wednesday at One”. This series consisted of 10 sessions, each with a key focus that explored healthy lifestyle issues, advanced/ proactive care planning and health care plans, understanding the individuals’ experience and supporting health needs such as epilepsy. On average 80 delegates joined each session from across the south east region from a diverse range of settings.
- Key areas identified as requiring further improvement are:
 1. Annual Health Checks (AHCs) and Health Action Plans (HAPs) / Education and Health Care Plans (EHCPs) need to be more closely aligned and linked so they inform each other, both being valued by all.
 2. Transition from child to adult services needs to start with earlier discussions across teams and service, including primary care. This needs to include hearing the voice of the individual, their views and choices more consistently, whilst not excluding families.
 3. Anticipatory care plans, and preparing for lifestyle changes needs to be more proactively supported across the system, including end of life choices, best interest decisions, advocacy and family roles.

Learning Disabilities Mortality Review (LeDeR)

Process Headlines



2019-2020

- 47 Notifications
- 58 Completed this year (including cases from previous years).
- 21 of the 47 notifications were completed within 6 months of notification. This gives us a compliance rate of 45%



Oxfordshire CCG team have completed 96% of the reviews

2020-2021

- 41 notifications (until 1st March)
- 61 reviews completed this year (including cases from previous years).
- 32 of the 33 2020-2021 notifications completed up to 31st March, were completed within 6 months of notification. This gives us a compliance rate of 97%

The new NHSE LeDeR platform will be become live in June 2021. It is anticipated that this will change the way the reviews are conducted.

Background

Presenting some of the headlines in the Oxfordshire Joint Strategic Needs Assessment (JSNA) 2021 gives us a picture of the area to use as a compassions to the data presented in this report. It tells us that:

- As of mid-2019, Oxfordshire was the most rural county in the South East and the count of registered patients with an Oxfordshire GP was 773,400. 22% of Oxfordshire's population are resident in Oxford City and 38% in the county's main towns. The remaining 40% live in smaller towns and villages. Oxford City has a higher population of 20-24 year olds due to the majority of university students living within the City.
- There are 3,025 people identified as living with a Learning Disability (all ages) registered with primary care practices within the boundaries of Oxfordshire, this is 0.37% of the total Oxfordshire GP patient register. In England this average is 0.5% of a clinical commissioning group GP register.
- Life expectancy and healthy life expectancy in Oxfordshire are each significantly higher than national and regional averages for both males and females when looking at a range of public health statistics.
- Despite Oxfordshire's relative affluence, there are wide inequalities in health and wellbeing. Males living in the more affluent areas of the county are expected to live around 11 years longer than those in poorer areas. For females the gap in life expectancy is around 12 years.
- Isolation and loneliness have been found to be a significant health risk and a cause of increased use of health services.
- For the combined years 2017 to 2019, cancer was the leading cause of death in males and females in Oxfordshire, accounting for 33% of male deaths and 27% of female deaths. The other leading causes were cardiovascular disease, liver disease and respiratory disease.
- According to the Office for National Statistics, the total number of deaths (including COVID-19 and other causes) in the 12 months between January 2020 and December 2020 in Oxfordshire was 6,150.
- There were approximately 700 deaths with COVID-19 on the death certificate in Oxfordshire in 2020, 10 of which were individuals living with a learning disability.

Key Findings



- COVID-19 was the largest cause of death in the past year but there was no increase in the overall number of deaths reported. This was one of three respiratory related causes of death identified on certificates as the primary cause. Initiating a process of rapid reviews (within 14 days of a notification) gave providers and commissioners some real time learning and enabled service changes to be implemented, for example: altering a visiting policy, introducing COVID passports and agreeing some clearer communication procedures between health services and carers.
- Annual Health Checks have been found to be separate to the provider support service led Health Action Plans resulting in both lacking some details. Promoting the use of the health action plans to inform the annual health checks and the annual health checks to promote a review of the health action plans increases the value of both and creates opportunities for support workers and carers to contribute to more effectively supporting healthy lifestyles, supporting timely access to health care and ensuring greater understanding of all health needs for individuals requiring support.
- Conversations about death and dying are never easy, but where they have been proactive there is evidence of much greater levels of understanding. There have been more opportunities to represent views and wishes of an individual more effectively in times of crisis and sadness. Developing anticipatory end of life plans proactively has been recognised as good practice, valued by those who are mourning a loved family member or friend.
- In situations when joint assessments are undertaken a more comprehensive and better understood care package is created. Care coordination has not been seen to be routinely used. This has impacted on the care quality, particularly for those with multiple or more complex care and support needs. The use of a care navigator in primary care also was seen to provide emotional and social oversight alongside health issues, and should be considered more frequently as part of the support team.
- Best interest assessment records were found to be limited and could not always be identified in documentation. In many cases they also lacked detail on the rationale for decisions, reducing understanding and their value to those not directly involved in the conversations.

Governance arrangements



- In 2016, Oxfordshire introduced a Vulnerable Adults Mortality steering group (VAM), as a valued subgroup of the Oxfordshire Adult Safeguarding Board (OSAB). It follows the LeDeR (learning disabilities mortality review programme) methodology, to ensure that all deaths of those living with a learning disability are reviewed in a consistent manner. The administration of the Oxfordshire Vulnerable Adults Mortality process is hosted by Oxfordshire Clinical Commissioning Group (OCCG). The Chair is the Designated Nurse and Safeguarding Lead, who is also the Local Area Contact (LAC) for Oxfordshire.
- The VAM steering group has chosen not to confine reviews to those with a diagnosed learning disability but uses the term 'vulnerable adult'. Professionals and practitioners are encouraged use their judgement and if they believe that an individual's vulnerability contributed to their death, they should make a referral to VAM requesting a review.
- The steering group has representation from providers and families as core members, creating an inclusive approach. Every review is taken to the VAM steering group for actions to be assigned and learning points shared. Completion is then the responsibility of the assigned person. During 2020, those living with a learning disability were provided with updates about the Covid 19 mortality figures, through My Life My Choice and Oxfordshire Family Support Network.
- Reporting is to the CCG governing body through the Quality Committee, into the joint commissioning teams to inform service development and into the Oxfordshire Safeguarding Adult Board through the sub group reporting processes, resulting in regular Executive updates. Annual reports are presented to both and published alongside the Safeguarding Adult Board Annual report, on the OSAB website.
- When the death of a person with learning disabilities occurs, mandatory review processes (such as Safeguarding Adult Reviews, Coronial processes and Serious Incident Processes) need to take precedence. The LeDeR process aims 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. 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 an information gathering stage prior to assigning the review to a reviewer. This has improved efficiency, maintaining a robust and effective process. It has been possible using this process to triage cases, identifying key expertise required to undertake the review, 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.
- In 2020-21, this process was enhanced with the introduction of a rapid review option driven by the COVID-19 pandemic. This involved an initial scoping and collation of knowledge within 14 days of a person's death. This was also used more broadly to consider any immediate learning, to promote greater joint planning for support and agree investigation approaches. It followed the principles of the children's joint agency review meeting process.

Equality Impact- Ethnicity



Public bodies have legal duties to eliminate unlawful discrimination, advance equal opportunities and promote good relations between people. Actively considering the ethnicity of an individual is essential to proactively explore any relationship between mortality and ethnicity.

According to the Office for National Statistics (ONS) Census 2011 survey, 16% of the total resident population of Oxfordshire was from an ethnic minority background, compared with 20% across England. Between 2011 and 2020, the only updated diversity data regularly reported is from school registrations. This data showed that the diversity of Oxfordshire’s pupils had increased. As of January 2020, 27% of pupils in state primary schools (in years 1 to 6) and 25% of pupils (years 7-11) in state secondary schools in Oxfordshire were from ethnic minority backgrounds.

In 2019-20, according to JSNA data, there were a total of 3,025 people with learning disabilities (all ages) registered with GP practices within the boundaries of the Oxfordshire Clinical Commissioning Group. There is no reliable data about heritage of these individuals. What can be reported is that 79% of the reviews undertaken were on those with a white British heritage, this compares to the general local populace being 64%.

Ethnicity	White				Mixed/Multiple ethnicity groups				Asian or Asian British				Black or Black British			Other Ethnic Groups		
	British	Irish	Traveller or Gypsy	Any other White background	White & Black Caribbean	White & Black African	White & Asian	Any other mixed background	Indian	Pakistani	Bangladeshi	Any other Asian background	Caribbean	African	Any other Black background	Chinese	Any other ethnic group	Not stated
No. of reported deaths	48	0	0	3	0	0	0	0	0	0	0	1	0	0	0	1	2	6
% of all reported deaths	79	0	0	5	0	0	0	0	0	0	0	1.5	0	0	0	1.5	3	10
Ethnicity% of local populace	64	2	0.1	12	1	0.5	1	1	3	3	1	3	1	3	0.5	2	1	

The table shows the ethnicity breakdown of the people whose lives and deaths we reviewed this year.

It has not been possible to draw any conclusions from this analysis.

One limitation of this data is that 10% of those deaths reviewed did not have a record or heritage.

During 2020-2021 a member of the VAM steering group had a key role in ensuring equality issues were addressed within reviews. In 2021-2022 this role needs to be enhanced to ensure equality and diversity issues are a key component within all reviews.

Deaths of People in our CCG/ICS: Pen Portrait 1- Family, Friends and Community



- Fred was in his seventies when he died, and it was clear he had a full and productive life - loved and nurtured by his family. Family was especially important, being part of a large family, and he was supported to live with them all his life, ensuring he knew all his nieces and nephews well.
- Locally friendships and activities were central to life. These included being part of voluntary teams in Oxfam, a Care Home and a furniture restoration centre. Church and community social activities, such as line dancing, were important for this friendly, people loving gentlemen.
- He was known by his smartness and in his independent way managed to buy lovely suits with accessories. In his time, he enjoyed country and western dancing, loved a lager at the British Legion and could be found enjoying any parties he was invited to, especially in his younger years. He maintained a close childhood friendship and would exchange phone calls, his sister continues to receive these.
- When the COVID restrictions came into force this had to stop and his sister says this broke his heart and signalled a decline in his wellbeing. He still had his Netflix and his I-Pad, but it wasn't the same as seeing the people he enjoyed socialising with.

We found that:

- COVID restrictions resulted in isolation for Fred from his community and the activities that made him feel good. Those supporting him tried to maintain contact via the phone, FaceTime and Zoom calls however this was not enough. Fred was described as deteriorating because of the lack of community connections by his family.



- Fred's review flagged the importance of family involvement and community life. Where relationships are actively promoted a better quality of life is achieved. Connections in the community and a role within it, is key to building emotional wellbeing and self esteem.
- All services are to be encouraged to develop and use this good practice in their environments.
- Quality monitoring will review this when doing reviews in the future.

Pen Portrait 2- Communication developed well



Agnes, who was in her seventies, had very good verbal communication skills, but this was sometimes an issue. Those communication skills were such, that it could seem that she understood more than she did. Therefore, information would need to be given to her simply, support workers needed to make sure that she fully understood, before moving on. People speaking to her using jargon were disliked. For more detailed and difficult conversations, support workers used easy read guides and picture stories, to help Agnes understand the information. Support workers encouraged her to talk through any feelings she was having. At times attention seeking behaviour was challenging within the shared home. Support workers would chat to her, but remind her that others needed their attention also. If they were trying to talk about something and she didn't want to discuss it, she would change the subject. If it was important, they would try and steer the conversation back, or get someone else to try.

Although activities were enjoyed they were often declined initially, choosing to lay on her bed instead. Support workers would need to encourage her to come out of her room and offer her activities every day. They recognised that boredom and lack of attention resulted in Agnes feeling upset and disruptive.

A key enjoyment was being involved in planning and taking part in house meetings. She was a very sociable person and liked to chat and spend time with people. The Day Centre was a place she really enjoyed. She called it her "work" and had a special friend who was especially important. A relationship she was supported to maintain until the end of her life.

We Found that:

The importance of knowing someone really well to support them properly was clear. Understanding behaviour and being able to interpret this way of communication is key.

We also found that:

Recognising choices may not always be in the individual's best interest and working to encourage and empower creates a better quality of life.



Really good person centred support requires a good understanding of how the person communicates through words and behaviours. It is essential for other professionals less aware of the individual, to use the support staff expertise and knowledge of the person when involved in their care or treatment.

Pen Portrait 3- Proactive End of Life Preparation



Stanley moved away from his family aged 8 years old, however he maintained close connections all his life. He was a big part of his nieces and nephews lives and they were actively involved in supporting him to live life to the full.

Stanley moved into his supported living home in 1990 and was the last original resident of the four living in this house. If Stanley was not going out he was often found at his desk looking at pictures, doing jigsaws or playing cards. He preferred his own space and company but did enjoy one to one company when in the community. Stanley attended day services once a week and often commented on enjoying his day with the grannies. Stanley made 2 visits to Disney, which he loved, and frequently visited his family. Outdoor activities needed careful planning, because he really suffered when the pollen counts were high, but they were described by the family as always being really lovely events. His favourite places to visit were garden centres, especially those with an animal section.

Stanley was described as generally fit and healthy. During his life support workers and his GP worked to desensitize him to the issues he had with physical examinations and support him in getting health care when necessary. Family commented on valuing the consistency and care of support workers, praising their creativity. Stanley's only admission to hospital, aged over 70, was also his first ambulance trip. During this admission he tolerated and cooperated with many invasive and prolonged treatments. His end of life care was well supported through a fast track system that enabled him to have a final week of life at home in his own surroundings supported by those he knew and had cared for him during his life. The rapid and comprehensive nature of this package was commented on by family as particularly valued by them and encouraging to see happen.

Staff had made and maintained an up to date funeral plan with Stanley so his family described being able to follow his wishes, creating a really personal event that everyone recognised as being truly Stanley's funeral. Stanley wanted to be remembered as a happy and gentle soul. He wanted people to think of him, when they were doing a jigsaw puzzle, or when they heard one of his favourite songs.



- Death and dying was not a taboo subject in this house. Valuable bereavement support and creative discussions enabled individual end of life choices to be clearly understood.
- Stability in the support team and the GP over many years built relationships that provided a good quality of life and trust, that enabled care and treatment to be provided more effectively.
- Safe non-frightening opportunities to plan for dying and funeral arrangements, which are well documented and kept up to date should be embedded in practice.
- Proactive desensitisation should be essential to enable access to the full range of health care treatments and investigations.

Pen Portrait 4- Support through Care Coordination



Margaret was in her late 60's when she died. She had a mild learning disability and lived in independent retirement living accommodation, supported by personal assistants (PA), who were paid from a personal budget. Margaret was a very outgoing lady, who liked to mix with others. She got on with most people and she liked to have a laugh. Margaret was very talented in crafting and her work was said to be beautiful. She liked to go out shopping but needed support from her PA to do so.

Margaret had no issues with communication and could understand what was being said to her, and said if there was something she didn't understand. She was very independent and was able to make her own meals and hot drinks. Some support was needed with personal care and house work but she usually chose all her own clothes and liked a clean tidy house.

Margaret had serious long term health condition, which required follow up from various teams and led to multiple hospital admissions for infections. Margaret needed support to book and attend medical appointments, however, she would attend appointments by herself and would not consent to having anyone with her in the appointment. She would inform the support worker of anything she thought they needed to know. This limited the support workers understanding of her health needs, restricting their ability to offer effective support.

Unfortunately, Margaret had not had an Annual Health Check with her GP since 2013 and missed health reviews regularly. In the last 12-18 months before her death, whenever an appointment was booked, it had to be cancelled. Invariably, this was due to her being admitted to hospital for infection, or due to her having an impromptu hospital appointment to discuss her other significant medical problems.

Her final illness was very rapid and due to her only relative having a cognitive impairment they were not included in end-of-life care decisions. Care coordination from a specialist team may have been able to support her in coordinating all her health needs and support her relative in the final care decisions.



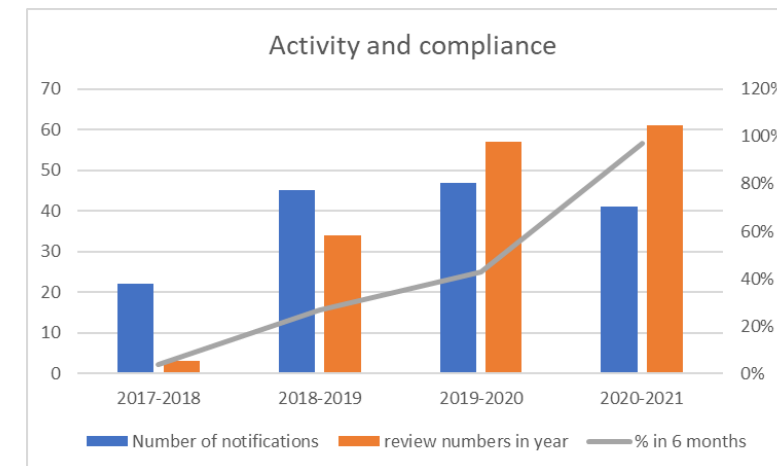
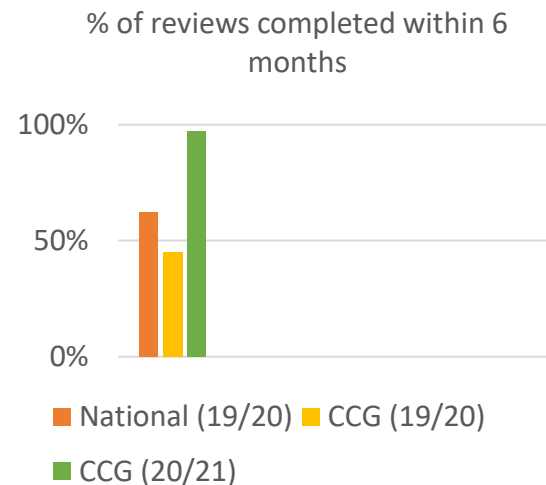
- Complexity of care needs to be understood and coordinated. Hindsight has identified that for someone with this level of complex health there needs to be much more proactive care coordination from a specialist team or named practitioner.
- A clear understanding of an individual's wishes is key to ensuring the right support can be offered. Ensuring that choices are informed, including understanding the consequences of any decisions, is a key role for any support worker and practitioner. It must be a proactive conversation, understood by all involved.
- Annual Health Checks need to be valued and their importance in supporting good health must be recognised by all professionals and support teams. Non-attendance must be followed up, curiosity is essential and adjustments may be required.

Data Set: Performance



	Notifications in year No. & %		Completions in year* No. & %		Multi Agency Reviews in year	% of all Reviews completed within 6 months:
2019/2020	47		58	100	2	45
2020/2021	41		61	100	5	97

- *Completion may be from more than one notification year.



At the time of completing this annual report there are no case reviews outstanding. Oxfordshire has met the target of completing all reviews from the existing programme platform. The new platform is due to go live on June 1st 2021 when an updated process and policy will be introduced.

During 2020-2021 the follow reviews were completed:

- eight case completed by an external review panel
- one from a 2018/19 notification
- nineteen from 2019/20 notifications
- thirty three from 2020/21 notifications.

In 2020-21, 28 of the case reviews completed were subject to external investigations. However of notifications in year and completions within 6 months, a compliance rate of 97% was achieved, an improvement from a compliance rate of 45% in 2019-2020.

These figures include eight Child deaths reviewed in 19/20, but zero in 20/21.

Local Reviewer Arrangements

- The Oxfordshire Clinical Commissioning group (OCCG) safeguarding team coordinates the review processes.
- Provider teams and support organisations all contribute records and information, which is centrally collated and written up ready for the reviewer.
- The reviewer is then responsible for interactions with the family and carers, ensuring their contribution is integrated with the review documentation, undertaking the analysis and identification of learning points.
- In 2020-2021, 96% of reviews were completed by OCCG reviewers, all from within the Quality Directorate, including clinical staff, patient safety team members and safeguarding officers.
- The reviewer profile includes frontline staff and these in the past have been found to contribute effectively, offering real time learning. This year they have been focused on supporting pandemic care provision.

Data Set: Demographics

- National Overview.**

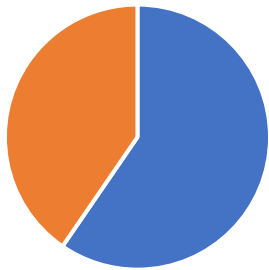
In 2019-2020, of those deaths notified to LeDeR nationally, 58% were male, 90% were White British, 30% were known to have a mild learning disability, 33% had a moderate learning disability, 27%, severe learning disabilities and 10% profound, multiple learning disabilities.

The Oxfordshire data for 2020-2021 is set out in the following section.

- Gender by notification years.**

	2019/2020		2020/2021	
	Male	Female	Male	Female
No.	28	19	22	19
%	60	40	54	46

19/20 Gender Comparison



■ Male ■ Female ■

20/21 Gender Comparison



■ Male ■ Female ■

- Level of Learning Disability**

Those living with a learning disabilities have a wide range of skills, abilities and capabilities. Their requirement for any support or assistance to live their lives to the full is diverse. A scale is used to assist in describing the severity of this disability. Local authorities and GPs have different registers and locally both are used to identify the understanding of support needs for an individual.

A person who is said to have a **mild learning disability** is usually able to hold a conversation, and communicate most of their needs and wishes. They may need **some** support to understand abstract or complex ideas. People are often independent in caring for themselves and doing many everyday tasks.

Moderate disability is defined as observable delays in the development of speech or motor skills, which may be accompanied by physical impairments. Individuals with moderate disability possess basic communication skills and are able to maintain self-care.

Someone who has a **severe learning disability** will: have little or no speech, find it very difficult to learn new skills, need support with daily activities such as dressing, washing, eating and keeping safe.

A profound and multiple learning disability (PMLD) is when a **person has a severe learning disability and other disabilities** that significantly affect their ability to communicate and be independent. Someone with PMLD may have severe difficulties seeing, hearing, speaking and moving.

For every review carried out, the level of learning disability for that person is confirmed and recorded. This is shown in the table for all of the people reviewed in the last year. The two unknown individual were those who were not on a learning disability register but were included at practitioner requests.

Level of Learning Disability	No.(61)
Mild	25
Moderate	18
Severe	14
Profound/Multiple	2
Unknown	2

Data Set: Demographics, Age of death and Gender



All Adults living with learning disabilities who died in 2020-2021:

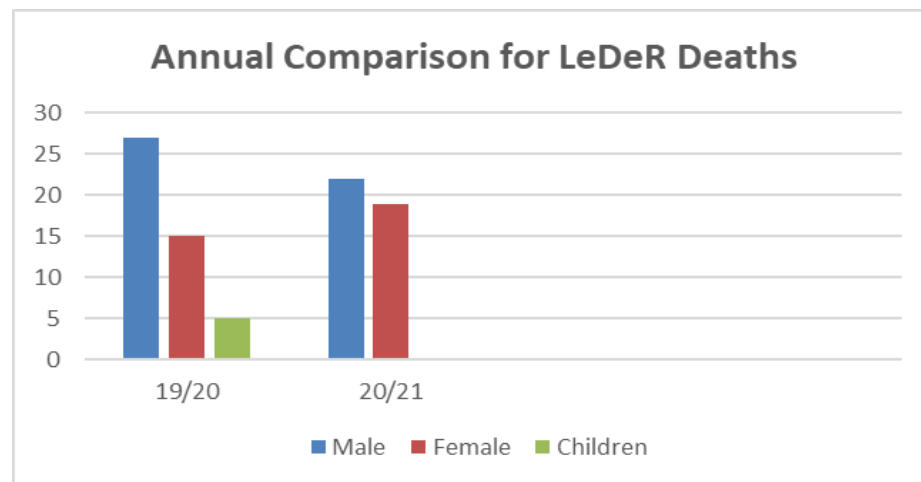
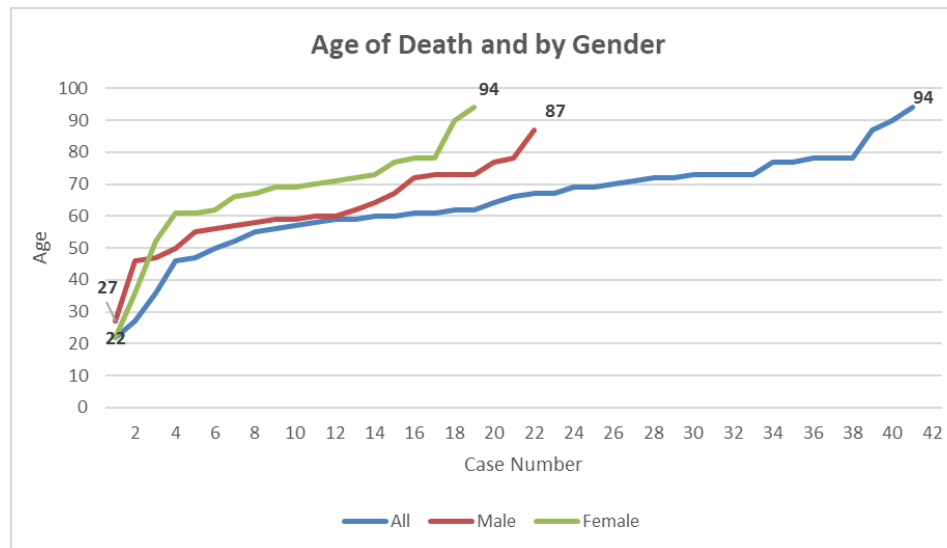
- There were a total of 41 deaths
- The range of age at death was 22 – 94
- The mean average age of death was 64
- The median average age was 65

Women living with learning disabilities who died in 2020-2021:

- There were a total of 19 deaths
- The range of age at death was 22 – 94
- The mean average age of death was 67
- The median average age was 69
- Female life expectancy in the general population of in Oxfordshire is 85.

Men living with learning disabilities who died in 2020-2021:

- There was a total of 22 deaths
- The range of age at death was 27 – 87
- The mean average age of death was 62
- The median average age was 60
- Male life expectancy in the general population of Oxfordshire is 81.7.



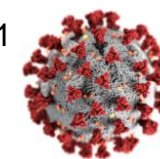
Who died from confirmed or suspected COVID-19 in 2020-2021?

In Oxfordshire in 2020 there were over 19,000 confirmed cases of COVID-19 in people living in Oxfordshire.

Approximately 700 deaths were recorded with COVID-19 on the death certificate locally.

For all adults with learning disabilities there were a total of 10 deaths reported. Half of these individuals also had Down's syndrome. Reviews were completed in year, and the findings were:

- The range of age at death was 52 – 94
- The mean average age of death was 66
- The median average age was 61
- No. of women who died 6
- No. of men who died 4
- All had access to specialist respiratory care



Children living with learning disabilities who died in 2020-2021:

- There were no deaths of children living with a learning disability in 2020-2021



Data Set: Cause of Death and Quality of Care



• Cause of Death

The table below shows the top 5 primary and secondary causes of death

No	Primary Cause of Death	No	Secondary Cause of Death
1	Covid-19	1	Epilepsy
2	Pneumonia	2	Pneumonia
3	Cancer	3	Bowel Obstruction
4	Aspiration Pneumonia	4	Cardiac Arrest
5	Sepsis	5	Deep Vein Thrombosis

In 2020-21 the most common cause of death was Covid-19. This accounted for 24% of all deaths this year. However the overall number of deaths reported is less than in 2019-20.

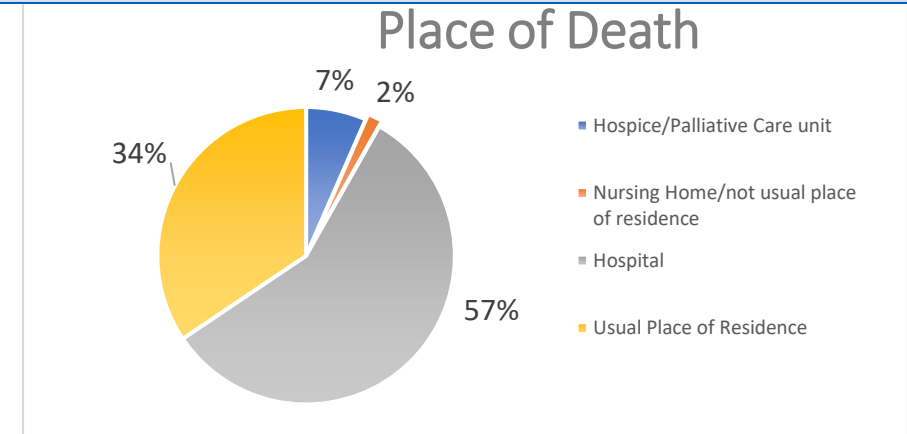
It is notable that three respiratory illness are identified in the top 5 primary causes. This remains in line with the findings of last year's Annual Report, in which 20% of primary causes of death were attributed to respiratory diseases.

Based on Oxfordshire published data the primary cause of death in 2017-2019 was Cancer for the general population. Cancer this year registered as the 3rd primary cause for those living with a learning disability.

Nationally the percentage of patients with a learning disability, who have a diagnosis of epilepsy, are currently on drug treatment for epilepsy and have a record of seizure frequency was 29.6% in 2019-20. Locally epilepsy was the highest secondary cause of death, however no deaths were recorded that related to Sudden Unexpected Death in Epilepsy.

• Place of Death

The table below shows the place in which an individual died. Hospital remains the most common location but with a lower percentage than last year. The number of those in home settings is now the second most common and more were seen to have accessed hospice care than in any previous year. Whilst this year the impact of the pandemic has yet to be fully understood it is anticipated that this trend should continue. Alongside good proactive end of life planning, to ensure personal choice is promoted and supported.



Place of Death		
Place	N=61	%
Hospice/Palliative Care Unit	4	7
Hospital	35	57
Nursing Home	1	2
Usual Place of Residence	21	34

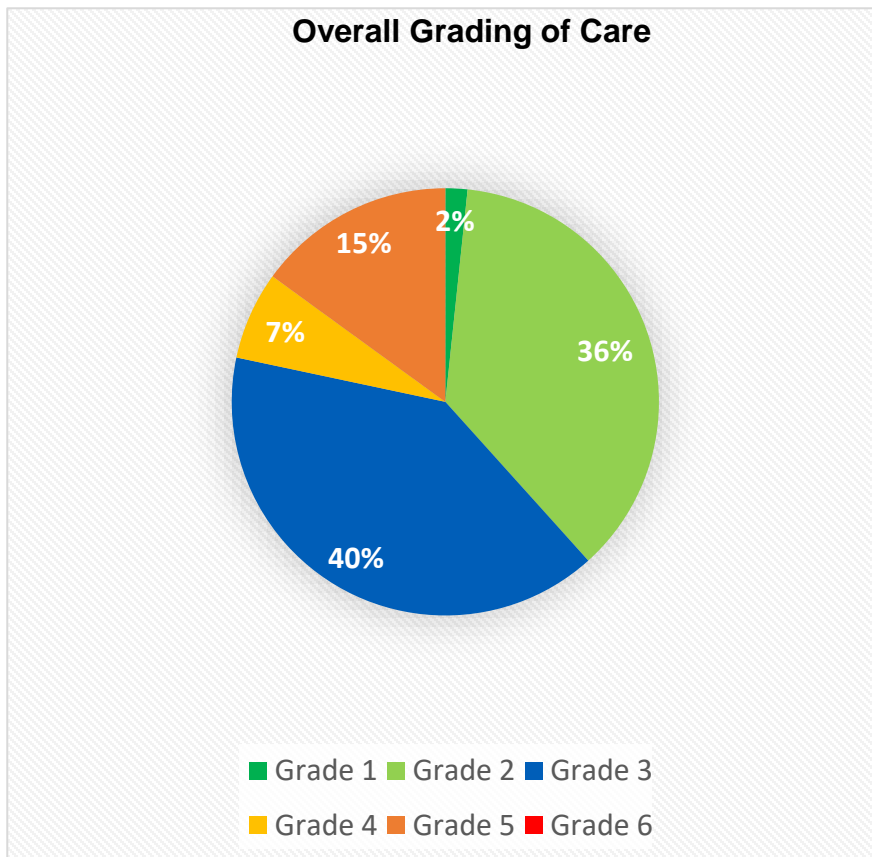
Data Set: Quality of Care



- **Quality of Care**

Every review is graded by the reviewer and this is quality assured by the steering group. A table of grading descriptions is presented and a pie chart shows the percentage of completed reviews graded at each level of the overall quality of care received by the person in Oxfordshire from this year's reviews.

Grade	Grading of Care Criteria
1	This was excellent care (it exceeded expected good practice).
2	This was good care (it met expected good practice).
3	This was satisfactory care (it fell short of expected good practice in some areas but this did not significantly impact on the person's well-being).
4	Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death.
5	Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.
6	Care fell far short of expected good practice and this contributed to the cause of death.



Within Oxfordshire 38% of all cases reviewed in 2020-2021 were graded as good or above. Reviewers reported that families could identify good practice, frequently commending an individual who stood out. There were examples of good practice across the services, which are presented elsewhere in this report. Continuity of care and the level of knowledge about their family member were particularly valued.

Although there were no reviews graded as level 6 there were 22% of the reviews which were below a satisfactory standard of care. Issues identified in these reviews frequently included comments about poor communication between families and services, a lack of reasonable adjustments been made impacting on the quality of the care and support offered, or services not fully understanding the extent of care and support required by an individual.

Eight cases, dating back to 2018, were reviewed during 2020-2021, by the North East Clinical Support Unit (NECS), as part of a national support programme for LeDeR. This provided a quality assurance opportunity. Quality of care scores made by local reviewers was consistently graded as 2 when one provider offered good care, whilst the NECS team would score the equivalent as a 3, only using a 2 when multiple services were seen as good. All other scoring levels were similar. As a result, local reviewers now only score care as demonstrating of good practice when it is seen across more than one service.

Data Set: Quality of Care

- **DNACPR – Do not attempt cardio-pulmonary resuscitation**

A DNACPR decision is designed to protect people from unnecessary suffering by receiving CPR that they don't want, that won't work or where the harm to them outweighs the benefits.

The DNACPR decision-making process should always take account of the benefits, risks and burdens of CPR and consider the individual person's wishes and preferences, the views of the healthcare team and, when appropriate, those close to the person.

Hospital trusts and other providers are legally obliged to have a clear DNACPR policy for staff to follow. It must be accessible so that patients and/or their families are able to understand the decision-making process.

During the first wave of the Covid-19 pandemic, concerns were raised about the potential for “blanket” decisions being made around resuscitation, particularly for more vulnerable populations. As a result, the Care Quality Commission undertook a review of practice across a number of systems, taking into account the understanding and application of the Mental Capacity Act, both when it comes to clinical decision making and taking into account the views of individuals. Within Oxfordshire all DNACPR decisions were closely scrutinised by reviewers.

Of the 61 completed reviews during 2020/21, a DNACPR was recorded in 45 cases (74%)

In 44 situations they were identified as being completed and followed correctly.

In 15 situations it was reported that there was no DNACPR in place for the individual who died and all treatment was offered appropriately.

In one case it was reported as “not known” whether a DNACPR order was in place by the reviewer, suggesting that records were incomplete.

A review of how practitioners used DNACPR decisions during COVID-19 was undertaken and provided assurance that no blanket DNACPRs had been proposed by any services within Oxfordshire. It was found that many providers undertook checks to ensure all existing DNACPRs were up to date. Within the emergency department there was evidence of DNACPR checks being completed and status confirmed with families, in many cases leading to real time completion of the correct unified DNACPR form.

Reviews undertaken during 2020-2021 identified that not all families were aware of the existence of a DNACPR, particularly when they were made in a hospital setting or a residential care provision. In several cases there was also some misunderstanding of the purpose of this decision.

Data Set: Quality of Care



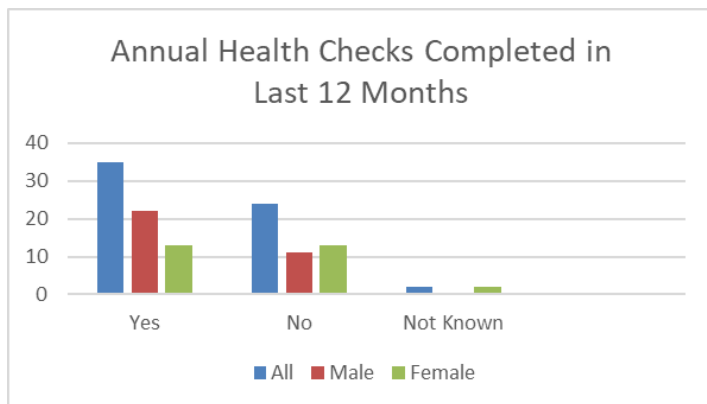
Annual Health Checks (for 14 year olds plus)

Patients recorded on their GP's Learning Disabilities Register are entitled to a Learning Disability Health Check under the Enhanced Service.

In 2019-20 57% of the eligible local population received a health check against the England average of 55%.

In 2020-2021 annual health check completion has been more complex, because of the pandemic changing the way services have been provided. Resources and support have been provided to promote effective completion in a safe manner.

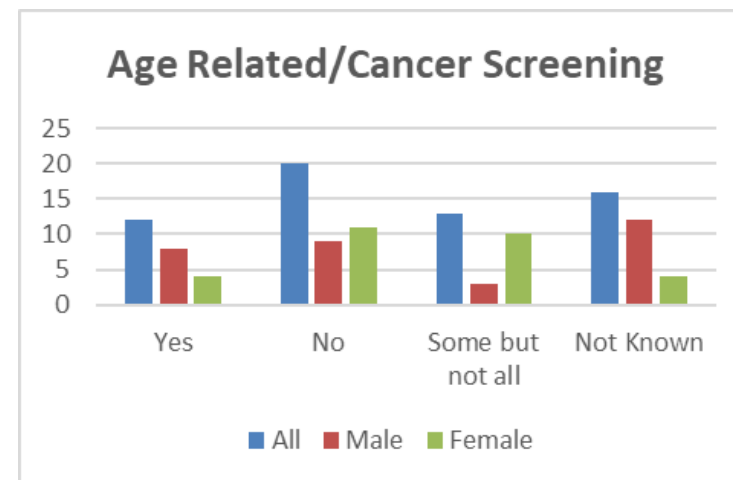
The bar chart and table show how many were found to have been completed in the reviews undertaken this year.



Annual Health Checks Completed in Last 12 Months		
	N=61	%
Completed	35	57
Not Completed	24	39
Not Known	2	3

Role of cancer screening

- In 2017/18 patients with learning disabilities had lower rates of cancer screening than patients without a learning disability, particularly so for cervical screening in Oxfordshire.
- The chart below shows that in 2020-2021, completed screening was confirmed in only 41% of cases. In 26% of cases, there was no record of any conversations about cancer screening.
- Reviewers identified in several cases during 2020-2021, that there was no evidence of any reasonable adjustments being made or offered.
- Best interest decisions are not well documented and assumptions about capacity to cope with procedures were cited as a reason for not “putting them through the procedure” .

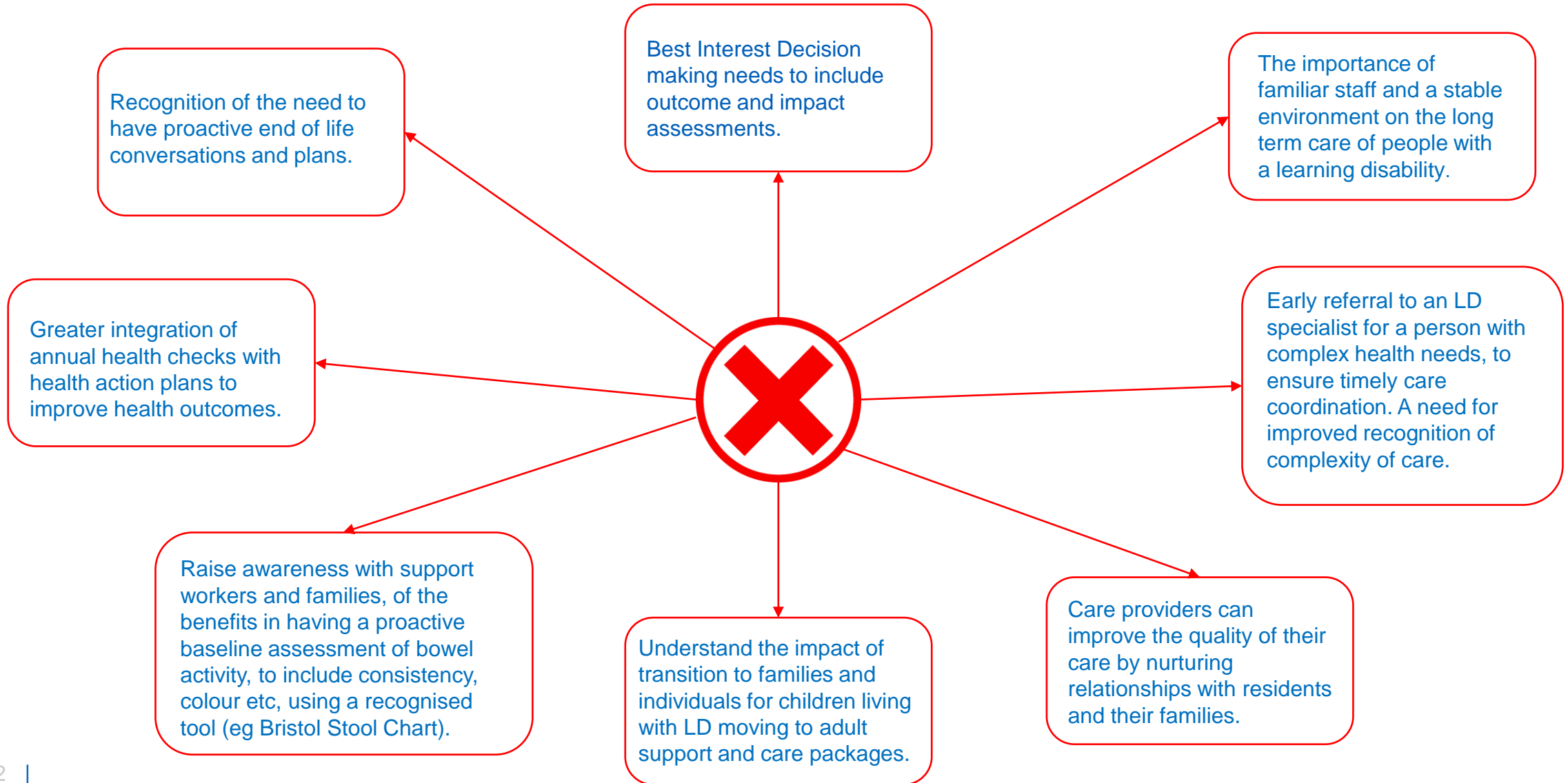


Age Related/Cancer Screening		
	N=61	%
Yes	12	20
No	20	33
Some but not all	13	21
Not Known	16	26

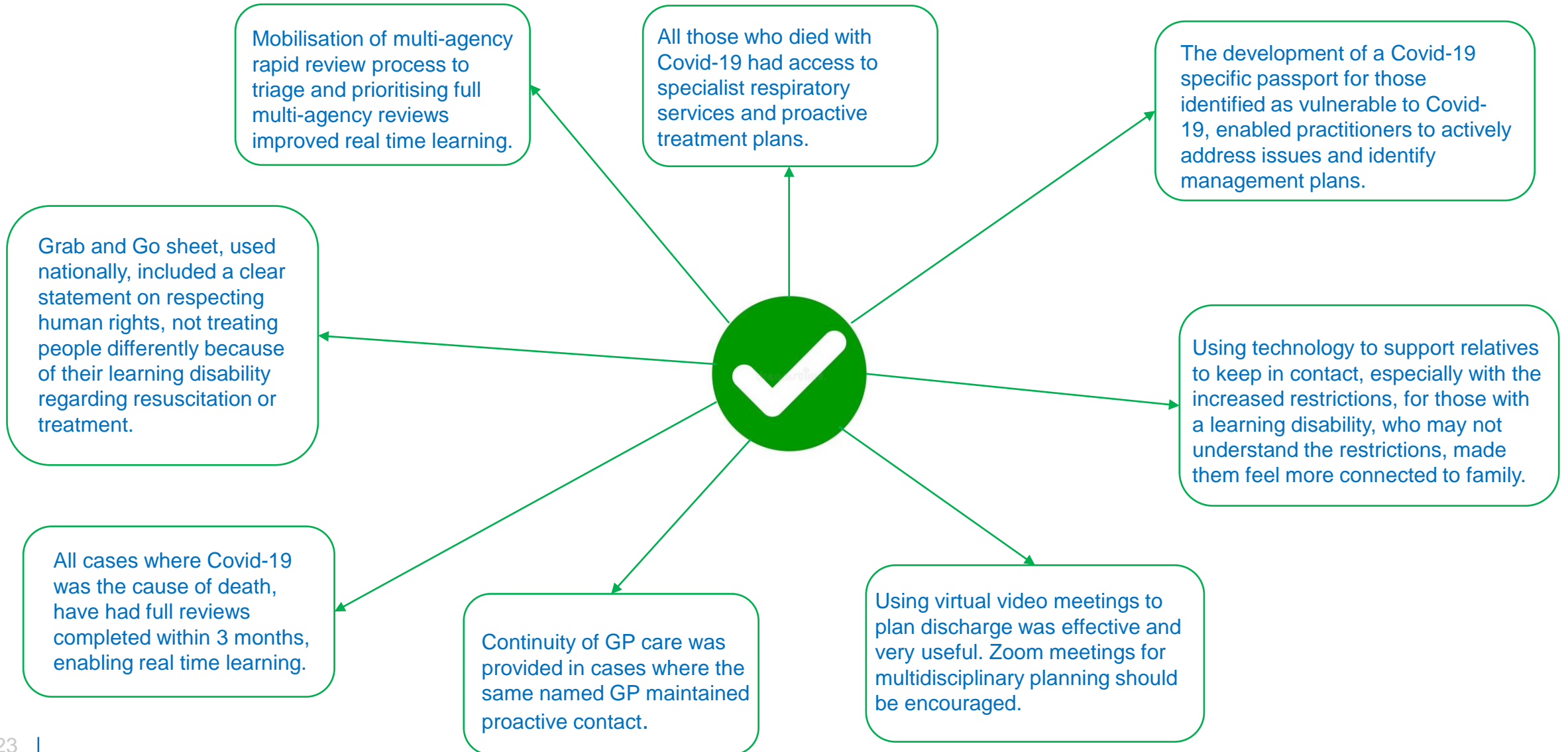
Action from Learning: What best practise and positive outcomes have been learned from the reviews



Action from Learning: What areas for improvement were identified in recommendations from reviews



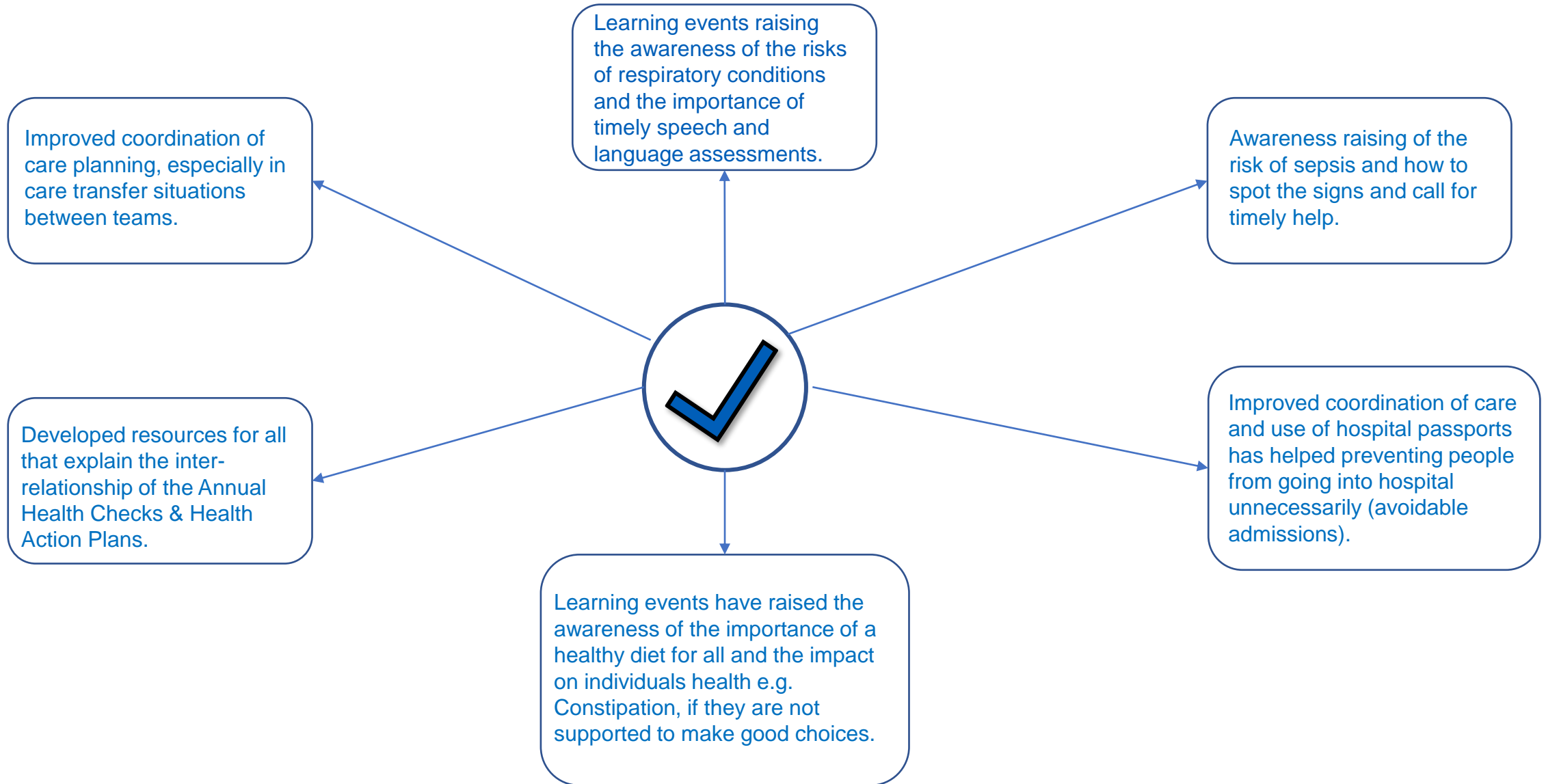
Action from Learning: What best practise and positive outcomes have been learned from the reviews of Covid-19 deaths



Action from Learning: What areas for improvement were identified in recommendations from reviews of Covid-19 deaths



Action from Learning: What has been done to address the learning/themes in the national LeDeR reports?



Learning from Older Reviews completed in 2020-2021



During 2020-2021, eight historic cases were completed by the NECS team. These cases were older than 12 months from notification and had been delayed for a range of reasons including external investigations, delays in getting records and limited reviewer capacity to contact families. The external reviewers provided a quality assurance opportunity for us in relation to comparing to local reviewers completions.

It was noteworthy that many of the learning points identified had already been translated into service improvements and were not being identified in reviews of those who died more recently. These improvements included:

- increasing awareness of the hospital passport and routine referrals to the acute learning disability specialist nurses;
- support workers and families being listened to by health professionals and their views being a key part of any decision making;
- communications between hospital staff and support workers being formalised to ensure they are updated and able to prepare for supporting the individual when they return to their home.
- Supporting care providers, families and support workers to stay if support is felt to be beneficial to reduce anxiety, maintaining continuity and promote greater understanding of the individual's needs.

Good practice was seen in all the cases reviewed and these need to become more consistently seen. They included:

- Appropriate specialist consultations and expertise were identified in a number of cases, ensuring care and treatment was comprehensive, enabled adjustments to be made to care and best interest decisions to be made by multidisciplinary teams.
- Examples of good proactive holistic care in which social and spiritual needs were recognised and supported
- Resources and toolkits appeared to assist in promoting continuity of care, such as the epilepsy assessment tool and a care planning template.
- Several examples were identified of GPs working with individuals to ensure they got their health care, visiting them in alternative locations and working with support workers to reduce anxiety and stress related to physical interventions such as examinations and blood tests.

Promoting anticipatory care planning with families, carers and professionals remains an area for improvement. Anticipatory/end of life care planning is important, however a collaborative and person centred approach to plans is vital in ensuring they are completed in a timely manner and support the rights of the person involved to die in their preferred place of care. This has been identified again during the pandemic this year and will be a key objective for change during 2021-22.

Another area that remains a key focus relates to the need to improve communications during periods of transition. In particular it was found that work is still required to ensure a smooth transition from Children's Services to Adult Services, ensuring families and practitioners have clear understanding of the roles and responsibilities between different teams. Recognising the differences between children in education supportive settings moving to adult environments and services needs to be considered earlier and assessments undertaken on the impact these changes have on all those involved.

A key finding from the external review completion was that the overall grading of care was consistently lower between grades 1-3 compared with local assessments, although it was consistent in identifying poor care and support, grades 4-6. This was found to be the result of differing interpretations of satisfactory care and good care. It has now been clearly defined as being possible to score it good care if several positive learning points can be identified and there is no more than one area for improvement.

What we achieved in 2020-2021



Online event about constipation - 'Lets talk about Pool'
Film of Event on You Tube
Bowel Health resources shared online

Shared resources and closer working alliances were established and sustained

Regular welfare calls to vulnerable patients and carers set up

Nurses with learning disability specialist knowledge have been at vaccination centres to support with encouraging reasonable adjustments to promote accessibility

Visiting arrangements in hospital were challenged and an assessment process for support was developed to create individual plans

Remote assessments have been utilised to support with case co-ordination and management to mitigate the risk to our clients whilst health services were restricted

DNACPR has been a priority action and we have worked with partners to ensure that DNACPR's are only in place for those where it is clinically relevant, this learning and process will be continued

COVID grab sheets have been highly successful and we need to make sure the grab sheet initiative is kept.

Regional Webinar learning programme:
"Wednesday at One".
A series of lifestyle topics explored and discussed developing knowledge and sharing resources.

Moving into Adulthood handbook: funding was secured, and the handbook developed will include sections on Health and Well-being

We have supplied easy read materials about COVID and provided consultation / support to recognise early signs of illness. Information and advice about the COVID vaccine included in teaching

Desensitisation techniques shared and resources developed to support vaccination uptake

Local priorities in 2021/2022



Priority	What we will do	How we will measure it
<p>Ensure that the mental capacity of every individual is considered and recorded, and when best interest decisions are made ensure they are in accordance with guidance and appropriately recorded.</p>	<ul style="list-style-type: none"> • Raise awareness of MCA and BI with all providers and services • Raise awareness of the importance of accurate record keeping with all providers and services • Report back to providers and practitioners any recording gaps or omissions for learning and development purposes. 	<ul style="list-style-type: none"> • Monitor through future Leder reviews
<p>Improving the number of Annual Health Checks (AHCs) completed and the integration between these and the individual's Health Action Plan (HAP) or Education and Health Care Plan (EHCP)</p>	<ul style="list-style-type: none"> • Promote the importance of AHCs with all primary care services. • Work with GPs and providers to develop the content of AHC and the process of integration with HAPs. • Ensure that AHCs are embedded within the EHCP from the age of 14 • To conduct an audit of annual health checks in place for our clients for quality and linking to required health activities • To support with ensuring that annual health check information is then used to update health action plans 	<ul style="list-style-type: none"> • % AHC completed • Quality of HAP and evidence of integration • Monitor the number of EHCPs that contain a AHC for 14+ • Audit report
<p>Promote timely conversations about proactive care planning (life choices) for any individual living with a learning disability (LD). This includes addressing obesity and bowel related support needs</p>	<ul style="list-style-type: none"> • Work with providers and services to ensure they are trained and equipped (with access to easy ready resources) to have proactive conversations with individuals and their families. • Review our respiratory guidance and to develop a respiratory pathway (all the information is in our Care Action Plans (CAPs) but we will make sure that this is now pulled into one document) this is to try and improve our impact re acquired pneumonia and better management of respiratory conditions, we will be doing this with our Oxford Health respiratory team and link with the Oxford University Hospital respiratory services. • We have identified that we have a high level of obesity in our LD population so we will be focusing on work around health lifestyles and diet. • Continued work with dentistry services for support with regular reviews of people with LD with the hope to support with pick up of mouth and throat cancer as well as respiratory pathway work. • Working with support staff and families work continue to promote health bowels, including more proactive monitoring and discussions of bowls habits and stool types, to establish "normal"! 	<ul style="list-style-type: none"> • Monitor through future LeDeR reviews • Evidence of regular dental checks • Reduced numbers of obese individual's in the community • Evidence of the use of stool recognition charts and proactive monitoring in care plans that are reviewed in AHCs.

Local priorities in 2021/202



Priority	What we will do	How we will measure it
Improve the rate of Health Screening Uptake	<ul style="list-style-type: none"> • Ensure that individuals living with an LD are given timely information about appropriate health screening. • Ensure that information is presented to them, or their advocate, in a way that they can access it. • Ensure that all reasonable adjustments are made to maximise the uptake of health screening, for example consider Ultrasound scans rather than mammograms. 	<ul style="list-style-type: none"> • Monitor through future LeDeR reviews. • Improved health screening numbers. • Evidence of reasonable adjustments.
Reduce the number of people with LD dying in hospital to more in line with general population	<ul style="list-style-type: none"> • End of life care and the provision of care plans to be developed and promoted. • For those with the most complex physical health presentations coordination by skilled staff, supporting specialists, families and support staff. 	<ul style="list-style-type: none"> • Monitor through future LeDeR reviews. • More individuals dying in their place of choice. • Clear evidence of good care coordination.
Support social care teams and providers to work in a person centred way to reduce the need for hospital care and to ensure that people live well in their community.	<ul style="list-style-type: none"> • We will continue to promote the training and development of social care providers. • We will work across health and social care teams to ensure quality resources are available to support teams. 	<ul style="list-style-type: none"> • Monitor the reasons for hospital admissions to reduce stays for conditions that could be cared for in the community.
Improve the experience for individuals and their families when they move from children to adult services.	<ul style="list-style-type: none"> • Ensure that AHCs are embedded within the EHCP from the age of 14. • Work with services to establish clear pathways for handover of care. • Ensure that individual's own wishes and views of life and care are paramount. 	<ul style="list-style-type: none"> • Monitor the number of EHCPs that contain a AHC for 14+. • Monitor through future LeDeR reviews.