LeDeR Annual Report
Surrey Heartlands CCG / ICS

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

NHS England and NHS Improvement

Content

Executive Summary

The Surrey LeDeR team are committed to improving care, reducing health inequalities and preventing the premature mortality of people with learning disabilities in Surrey. Through the completion of LeDeR reviews, we can identify the care experienced locally, including any areas of good practice and any areas that require improvement.

During 2020 / 2021, Surrey LeDeR team have made extensive progress in the delivery of the LeDeR programme, with 239 reviews being completed. Of these, 152 were completed by Surrey reviewers, the remainder were completed by an external clinical support service. The progression of the reviews has provided a large evidence base for this report. 38 of these related to deaths that occurred prior to 2020. This has been achieved in partnership with families, care agencies, local health providers and social care services. There were 114 deaths reported to LeDeR in 2020 / 2021. 97 of these reviews have been completed. The remaining 17 are currently on hold pending the National LeDeR electronic system reorganisation.

The findings from this report are that in Surrey, women with learning disabilities die 21.6 years sooner than the general population and men with learning disabilities die 10.7 years sooner than the general population.

The most common cause of death was COVID-19 followed by pneumonia.

Our priorities going forward are:

- To work to ensure that we hear the voices of people with lived experience and others from minority groups. This will help us improve access to services, reduce health inequalities and prevent premature mortality
- To maintain focus on LeDeR priorities during a time of changing landscapes within the Surrey Clinical Commissioning Group / Integrated Care System (CCG / ICS).
- To improve the uptake of cancer screening across Surrey Heartlands CCG / ICS and ensure that the Mental Capacity Act (MCA) is followed when making decisions around screening.
- To increase confidence and skills in identifying when a family member may be deteriorating through the expansion of the delivery of Restore 2 Mini training to family carers.
- To increase awareness and expand the use of the ReSPECT documentation.
- To support the implementation of the Oliver McGowan training.
- To work with the medication management team to ensure that people with learning disabilities and autism receive the right medication to meet their needs and medication is reviewed regularly.
- To work to ensure that people with learning disabilities and autism receive good bowel management. Surrey Heartlands CCG / ICS will work with both health and social care colleagues to improve awareness and management of constipation to implement best practice across the system.

Key Findings

- There was a disproportionately high number of deaths in relation to people from a black or black British community.
- In Surrey, women with learning disabilities die 21.6 years sooner than the general population and men with learning disabilities die 10.7 years sooner than the general population.
- The number of men who died in Surrey, in 2020 / 2021 was 12% higher than in 2019 / 2020.
- Male deaths accounted for 63% of all COVID-19 deaths reported to LeDeR in 2020 / 2021.
- In Surrey, 48% of people who died experienced care that was found to be good or exceeded standard expectations of care. This means that just over half of the people who died (52%) received care that was found to have fallen short of the expected good practice in some areas.
- Of the people who died, 77% had a 'Do not attempt cardiopulmonary resuscitation' form (DNA CPR) completed correctly and this was followed.
- The report found that often these forms were completed in response to an acute admission to hospital and late in the patient's pathway. This may indicate that there was a lack of advanced care planning.
- Four of the DNA CPR forms had an inappropriate reason provided such as frailty, learning disability or Downs Syndrome.
- Only 68% of the people who died this year had an annual health check, 19% had no annual health check and 13% had no evidence that a health check had taken place.
- There was a very low uptake of cancer screening in Surrey and North East Hampshire however information around screening uptake was unavailable for approximately 50% of the deaths reviewed.
- Only 2% of people eligible for cervical screening had this performed.
- A higher uptake of screening could potentially reduce cancer related deaths as it is the fourth most common primary cause of death in people with learning disabilities in Surrey.

Introduction

LeDeR is the National programme which reviews the deaths of people with learning disabilities across England. The National LeDeR report in 2019 found that people with learning disabilities died sooner than the general population. This was 22 years sooner for men and 27 years sooner for women. The aims of the LeDeR programme are to improve the care received by people with learning disabilities, address any health inequalities and prevent premature mortality.

Surrey Heartlands, Surrey Heath and North East Hampshire and Farnham Clinical Commissioning Groups have worked together to deliver the LeDeR programme across Surrey and Hampshire healthcare systems. This report documents the delivery of the programme and the findings from the reviews carried out.

The Surrey LeDeR Steering Group have had strategic oversight of the programme since it began in 2017. It is acknowledged that family involvement is of great value in the LeDeR process. As a result the Surrey LeDeR team are committed to ensuring that there is family representation at LeDeR meetings and in the review process.

Acknowledgements

- We would like to thank the families and carers who have contributed to the LeDeR reviews. In addition to this we would like to thank the local health and social care services for the provision of information.
- The LeDeR team have recently met with the four local Valuing People Groups and the Surrey People's Group to gain their view on how people with learning disabilities would like to be involved in the programme and informed about the findings. We would like to thank the attendees for their ongoing input. We are now in the process of redesigning the Surrey Heartland's CCG /ICS LeDeR webpage and would like to thank them for volunteering to be part of the development of a short video which explains why LeDeR is important.

Governance arrangements

- The Surrey LeDeR programme has been managed through the Clinical Commissioning Groups (CCG) to date however, this will move to Integrated Care System (ICS) responsibility, as of June 2021.
- LeDeR reporting for North East Hampshire and Farnham CCG and Surrey Heath CCG moved into the Frimley Health and Care System as of April 2021. Learning themes from completed reviews shall continue to be shared across the boundary to ensure any joint learning can be addressed.
- The Surrey LeDeR Steering Group has been the driver for the LeDeR programme and has monitored the learning themes across the Surrey and North East Hants and Farnham area. The introduction of the new LeDeR policy in March 2021 has prompted some adjustments to the LeDeR programme. As such the LeDeR Steering Group has been disbanded and a new LeDeR Governance Panel has been created. The first meeting for this panel will be on the 26th May 2021 and monthly thereafter.
- The Governance Panel will have senior representatives from across local health providers, commissioners and social care partners. It will address the learning from completed reviews and will agree the actions from this learning. In addition to this, the meeting will review the ongoing learning themes and track and monitor the impact of any actions as a test of effectiveness.
- The LeDeR programme reports into the Surrey Heartlands ICS Quality and Performance Board and the Surrey Learning Disability & Autism Programme Board.
- In turn, the Surrey Learning Disability & Autism Programme Board reports in to the Surrey Learning Disability and Autism Strategy Board.
- Ultimately the work of the Surrey Learning Disability & Autism Programme Board reports to the Surrey Health & Wellbeing Board.

Equality Impact

The Surrey LeDeR programme is committed to better health outcomes and improved access to services for people with learning disabilities and autism. We will also work with our system partners to eliminate discrimination and advance equality of opportunity in respect of the services that are commissioned in Surrey.

Ethnicity

The table below shows the ethnicity breakdown of the people whose lives and deaths were reviewed this year. This showed that 87.7% of the deaths reported were of White British ethnicity.

Notifications in relation to people from a Black or Black British community were disproportionately high (2.7% of the deaths reported) in comparison to the local population data.

The data also demonstrates disproportionately low reporting of the deaths in relation to people from White Irish, Traveller or Gypsy and any other White community (1.8%) and Asian or Asian British communities (0.9%). There were no notifications received in relation to people from Mixed / Multiple Ethnicity communities (0%) despite the fact that they represent 2.1% of the local population. This could suggest a reporting bias in the data with the deaths of people with learning disabilities from the above minority groups being under-reported to the LeDeR programme however this is difficult to confirm with the data available.

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	100	1	0	1	0	0	0	0	0	1	0	0	2	0	1	0	8	0
% of all reported deaths	87.7%	0.9%	0%	0.9%	0%	0%	0%	0%	0%	0.9%	0%	0%	1.8%	0%	0.9%	0%	7%	0%
Ethnicity% of local populace	83.5%	1.1%	0.2%	5.5%	0.4%	0.2%	0.9%	0.6%	1.8%	1.0%	0.3%	1.7%	0.3%	0.7%	0.1%	0.8%	0.9%	0%

Deaths of People in our CCG/ICS: Pen Portraits

Eleanor, 46 years old, died from bowel cancer

Eleanor was described as a very determined young woman who from a young age had been encouraged and guided by her parents to be independent. She lived in supported accommodation and very much enjoyed her independence. On various occasions she held down part time supported employment. She had worked at a company doing general office duties and reception work which she particularly enjoyed.

She was able to express herself and her needs verbally in English, however, due to her autism, she experienced problems with social communication and interactions and expressing herself especially to new faces. She needed a lot of time and persuasion to alter these routines, even for a medical appointment.

Eleanor had a wide circle of friends and a very good support network. She loved socialising with her friends and family and accessed the local community independently. She enjoyed looking after others who were less able than herself and would often assist them in chores or trips out.

Kieran, 57 years old, died of COVID-19

He was described as a highly sociable gentleman who had a close relationship with his family. He loved to have fun. His family and care staff report that he had a very good sense of humour and loved a joke.

Kieran was very creative and enjoyed arts and crafts activities such as making hats, puppets, colouring and painting. He also loved playing with his soft toys and going to events such as parties, the theatre or the cinema.

Lee, 42 years old, died of respiratory failure

Lee was reported to enjoy music, particularly Bob Marley which he liked to be put on before he was helped to get up in the morning. He was able to make some noise with maracas and bells in music sessions and enjoyed karaoke.

He loved his weekly hydro sessions and sensory cookery sessions. He seemed to enjoy company and people talking to him, as well as trips out and being included in activities. He liked hearing from his family and getting visits from them.

Pen Portraits continued:

Billy, 91 years old, died from heart failure

Billy was a gentleman with mild learning disabilities. He was able to communicate his needs and wishes verbally and could read and write. He was fiercely independent and was capable, up until the last few years of his life, to look after himself with little support. He accessed his GP independently and would make appointments by himself with no support or guidance.

He had a very good relationship with his GP.As he aged he did become more reliant on staff for support and care. He was an avid sports fan and enjoyed cricket and especially football. He supported Chelsea FC and loved talking to staff about matches, players, tactics etc. He also loved movies and spending time in his room. He expressed a wish to go on an overseas holiday and staff with the aid of magazines, brochures and pictures enabled him to decide that he would like to go to Canada. He holidayed in Canada with staff support in 2014. It was reported that Billy had a wonderful time and thoroughly enjoyed his stay.

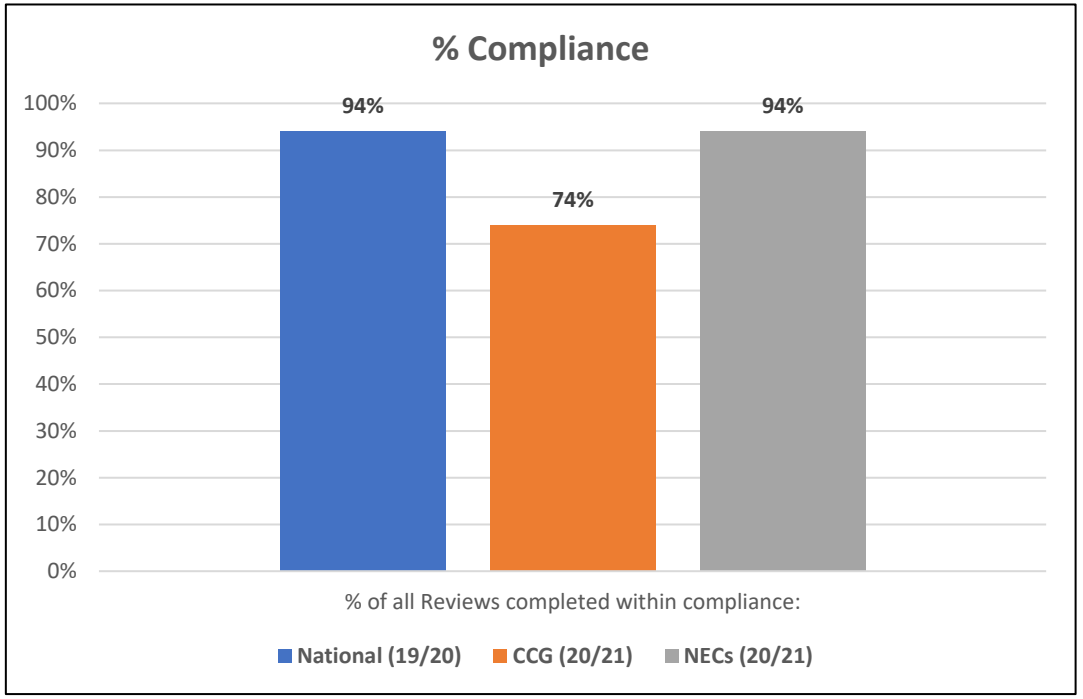
Lisa, 50 years old, died from COVID-19

Lisa was very independent and had good reading and writing skills. She had brought herself a new laptop, enjoyed working on computers and could type. She walked independently to the day services she attended, and could take public transport. Lisa really liked going out and socialising, being independent and walking or getting the bus by herself.

Lisa could communicate very well but needed staff to listen patiently when she was telling them something. There were times when she needed staff to use alternative methods of communication like gestures or visual aids. When she was in pain, she could tell you or indicate where the pain was. Nonetheless, sometimes she could be in pain and not say so. She required to be prompted or asked her if she was in pain if she looked as though she was struggling.

Data Set: Performance

	Notifications No.	Completions No. & %		Multi Agency Reviews	% of all Reviews completed within compliance:
2019/2020	73	73	100%	4	10%
2020/2021	118	106	90%	6	74%



In 2019 / 2020, 73 reviews were received, 100% of these reviews have been completed. The aim is that every death reported to LeDeR has the review completed within 6 months of receipt of the notification. Only 10% of these reviews were completed within the 6 month compliance timeframes due to the volume of reviews and availability of reviewers. In late 2019, the LeDeR team was being established and went on to make extensive progress in the completion of LeDeR reviews going forward.

Of the 118 notifications received in 2020 / 2021, 90% of the reviews have been completed. The remaining 10% are on track to be completed by their compliance date of Sept 2021 and are currently 'stacked'. The LeDeR system is being transferred between online platforms and will be live as of the 1st June 2021. The 'stacked' reviews (10%) will be completed when the platform becomes available as anticipated. There are currently 5 child death reviews awaiting completion, these are expected to be completed by October 2021.

Of the reviews reviews notified to LeDeR in 2020 / 2021, 74% were completed within the required timeframe. Throughout 2020 the backlog of reviews was cleared. In total there were 152 reviews completed by Surrey reviewers in 2020 / 2021. This impacted on this years compliance however by December 2020 this backlog had been fully completed and compliance timeframes for new reviews were being met. The LeDeR team is in a good position for compliance going forward and are confident that we can achieve 100% compliance in the following year.

Local Reviewer Arrangements

Surrey Heartlands CCG / ICS employ a LeDeR co-ordinator to oversee the LeDeR programme in Surrey and formerly North East Hampshire and Farnham (prior to recent boundary changes). Reviewers are employed by Surrey Heartlands CCG / ICS on a bank basis (as work requires) and work a varied number of hours. There are currently 9 reviewers on the LeDeR bank. The reviewers come from a variety of backgrounds, including learning disability nurses, social workers, psychologists and general nurses.

Data Set: Demographics

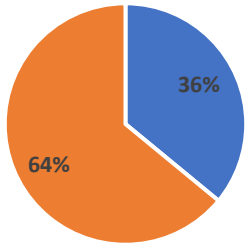
- **Gender**

In Surrey, in 2019/ 2020, 52% of the deaths reported were male and 48% were female. There has been a substantial increase in the number of deaths reported that are male in 2020 / 2021 (12%). Of the 114 deaths reported, 64% of the deaths reported were male and 36% were female. This figure is higher than the national LeDeR findings in the 2019 / 2020 report which found that 56% of deaths were male.
Of the deaths in relation to COVID-19, 63% were male and 37% were female, this explains the disproportionate increase in male deaths reported to LeDeR this year.

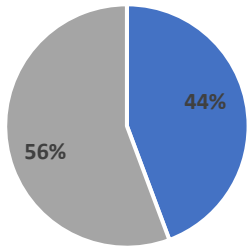
	2019/2020	
	Male	Female
No.	36	33
%	52	48

	2020/2021	
	Male	Female
	73	41
	64	36

Gender CCG 20/21



Gender Nationally 19/20



- **Level of Learning Disability**

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. Of the 114 deaths reported in 2020 / 2021, 97 have had their review completed. The table below shows the breakdown of these deaths.

Level of Learning Disability	No.
Mild	28 (29%)
Moderate	30 (31%)
Severe	30(31%)
Profound/Multiple	4 (4%)
Unknown	5 (5%)

Of the 3557 reviews reported in the National LeDeR report 2019 / 2020, 30% of the individuals had a mild learning disability, 33% had moderate learning disabilities, 27% had a severe learning disability and 10% had a profound and multiple learning disability. This figure was similar to the level of learning disability for Surrey deaths reported in 2020 / 2021 for mild, moderate and severe learning disability. The level of learning disability was unknown in 5% of the completed reviews. The evidence suggests that these individuals had either not received input from learning disability services, had not had an assessment of their level of functioning or the reviewer was unable to source this information.

Data Set: Demographics, Age

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

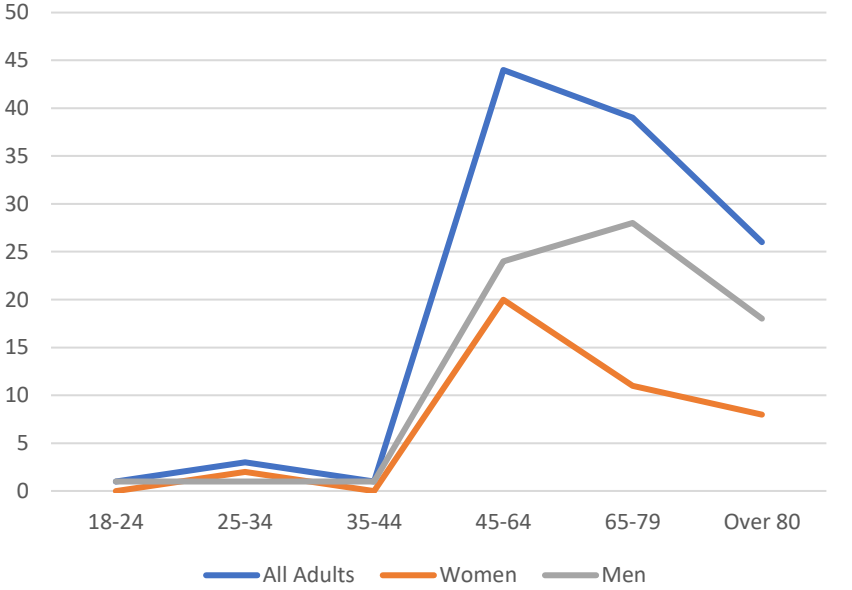
- There was a total of 114 deaths
- The range of age at death was 20 – 96
- The mean average age of death was 67
- The median average age was 68

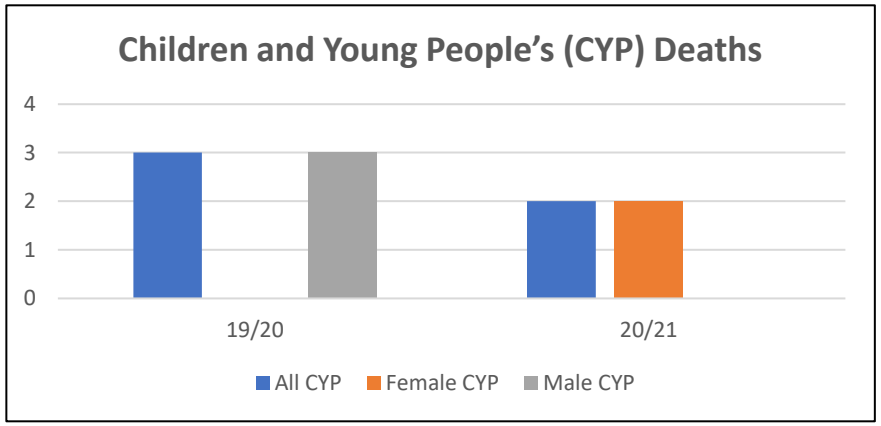
Women with learning disabilities who died in 2020-2021:

- There was a total of 41 deaths
- The range of age at death was 27 – 96
- The mean average age of death was 65
- The median average age was 63
- Female life expectancy in the general population of Surrey is 85.1.

Men with learning disabilities who died in 2020-2021:

- There was a total of 73 deaths
- The range of age at death was 20 – 95
- The mean average age of death was 68
- The median average age was 71
- Male life expectancy in the general population of Surrey is 81.8.





All Adults with learning disabilities who died from confirmed or suspected COVID-19 in 2020-2021:

- There was a total of 51 deaths
- The range of age at death was 30 – 96
- The mean average age of death was 67
- The median average age was 69
- No. of women who died 19
- No. of men who died 32

More men died from COVID-19 than women. 63% of the COVID-19 deaths reported were males and 37% were females. Only two of the deaths reported related to someone from a Black, Asian or Minority Ethnic community. In this instance, the individuals were both from a Black British community.

Children with learning disabilities who died in 2020-2021 (CYP):

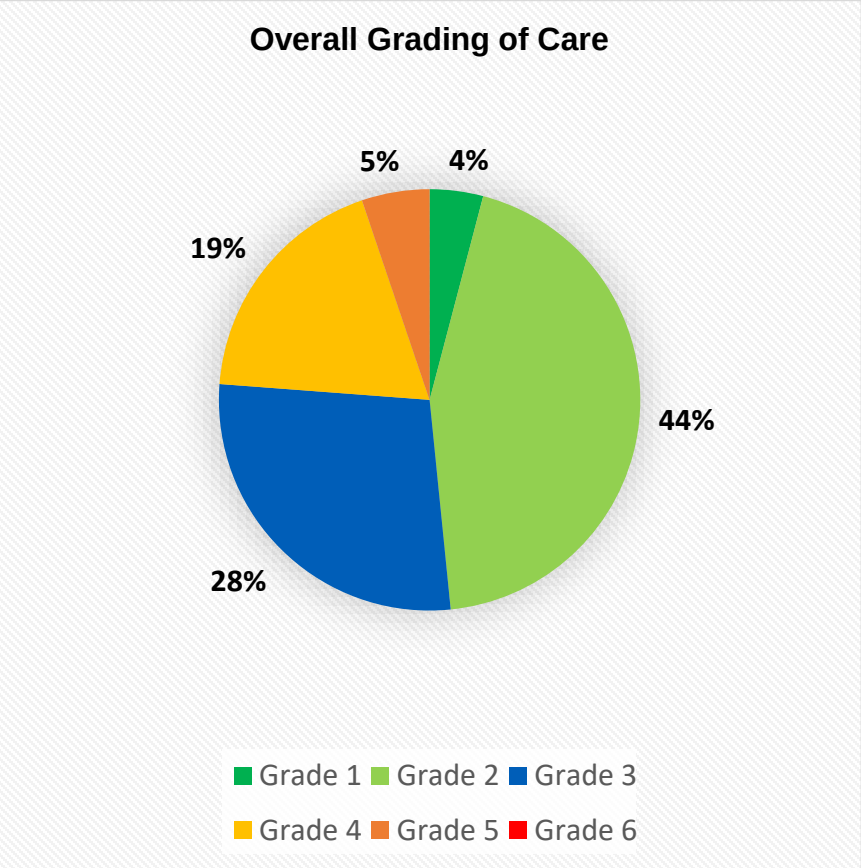
- There was a total of 2 deaths
- The range of age at death was 9 – 14
- The mean average age of death was 11.5
- The median average age was 11.5

Data Set: Cause of Death and Quality of Care

- **Quality of Care**

The table below shows the number and percentage of completed reviews graded at each level of the overall quality of care received by the person.

Grade	Grading of Care
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.



48% of the reviews found that the care met or exceeded the expected good practice, in comparison to last year where only 14% met this standard of care. This figure may be distorted by the low number of reviews that were completed last year but is still significant.

Examples of the reasoning for the high grading included; 'Personalised care management, proactive anticipatory care plan and mental capacity assessment completed in community by GP, Care Home Manager and the individual 2 years prior to hospital admission'. A second review reported that the individual '… was treated promptly and efficiently on every admission to hospital. Acute learning disability liaison nurses had involvement on each of these admissions. Appropriate referrals and involvement from clinicians, e.g. Speech and Language, dieticians.'

Where care was rated as having fallen short of expected good practice, some of the themes identified included; recognition of a deterioration in the person's health, a lack of anticipatory approach to end of life care planning (ReSPECT document completed late or not completed), a lack of best interest decision making concerning 'Do not Attempt Cardio-pulmonary Resuscitation' (DNACPR) form, reasoning for DNA CPR not always clear / appropriate and a lack of application of the Mental Capacity Act (particularly around best interest decision making).

The findings demonstrate that people's wishes are not necessarily reflected in their end of life care decisions. It also demonstrates that there may be an under-recognition of people nearing the end of their life. Education on ReSPECT forms is well established in Surrey Heartlands CCG / ICS and is an on-going process. The CCG / ICS are supporting East Surrey Integrated Care Partnership who were late adopters of the ReSPECT forms.

Restore2 mini training is being delivered to care home staff along with the provision of Oximeters. The LeDeR programme aims to ensure that this training is available to family carers in due course. This will aid identification of when health is deteriorating.

Other themes included delays or poor uptake in screening. It was found that this was often the responsibility of the care provider, however the care provider was not always clear on the correct process that should be followed in this area. A carers guide is currently being developed to provide guidance.

Data Set: Cause of Death and Quality of Care

- **Cause of Death**

The most common cause of death this year was COVID-19. The number of deaths from this was 30 which is 31% 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	COVID-19	1	COVID-19
2	Pneumonia	2	Downs syndrome
3	Sepsis	3	Heart Failure
4	Cancer	4	Diabetes
5	Aspiration Pneumonia	5	Sepsis

Of the deaths reported to LeDeR in 2020 / 2021, the primary cause of death was COVID-19. This equates to 31% of the deaths of people with learning disabilities in Surrey. Pneumonia was the second most common cause of death, it accounted for 23% of the deaths reported. In the National LeDeR report findings in 2019, pneumonia was the most commonly cited cause. Sepsis was the third most common cause in 8% of cases followed by cancer and aspiration pneumonia which were both cited in 7% of the deaths reported.

Of the 97 reviews completed, only 18 cases had a secondary cause of deaths recorded which equates to very small numbers.

Although not a direct cause of death, the report identified that constipation and polypharmacy were two recurring factors that were found in the reviews. The reviews found that many people were found to have severe constipation or faecal impaction on admission to hospital. As a result of this, further work is required to support constipation management across the system including health services and education to family member and paid carers.

In addition to this, an audit is recommended to understand the concerns around polypharmacy in more detail.

- **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 DNA CPR 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 (CQC) 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 the individual's views.

Out of the 97 reviews which were completed for people who died in 2020 / 2021, there were 82 people who had a DNACPR in place. Of these, 77% were felt to be completed correctly and followed however it was identified in four of the reviews that the reasoning was felt to be inappropriate. These reasons included frailty, learning disabilities or Down's syndrome. Although the report found high levels of DNA CPR forms being completed correctly and followed, often these forms were completed in response to an acute admission to hospital. This may indicate that there was a lack of advanced care planning.

This learning was addressed at the local LeDeR Steering Group and Operational Groups. One hospital within the Surrey boundary participated in the DNA CPR CQC thematic review. We are working locally to apply the learning from this report. The report can be accessed via the following link: Review of Do Not Attempt Cardiopulmonary Resuscitation decisions during the COVID-19 pandemic: Interim report (cqc.org.uk)

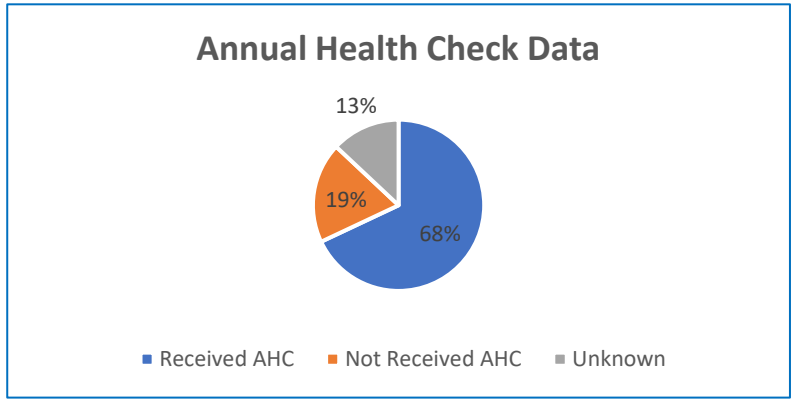
In addition to this Surrey Heartlands CCG / ICS facilitated Mental Capacity Act master classes which were provided by Alex Rucks Keen, a Barrister who specialises in this field. One of the subjects covered in this session was 'Do Not Attempt Cardio-Pulmonary Resuscitation' and End of Life Care Planning.

One of the reviews, which was graded as 'Excellent care', identified a positive experience of the Advanced Care Planning process. This example demonstrated a close collaboration between the individual and the multi-disciplinary team resulting in the individuals wishes being respected and adhered to.

Data Set: Cause of Death and Quality of Care

- **Annual Health Checks (AHC)**

Of the 97 reviews completed for individuals who died in 2020 / 2021, 68% had received an annual health check in the last 12 months. Data demonstrates that 19% had not received the health check and in 13% of reviews there was no evidence that a health check had been completed within the notes available.



Over the past year there has been a marked increase in the number of annual health checks carried out across Surrey. As of the 31st March 2021 the annual health check uptake was 80%. This is 13% above the national target of 67%. There has been a significant increase in the number of practices offering annual health checks. This will mean that more people will have access to annual health checks.

Although there has been an increase in the uptake of AHCs there has been some disparity in the quality of the checks and the lack of health action plans being generated.

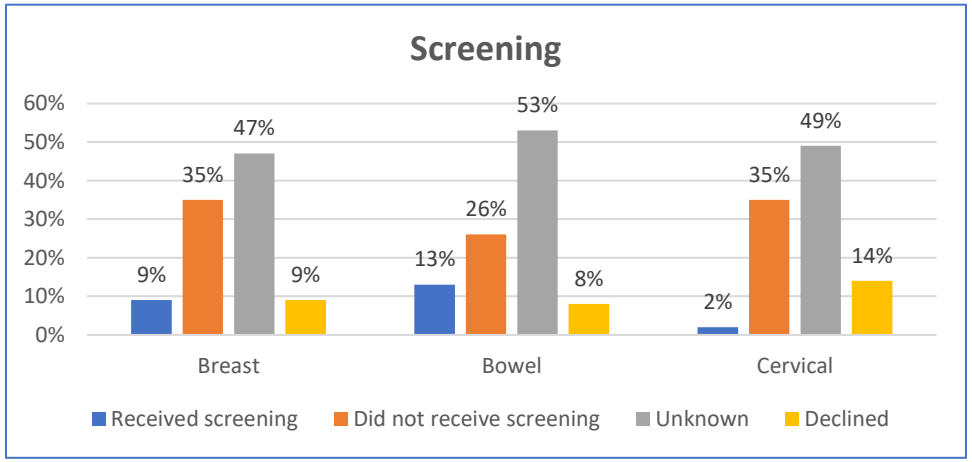
The LeDeR programme plans to review the quality of annual health checks through audit and engagement with service user groups and primary care colleagues.

- **Role of Cancer Screening**

From the information available, there has been a very low uptake of cancer screening across the breast, bowel and cervical screening programmes. The chart below demonstrates that screening information was unavailable for approximately 50% of the deaths reviewed. The reviewers found it difficult to obtain information from both health records and interviews. This may demonstrate a lack of confidence in this area or a lack of appreciation of the importance of screening in ensuring that people with learning disabilities have their health needs met in a proactive manner.

Cancer was the fourth most common primary cause of death in people with learning disabilities in Surrey. Early identification of cancer through the screening programmes would potentially prevent late diagnosis and metastatic cancer. This is when cancer spreads to another area of the body.

Further work is required to understand screening uptake better. The current work on the Surrey Care Records may aid reviewers to obtain more detailed information. Screening will be a key focus of LeDeR going forward.



Learning from older Reviews completed in 2020-2021

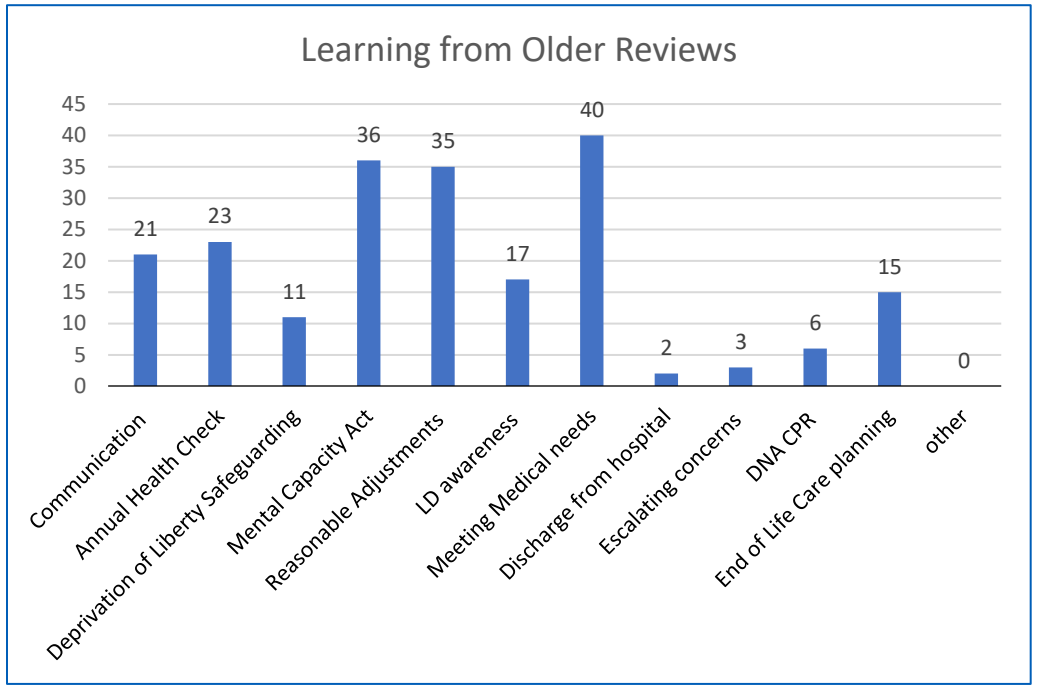
Older reviews completed in 2020 / 2021 identified similar learning to that within the 2019 annual report. A break down of the learning can be seen in the table to the right hand side. This shows that the top 5 learning themes were meeting medical needs, Mental Capacity Act compliance, reasonable adjustments, uptake of annual health checks and communication issues.

'Meeting the patients medical needs' was the most reported learning theme from older reviews. This category included issues such as recognising when patients were deteriorating and also diagnostic over shadowing. This is when an individuals presentation is attributed to the fact that they have a learning disability as opposed to looking for a clinical cause. In order to address this, the Surrey and NE Hampshire CCG /ICS have been working with our local providers to share the learning from LeDeR reviews through attendance at mortality meetings to highlight the findings, good practice and areas for improvement.

To develop the skills of care providers in identifying deteriorating health, Surrey Heartlands CCG / ICS is working to deliver Restore 2 mini training to care providers. This is a tool which aids carers in identifying the soft signs of deteriorating residents, facilitating earlier treatment and avoiding unnecessary transfers to hospital. The LeDeR team recommend the expansion of this training to family and informal carers.

Online master classes have been delivered to increase local knowledge and compliance with the Mental Capacity Act. These were very well received with attendees from across the system.

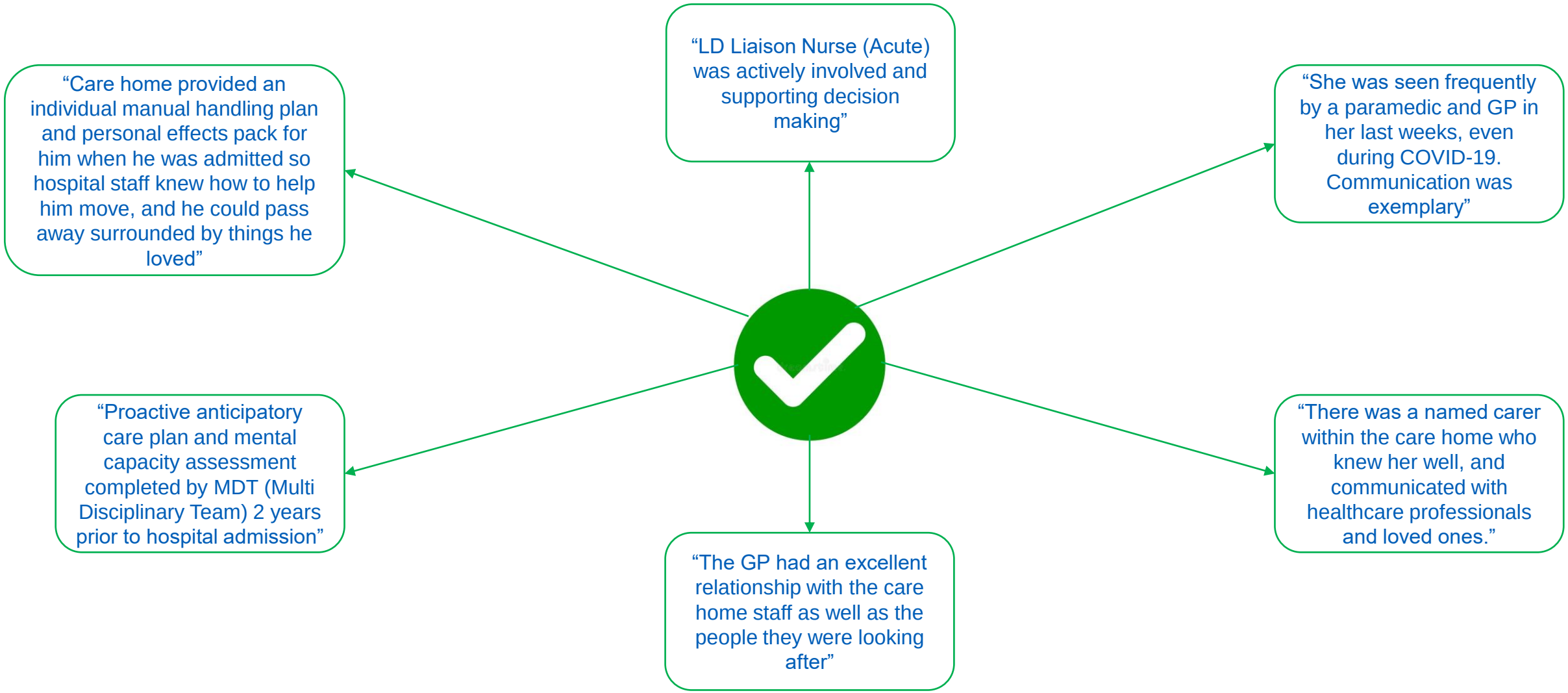
Work is currently under way to improve communication of the needs of people with learning disabilities through Surrey Care Records. This software will allow sharing of information between organisations to better communicate across the system. It will be used to record reasonable adjustments information and hospital passport documents.



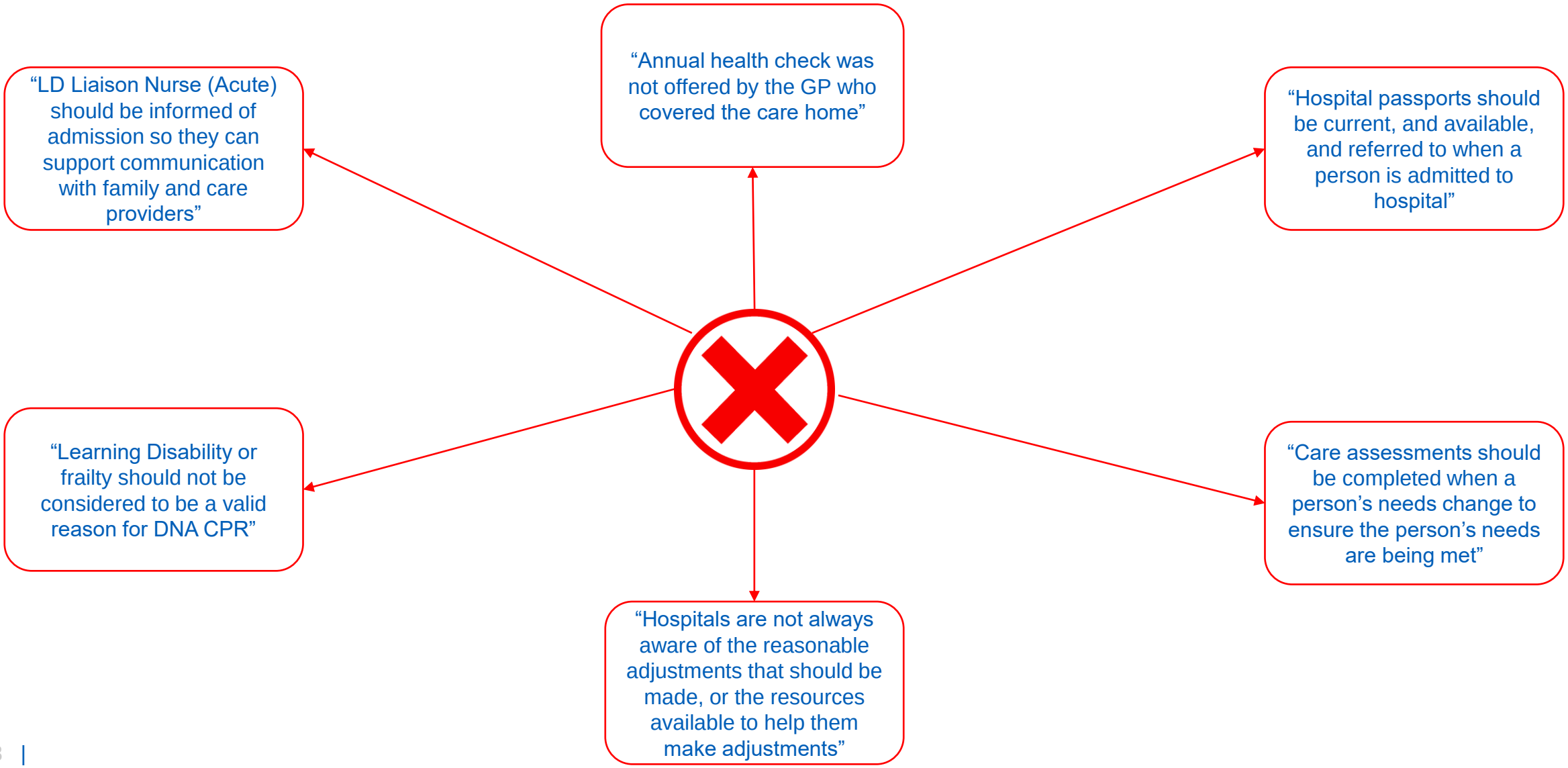
Please see page 15 for an update on the progress on AHCs in Surrey Heartlands CCG /ICS.

Concerns over early discharge which often result in readmission to hospital were reported less in the older reviews than they have been reported in 2020 / 2021. This may represent the pressure the system has been under during the COVID-19 pandemic.

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

There was clear evidence of compassionate care being delivered to people with learning disabilities and their families.

Where there was good interagency working it resulted in effective communication, a proactive approach to care and clear decision making.

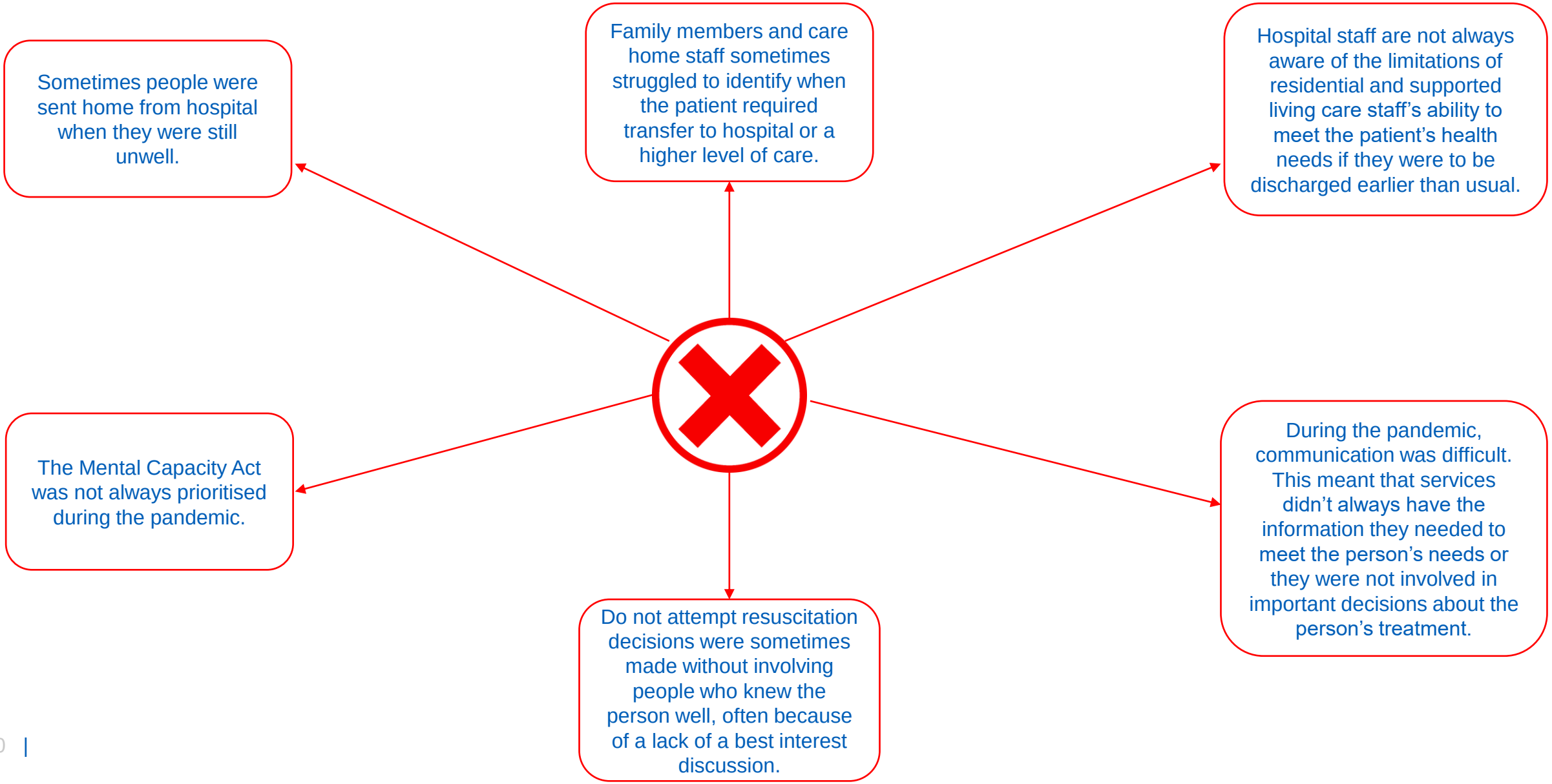
In the first wave of COVID-19 there was a reduction in families and carers being allowed to support patients during the pandemic however each of the hospitals have addressed this and now allow carer support to ensure patients with learning disabilities have the appropriate support.

There was good evidence of the hospital passport being completed and sent in with the patient.

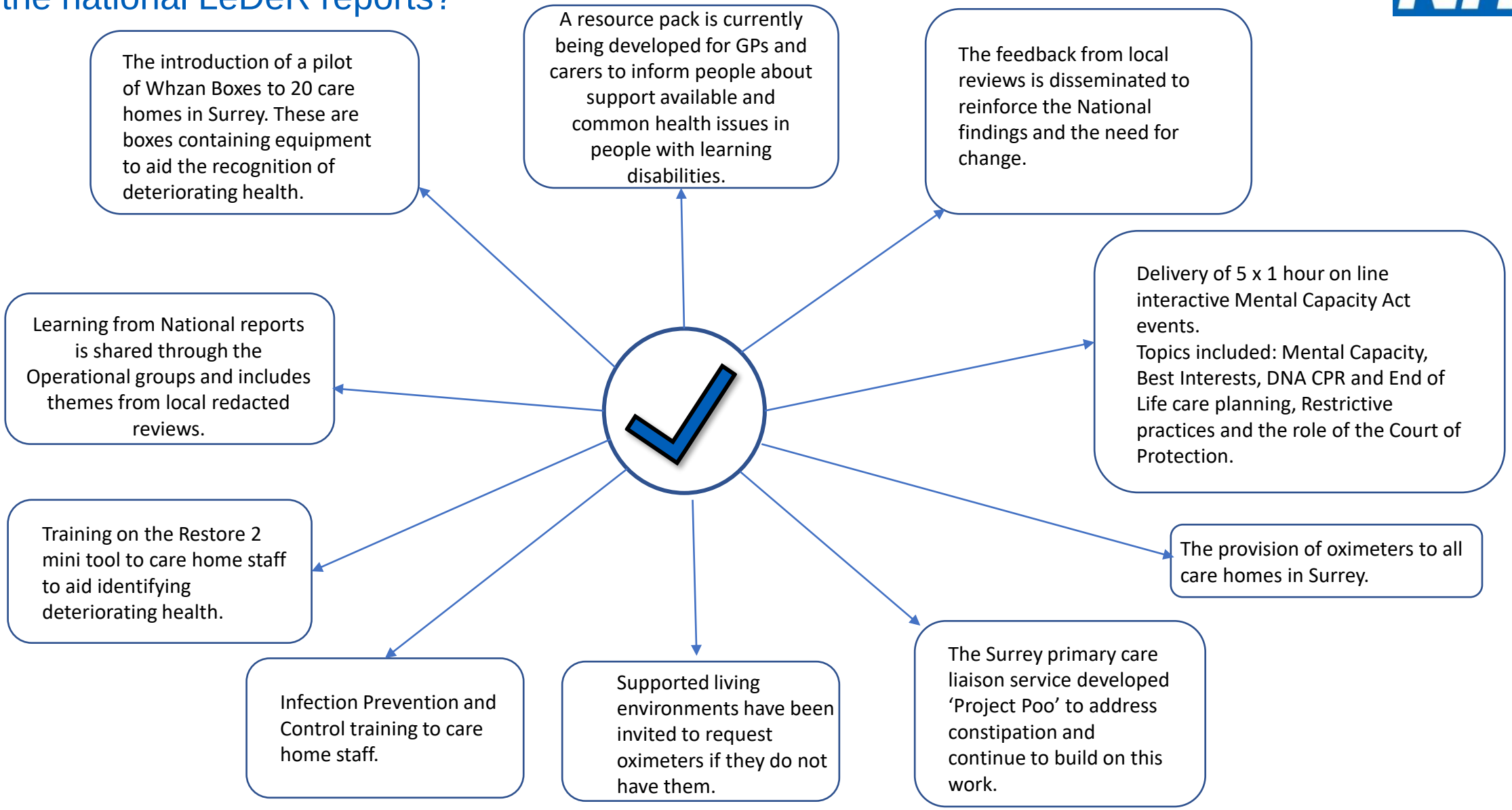
There was a good use of videoconferencing to support patients when they were unable to be with their families and familiar carers. This appeared to have clear benefits to the patient.

There was good evidence of referrals being made to the learning disability liaison service and this having a benefit to the patient.

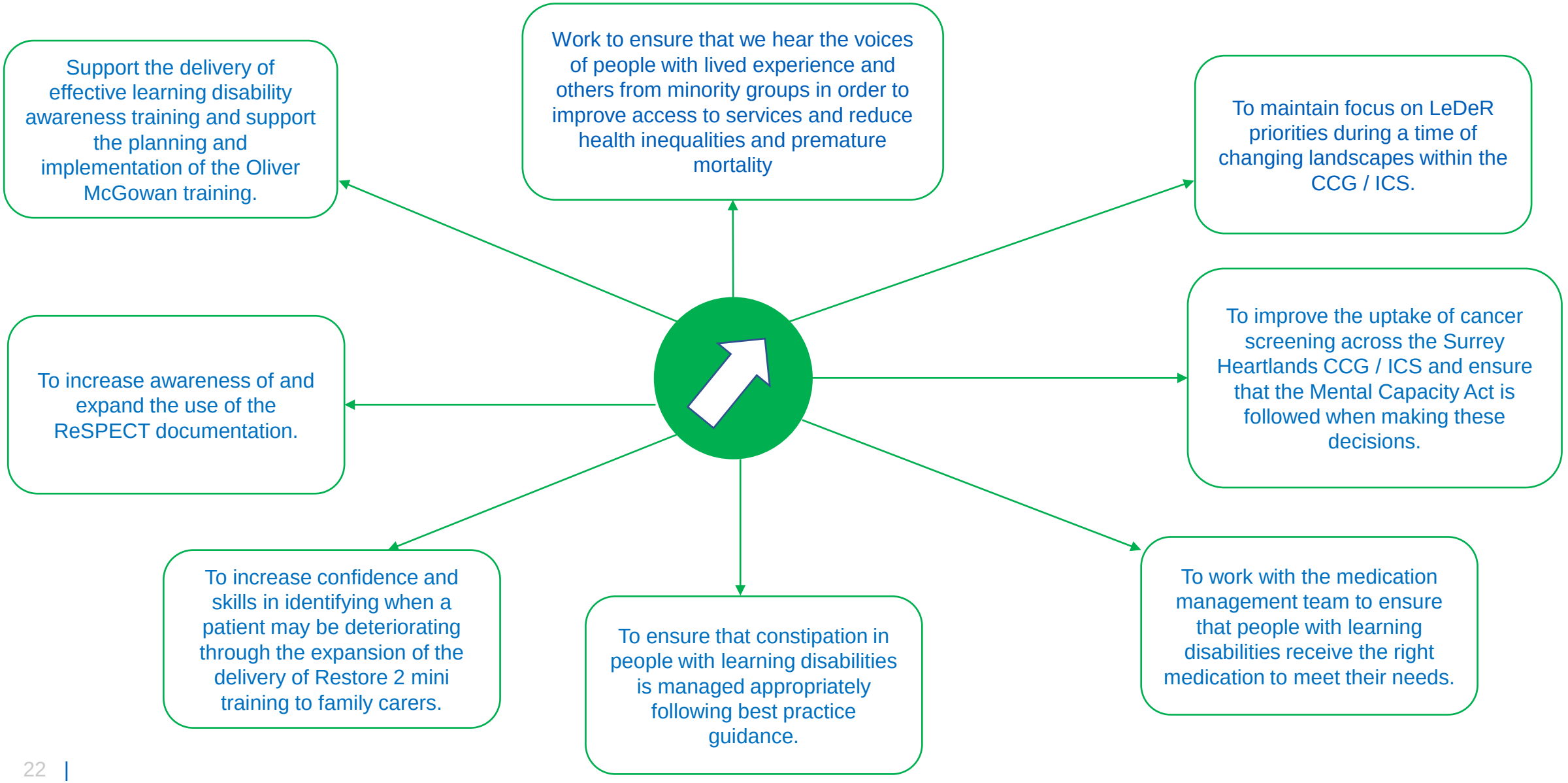
Action from Learning: What areas for improvement were identified in recommendations from reviews of COVID-19 deaths



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



Action from Learning: Local Priorities for delivery in 2021/2022 based on the learning from reviews locally and nationally



Action from Learning:
The evidence base for local priorities in 2021/2022

- Surrey Heartlands CCG / ICS value the input of people with lived experience. We are committed to involving families and people with learning disabilities in the LeDeR programme to develop the work of the programme and expand the qualitative evidence from people with lived experience in order to improve services.
- Surrey Heartlands CCG / ICS will work to better understand the needs of people with learning disabilities from Black and Ethnic Minority communities to ensure there is equal access to services in Surrey.
- There was clear evidence of a low uptake of cancer screening yet cancer was the fourth most common primary cause of death. This may demonstrate that cancers are often picked up at an advanced stage or treatment decisions may differ from that of the general population. To aid this work, Surrey Heartlands CCG / ICS will also address Mental Capacity Decision making.
- The learning from the COVID-19 deaths highlighted that families and care staff may benefit from additional support to identify when a person with learning disabilities' health is deteriorating and there is a need to seek support from local health services. To address this, a recommendation has been made to expand the Restore 2 mini training to families and all carers of people with learning disabilities.
- The report found that often 'DNA CPR' forms were completed in response to an acute admission to hospital and late in the patient's pathway. This may indicate that there was a lack of advanced care planning. As a result the LeDeR programme will work to increase awareness of advanced care planning with both families and care providers.
- Learning disability awareness training has been a recurrent recommendation throughout both local and national LeDeR reports. Surrey Heartlands CCG / ICS aim to deliver unconscious bias training to system partners and will work to ensure that learning disability awareness training is effective across the system. The LeDeR team will support the planning and implementation of the Oliver McGowan training.
- It was found that many people with learning disabilities were on several medications and they did not always have a medication review. Surrey Heartlands CCG / ICS will work with the medication management team to ensure that people receive the right medication to meet their needs and medication is reviewed regularly.
- Constipation was a recurring theme in the reviews. Surrey Heartlands CCG / ICS will work with both health and social care colleagues to improve awareness and management of constipation to implement best practice across the system.

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:

- The new governance structure will ensure that there is clear communication of the learning from LeDeR reviews. This meeting will have representation from system partners and Integrated Care Partnership (ICP) representatives. The attendees will have a duty to take the learning back to their organisation and present monthly updates on action taken to address the learning.
- The learning from LeDeR will be presented in a quarterly report which will be disseminated to the LD and Autism Partnership Board and the Surrey Heartlands CCG / ICS's Quality and Performance board along with the Health Inequalities Forum.
- ICPs will drive forward action across the system including their Primary Care Networks.
- The implementation of learning from LeDeR reviews will be reported on a 6 monthly basis through the Schedule 4 Quality reports.
- The LeDeR team will undertake quality audits as required. The first audit has been identified as an annual health check audit to take place later this year.

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

- CCG / ICS Quality Leads will engage with providers to monitor the effectiveness of action plans.
- Effectiveness of change will be monitored through the continual review of the learning themes and trends at the Governance panel.
- Audits will be undertaken to measure the effectiveness of change, identify areas where performance meets or exceeds expectation, and areas where improvement is either desirable or helpful to improve the outcome for people with learning disabilities.
- Local service user forums will be consulted to gain feedback on their experience of local services.