



**Buckinghamshire, Oxfordshire  
and Berkshire West**  
Integrated Care Board



# LeDeR Annual Report for Berkshire West - BOB ICB

For the period 1<sup>st</sup> April 2022 – 31<sup>st</sup> March 2023



Learning Disabilities Mortality Review  
(LeDeR) Programme

NHS England and NHS Improvement



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# Introduction



The Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB) was formally established as a new statutory body on 1st July 2022, replacing the three clinical commissioning groups. This includes 5 NHS Trusts, 6 Local authorities and 5 district councils. The total population across the ICB is approximately 1.8 million people, of which there are 43,000 adults and 50,000 children with a learning disability. This annual report will only focus on Berkshire West place data.

This is the sixth Annual Report for Berkshire West 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. LeDeR continues to be an important tool in addressing the health inequalities experienced by people with a learning disability and autistic people. The LeDeR policy set outs a structured way to review the lives and deaths of people with a learning disability and now autistic people, to identify the service development needed to address the health inequalities that are leading to premature death.

This report was completed and presented before the national report was published therefore any national comparatives within this report are from the previous year.

## Acknowledgements

Considerable acknowledgement and thanks go to all those who provided information when requested, especially considering the additional pressures faced during the last year. These include:

- GP surgeries
- NHS Trusts
- Local authority
- Care managers and their staff

Further thanks go to our reviewer for their compassion when completing the reviews, keeping the person at the centre of the process in order to identify learning and share good practice. At the core of LeDeR are the people and their families, our thanks go to the incredible carers, families and friends of those who have died, for sharing their stories, sadness and fond memories.

## Governance arrangements

- The LeDeR steering group meeting is Chaired by the Deputy Director of Quality & Nursing. Reporting is to the BOB ICB governing body through the Berkshire West Integrated Care Partnership Quality Committee, into the joint commissioning teams to inform service development.
- This LeDeR Steering committee follows the LeDeR (Learning disabilities Mortality Review programme) methodology, to ensure that all deaths are reviewed in a consistent manner.
- To note, neither the confidential inquiry of 2010-2013 into premature deaths of people with learning disabilities (CIPOLD report), nor the LeDeR process, define a learning disability. As such, the steering committee has chosen not to define it, or what is meant by a 'vulnerable adult'. Rather professionals use their judgement and if they believe that an individual's vulnerability contributed to their death, they should make a referral to LeDeR Steering committee.
- When the death of a person with learning disabilities occurs, mandatory review processes (such as Safeguarding Adult Reviews and Structured Judgement Reviews) takes 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 focus on learning disabilities.
- The steering group has representation from all providers as core members, local authority and voluntary organisations, creating an inclusive approach allowing honest and open discussion.
- Berkshire West BOB ICB has an information gathering stage prior to assigning the review to a reviewer. Reviewers have been able to use their clinical expertise to focus on family involvement and analysis of care and treatment.
- Each review is taken to the LeDeR Steering committee for actions to be assigned and learning points shared and good practice to be cascaded to organisations as appropriate.

# Executive Summary



## Local reviewer arrangements

- Berkshire West Quality Team within the ICB has an information gathering stage prior to assigning the review to a reviewer. Provider teams and support organisations contribute records and information for each case and this is provided to the reviewer
- If further information is required this can be requested by 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.

## Performance

- In 2022-23, 24 notifications were received, 15 case reviews were completed including 12 notifications from the previous year
- Percentage completion rate is 62.5% for Berkshire West.

## Learning from reviews

- Evidence of end-of-life plans and advanced care planning were documented, regularly reviewed and communicated to key people involved. Documentation to support a person-centered approach where the person with a learning disability was able to express their views in a non-verbal or unconventional way, and this was taken into consideration
- Families were largely complimentary of the services their loved ones received
- There is evidence of some excellent multidisciplinary working across acute and community services
- There is a need to improve the quality of annual health checks for learning disability population and health action plans. This includes easy read information for people with learning disability
- Further work is required to seek opportunities to make reasonable adjustments for people with a learning disability to cancer screening.

# Key Findings

- Annual health checks remains fragmented and there needs to be more work to ensure that annual health checks in primary care are effective in identifying unrecognized health needs. However, we did see some good examples of annual health checks completed and health action plans in place with documented reasonable adjustments made by the care home and GP practice.
- There was examples of good practice in documentation recorded with families about their loved ones end of life plan. Documentation included additional information to the GP care records, recording of discussions with families and support of the person with a learning disability. There was good documented evidence of GPs offering extended appointments for people with learning disabilities.
- Multi-disciplinary team working was evident with excellent multiagency working across acute and community services. Conversations were documented across health professions working together and decision making regarding treatment of individual patients and service users. Good evidence of professionals from local and wider system working together to meet the needs of our patients.
- Documentation in Mental Capacity Assessments had improved from previous years with evidence of completed paperwork and discussions inclusive of accommodation and making decision about individual care. It was notable that the actions and approach of individual staff from across disciplines in the health and social care sector were singled out for praise, suggesting a real willingness and commitment to provide the best care possible.
- End of life plans and advanced care planning were well documented, regularly reviewed and communicated to key people involved. There was evidence of a person-centered approach where the person with a learning disability was able to expressed their views in a non-verbal or unconventional way, and this was taken into consideration.
- Review of cancer screening showed that some GPs were providing easy read information and there was evidence of good conversations captured in the care records. Work is ongoing to share best practice across primary care to ensure consistency in information provided in easy read format for people with a learning disability.
- Early identification of deteriorating patient where DNACPR and Respect forms were completed with evidence of clinicians prioritising comfort and dignity.
- Discussions with the family members remained largely positive and complimentary of the services their loved ones received. Many expressed their sincere thanks to all healthcare professionals involved and spoke fondly of individual staff members, referring to carers as extended family members.
- Challenges remain around lack of reviewers as highlighted in earlier annual reports with completing the backlog of LeDeR cases from the previous years with one reviewer.

## Performance : Year 2022-23

- ❖ Total number of notifications: **24** cases
- ❖ Backlog of cases from previous year: **12** cases
- ❖ Total reviews completed in year: **15** (*this figure includes 21-22 cases*)
- ❖ Reviews outstanding: **21**
- ❖ Percentage completed: **62.5%**
- ❖ The biggest challenge previously had been completing the backlog of LeDeR cases from the previous years with one reviewer.



# Action from Learning 2021-22

## What has been done so far:

Learning point	Actions in place	Expected Outcome
Screening	Berkshire West Integrated Care Board runs a monthly meeting with a Learning Disabilities Partners Group to share good practice, identify gaps and explore solutions towards achieving equality of access to health services.	Promote access for health screening to achieve well being of people with an LD
Equality	The CCG promotes equality of access through Easy Read advocating reasonable adjustments in all aspects of an individual's needs to access health and social care services	Improved health outcomes through developing accessible information and workshops with partners
Annual Health Checks	The ICB commissioned 'The Advocacy People to' deliver training into the community in collaboration with the GP lead for Learning Disabilities.	To increase registration of people with a learning disability and access to Annual Health checks for both adults and children aged 14 and upward.
Mental Health Capacity assessment implementation/ record keeping	MCA is carried out by the local authority Approved Mental Health Practitioners	Capacity is assessed to ensure that people have their Human Rights protected and experience least restrictive practices.
Healthy Living and improving health life choices	The ICB commissioned 'The Advocacy People to improve quality of life and promote Health and Wellbeing for people with Learning Disabilities and Autism (LDA), promote equality of access to good healthcare and reduce early mortality.	<p>The provider to have a clearer idea of the numbers of people with learning disabilities and autism that are experiencing blocks and barriers in accessing health and wellbeing services.</p> <p>Partners and service users informed to improve awareness, make reasonable adjustments to promote access to Health and Wellbeing services.</p>
Discharge arrangements including proactive planning and family engagement	The ICB employs a Discharge Coordinator to support discharge from hospital and carry out 6-8 week commissioner over sight visits to ensure that patients are safe. The ICB also delivers Care Education Treatment Reviews (CETRs) for children and Care Treatment Reviews CTRs for adults. CETRs/CTRs enable the ICB to work with an independent panel, professionals and families to formulate plans exercising people's rights to receive appropriate levels of care aligned to their needs and both avoid unnecessary admissions and reduce length of stay. A Dynamic Support Register is in place for children aligned to the key worker programme. The ICB commissioned BHFT to develop an adult DSR to identify at risk patients and promote support through the community teams.	<p>Admissions Avoidance and reduce length of stay</p> <p>Reduce hospital admissions and promote quality</p>

# Data Set: Performance



Year	Notifications	Completions	Focused Reviews	% of all Reviews completed within compliance:
21-22	33	21	3	64%
22-23	24	15	6	62.5%

15 cases were completed in the reporting year, of these 12 cases were from the previous years backlog.

Although our organisation has ceased from Berkshire West CCG and has transferred into the BOB ICB, there is still an ongoing piece of work to identify, streamline and standardise the LeDeR process across BOB. Therefore, this dataset is based on Berkshire West demographics only.

Currently, Berkshire West has one independent reviewer to review the LeDeR cases. There is a need to ensure we have more reviewers/trained professionals within the organisation to guarantee the reviews can be completed within the timely manner of the 180 days national target.

There has been delays with receiving provider/local trust information as the cases will go through an internal SJR review first prior to assigning a case to a reviewer. Additionally, if other professionals or services are involved such as safeguarding, police or coroner this can further delay the process. While there is a recognition for more reviewers this has been escalated BOB wide and a plan is in place for Commissioning Support Unit (CSU) to take over from August 2023 with a dedicated pool of reviewers to continue the LeDer review process.

The LeDeR system platform has been in development nationally to improve data collection to ensure data is being collected in a more structured and consistent way. While the new features should aid improved data collection, there is still no export function to retrieve data which has meant that LACs are required to develop their own data collection tools to collate local data for interpretation.

Cases (15)	Days Taken	Days over 180 day target
Case A	292	112
Case B	328	148
Case C	390	210
Case D	326	146
Case E	330	150
Case F	253	73
Case G	195	15
Case H	413	233
Case I	391	211
Case J	258	78
Case K	258	78
Case L	364	184
Case M	320	140
Case N	202	22
Case O	237	57

### Average completion rate (2021-22):

On average it took **303** days to complete a case review. Ranging from 195 days to 413 days. This concludes to cases on average being completed **123** days over the expected national target of completion within 180 days from the data reported. These cases were from the previous years backlog and took longer to complete due a gap in identifying a reviewer. Further delays were due to cases requiring a 'stop the clock' as they were being investigated by the police.

No. of cases completed (3)	Days Taken
Case 1	320
Case 2	202
Case 3	237

### Average completion rate (2022-23):

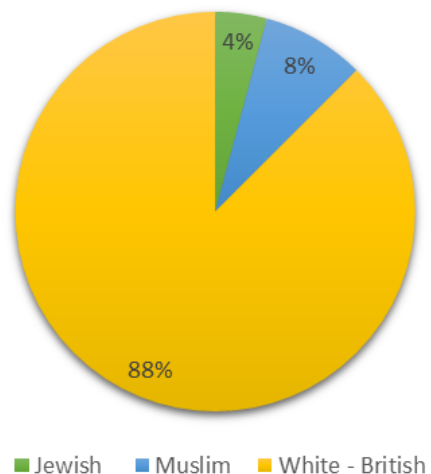
On average it took **253** days to complete a case review for cases reported in 22-23. This concludes to cases on average being completed **73** days.



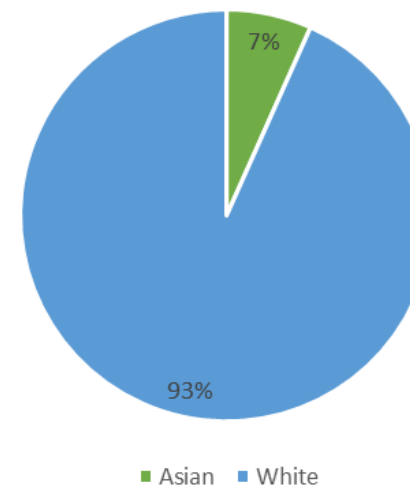
# Equality Impact



Ethnicity of reported cases in 22-23.



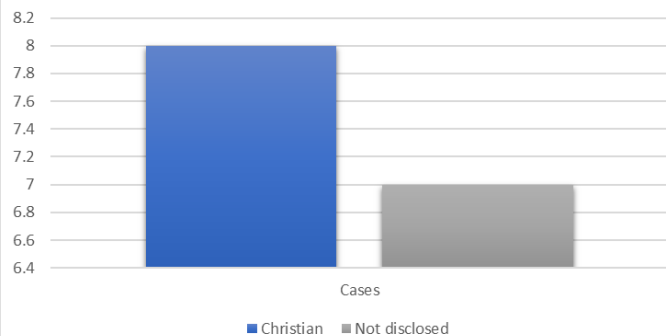
Ethnicity of completed cases in 22-23



## Ethnicity

Nationally, COVID-19 has disproportionately impacted people from minority ethnic backgrounds. This has also been reflected in local population data as those with learning disabilities from minority ethnic groups, are consistently underrepresented in the notifications of deaths. All adult reviews of a person from a minority ethnic community will receive a focused review to further understand the impact and interaction between ethnicity and learning disability.

## Religion



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	Muslim	Pakistani	Bangladeshi	Any other Asian background	Caribbean	African	Any other Black background	Jewish	Any other ethnic group	Not stated
No. of reported deaths	21								2							1		
% of all reported deaths																		
Completed cases in 22-23 (15)	14								1									

# Deaths of People in our CCG/ICS: Pen Portraits



The following pen portraits provide a brief outline of the person and the circumstances of their life and death, names have been changed to protect identities.

Sally\* was born in Canada, she was fostered and spent the first 7 years of her childhood, she was well cared for by her foster family. When Sally was around 7 years of age, she moved to XX due to political concerns.

In XX, Sally stayed in a group home and then moved to XX Village in the early 1980's where she lived. Sally has remained living at XX Village ever since as this is her home and her community. Sally met her husband after moving to the village and they married in 1991. She converted to Judaism when she married.

Sally lived in the village for around 40 years and lived with another service user for the majority of this time. Sally's diagnosis was Down syndrome, a mild learning disability, schizophrenia, underactive thyroid, sleep apnoea for which she had a CPAP machine. Sally had dementia which had declined rapidly within the last 6 months before her death.

Sally was married previously, and they used to live together at XX. Her husband sadly passed away 20 years ago but she remained in XX. Sally had lots of friends in the village, where she worked in a café and did lots of work with the complementary services team. She was very active in plays and village productions. Sally liked makeup and having her nails done, Sally really enjoyed her food, going for meals and being out and about, she had a very active social life.

Sally and partner moved to XX and lived happily as a couple until her partner was diagnosed with dementia. Sally found this especially difficult to understand what was happening and watch her partner's health decline. Due to her partner's needs, he had been moved to other services within the village and Sally found it very difficult to feel comfortable visiting him due to the mix of other residents and watching her partner struggling with communication and remembering who she was. Her partner sadly died in 2005 and Sally had much difficulty in managing her grief and the impact of this. She received therapy and this enabled her to understand her emotions and come to terms with his passing.

Sally is a Christian (non-practising) and she also observes the Jewish holy days but did not attend the synagogue in the village. Sally has a Kosher diet in general due to living at XX.

Sally's father lives in XX and she visits three yearly, he is unable to support her on his own. She also has a brother who is unable to provide support and only sees her when they visit their father. Her mother used to live in New York but passed away in 2022. Towards the end of Sally's life, they had rare contact, possibly once a year when Sally would visit at Christmas. This was due to her dad's age and medical conditions that caused visits and contact to be reduced. Sally's mum passed away around six months before her death. Her mother lived in New York and would fly over to visit once a year. Sally's mum kept in contact by sending cards and letters throughout the year.

Sally knew many people in the village but tends to gravitate towards staff to try to form friendships. This is likely due to their ability to help/ support her, but also understood her communication better than other residents.

Sally is described as a charming, polite, and funny woman who is very kind and caring. Staff report that they enjoy working with her and loved her sense of humour.

Communication - Prior to Sally's dementia she was very independent, but towards the end of her life she found it a lot harder to communicate her needs. Sally would sometimes try and write down what she was trying to say and used her own type of Makaton using objects of reference. Sally was slow to respond verbally and needed to be given time to respond. She also has a writing pad provided for her if she prefers to write. Sally communicates by facial expressions and thumbs up or down.

Activities - Sally had a full timetable. The following activities were arranged: Monday- Walk. Tuesday - shopping with staff at a local supermarket). Wednesday- Drama. Thursday- music at another supported living service. Friday- 1-1 to do what is needed, e.g. appointments, spending time with staff etc.

## Pen Portraits continued:



Helen\* was a 51-year-old woman who had been a resident in a supported living arrangement. Helen was placed there by local authority and was under a Court of Protection Order to reside and receive care there in her best interests. Helen had a learning disability and was diagnosed with Emotional Personality Disorder. Helen received daily living support from care staff to support her with her activities of daily living. She had 35 hours of 1:1 support a week plus 35 shared hours. There was a 1.5 ratio of support staff during the day with a sleep-in carer during the night.

Helen could express her views and wishes. She could not reliably communicate her needs due to being unrealistic about her abilities & her limited ability to assess risk. Frequent displays of anti-social behaviour resulted in numerous calls to the police and emergency services. Helen was vulnerable to sexual and financial exploitation by others. Care packages and a live-in carer were tried, but this failed due to Helen not accepting carers in her home and her challenging behaviours.

Helen had a bedroom in a quiet residential area with a garden. She shared her communal accommodation with two other females. Before moving Helen lived independently in a two-bedroom flat. However, she was unable to manage both emotionally and practically due to her problems with hoarding, alcohol misuse, self-harming, and high levels of anxiety. Staff needed to be familiar with her care and health needs as well as her behaviours. Helen had difficulty processing information and decision-making difficulties. Staff needed to speak clearly, simply with not too much information at once.

Helen's mother acted as her advocate and provided her views. During her last Social Care Review, Helen said she had no other health issues besides a bad toe on her left foot, which was bandaged. She said her toe was a result of her diabetes and her kicking the side of her bed by mistake. When asked why she did not wear the prescribed stockings by her GP, she said the stockings made her leg/feet swell. Helen said she could manage her health and well-being independently, including ordering prescriptions and did not need this to be done by staff or to be witnessed that she has taken. During the review, she expressed that she felt stressed out due to the new resident in the house who was always talking about her problems.

Helen could physically attend to her hygiene but needed verbal encouragement and monitoring to change into clean clothes and incontinence pads. Support staff reported that Helen was in a routine of bathing once a fortnight when she saw her parents. However, this became even longer because she was not visiting her family regularly during the lockdown. She complained of difficulty getting in and out of the bath but did not want help from staff or any aid to support her.

Helen had an appointee to manage her finances at the council. In 2021, there was a review with her appointee, and it was decided to give Helen the full personal allowance, which was put on a bank card rather than £4.00 daily. Helen found not having cash extremely stressful. Using the card confused her, so she returned to cash with the total amount instead. She was given an additional £30 a week for shopping. Helen denied needing prompting, encouragement, or emotional reassurance from support staff and said she was completely independent. In 2017, Evidence of Capacity assessment to establish if Helen was able to decide where to live and how she planned to meet her care needs and manage the risks. Outcome: Helen did not have the capacity to make the decision. DOLs application was made in 2020.

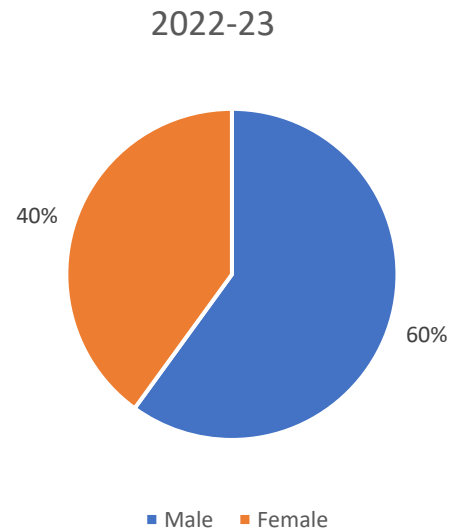
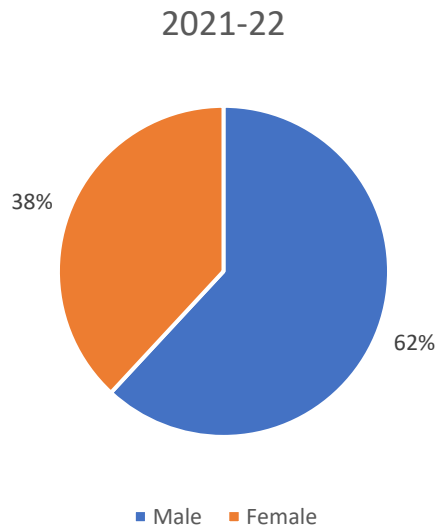
# Data Set: Demographics (from local data)



- Gender

Gender variance is similar to the previous year. In both genders the age of death remains below the average in the general population.

	2021-22	2022-23
Male	13	9
Female	8	6



- Level of Learning Disability (if known)

For each review carried out the level of learning disability is recorded as either mild, moderate, severe or profound/multiple. The information below shows the breakdown of this information for all cases reviewed and completed for in the reporting period. Previously, this information was not captured and the unknown cases were due to the detail not being established following the new forms and process. Subsequently, reviewers are asked to confirm the level of LD as part of their review.

Level of Learning Disability/Autism	Cases.
Mild	4
Moderate	2
Severe	3
Not Answered	5
Unknown	1

- Review Types

Focused reviews are completed for anyone with a clinical diagnosis of autism or if the person is from a Black, Asian or minority ethnic (BAME) background. Of the cases completed four were logged as focused review – 4 (BAME) and 1 diagnosis of autism.

Review Type	Cases
Focused LD	4
Focused LD & A	1
Initial LD	10

# Data Set: Demographics, Age (local data)



## All Adults with learning disabilities who died in 2022-2023:

- There was a total of 15 deaths
- The range of age at death was 21 – 89
- The average age of death was 59
- The median average age was 60

## Women with learning disabilities who died in 2022-2023:

- There was a total of 6 deaths
- The range of age at death was 24 – 89
- The average age of death was 60
- The median average age was 60

## Men with learning disabilities who died in 2022-2023:

- There was a total of 9 deaths
- The range of age at death was 21 – 79
- The average age of death was 58
- The median average age was 69



## All Adults with learning disabilities who died from confirmed or suspected COVID-19 in 2022-2023:

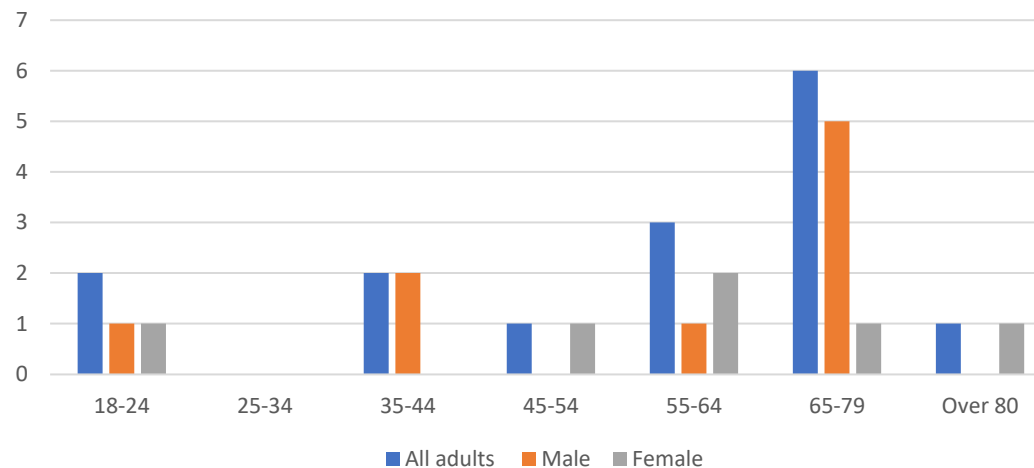
- There were no deaths from COVID-19 in 2022-2023
- 2 cases were unknown if Covid was suspected.



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

- There was 1 death (age 12) of a child living with a learning disability in 2022-2023

Age at death (2022-23)



Comparative data from the past three years is not showing significant differences in relation to median age of death. Small numbers result in any statistical differences being difficult to establish, however, in the future, it is anticipated that the larger BOB ICB data set may enable this to be analysed more thoroughly.

# Data Set: Cause of Death



- **Cause of Death**

The most common cause of death in the reporting period was respiratory disease. However, this data is based on completed reviews only (15). The national data in the previous year (2021-22) showed cancer and pneumonia were the most common cause of death recorded for people who died with a learning disability.

Primary Cause of Death			
No	2021-22	No.	2022-23
1	Cancer	1	Respiratory disease
2	Pneumonia	2	Pulmonary embolism
3	Aspiration Pneumonia	3	Ischaemic heart disease
4	Ischaemic heart disease	4	Frailty / old age
5	Cardiac arrest	5	Cardiac arrest

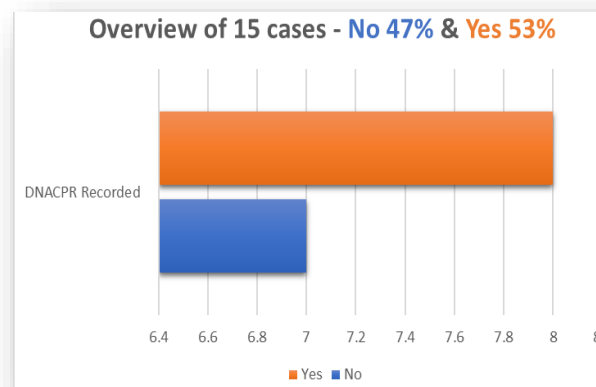
- **DNACPR – Do not attempt cardio-pulmonary resuscitation**

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 several systems, considering 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.



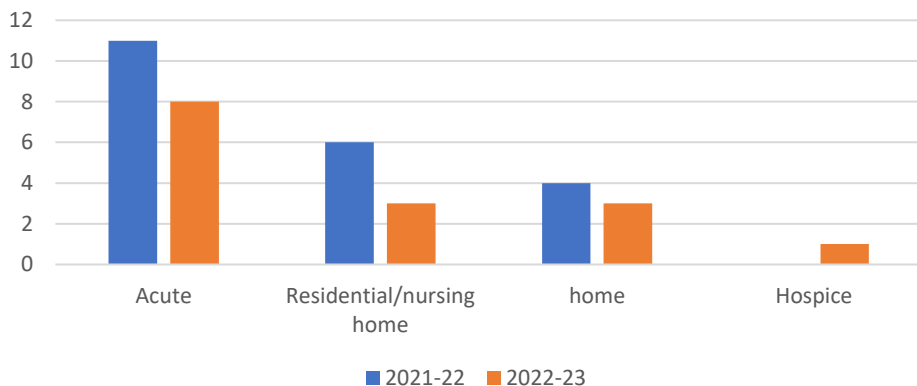
Of the 15 completed reviews during 2022/23, a DNACPR was recorded in 8 cases (53%). In these cases they were identified as being completed and followed correctly. There was no evidence of care restrictions or altered pathways for these individuals. Conversations with next of kin were recorded to have taken place in all cases. In 7 situations it was reported that there was no DNACPR in place for the individual who died and all treatment was offered appropriately.

# Data Set: Cause of Death Continued



	<u>2021-22</u>		<u>2022-23</u>	
<b>Place of death</b>	<b>No</b>	<b>%</b>	<b>No</b>	<b>%</b>
Acute	11	52%	8	53%
Residential/nursing home	6	29%	3	20%
Home	4	19%	3	20%
Hospice	0		1	7%
<b>Total</b>	<b>21</b>		<b>15</b>	

Place of death

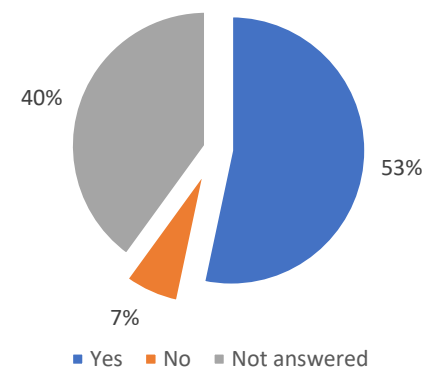


National data from 2021 showed 61% of people with LD died in hospital, this is broadly in line with our local data where 53% died in hospital in the reporting year vs 52% in the previous year. A greater proportion according to national data also showed that people with an LD will die in hospital compared to the general population - 59% of people with a learning disability in 2018-2021 vs 42% of the general population in 2020.

## Annual Health Checks

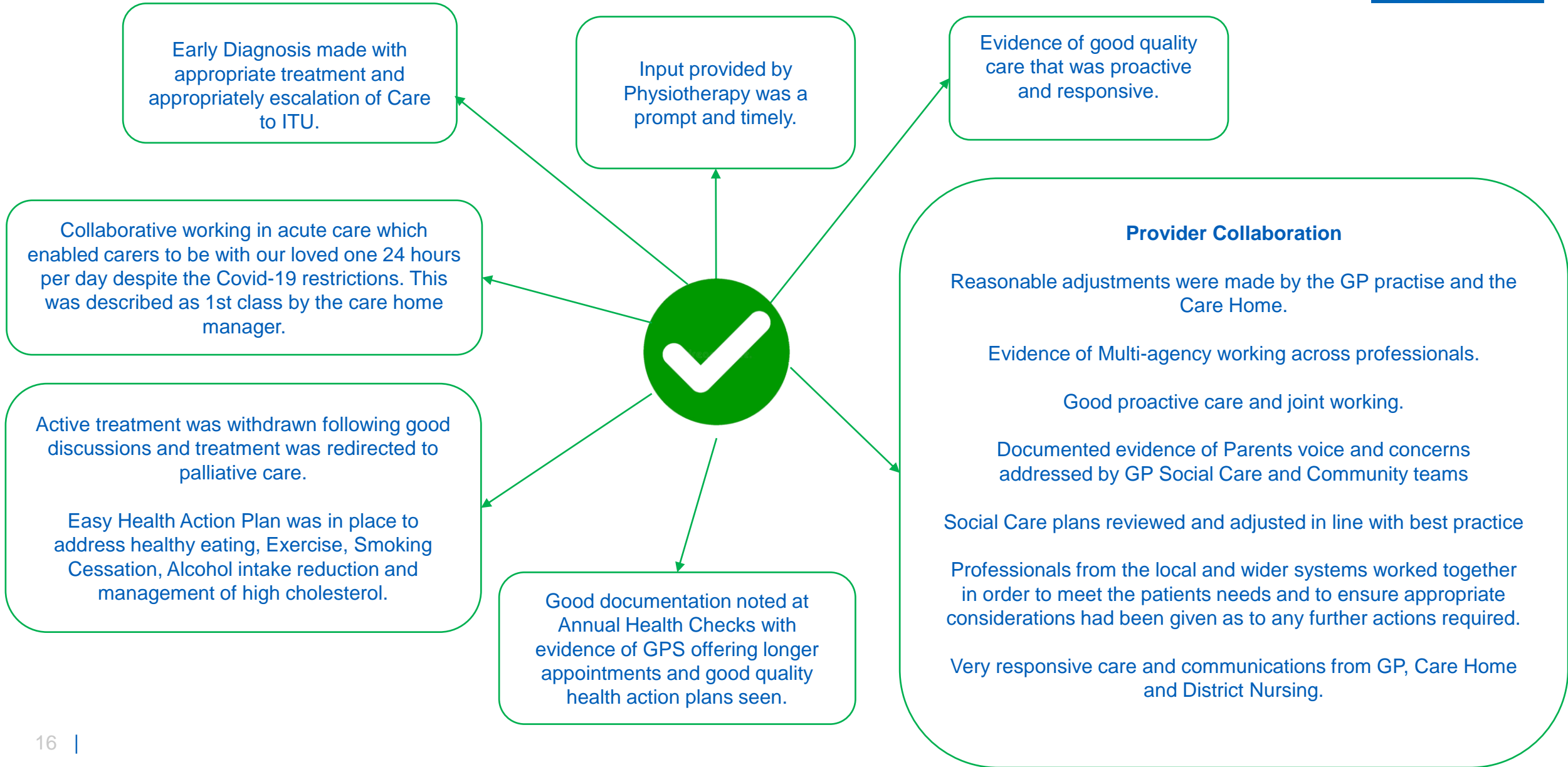
- 8 cases has an annual health check within the past year.
- 6 were not answered
- 1 case did not have an annual health check

Annual health checks



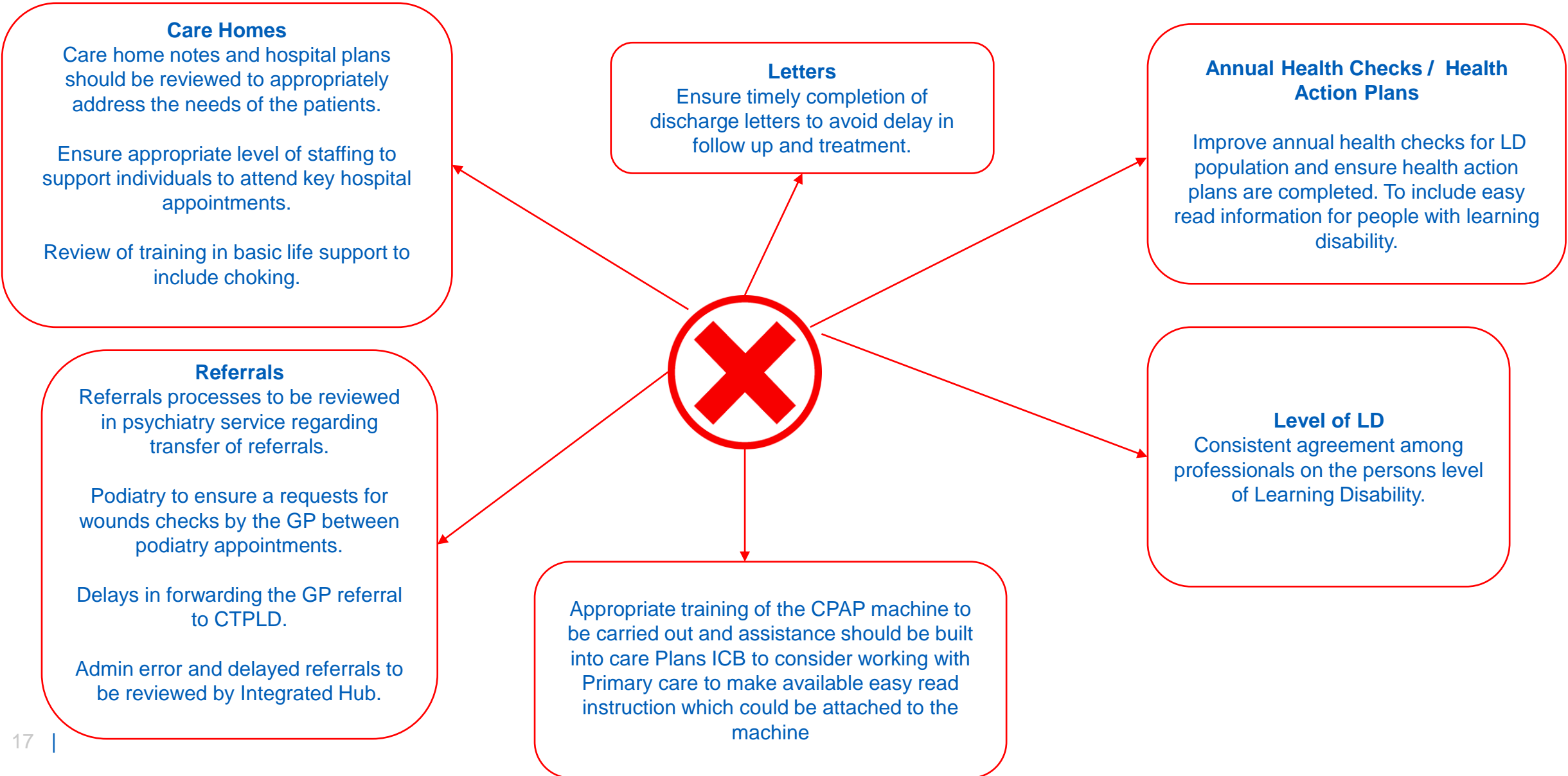
For over half the cases reviewed there was evidence of annual health checks completed with clear documentation and reasonable adjustments for the individual to access healthcare. However annual health checks remain an issue and within the reporting period the ICB commissioned 'The Advocacy People to' deliver training into the community in collaboration with the GP lead for Learning Disabilities in 2022-23.

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

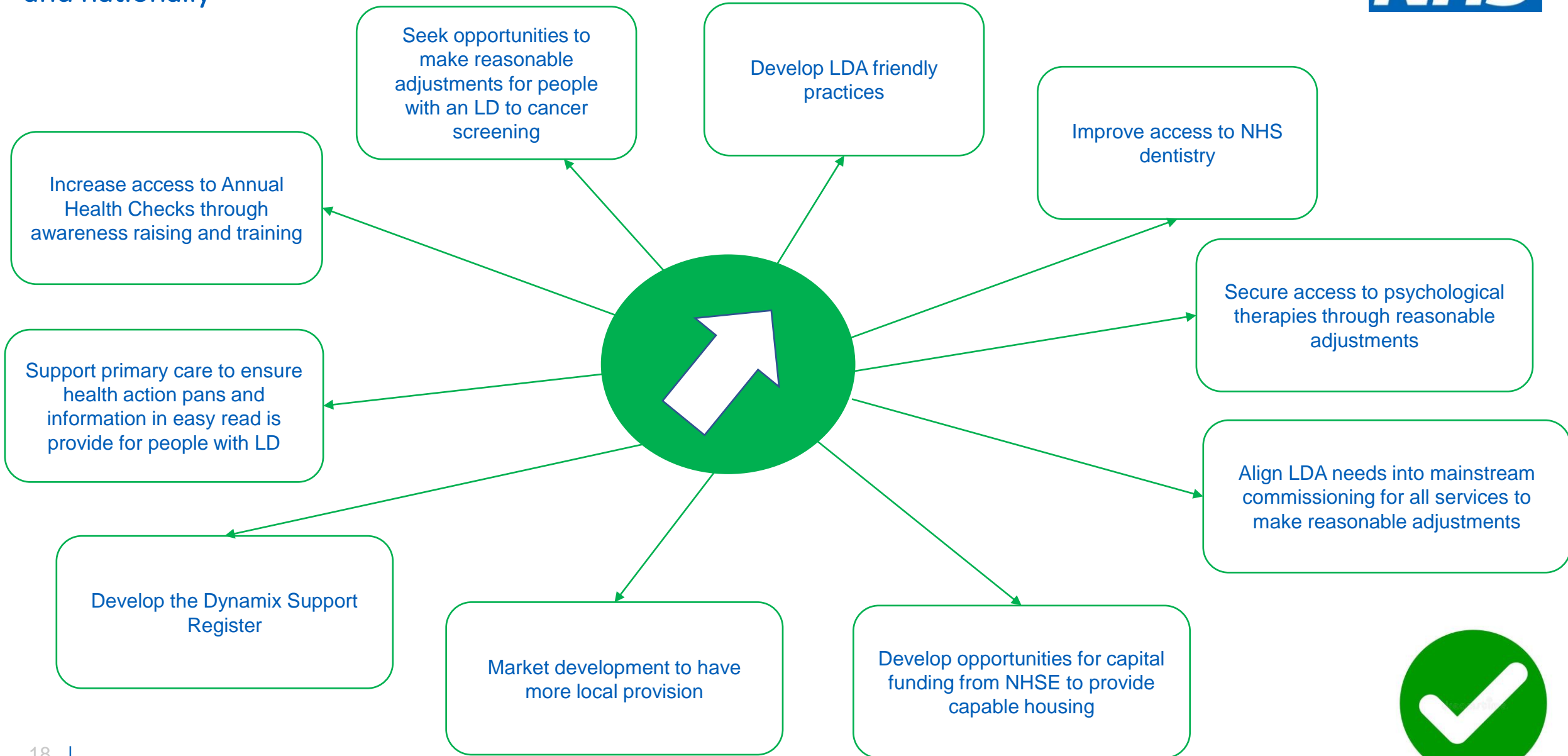




# Action from Learning: What areas for improvement were identified in recommendations from reviews



# Action from Learning: Local Priorities for delivery in 22-23 based on the learning from reviews locally and nationally



# LeDeR Project: Health Resources Online

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

Building on the successful “Wednesday At One” series and other excellent materials and activities already in place create an online accessible health resource portal

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

Initiated in Oxfordshire and extended into a joint project with Berkshire West in May 2022. Links into the Physical Health Strategy and identified local expertise from all providers. Who all assisted in scoping resources.

A co-production project coordinated by Oxfordshire Family Support Network (OxFSN) with My Life My Choice and many other teams, now involved in testing the online site.

The platform launch is planned for November 2023. It will be hosted and maintained by OxFSN, with all project partners committing to maintaining and sharing updated links and resources as they develop.