# LeDeR Annual Report Oxfordshire





For the period 1<sup>st</sup> April 2021 – 31<sup>st</sup> March 2022

<sup>\*</sup> OCCG was merged into the BOB ICB on 1st July 2022 but this report relates to the last full year in which CCGs was the legislative body.

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# **Executive Summary**

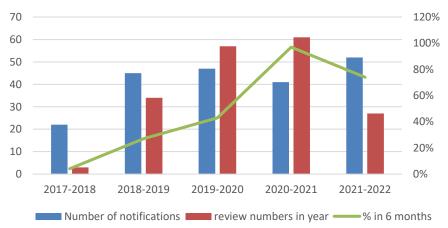


### **Performance:**

The new NHS England LeDeR platform went live in June 2021 The new review process and policy has incorporated into working practice. This has causes some delay in completion.

- 52 notifications in the year 1 April 21 31 March 22.
- 27 reviews completed this year (including some cases from previous years). (UoB platform closed to review access 1 March, NHS Digital platform opened in June 2021).
- 74% of the reviews were completed within six months of notification.
  This reduction is largely due to the gap in access to records as the
  platform was transferred, and changes in review processes that
  resulted.

### Activity and compliance



### Local reviewer arrangements

- The \*Oxfordshire Clinical Commissioning group (OCCG) Safeguarding team coordinates the review process.
- Provider teams and support organisations all contribute records and information, which is centrally collated and written up ready for the reviewer.
- The reviewer is responsible for contacting the family and carers, ensuring their contribution is integrated with the review documentation, undertaking the analysis and identification of learning points.
- In 2021-22, 100% of reviews were completed by OCCG reviewers, all from within the Quality Directorate Safeguarding team.
- 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 care provision.

### **Learning from the reviews:**

- There is evidence of some excellent multiagency working crossing acute and community services.
- Prompt relocation to appropriate care facility when care needs changed were seen. It is
  recommended that the health and care system needs to consider how this was achieved within the
  timeframe to model a protocol on this approach.
- There needs to be a proactive process for specialist practitioners to seek support and follow up
  actions from GPs to prevent time delays, especially when there are changes in care or treatment
  needs.
- To ensure a safe and effective discharge, a solid discharge planning procedure to be put in place that involves next of kin and other allied health providers. The process needs to include ensuring that checks on caregivers' physical health abilities, competency in planned discharge care updates for family, and mutual agreement on discharge arrangements have been completed.
- 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 also 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.

### Introduction



- This is the Fifth 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 27 case reviews undertaken in 2022-2023.
- The LeDeR review system was changed in this year and is now managed any NHS Digital overseen by NHS England.
   This has created challenges and offered us opportunities. It has prompted different ways of working and closer working relationships.
- This report was completed and presented before the national report was published so there is no national comparatives within this report.

# Acknowledgements

- The Oxfordshire steering group continued to support reviews, however resource pressures and increased workload has led to less activity
  this year. However the commitment to learning and improving service provision and person centred care remains paramount and central to
  activities.
- Oxfordshire Association of Care Providers (OACP) has been an extremely valuable partner, disseminating resource, information and advice
  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.

# Key Findings



- There is evidence of some excellent multiagency working crossing acute and community services, creating good joint care.
- Prompt relocation to appropriate care facility when care needs changed were seen. It is recommended that the health and care system needs to consider how this was achieved within the timeframe to model a protocol on this approach.
- There needs to be a proactive process for specialist practitioners to seek support and follow up actions from GPs to
  prevent time delays especially when there are changes in care or treatment needs.
- Annual health checks have improved in consistency of completion the past year, however the correlations with the
  provider held health action plans remains limited or missed. An example of this is the lack of coordinated approaches to
  age appropriate screening being completed with correct preparation and planned reasonable adjustments.
- Mental Capacity Act related record keeping is weak or non-existent in both health and social care records in relation to best interest decisions. An example is where age appropriate health screening has not been undertaken, there is no evidence of Best Interest Decision making having been undertaken.
- To ensure a safe and effective discharge, a solid discharge planning procedure to be put in place that involves next of kin and other allied health providers. The process needs to include ensuring that checks on caregivers' physical health abilities, competency in planned discharge care updates for family, and mutual agreement on discharge arrangements have been completed.
- 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 also 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.
- There was evidence where the anxiety and concerns felt by families are actively recognised and skilfully incorporated into care and treatment plans. Where those anxieties reduced and families reports of quality of care improved. Staff need to be encouraged and supported to make this a core element of care and treatment planning and delivery.

# 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 2021-2022, those living with a learning disability were provided with updates, through My Life My Choice and Oxfordshire Family Support Network. Their roles within the VAM steering group have been strengthened.
- Reporting has been 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. In 2022-2023 it is expected that the LeDeR learning and reporting will be into the Learning Disability I(CB programme board to collate with the Buckinghamshire and Berkshire West place based LeDeR teams.
- ❖ 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.
- During 2021-2022 the review programme was expanded to include those living with a clinical autism diagnosis and this has resulted in a further review of reviewer capacity and specialist advisors and support to the VAM group.
- 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.
- The CCG have continued to work with Oxfordshire County Council to develop a more robust monitoring overview process for the identified priorities ascertained from the Learning Disabilities and Autism annual reviews. This has resulted in the setting up of the Oxfordshire Learning Disabilities & Autism Improvement Board, which brings together commissioners and partners across health, social care and housing services to oversee the development and delivery of services for people with learning disabilities and / or autism.

# **Equality Impact**



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 92% of the reviews undertaken were on those with a white British heritage, this compares to the general local populace being 64%.

### **Ethnicity**

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 only 4% of those deaths reviewed were of a non-white British heritage and 4% did not have a record or heritage in records provided by providers.

|    |                            |         | Wi    | nite                  |                                  | Mixe                       | d/Multi<br>gro           | ple eth       | nicity                           | Asia   | an or As  | sian Br     | itish                            | Bla       | ck or B<br>British |                                  |         | her Ethi<br>Groups        |            |
|----|----------------------------|---------|-------|-----------------------|----------------------------------|----------------------------|--------------------------|---------------|----------------------------------|--------|-----------|-------------|----------------------------------|-----------|--------------------|----------------------------------|---------|---------------------------|------------|
| E  | thnicity                   | British | lrish | Traveller or<br>Gypsy | Any other<br>White<br>background | White & Black<br>Caribbean | White & Black<br>African | White & Asian | Any other<br>mixed<br>background | Indian | Pakistani | Bangladeshi | Any other<br>Asian<br>background | Caribbean | African            | Any other<br>Black<br>background | Chinese | Any other<br>ethnic group | Not stated |
|    | o. of reported<br>eaths    | 48      | 0     | 0                     | 0                                | 0                          | 0                        | 2             | 0                                | 0      | 0         | 0           | 0                                | 0         | 0                  | 0                                | 0       | 0                         | 2          |
| re | of all<br>eported<br>eaths | 92      | 0     | 0                     | 0                                | 0                          | 0                        | 4             | 0                                | 0      | 0         | 0           | 0                                | 0         | 0                  | 0                                | 0       | 0                         | 4          |
|    |                            |         |       |                       |                                  |                            |                          |               |                                  |        |           |             |                                  |           |                    |                                  |         |                           |            |

# Deaths of People in our CCG/ICS:

### Pen Portrait 1 – End of Life Care

- Jane was in her 70's when she was diagnosed with breast cancer, whilst living in Extra Care housing. It was recognised that following her treatment, she needed more support and the nursing home she was previously familiar with was contacted to provide respite on discharge from hospital. This contact was made prior to her having treatment.
- Following assessment by Social Services, it was agreed that Jane could stay there permanently, as it provided for her spiritual needs. Being able to participate in church services was a huge comfort to her. This continued when Jane's health deteriorated and she was less able to take part. Adjustments were made so as Jane could attend the services either in a wheelchair, or from her bed. Jane was very happy and felt safe.
- When it was discovered the cancer had returned, chemotherapy was an option, but was likely palliative. Discussions took place and with help, Jane made it clear that she didn't want to go into hospital and remain at the nursing home. She was also adamant that she didn't want chemotherapy. It was suggested to refer to the local hospice, but as the staff in the nursing home were trained to give palliative care, it enabled Jane to spend her last days being cared for by staff who loved her and felt privileged to look after her.

### We found that:

 Spiritual and cultural needs were both well understood and supported for Jane to enable her wishes and feelings to be heard and included in decision making.





- Jane's review showed how valuable personal cultural and spiritual awareness and active support can be in improving quality of live 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.

## Deaths of People in our CCG/ICS:

# NHS

### Pen Portrait 2 – Changes in care provision: Recognising feelings and supporting shared decision making



- Jack's review has reminded us of the need to understand the reason behind behaviours along side treating the symptoms and not to see them in isolation.
- We need to ensure that professionals become more curious, look back to past challenges and proactively ask the question why more often when behaviour changes

- Jack was 65 when he died of aspiration pneumonia. He had a moderate learning disability and lived in the family home until his mid forties, having tried supported living a couple of times, which he didn't like.
- In his final shared care placement it was planned in association with a Shared Lives placement team,
   that had worked well and he kept occasional contact with the carers there.
- After he moved permanently into supported living again he was reported to be happy. Jack attended
  day service every other week, though he would have liked more. He also did some voluntary work at
  that time.
- After a prolonged admission to hospital, Jack was discharged to a care home, following a full care
  assessment. The care home reported that Jack had capacity and was able to understand what was
  said and give consent for care. He was able to make decisions about his health and diet.
- At that time, he was diagnosed with depression and experienced high anxiety. However, it was thought he had settled well in the home, though he preferred to sit in his own room watching television, playing games or listening to music. He did not want to mix with the other residents. He also started to refuse nearly all meals and snacks that were offered to him. At times, he would hide any food he did have and only accept cold milk.
- Jack was seen by the GP on several occasions and staff encouraged him to eat and drink, as well as
  keeping charts and monitoring weight. A referral to a Dietitian was also requested. Jack was admitted
  to hospital with Covid 19, where he continued to refuse food. A feeding tube was inserted into his
  stomach (a PEG) a couple of months later, to aid nutrition. The plan was discharge home with PEG
  feeds, but sadly, Jack passed away before that could happen.

#### What we learnt:

- Anxiety and depression was not linked back to his historical difficulty with new settings.
- The reason behind his refusal to eat and drinks was not fully explored limiting the ability of Carers and professionals to develop effective supportive care plans.

### Pen Portrait 3: Reasonable Adjustments and Person Centred Care



- Larry was 65 when he passed away from an acute large bowel obstruction, secondary to metastatic cancer. Larry refused any involvement from Social Workers, but eventually accepted support from a community support worker, with whom he formed a strong bond. This enabled him to live on his own in his flat for 36 years, where he felt safe and had his independence,
- Larry was a heavy smoker and was not interested in any cessation advice he was given.
  He was described as having a good sense of humour and enjoyed playing jokes on others.
  Larry's main contact with the GP was for monitoring of his epilepsy, as the Neurologists
  found it difficult to engage with him. It was a challenge to get Larry to attend the surgery
  for his LD reviews, but with perseverance, this was accomplished.
- Larry was deemed to have capacity and refused to have healthcare professionals visit him at home. Larry's GP had documented he was living with a mild learning disability making him vulnerable to exploitation. He could communicate verbally and wanted to be consulted on any decisions made. He didn't like being put under pressure or challenged. He wanted people to talk him quietly when asking, not telling, him to do something.
- When Larry's support worker contacted the GP to say that he was experiencing chest pain and a cough, lung cancer was suspected. It was later confirmed that he had metastatic colon cancer, with lung being secondary. The Oncologists made it clear he would have palliative care and support. Larry was offered one-off palliative radiotherapy treatment and it was established that he understood the treatment offered and his end of life diagnosis.
- The GP involved the Community Palliative Team and District Nurses early, but Larry was
  reluctant to let anyone into his home. He did agree to meet the Palliative team in a café.
  Larry was persuaded to attend the GP surgery a few times, but the main contact was
  between the GP and Larry's support worker. Sadly, Larry was admitted to hospital with an
  acute bowel obstruction and he passed away peacefully in his sleep.

#### What we learnt:

The best interests for an individual may not always be proactive treatment. However it is
essential for professionals to use the expertise and knowledge of those who know the
person well when planning their care or treatment, to ensure that they understand fully the
options.



- Larry's review showed how person centred care is not always about doing something proactive. Professionals need to feel empowered to support all types of decisions.
- Practitioners, and support workers need to recognise the importance of building a relationship and developing understanding. This is key to promoting and advocating for a person when they require support.

# IMPACT- some quotes from families and carers



Listening only works if the it is understood, I feel that I have been heard.

"It was helpful to know someone was looking into our concerns even though we could not." "We have a dedicated bench outside, where her friends can sit and think of her when they are sad"

"We had a celebration of life party after her passing, as we thought it may help her friends process her no longer being here".

"A memorial rose was presented to our home on what would have been her birthday, and we will love and care for it as much as we did her"

NHS England and NHS Improvement



### Data Set: Performance

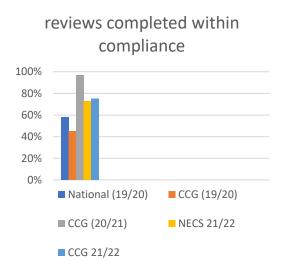


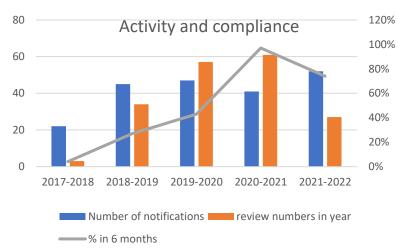
|         | Notifications<br>No. & % | Completions<br>No. & % | Focusse<br>d<br>Reviews | % of all Reviews completed within compliance: |
|---------|--------------------------|------------------------|-------------------------|---|
| 2020/21 | 41                       | 61                     | 5                       | 97  |
| 2021/22 | 52                       | 27                     | 7                       | 74  |

#### **Performance:**

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### **Local Reviewer Arrangements**

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- In 2021-2022, 100% of reviews were completed by OCCG reviewers, all from within the Quality Directorate safeguarding team.
- 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 care provision.

# Data Set: Demographics, Age( local data)

# NHS

# All Adults with learning disabilities who died in 2021-2022:

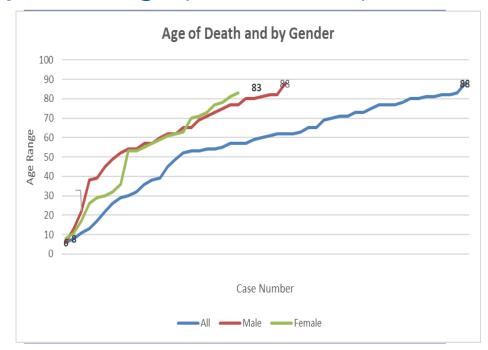
- There was a total of 47 deaths
- The range of age at death was 22 88
- The mean average age of death was 61
- The median average age was 62

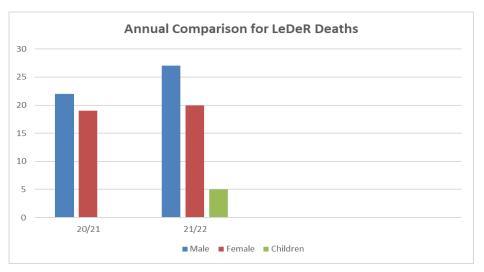
# Women with learning disabilities who died in 2021-2022:

- There was a total of 20 deaths
- The range of age at death was 26 83
- The mean average age of death was 57
- The median average age was 60
- Female life expectancy in the general population of UK is 82.

# Men with learning disabilities who died in 2021-2022:

- There was a total of 27 deaths
- The range of age at death was 22 88
- The mean average age of death was 65
- The median average age was 65
- Male life expectancy in the general population of UK is 79





# All Adults with learning disabilities who died from confirmed or suspected COVID-19 in 2021-2022:

- There was a total of 3 deaths
- The range of age at death was 59 81
- The mean average age of death was 70
- The median average age was 71
- No. of women who died 3
- No. of men who died 00

All deaths related to COVID-19 were reviewed and all care provision was provided according to family and personal wishes. Respiratory specialist support was offered in all cases.

# Children with learning disabilities who died in 2021/2022:

- · There was a total of 5 deaths
- The range of age at death was 6 17
- The mean average age of death was 11
- The median average age was 11



# Data Set: Demographics (from local data)

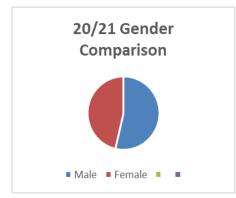


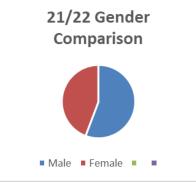
#### Gender

Gender variance is very similar this year to last year. This is in line with those registered on GP lists.

|     | 2020/2021 |        |  |  |  |
|-----|-----------|--------|--|--|--|
|     | Male      | Female |  |  |  |
| No. | 22        | 19     |  |  |  |
| %   | 54        | 46     |  |  |  |

| 2021/2022 |        |
|-----------|--------|
| Male      | Female |
| 29        | 23     |
| 56        | 44     |





In both genders the age of death remains below the average in the general population. It is lower than last year due to their being 5 under 18s who died in this year with complex conditions.

### Level of Learning Disability( if known)

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.

| Level of Learning Disability | No.<br>(27) |
|------------------------------|-------------|
| Mild                         | 7           |
| Moderate                     | 6           |
| Severe                       | 6           |
| Profound/Multiple            | 1           |
| Unknown                      | 7           |

For every review carried out the level of learning disability for that person is confirmed and recorded as either mild, moderate, severe or profound/multiple. The information below shows the breakdown of this information for all of the people reviews have been completed for in the last year.

The unknown cases were due to the detail not being established following the new forms and process. Subsequently, all reviewers are asked to confirm the level of LD as part of their review.

### Data Set: Cause of Death.

#### Cause of Death

The most common cause of death this year was Cancer.

The number of deaths from this was 9 which is 17% of all deaths this year.

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

| No | Primary Cause of Death | No | Secondary Cause of Death |
|----|------------------------|----|--------------------------|
| 1  | Cancer                 | 1  | Epilepsy/Seizures        |
| 2  | Pneumonia              | 2  | Cancer                   |
| 3  | Aspiration Pneumonia   | 3  | Downs Syndrome           |
| 4  | Sepsis                 | 4  | Hypertension             |
| 5  | SUDEP                  | 5  |                          |

For the first time since commencing LeDeR reviews, Cancer has become the leading cause of death, with Epilepsy being the top secondary cause.

Respiratory illness remains very prevalent, however the potentially preventable causes of death have altered in this year.



### 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.

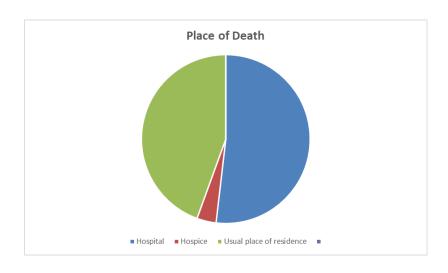
During the first wave of the Covid-19 pandemic, concerns were raised about the potential for "blanket" decisions being made around resuscitation, particularly for more vulnerable populations. As a result, the Care Quality Commission undertook a review of practice across a number of systems, taking into 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.

Of the 27 completed reviews during 2021/22, a DNACPR was recorded in 18 cases (67%) In 13 situations they were identified as being completed and followed correctly. No evidence was found of any care restrictions or altered pathways for these individuals than would be expected from any other population group.

In 9 situations it was reported that there was no DNACPR in place for the individual who died and all treatment was offered appropriately.

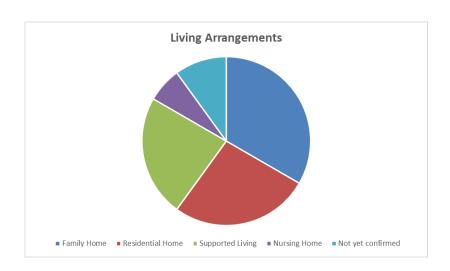
# Data Set: Place of Death and Living Arrangements





| Place of Death |    |     |  |  |  |
|----------------|----|-----|--|--|--|
| Hospital       | 14 | 52% |  |  |  |
| Hospice        | 1  | 4%  |  |  |  |
| Usual Place of | 12 | 44% |  |  |  |
| Residence      |    |     |  |  |  |

| In 2021-2022 more examples were seen in which an         |
|--|
| individual living with a learning disability was offered |
| alternative end of life locations compared to previous   |



| Living Arrangements |    |     |  |  |  |
|---------------------|----|-----|--|--|--|
| Family Home         | 10 | 37% |  |  |  |
| Residential Home    | 8  | 30% |  |  |  |
| Supported Living    | 7  | 26% |  |  |  |
| Nursing Home        | 2  | 7%  |  |  |  |

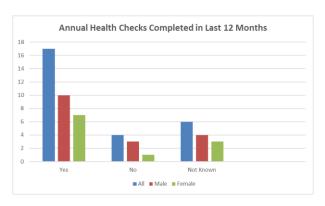
The range of living arrangements reflects the diversity of settings in the local area. In 2021-2022 there will be more care consideration of the support and advice provided to those living in family homes, which on the cases seen this year were very limited

review data.

### Data Set: Cause of Death.

#### Annual Health Checks

Table and chart below show the number of annual health checks completed in 2021-2022. There continues to be lack of link and cross referencing between GP based annual health checks and provider/ care health action plans, which results in actions and activities not always being mutually understood or completed, such as screening.



| Annual Health Checks Completed in Last 12 Months |      |    |  |  |  |  |  |
|--|------|----|--|--|--|--|--|
|  | N=27 | %  |  |  |  |  |  |
| Completed  | 17   | 63 |  |  |  |  |  |
| Not Completed                                    | 4    | 15 |  |  |  |  |  |
| Not Known  | 6    | 22 |  |  |  |  |  |

During the year linked to assessing proactive health action plan and national requirements data on how many had retinal screening patients with LD and diabetes. Numbers of patients included in the sample for some practices are low but the summary in the past 12 months

Across Oxfordshire of those living with a learning disability there are

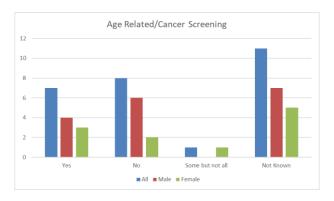
- 28% of those with type 1 diabetes have had retinal screening
- 33% of those with type 2 diabetes have had retinal screening

This will be part of the action plans for improvement in 2022-2023.



### Role of cancer screening if appropriate to your area

Age related screening completion remains low, and in 2022-2023 needs to be more closely assessed to consider the reasons why age appropriate screening is either not offered or not taken up. Offers of screening are nationally generated, these letters are not in easy read or basic format. Additionally, local sites do not review any information prior to appointments about whether an individual may require any reasonable adjustments. This finding has been feedback to the national team.

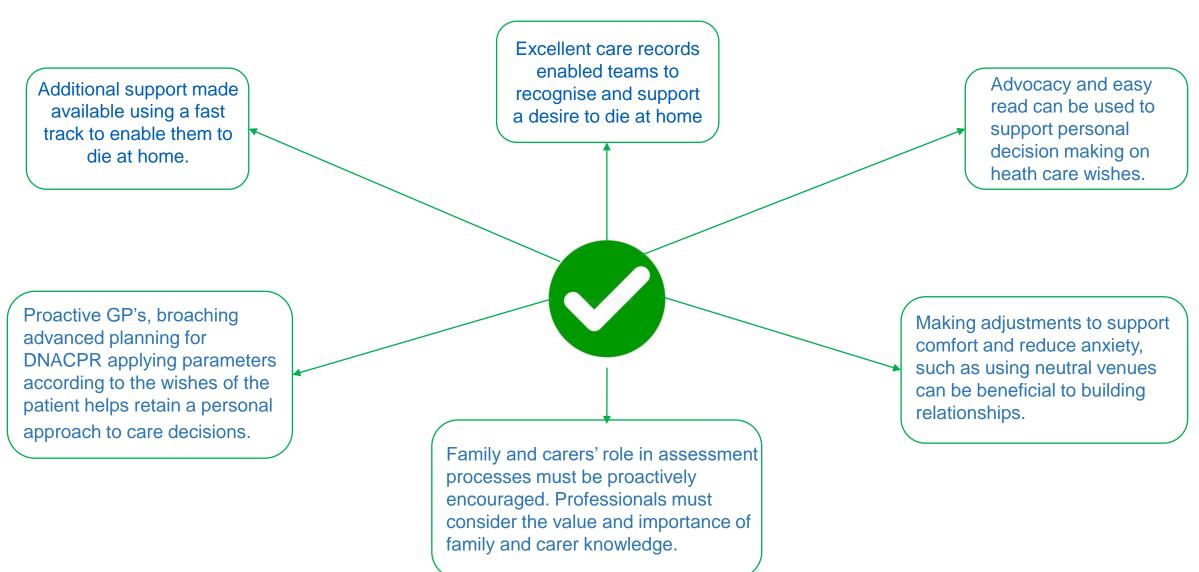


| Age Related/Cancer Screening |      |    |  |
|------------------------------|------|----|--|
|                              | N=27 | %  |  |
| Yes                          | 7    | 26 |  |
| No                           | 8    | 29 |  |
| Some but not all             | 1    | 4  |  |
| Not known                    | 11   | 41 |  |

# Action from Learning:







# LeDeR Health Resources Project

Funding from NHS England to improve and support local service development projects awarded. Project commissioned in March 2022, due for completion March 2023

Building on the successful "Wednesday At One" series and other excellent materials and activities already in place Aim: to create a resource that meets the information needs of a range of individuals, families, support staff and people with learning disabilities and autism, which is Easy to Find, Easy to Navigate and Easy to Read

A co-production project coordinated by Oxfordshire Family Support Network with My Life My Choice and health and Social Care teams

Developed initially in Oxfordshire and extended into a joint project with West Berkshire in May 2022.

Links into the Physical Health Strategy and identified local expertise from all providers.

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



To ensure that an individual with a learning disability has an up-to-date hospital passport, to support staff in the acute setting with understanding their care and support needs.

To ensure discharge planning includes checks on physical health skills by carers, competence in care planned for discharge updates for family and mutual agreement on discharge arrangements.

Mental capacity and best interest decision making should be clearly and consistently recorded within healthcare records in line with statutory procedure and guidance.

Individuals placed a long way from home, increase family anxiety and impact on the ability to communicate effectively.

Discharge planning needs to be coordinated and all practitioners involved in the preparations to ensure good quality care transfer. Annual health checks and health action plans need to clearly contain documentation about the required reasonable adjustments required for an individual to access health care.

# Action from Learning: Local Priorities for delivery in 2022-2023 based on the learning from reviews locally and nationally



Supporting healthy living and improving health life choices remains a key area where education and experience still need developing Health screening should be fully understood by families, carers and support workers so they can support individuals to access them.

More is required to ensure that as public bodies and providers we have eliminated unlawful discrimination, advanced equal opportunities and promoted good relations between people.

MCA implementation of best interests assessments and capacity to make decisions, clarity is not always proactively undertaken. Record keeping is limited and inconsistent.

Discharge arrangements, including proactive planning and family engagement needs to be a partnership process with agreement on best interests and carer skills.

Annual Health Checks (AHCs) need to be completed for all aged 14 and over. There needs to be integration between these and the individual's Health Action Plan (HAP) or Education and Health Care Plan (EHCP), help in provider organisations and individuals homes.

# Action from Learning: The evidence base for local priorities in 2022-2023



| Learning point   | How will we do it?   | How will we measure it?  | Who will lead? |  |
|--|--|--|----------------|--|
| Health screening should be fully understood by families carers and support workers so they can support individuals to access them.   | <ul> <li>Ensure that individuals living with an LD are given timely information about appropriate health screening as part of AHCs, so they can prepare for when letters come.</li> <li>Ensure that information is presented to them, or their advocate, in a way that they can access it.</li> <li>Ensure that all reasonable adjustments are made to maximise the uptake of health screening, for example consider Ultrasound scans rather than mammograms.</li> </ul>   | <ul> <li>Monitor through future LeDeR reviews.</li> <li>Improved health screening numbers.</li> <li>Evidence of reasonable adjustments.</li> </ul>       |                |  |
| Annual Health Checks (AHCs) need to be completed for all aged 14 and over. There needs to be integration between these and the individual's Health Action Plan (HAP) or Education and Health Care Plan (EHCP), help in provider organisations and individuals homes. | <ul> <li>Promote the importance of AHCs with all services.</li> <li>Provide families and individuals living with a learning disability more information about the value and use of AHCs and HAPs.</li> <li>Ensure they proactively use HAPs in those assessment processes.</li> <li>Work with GPs and providers to develop the content of AHC and the process of integration with HAPs.</li> <li>Support with ensuring that annual health check information is then used to update health action plans</li> <li>Ensure that AHCs are embedded within the EHCP from the age of 14.</li> </ul> | <ul> <li>% AHC completed</li> <li>Quality of HAP and evidence of integration</li> <li>Monitor the number of EHCPs that contain an AHC for 14+</li> </ul> |                |  |
| MCA implementation of best interests assessments and capacity to make decisions, clarity is not always proactively undertaken. Record keeping is limited and inconsistent.   | <ul> <li>Raise awareness of the importance of accurate record keeping with all providers and services.</li> <li>Raise awareness of MCA and BI with all providers and services.</li> <li>Report back to providers and practitioners any recording gaps or omissions for learning and development purposes.</li> </ul>   | <ul> <li>Monitor through future Leder reviews</li> <li>Review when undertaking other case management reviews and records audits.</li> </ul>              |                |  |

# Action from Learning: The evidence base for local priorities in 2022-2023 (2)



| Learning point   | How will we do it?   | How will we measure it?   | Who will lead? |
|--|--|---|----------------|
| Supporting healthy living and improving health life choices remains a key area where education and experience still need developing.   | <ul> <li>We will work across health and social care teams to ensure quality resources are available to support teams.</li> <li>Ensure that information is presented to them, or their advocate, in a way that they can access it.</li> <li>Work with families and providers to support them in developing skills to make health live choices within a budget.</li> <li>All services to support and contribute actively to the development of the health resources online package.</li> </ul> | <ul> <li>Monitor through future LeDeR reviews with the goal of identifying less obesity, fewer live style linked deaths and more activities in peoples lives.</li> <li>Continue to build a comprehensive, valued shared resource.</li> <li>To monitor the use of the health resources online package</li> </ul>                             |                |
| Discharge arrangements, including proactive planning and family engagement needs to be a partnership process with agreement on best interests and carer skills.                      | <ul> <li>Share learning in training to service teams and discharge coordinators about the value of inclusive planning.</li> <li>Ensure coordination of discharge includes families, carers and support workers in discussions about any new or different care needs.</li> <li>Work with families, carers and support workers to empower them to seek greater detail about and involvement with discharge decision making.</li> </ul>   | Discharge plan records are clear about discharge coordination processes and showing full involvement of those to whom care and support will transfer. Families, carers and support workers will be able to describe training, on new skills, and active conversation they have been included in to prepare for a discharge into their care. |                |
| More is required to ensure that as public bodies and providers, we have eliminated unlawful discrimination, advanced equal opportunities and promoted good relations between people. | <ul> <li>Review registers of those living with a learning disability to ensure all have access to appropriate services and support regardless of gender, values, culture or spiritual beliefs.</li> <li>Support practitioners and support workers to proactively seek to understand behaviours and not just manage them.</li> </ul>  | <ul> <li>A shared understanding of the demographic make up of those living with a learning disability in our area.</li> <li>Evidence of active links being achieved, and adjustments made, by services with those struggling to engage with existing services.</li> </ul>   |                |

# Action from Learning: Evaluating the Impact



What is in place to monitor and review action plans /service improvements to ensure that they are implemented and effective in improving care, reducing inequalities & saving lives:

- Provider monitoring
- Vulnerable Adults Mortality steering group
- Oxfordshire Learning Disabilities & Autism Improvement Board

How we will evidence that service improvements are making a difference to people with a learning disability and their families:

- Healthier lifestyles and fewer associated illnesses
- Higher take up of screening
- Reduction in Deaths
- Improved record keeping