LeDeR Annual Report
NHS East Berkshire CCG
FINAL v1.0

Author: Paul Corcoran, Senior Quality Manager, NHS Frimley CCG
Data Support: Daniela Bolton, Senior Quality Administrator, NHS Frimley CCG

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

NHS England and NHS Improvement

Contents

Executive Summary

- Throughout 2020/21 Frimley ICS has continued to operate three LeDeR programmes, in East Berkshire CCG, North East Hampshire & Farnham CCG, and Surrey Heath CCG.
- This Annual Report covers the programme in East Berkshire CCG.
- From June 2021, the three programmes will be merged to cover the footprint of the new Frimley CCG, formed from the previous three CCG constituent parts.
- In 2020/21, the East Berkshire programme received 22 LeDeR notifications; at the time of writing, 7 of these cases have been completed, with others due for completion imminently in time for the pause at end of April when the existing national LeDeR web platform is taken down; the new platform becomes available in June 2021.
- Some cases will need to be carried over onto the new platform, as completion cannot be achieved by end of April due to other formal review processes in progress, or availability of provider mortality review reports to support case completion.
- The programme has, historically, faced challenges in completing cases within the 3 month window from notification. This was due to previous reliance on a primarily volunteer reviewer resource whose available time was restricted by their substantive duties. During 2020/21, case completion accelerated with reviewer resource focused on a more readily available but smaller cohort of bank contract reviewers.
- A new national LeDeR policy has been published which will require some changes to the governance arrangements of the programme (in addition to the merging of the programmes within Frimley CCG). A paper will be presented to the LeDeR Steering Group in May 2021, outlining these changes and the implications for our future work.
- Key findings from the programme are summarised on the next slide. These have been reviewed and cross-checked against the new draft South East Region LD & Autism Improvement Plan 2021-24, which will form the basis of the learning into action work being progressed by our Operational Group.

Key Findings 1/2

- Our caseload split was 9 women (41%) and 13 men (59%). The local general population split is 50% / 50%. The national LeDeR case split for 2019 (latest data available) was 42% women and 58% men – roughly in line with our local split for 2020/21.
- The average age of death of all adults with a learning disability was 57 (mean), 59 (median).
- The average age of death of women with a learning disability was 57 (mean), 58 (median). The national median in 2019 was 59.
- The average age of death of men with a learning disability was 57 (mean), 61 (median). The national median in 2019 was 61.
- Seven people with a learning disability died from confirmed or suspected COVID-19. Average age was 54 (mean), 49 (average). Three cases were women, 4 were men. The latest cases involving COVID are still under review so firm conclusions have yet to be drawn, but what is apparent so far is that the disease has likely contributed to lower mean and median average ages of death by between 3 (mean) and 10 (median) years. Further review work is needed but the effects of COVID in respiratory conditions, already a key vulnerability for people with LD, seems significant.
- The ethnicity of cases was: 15 White British (68% vs general population of 60%), 1 White Other (5% vs general population of 8%), 2 Asian British or Asian Pakistani (9% vs general population of 7%), 2 Asian British or Asian Other (9% vs general population of 11%), 1 Other Ethnic Groups (5% vs general population of 1%), 1 Unstated. Outright numbers are too low to draw firm conclusions on variances with the general population percentages.

Key Findings 2/2

- Case data show that those with severe learning disabilities were the highest single category represented, but outright case numbers were low so conclusions regarding variance with national data are difficult to draw.
- The majority of East Berkshire care reviews completed in 2020/21 concluded that care was either good (grade 2 - 43%) or satisfactory (grade 3 - 43%). The remaining 14% were graded as falling short of good practice but not contributory to death (grade 4).
- The top four primary causes of death were: 1) COVID-19 Pneumonia (6 cases, 27%); 2) Pneumonia; 3) Aspiration Pneumonia; 4) Alzheimer's Disease
- Good practice identified: High standards of care and support in residential settings with examples of carers going above and beyond to be by the individual's side during episodes of deterioration / hospital admissions. Improvements in hospital LD liaison. Support from Community LD Teams and GPs. Co-ordination of care across multiple disciplines and involvement of families and carers. Appropriate use of mental capacity assessments and best interest decision-making. Application of reasonable adjustments.
- Areas for improvement identified: Use of the Mental Capacity Act and best interest decisions. Lack of consistency in completion of GP Annual Health Checks. Inconsistency in referral rates for age-related cancer screening. Improvements needed in Advance Care Planning. Improve consistency in use of LD health passports. Improve consistency of medication reviews (STOMP / STAMP tool use). Focus on early detection of deterioration in the community. Need for robust care co-ordination across primary / community / acute including ensuring effective follow-ups and minimising DNAs.

Introduction

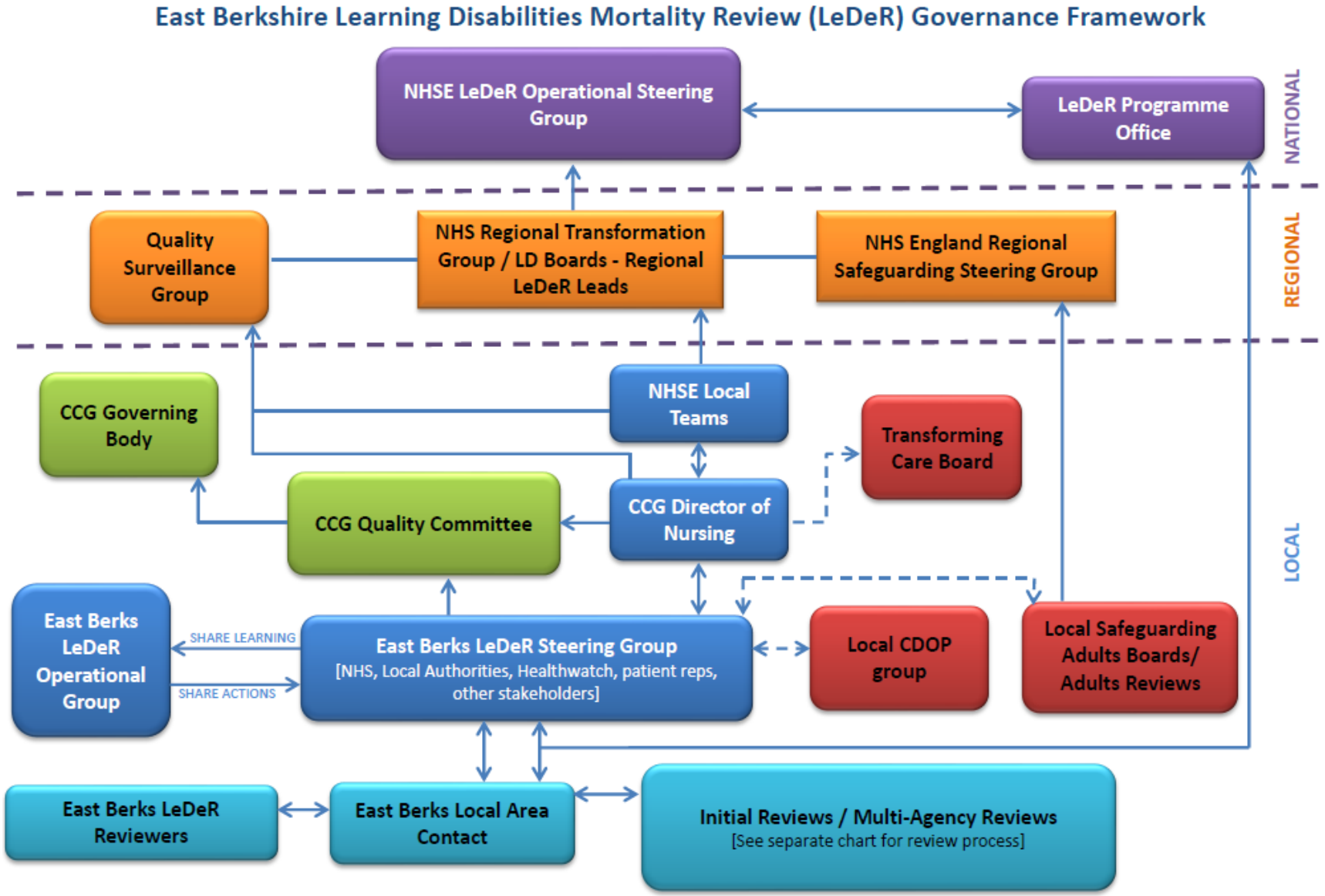
This is the annual report of the NHS East Berkshire Clinical Commissioning Group (CCG) Learning Disabilities Mortality Review (LeDeR) Programme for 2020/21. It presents information about the death of people with learning disabilities in East Berkshire aged 4 and over notified to the LeDeR programme from 1st April 2020 to 31st March 2021. Also included is some comparative data and historical learning from previous years.

NHS East Berkshire Clinical CCG delivers the LeDeR programme locally for the East Berkshire area, comprising the local authority areas of Slough, the Royal Borough of Windsor & Maidenhead, and Bracknell Forest. The programme has developed a structure in collaboration with stakeholders for the process of undertaking reviews and putting the learning into action. This report contains information about the types of cases notified to the programme, performance, demographics, equality, learning themes, and actions being taken to improve services and the quality of life for people with learning disabilities in East Berkshire.

Acknowledgements

We would like to thank family members, carers, service providers, reviewers, and steering group members who have contributed to the review of deaths of people with learning disabilities in East Berkshire and worked to put service improvements in place.

Governance arrangements



Deaths of People in our CCG: Pen Portraits

(names have been changed to protect privacy)

Pen Portrait 1 (Case ref 25370652)

Matilda was a lady in her early 70s with a mild learning disability who had lived in a stable supported living setting for many years, She lived alongside three other people with whom she got on very happily. She was reported to be a well-liked, lovely lady with a strong and endearing personality; she was described as the 'matriarch' of the household. She had been self-caring but had needed more help in the last two years of her life with personal care. She enjoyed going out for meals, shopping, and at home she knitted. She was particular about what food and drink she liked; preferring softer types of food such as soup, sandwiches and chicken, and enjoyed dining together with her fellow residents. Matilda was very communicative and was able to articulate her needs and wants very well. Her death had been expected, and she had, prior to becoming very ill, been involved in the planning of her funeral arrangements. Staff had known and loved her for a long time. Everyone was very sad about her death even though they had known her to be unwell over the past couple of years.

Pen Portrait 2 (Case ref 25442563)

Judy was a lady in her late 60s with a mild learning disability who had lived a life with a high degree of independence before moving into a nursing home setting. She had lived with her family for most of her life, following which she was able to live fairly independently in supported living accommodation. Unfortunately, the onset of symptoms consistent with dementia impacted on her independence to the point where she needed to be in a nursing home setting. Nevertheless, with reasonable adjustments, she was able to find enjoyment in her daily life. She loved to watch television and enjoyed listening to music. She also enjoyed talking to the staff, something that could be encouraged by staff talking with her in a low tone and friendly manner, maintaining eye to eye contact. Staff also used simple words and sentences to avoid confusion, and for her to be able to understand better there was need for limited background noise so that she could hear well. She was well-loved by her siblings and received regular visits from her brothers, one of whom described her as happy and settled in the nursing home.

Pen Portrait 3 (Case ref 25290453)

Roland, a gentleman in his early 50s with a moderate learning disability living in a residential care setting. He was a very sociable person who liked to have a laugh and was able to make his needs known. He was able to build good relationships with people who spent time with him. He had very limited verbal communication but was able to say key words such as yes and no, and to make tangible decisions such as what to eat or do. Staff supporting Roland knew him well and were able to understand him. He enjoyed being with people he liked (but not large groups of people) and liked sensory activities including music. Routine was very important to him and he also liked people-watching and being out in the community.

Data Set: Performance

	Notifications No. & %		Completions No. & %		Multi Agency Reviews	% of all Reviews completed within 6 months
2019/2020	19	100%	15	79%	1	5%
2020/2021	22	100%	7	32%	0	5%

Performance Narrative

Case completion has historically been slow due to challenges with reviewer resources (see box below for further information). However, East Berkshire accelerated its rate of completion significantly in the second half of 2020. This was due to a push to get historical cases finished and a more reliable source of bank reviewers; many of these cases were originally notified in 2019/20. The overall number of cases notified in 2020 (i.e. during COVID) was similar to the number in 2019. However, a rise in notifications was seen in the months of January and February 2021; these cases are still being reviewed, but this appears to be an increase in part caused by the effects of the COVID pandemic.

Local Reviewer Arrangements

The programme initially started with a large pool of voluntary reviewers, but it became clear that existing work commitments made completion of reviews in a timely way challenging using this method. Over the past year, the programme has transitioned to using mainly bank contracted reviewers who are either experienced NHS clinical retirees or part-time workers who are able to devote sufficient time to reviews. This small pool is clinically experienced and is supported by both the programme management team in the CCG, and senior clinical quality assurance leads in the CCG.

Data Set: Demographics

Gender

The 2019/20 split of 68% male vs 32% female represents a higher male presence in the data than the comparative national figures for 2019 (the latest available in the most recent national LeDeR Annual Report). However, the 2020/21 split is more in line with the 2019 national split: 59% male and 41% female in our local data, compared to 58% male and 42% female in the national 2019 data. The local (East Berkshire) male / female population split is 50%/50% - see ONS data below. The low outright case numbers means that the local percentages are sensitive to large changes based on a few cases, so insightful conclusions are difficult to draw.

ONS Census 2011 (2019 estimates)published at
https://berkshireobservatory.co.uk/
East Berkshire population: Total: 423,510; Male: 211,691 (50%); Female: 211,819 (50%)

	2019/2020		2020/2021	
	Male	Female	Male	Female
No.	13	6	13	9
%	68	32	59	41

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. The information below shows the breakdown of this information for all of the people whose reviews were notified in 2020/21 and have been either completed or are in progress.

Level of Learning Disability	No.	%	National % (2019)
Mild	5	23%	30%
Moderate	4	18%	33%
Severe	8	36%	27%
Profound/Multiple	0	0%	10%
Unknown	5	23%	-

The data above show levels of learning disability for all 2020/21 cases either completed, or in progress. Some of the reviews still in progress give this information so they have been included. Five of the cases currently in progress do not yet give this information, so are classified as 'unknown' at this time. The data show that those with severe learning disabilities were the highest single category represented, but outright case numbers were low so conclusions regarding variance with national data are difficult to draw.

Data Set: Demographics, Age

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

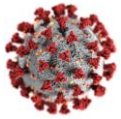
- There was a total of 22 deaths
- The range of age at death was 21 – 80
- The mean average age of death was 57
- The median average age was 59

Women with learning disabilities who died in 2020-2021:

- There was a total of 9 deaths
- The range of age at death was 31 – 80
- The mean average age of death was 57
- The median average age was 58
- Female life expectancy in the general population of East Berkshire CCG ranges between 82.9 to 85.0 years (ONS data across three local authorities).

Men with learning disabilities who died in 2020-2021:

- There was a total of 13 deaths
- The range of age at death was 21 – 71
- The mean average age of death was 57
- The median average age was 61
- Male life expectancy in the general population of East Berkshire CCG ranges between 78.6 to 81.0 years (ONS data across three local authorities).



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

- There was a total of 7 deaths
- The range of age at death was 33 – 72
- The mean average age of death was 54
- The median average age was 49
- No. of women who died 3
- No. of men who died 4

The latest cases involving COVID are still under review so firm conclusions have yet to be drawn, but what is apparent so far is that the disease has likely contributed to lower mean and median average ages of death by between 3 (mean) and 10 (median) years. Further review work is needed but the effects of COVID in respiratory conditions, already a key vulnerability for people with LD, seems significant.

Children with learning disabilities who died in 2020-2021:

- There was a total of 2 deaths
- The range of age at death was 7– 9 years
- The mean average age of death was 8 years
- The median average age was 8 years

Equality Impact

The public sector Equality Duty, part of the Equality Act (2010), requires public bodies to consider all individuals when delivering services, and that public bodies have due regard to the need to eliminate discrimination and advance equality of opportunity. The LeDeR programme seeks to support and enhance the CCG's fulfilment of this duty by identifying any areas for improvement and translating these into actions to ensure that each individual receives optimal care and treatment with proper consideration of personal circumstances and allowance made for any reasonable adjustments.

Ethnicity

The table shows the ethnicity breakdown of the people whose lives and deaths we reviewed this year.
The outright numbers are too low to draw any firm conclusions from the variance in percentages between reported cases and ethnicity of the local populace.

Reference:
ONS Census 2011 data published at
https://berkshireobservatory.co.uk/

- East Berks total pop = 423,510
- East Berks White pop = 291,112 – 68.7%
- East Berks White British pop = 256,562 – 60.1%
- East Berks White Other pop = 34,550 – 8.2%
- East Berks Asian or Asian British pop = 75,209 – 17.8%
- East Berks Asian or Asian British other than Pakistani = 45,584 – 10.8%
- East Berks Pakistani pop = 29,625 – 7.0%
- East Berks Other Ethnic Groups = 5,244 – 1.2%

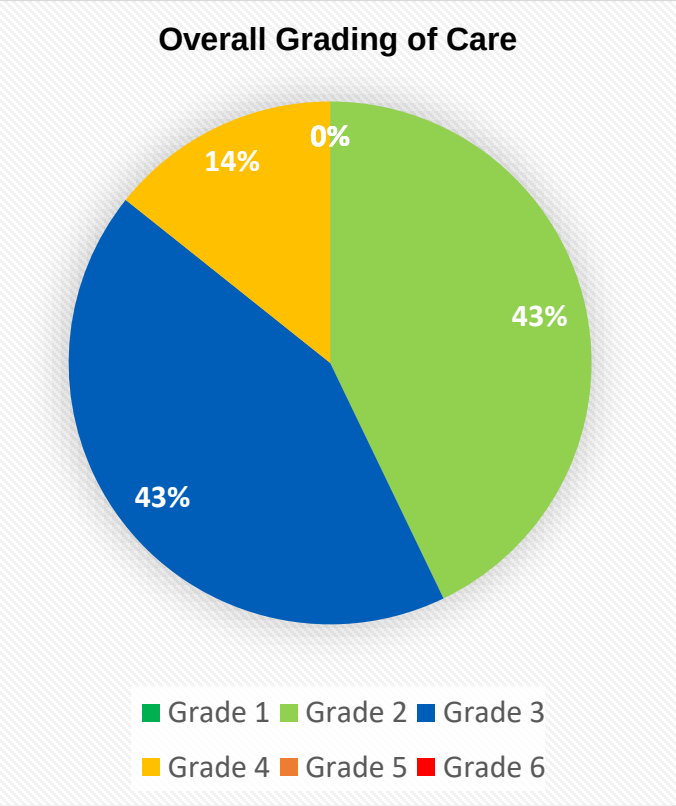
Ethnicity	White				Mixed/Multiple ethnicity groups				Asian or Asian British				Black or Black British			Other Ethnic Groups		
	British	Irish	Traveller or Gypsy	Any other White background	White & Black Caribbean	White & Black African	White & Asian	Any other mixed background	Indian	Pakistani	Bangladeshi	Any other Asian background	Caribbean	African	Any other Black background	Chinese	Any other ethnic group	Not stated
No. of reported deaths	15	-	-	1	-	-	-	-	-	2	-	2	-	-	-	-	1	1
% of all reported deaths	68%	-	-	5%	-	-	-	-	-	9%	-	9%	-	-	-	-	5%	5%
Ethnicity% of local populace	60%	-	-	8%	-	-	-	-	-	7%	-	11%	-	-	-	-	1%	n/a

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.



The majority of East Berkshire care reviews completed in 2020/21 concluded that care was either good (grade 2 - 43%) or satisfactory (grade 3 - 43%). The remaining 14% were graded as falling short of good practice but not contributory to death (grade 4).

Many cases showed good practice in the following main areas:

- High standards of care and support in residential settings with examples of carers going above and beyond to be by the individual's side during episodes of deterioration / hospital admissions.
- Improvements in hospital LD liaison.
- Support from Community LD Teams and GPs.
- Co-ordination of care across multiple disciplines and involvement of families and carers.
- Appropriate use of mental capacity assessments and best interest decision-making.
- Application of reasonable adjustments.

The main areas for improvement identified were:

- Use of the Mental Capacity Act and best interest decisions.
- Lack of consistency in completion of GP Annual Health Checks.
- Inconsistency in referral rates for age-related cancer screening.
- Improvements needed in Advance Care Planning.
- Improve consistency in use of LD health passports.
- Improve consistency of medication reviews (STOMP / STAMP tool use).
- Focus on early detection of deterioration in the community.
- Need for robust care co-ordination across primary / community / acute including ensuring effective follow-ups and minimising DNAs.

This learning has been fed back to local providers with the aim of working towards improving these outcomes over the next year.

A new LeDeR operational group has been set up in East Berkshire to focus on learning into action, with a plan to broaden system-wide alongside the integration of the 3 CCG LeDeR programmes post-merger.

Data Set: Cause of Death and Quality of Care

Cause of Death

The most common cause of death this year was Covid-19 Pneumonia. The number of deaths from this was 6 (27% of all deaths this year). The table below shows the top primary and secondary cause of death

No	Primary Cause of Death (1A)	No	Secondary Cause of Death (1B, 1C)
1	Covid 19 Pneumonia / Pneumonitis (5 cases)	1	Sepsis (2 cases)
2	Pneumonia (including Aspiration Pneumonia (4 cases)	2 =	1 case each: • Covid Pneumonitis • Sepsis • Staphylococcus bacteraemia • Poor swallowing and Epilepsy • Small bowel obstruction with Peritoneal Adhesions and Mesenteric band
3	Alzheimer's Disease (2 cases)	3	-
4 =	1 case each: • Septic Shock • Acute Kidney Injury • Cerebro-vascular event • Lung cancer • Multi-organ failure • Myocardial Infarction	4	-

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.

Although some cases early in the COVID pandemic pointed towards possible inappropriate decision-making around whether to transfer LD patients to intensive care, and ambiguous rationale for DNACPR decisions, most cases reviewed in 2020/21 found evidence of appropriate discussions, documentation and application of DNACPR decisions. National and local guidance has raised the profile of DNACPR among LD patients over the past year and there is reason to be optimistic that these messages are hitting home.

Data Set: Cause of Death and Quality of Care

Annual Health Checks

One of the main themes that routinely emerges in our LeDeR reviews is that the evidence points towards a lack of consistency in completion of annual health checks (AHCs) in primary care. In some cases, the lack of a formally documented AHC was offset by other evidence showing a good standard of GP knowledge, involvement and support for the patient. In other cases, lack of evidence of an AHC carried out in the past year pointed towards missed opportunities for an holistic appraisal of the individual's state of health, any recent changes in their condition, and a chance to co-ordinate support and interventions across multiple disciplines and agencies. In a time when, for the general patient population, getting to see a single named GP consistently is not operationally feasible, these findings underline the importance of ensuring that this does happen for people with learning disabilities. This gives consistency of care and treatment and an intimate knowledge of the person's circumstances by a named GP who will be more likely to be able, with the help of carers and those who know the individual well, to spot subtle changes in condition or behaviour that may point towards something clinically significant. The CCG is prioritising support and monitoring of GP AHCs and there has been an improvement in the percentage completed over the past year. Community Teams for People with Learning Disabilities have also worked closely with GPs to improve the accuracy of GP LD registers and AHC uptake. While continuing with this work, the CCG also aims to focus more closely on the quality (not just the number) of completed AHCs.

The current aim is to hit 75% completion of AHCs. During 2020/21, the percentage completion of AHCs among East Berkshire practices showed a marked improvement. Below is a comparison of figures at 31st March 2021 vs 31st Dec 2020

	At 31.12.20	At 31.3.21
Bracknell Forest	34.9%	88.0%
RBWM	40.2%	76.5%
Slough	61.5%	84.5%
EBCCG Total	**47.20%**	**82.90%**

Role of cancer screening

Another key area in which we need to ensure equality and consistency of uptake is cancer screening for people with learning disabilities. Our reviews in the past year highlight that consistency is yet to be achieved. In many cases there was an absence of clear evidence that age-appropriate screening had been carried out, and a lack of clearly documented rationale to indicate why screening may not have been undertaken for an individual.

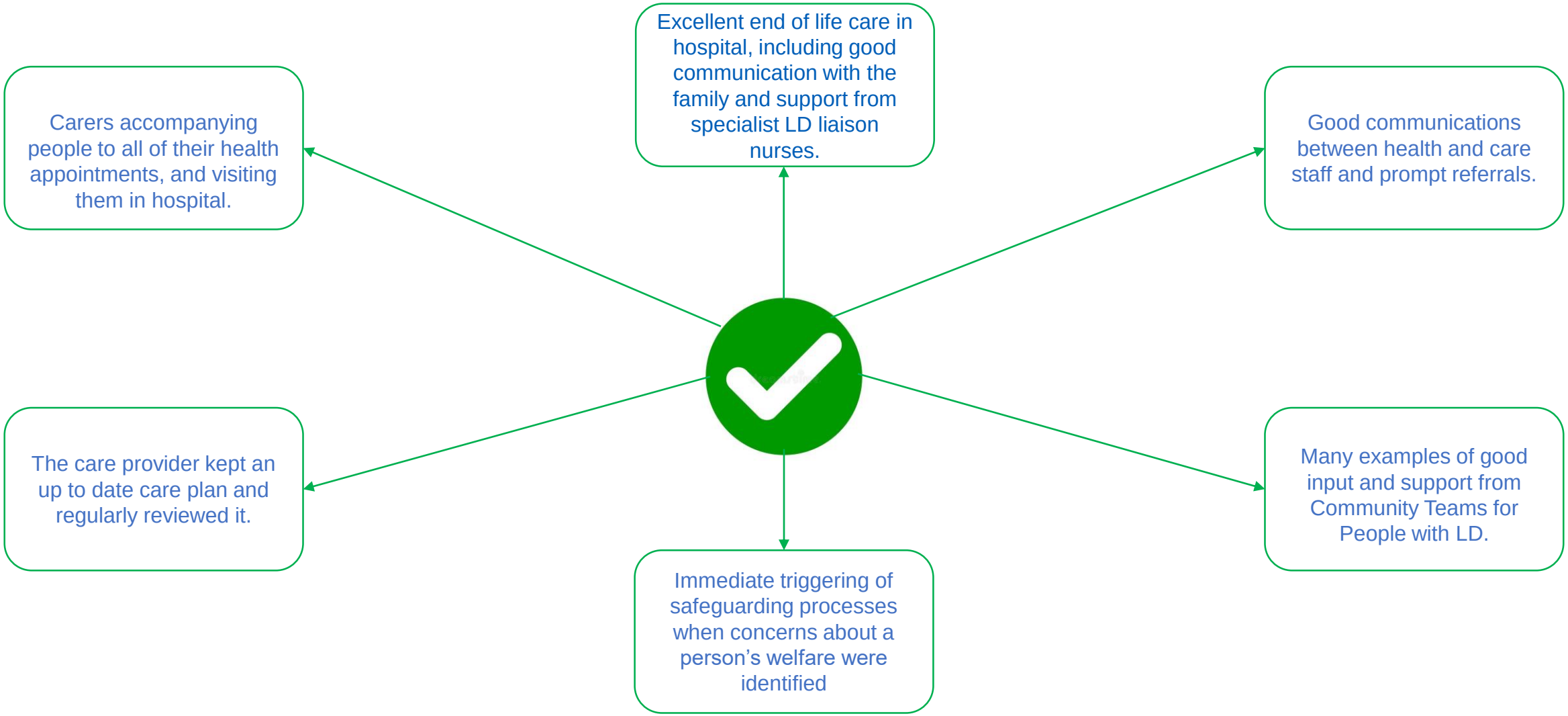
The new LeDeR Operational Group will incorporate cancer screening into its improvement plan; there is a need to collate and regularly update cancer screening uptake data for people with LD, and to use the data to target specific local improvement work.

Learning from older Reviews completed in 2020-2021

Learning	Status
Care staff coming into hospitals to support people during acute admissions	Protocol drafted for acute hospital wards (Frimley Health) to guide on bringing in carer support.
Implementation of the Red Bag scheme in LD residential care settings	Scheme being rolled out to residential settings.
Training regarding the needs of people with learning disabilities and working with carers to be offered to GPs and other clinicians.	Protected Learning events carried out with GPs. Scope for further support into care settings.
Support and education for care home staff working with patients who have complex health needs.	Support from CCG care homes teams – further support to be scoped.
Importance of MDT communication and co-ordination while patient is in hospital, in discharge planning including any decisions about DNACPR prior to discharge – important that ambulance services, community services and GPs are involved this alongside patients and carers / families.	Reiteration via acute improvement plan and staff training. ICS safe discharge group in place.
Soft food knowledge needs to be reviewed and upgraded for Nursing/Care homes, individuals and families both for generalised and national guidelines. This should include good, specific record keeping of daily food.	New international soft food descriptors published and in use.
HCP training need - any professional in contact with someone about whom there is a query about LD status can refer to the LD team (BHFT).	BHFT CTPLD has clarified and recirculated pathways / contacts for their teams.
Pain Management: To understand levels of pain and how they can be communicated by patients. Monitor and maintain a user friendly robust and effective pain measurement system.	Further work to be done on this.
Neurology/Specialist follow-ups to be explored by the LeDeR Operational Group. LeDeR reviews show evidence of some loss to follow-up particularly Neurology.	Part of operational group plan for 2021/21.
GPs, care homes and other community services to make contact with hospital-based LD liaison nurses to escalate concerns about any delays in secondary care interventions, including diagnostic procedures.	Reiterated via local providers.
There are separate DNACPR forms used in hospital and in the community. Had patient died before the community form had been completed, this could have led to a resuscitation attempt. - IMPLEMENTATION OF RESPECT FORMS	ReSPECT process implemented – further work to publicise and support understanding of process. For Operational Group consideration 2021/22.
Training on Learning Disabilities awareness for hospital staff – REF FHFT LD STRATEGY AND IMPROVEMENT PLAN	Covered within the acute (Frimley Health) LD strategy and improvement plan.
Recognition and response when patients who are medically fit for discharge from hospital deteriorate or their condition changes.	Learning from recent mental health SI used to revise medically fit for discharge processes in Frimley Health NHS FT.

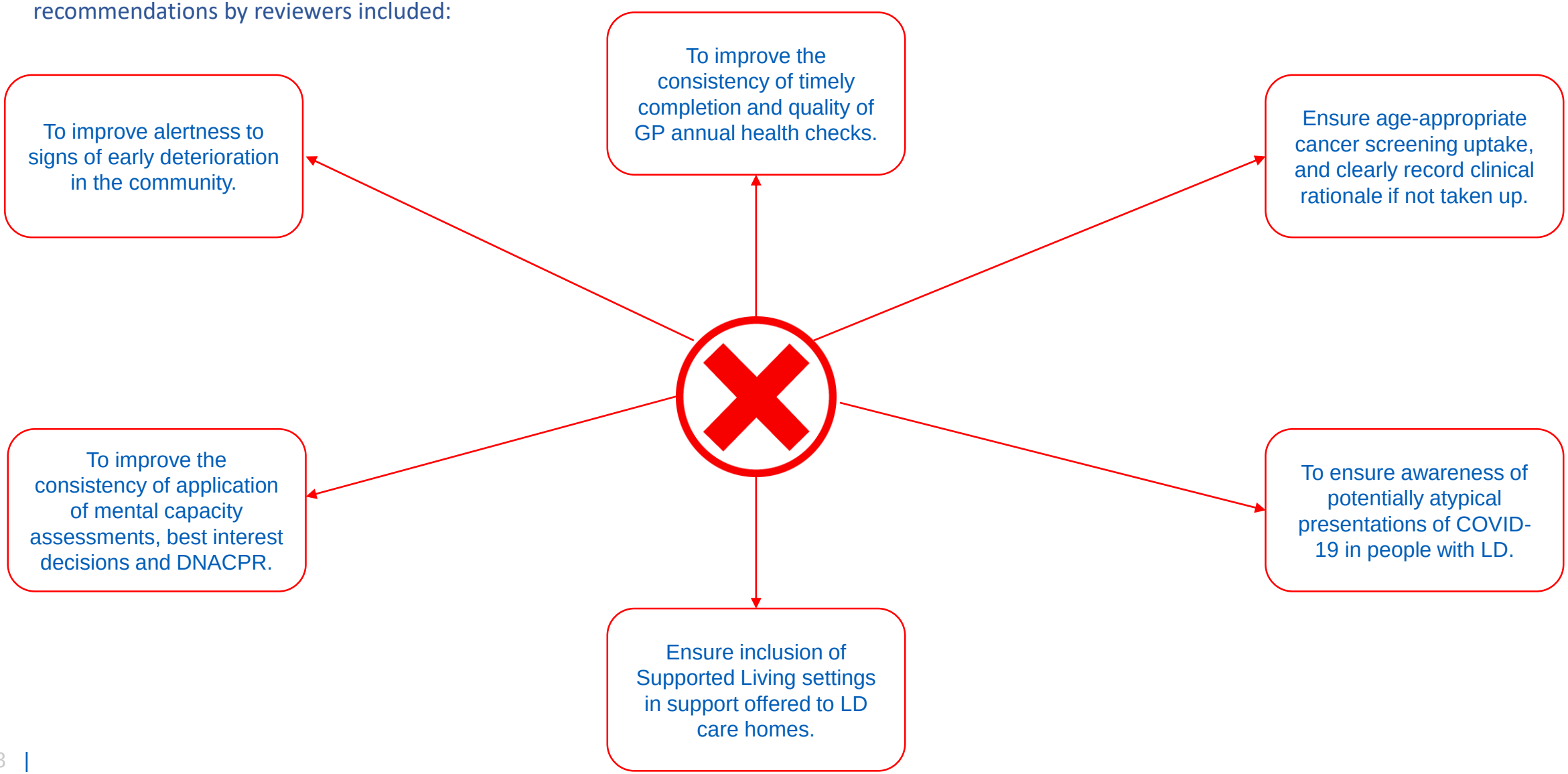
Action from Learning: Positive outcomes and achievements (best practice)

Examples of best practice included:



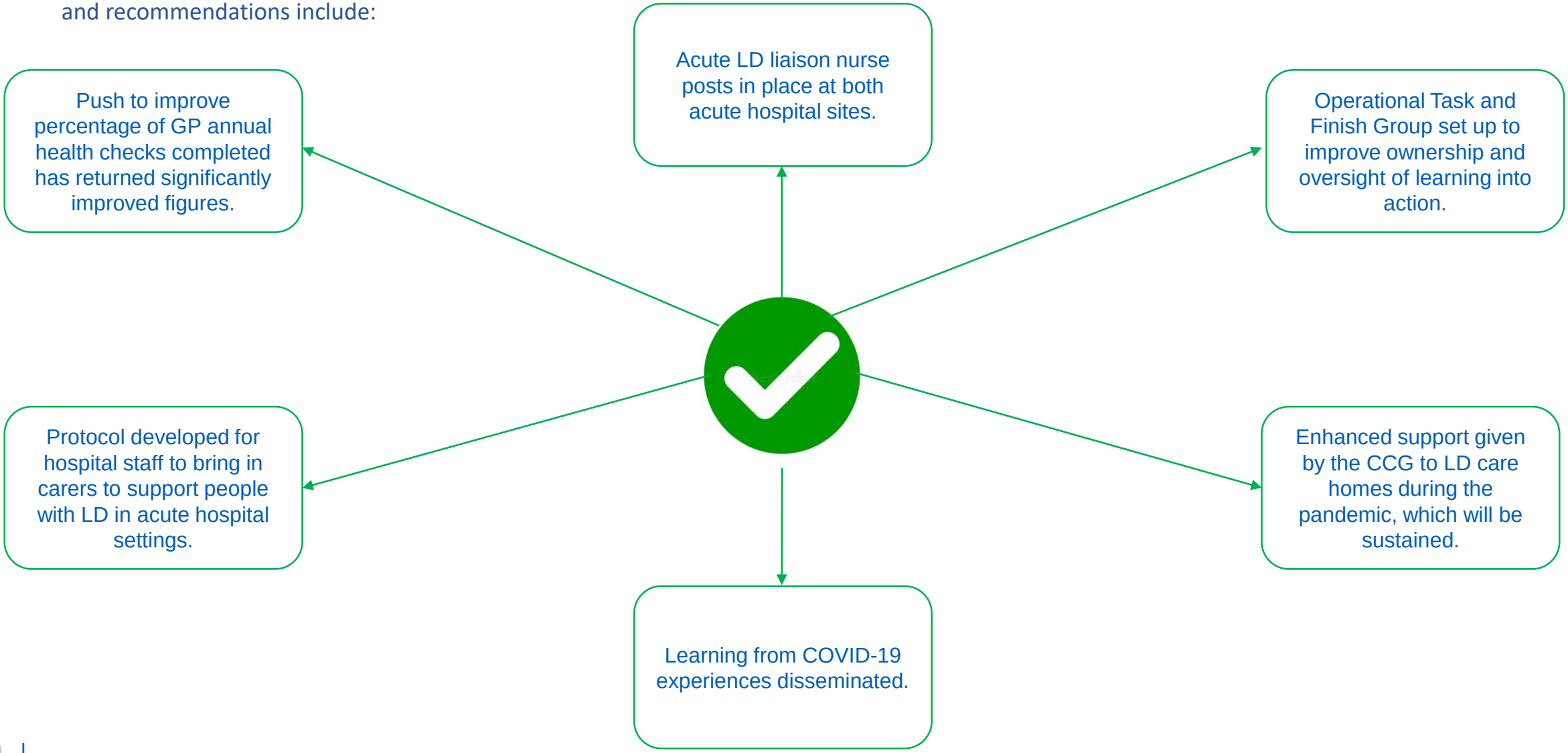
Action from Learning: Areas for improvement

Examples of areas for improvement for learning and recommendations by reviewers included:



Action from Learning: Recommendations for improvement

Some examples of actions to address learning points and recommendations include:



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

The new LeDeR Operational Group has reviewed several different key sources to use as its evidence base for local priorities in 2021/22. The main sources are:

I. The priorities and actions outlined in the draft South East Region LD & Autism Improvement Plan 2021-2024 which all systems have been asked to review and consider.. These priorities are informed by LeDeR learning at local, regional and national level. (Ref: *South East Region All-age Learning Disability and or Autism Quality Improvement Plan 2021-2024* Authors: NHS England & Improvement – South East Region Learning Disability and Autism Programme. Status: Draft April 2021). The finalised version of this plan will be the basis of the operational group's work plan for 2021/22. The key areas within it are:

- Pneumonia linked to National respiratory programme work
- Constipation
- Sepsis linked to learning from Covid 19 pandemic.
- Dysphagia (difficulty swallowing)
- Cancer-screening
- End of life care
- STOMP /STAMP
- Long term conditions-diabetes/epilepsy
- Annual health checks
- Human Rights/Reasonable adjustments.
- Restrictive practices.
- Personal health budgets.
- Mental Capacity Act (MCA)
- Learning Disability National Improvement Standards
- Transition.
- Co-production and advocacy.
- Host Commissioning/C(E)TR's
- Workforce

II. Local learning from LeDeR reviews completed in 2020/21. There is much common ground between this learning and the items in the draft SE Regional plan cited above. The operational group has cross-checked these against the regional plan to ensure that they are either already included, or can be incorporated.

II. Regional and national recommendations emanating from cases related to the COVID-19 pandemic. Again, some of these recommendations are covered in the regional draft plan, although some not explicitly. The operational group has cross-checked these against the regional plan to ensure that they are either already included, or can be incorporated.

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:

East Berkshire CCG has a LeDeR Steering Group which brings together all of the involved providers and agencies to review the learning from cases and disseminate among their staff. The group also reviews strategies and improvement plans from providers at this group. However, a need was identified to set up a separate but affiliated LeDeR Operational Group, with clinical / operational lead membership, to work on translating learning in to action across the system, taking both local and national learning and priorities into account. Inauguration of the operational group was delayed by the onset of the COVID pandemic, but it has now commenced and will work hand-in-hand with the wider LD and Autism commissioning programme, feeding back into the LeDeR steering group and the relevant commissioning / pathway groups.

In April 2021, East Berkshire CCG merged with North East Hampshire & Farnham CCG and Surrey Heath CCG to form the new Frimley Clinical Commissioning Group. The LeDeR programmes for these three areas will now be re-mapped into a single Frimley ICS programme, with both the Steering and Operational Groups having a system-wide remit from mid-2021.

We have received and reviewed the new LeDeR national policy, and work has commenced on reviewing our overall governance structures and workforce to ensure alignment with the policy. An overall strategy and implementation plan will be developed by September 2021.

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

There are some key metrics used to evaluate improvements in areas such as GP annual health checks and cancer screening uptake. In addition to these, the new LeDeR Operational Group will work with the Steering Group and with LD and Autism commissioners to develop an outcomes framework that takes into account learning from new LeDeR cases (through which consistency in areas identified for improvement are monitored), feedback from people with LD and carers, feedback from providers, and monitoring of other metrics developed to evaluate the impact of service improvements.