NHS South Tyneside Clinical Commissioning Group

NHS Sunderland Clinical Commissioning Group

NHS South Tyneside Clinical Commissioning Group and NHS Sunderland Clinical Commissioning Group Joint Annual Report on Learning Disability Mortality Review (LeDeR) 1st April 2020 - 31st March 2021

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1. Introduction

Welcome to the NHS South Tyneside Clinical Commissioning Group (STCCG) and NHS Sunderland Clinical Commissioning Group (SCCG) second joint annual report on learning disability mortality reviews (LeDeR) for 2020/21.

It has been an unprecedented year due to the impact of the pandemic and the effect of lockdown and social distancing being felt by us all. As we begin this year's report, with the same person-centred focus as last year, in sharing some brief glimpses of the people whose deaths have been reviewed, we reflect on that impact for people with a learning disability. How so many aspects of their lives may have changed, including their family relationships, their provision of care, their social engagement, and their working lives.

'She was very happy with her care package and before lockdown had a very fulfilled life full of activity, in discussion with her sister it was only during lockdown that she became very sedentary'

'He had many interests including watching John Wayne films and collecting and shopping for model buses. He enjoyed being out and about in the community, visiting cafes for coffee and cake, getting his haircut, and travelling on public transport. A highlight was a short break to Blackpool including taking rides on the open topped buses'

'He used to volunteer at a British Heart Foundation shop four days per week. He really enjoyed doing this and loved to sort out the new items donated to the shop so he was able to choose what he would like himself'

'She was cheeky and mischievous and was very much loved by all and had a loud but happy character. Her sister described her as an extraordinary character, who gave nicknames to family'

'He lived in an assisted living community with his wife. He was very happy living there they joined in with social occasions organised. He was a very private man and liked the support of his wife in social situations. Unfortunately, he was very unwell after contracting covid he really did not fully recover '

'He was a happy and bubbly gentleman with a good sense of humor. His Mum feels that he would have found it difficult to live in this new world of face masks and social distancing as there was nothing he liked better than giving someone a kiss and a hug.'

Last year we pledged that as learning organisations, SCCG and STCCG would ensure that learning gained from reviews would be shared across our health and social care services and have a positive impact on practice and service delivery. In this year's report we update on our progress and reflect on the challenges of that journey in the face of the pandemic.

We would like to take this opportunity to thank families, carers and all the health and social care professionals, who have supported us in our LeDeR work and share the Stop People Dying Too Young Group Statement for CCG Annual Reports.

'We have a right to have the same respect, value, and access to treatment as everyone else. Our lives have as much value as other people's. You need to understand our rights and know the Law. Start by listening to us - hear our worries but also what we want from our life. Listen to the people who know us best. This might be our family, friends, or paid support. Know how to make reasonable adjustments so that it is easy for us to get health care. Create good accessible information. Make it Easy Read and don't use jargon.

Don't let us die too young'.

We also wish to thank Equal People at Your Voice Counts for sharing the local view on the pandemic from people in our area and the work on co-producing the easy read version of this report.

Jeanette Scott
Executive Director of
Nursing Quality and Safety
South Tyneside CCG

Ann Fox
Executive Director of
Nursing Quality and Safety
Sunderland CCG

2. Summary

This second annual report presents an overview of the LeDeR work across South Tyneside and Sunderland, during 2020/2021. The report is intended to describe how SCCG and STCCG review the deaths of people with learning disability, how learning is identified and how this has influenced change and improvements in health and social care, for people with a learning disability across South Tyneside and Sunderland.

The report sets out:

- The background to LeDeR.
- Local arrangements and the governance that underpins how reviews are undertaken and the engagement of partners in this process.
- The number of reviews carried out and subsequent data.
- Performance against the timescales set out in the NHS Operational Planning and Contracting Guidance 2019/2020.
- The function of the CCGs' joint LeDeR panel in quality oversight and identification of learning.
- The sharing of learning and themes with commissioners of services for people with a learning disability.
- Commissioner and provider and Improvement outcomes.
- Comparisons and reflections on the progress from last year.
- Intentions going forward and an overview of the new national LeDeR Policy.

3. Background

The health inequalities for people with learning disability are well documented. Today, people with learning disabilities die, on average, 20-29 years sooner than people in the general population, with some of those deaths identified as being potentially amenable to good quality healthcare.

In response the Learning Disabilities Mortality Review (LeDeR) programme was established to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement initiatives.

Until recently the LeDeR programme was delivered by the University of Bristol and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. The University of Bristol commenced work on the LeDeR programme in June 2015, initially for three years but this was extended until the end of May 2021.

The LEDER programme is the first national programme of its kind in the world. Its overall aims being to:

- Support improvements in the quality of health and social care service delivery for people with learning disabilities.
- Help reduce premature mortality and health inequalities for people with learning disabilities.

The programme supports local areas in England to review the deaths of people with learning disabilities (aged 4 years and over), using a standardised review process.

The programme also collates and shares anonymised information nationally, about the deaths of people with learning disabilities, so that common themes, learning points and recommendations can be identified and taken forward into policy and practice improvements.

The programme developed a review process for the deaths of people with learning disabilities. All deaths receive an initial review and of those, where there are any areas of concern in relation to the care of the person who has died, or if it is felt that further learning could be gained, a multi-agency review of the death is completed.

Priority reviews of cases aged 18-24 years or from a black or minority ethnic background are also undertaken and may receive multi-agency review and expert panel scrutiny.

On completion of a LeDeR review, outcomes and recommendations are made by the reviewer and are shared with the CCGs Learning Disability Commissioning Lead. The Commissioning leads and respective CCG colleagues consider the information within the commissioning and planning process and identify any service improvements that may be indicated.

The LeDeR process is not implemented when other statutory process would apply e.g. Child Death Overview Panel (CDOP) or where the criteria is met for a Child Safeguarding Practice Review, Domestic Homicide Review or Safeguarding Adults Review. However, the learning from these statutory processes is captured in to the LeDeR process.

4. Local Arrangements across SCCG and STCCG

South Tyneside and Sunderland CCGs work collaboratively together on the LeDeR programme.

The Executive Directors of Nursing are identified as the Local Area Contacts (LAC) for LeDeR within the CCGs and hold overall accountability for the programme within their areas. They are supported by a deputy LAC, for STCCG this is the Designated Nurse for Safeguarding Adults, in SCCG it is the Head of Quality and Patient Safety.

A joint CCG LeDeR Assurance Panel is in place and delivered in collaboration with healthcare providers, reviewers, and commissioners. The purpose of this Panel is to ensure that the Clinical Commissioning Groups (CCGs) fulfil their responsibilities for the oversight and management of LeDeR reviews involving patients of the respective CCGs, in whichever sector they received care, and to share learning across the health and social care system.

The panel has responsibility for quality assuring the robustness of initial reviews and any subsequent multi-agency reviews. A key aim of the panel is to ensure the reviews elicit good practice and learning, to inform system improvement in care.

5. Governance arrangements

The LeDeR Assurance Panel is a subgroup of the STCCG's Quality and Patient Safety Committee (QPSC) and SCCG's Quality and Safety Committee (QSC). Throughout 2020/2021 the committees have received regular updates on progress and outcomes.

The two committees combined in April 2021 to form a Joint Quality and Safety Committee (JQSC) and the annual report will be presented to the June 2021 meeting for assurance and comment. LeDeR is a standing agenda item on the JQSC agenda.

This annual report will be shared with the respective CCG's Governing Body and the local Health and Wellbeing Boards and published on each website alongside an easy read version.

6. Reviewers

There are several professionals trained in completing LeDeR reviews across health and social care, for both SCCG and STCCG. As with last year, there is a difference across the two CCG areas on ways of engagement from partner organisations. The clinical priorities during the COVID-19 pandemic led to staff being re-deployed into different roles and clinical areas to meet priority need.

This emphasised the known challenge of a lack of dedicated reviewer resource to meet completion of reviews, within expected timescales.

7. Number of deaths and demographics

South Tyneside CCG

During the period 1st April 2020 to 31st March 2021, STCCG had **18 deaths** notified on to the system. This was an increase of 5 on the previous year. One case was removed as found not to have a learning disability.

At end of year, 16 were complete and 1 notification awaiting allocation to a reviewer.

One Child Death Overview Process (CDOP) case notified in 2019 remains open and will be closed on receipt of the CDOP report.

There were 7 cases from the year 19/20 that remained in process for completion and sign off. These were managed to completion in the period of this report and therefore, the outcomes and learning gained is included.

Sunderland CCG

For the same period, SCCG had **21 deaths** notified on to the system 2 more than the previous year.

At end of year, 20 cases were complete and 1 notification awaiting allocation to a reviewer.

There were 12 cases from the year 19/20 that remained in process for completion and sign off. These were managed to completion in the period of this report and therefore the outcomes and learning gained is included. One case was removed subsequently as no learning disability was found.

Demographics

Of the deaths notified on to the system in 20/21, 54% were above 60 years old with most deaths occurring in the 60-70 years age range. See figure 1.

Differing to last year there were 16% of deaths in people under 40 years old. A comparison can be seen in figure 2 with deaths occurring across the age ranges in 2020/2021.

Figure 1. Age range

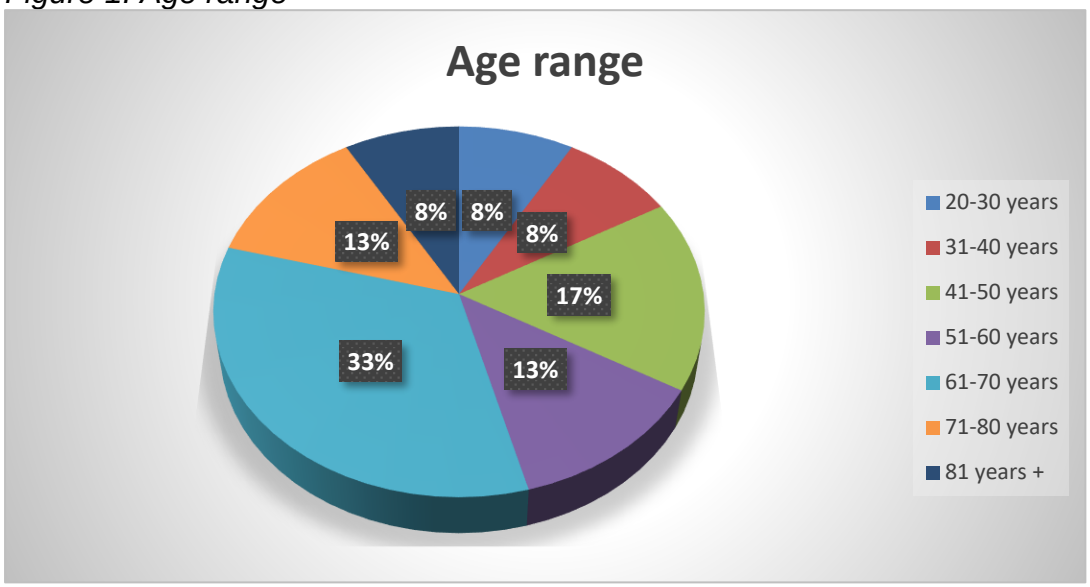
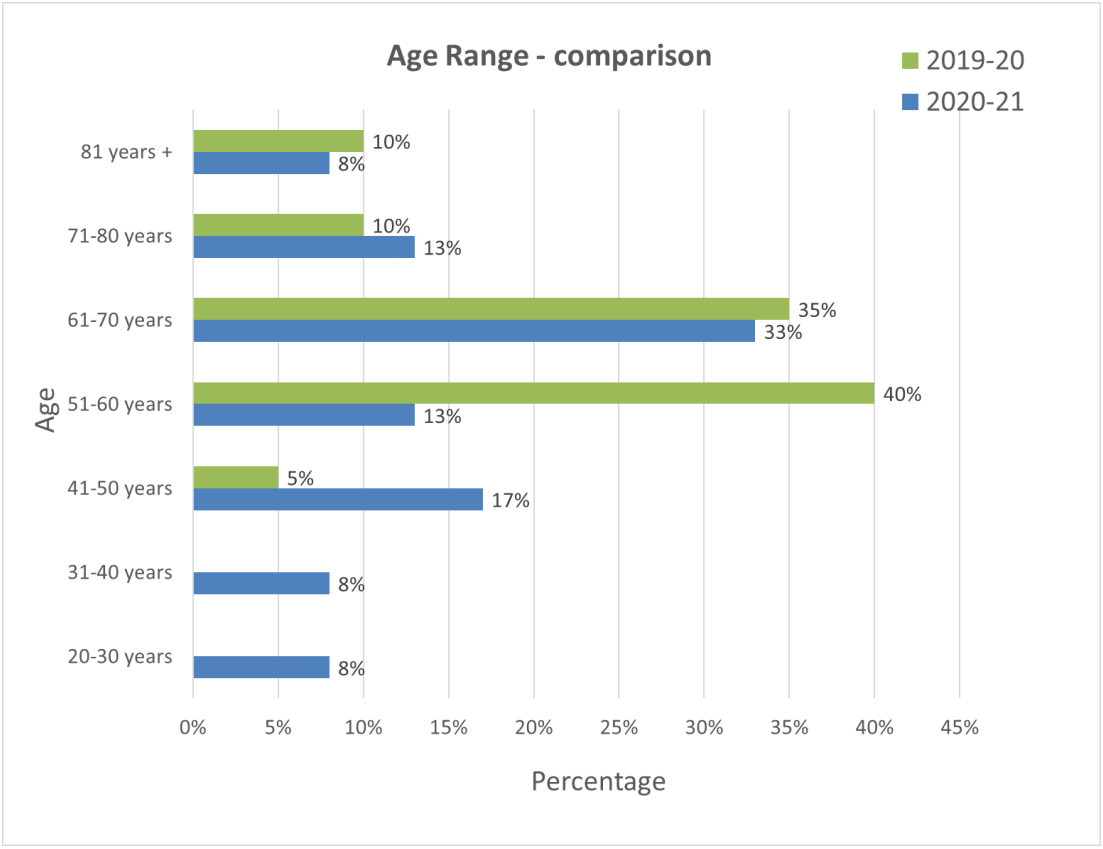


Figure 2- Comparison of age range between 2019/20 and 2020/21



Gender

The gender split has been balanced this year with similar numbers of male to female deaths reported on to the system.

Ethnicity and marital status

Where ethnicity is known most people were recorded as being white British, two people were recorded as Asian British and one was unknown. Like last year most are recorded as having single status; however, one was married, one divorced and one unknown however the person often mentioned their long-deceased husband.

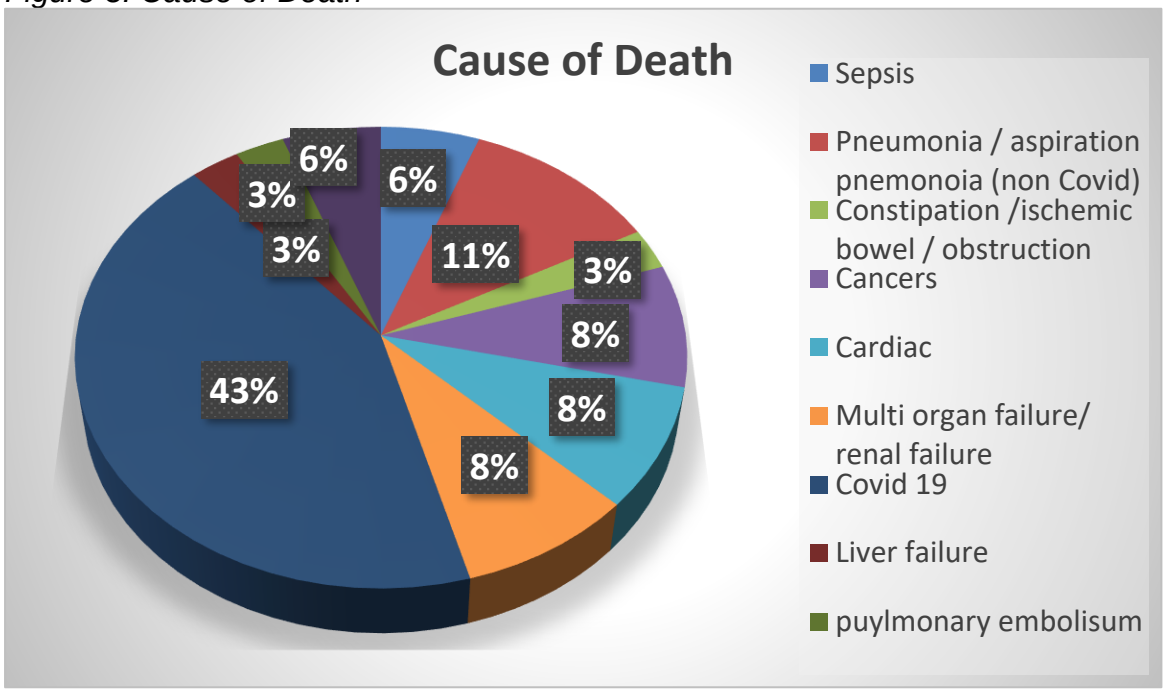
Place of death

Approximately 83% of people died in hospital with only a small number recoded as dying at home or a hospice. This is 2% less than last year.

Cause of death

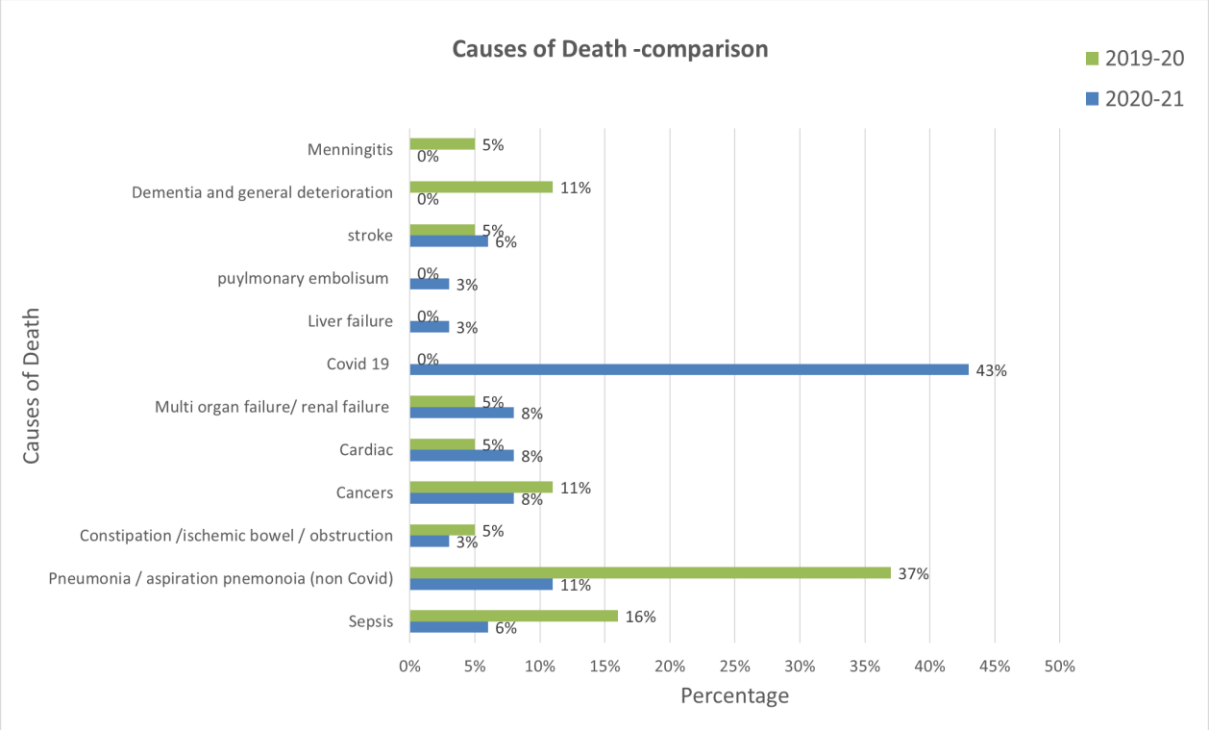
This year has seen the impact of Covid -19 as a cause of death on the whole population, and it is the highest cause of death for people with a learning disability across South Tyneside and Sunderland. This year the LeDeR system added a field for confirmation of Covid-19 status on to the review platform. There have been 15 Covid-19 related deaths. Other conditions that were identified as a cause of death included pulmonary embolism, aspiration pneumonia, chest infection and cancer of the breast, liver, lungs, and digestive tract. Heart conditions and renal failure were also identified, and sepsis was recorded in two cases of pneumonia and a twisted bowel.

Figure 3. Cause of Death



A comparison of cause of death can be seen as a percentage in figure 4.

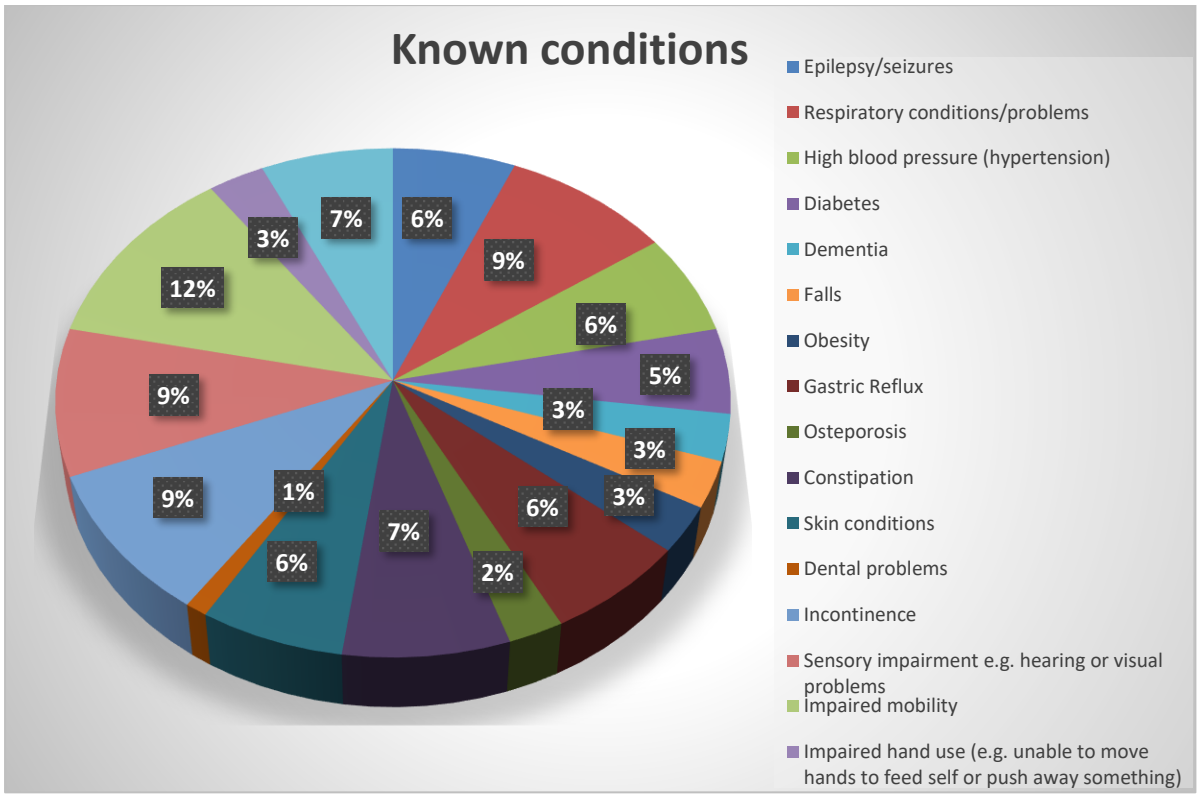
Figure 4: Comarison of cause of death in 2019/20 and 2020/21



Known conditions

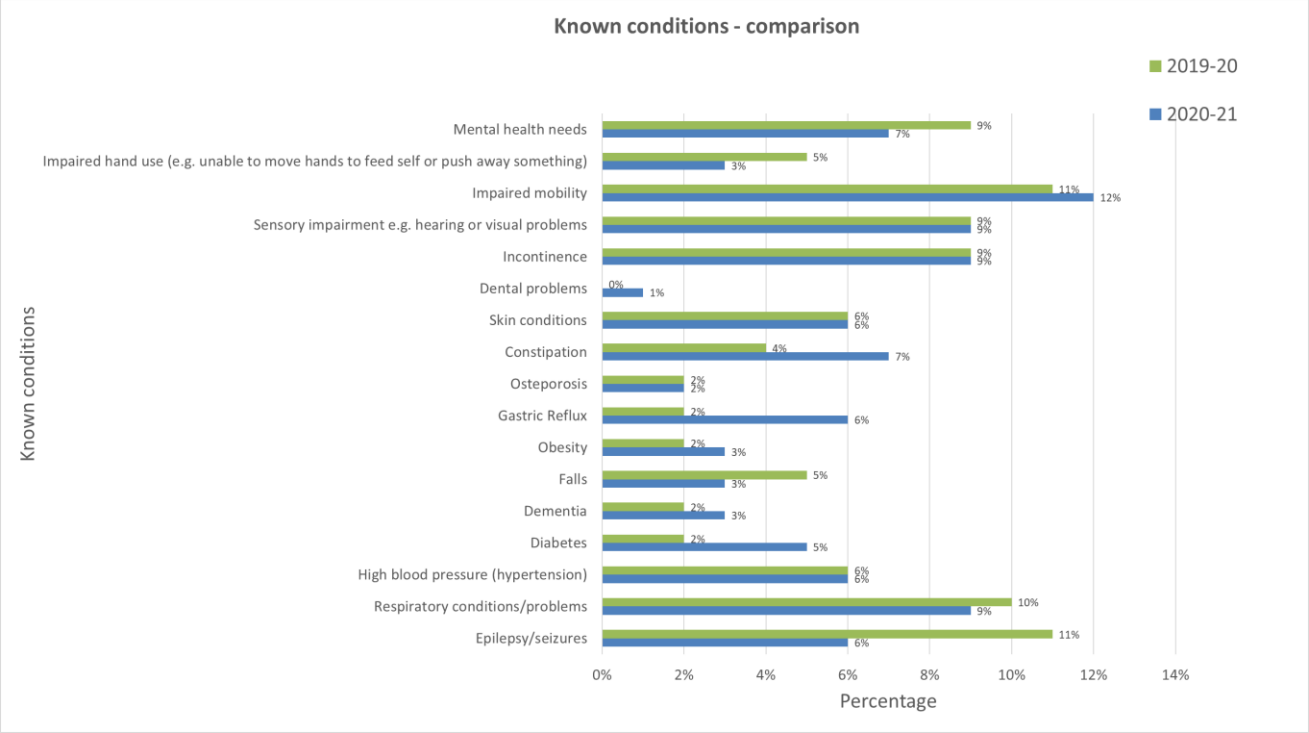
As in previous years the cases reviewed evidenced a wide range of conditions that individuals lived with. Many had multiple conditions with the most common this year being impaired mobility, sensory impairment, and incontinence. See figure 5.

Figure 5: Known conditions



This is a notable change from last year where epilepsy and respiratory problems also featured and there is a significant increase in constipation, gastric reflux and diabetes, as can be observed in figure 6.

Figure 6: Comparison of known conditions 2019/20 and 2020/21



Anti-Psychotic and Anti-Depressants

The review asks whether anti-psychotic or anti-depressant medication has been prescribed to the individual in the last 10 years, and whether this has been reviewed or attempts made to reduce or stop. There has been much work done on medication reviews with evidence that 92% of people had a general mediation review. However, where information on a prescription of anti-psychotic or anti-depressant was recorded, specific evidence in the records of a successful withdrawal or attempt to review was mostly recorded by reviewers as not known.

Annual health checks and health screening

The uptake of an annual health check (AHC) is much improved with evidence that reviewers found across South Tyneside and Sunderland that 78% of people who died had had an AHC in the last year - 2 people had been offered and declined and 2 people had been too ill to attend. In 1 case it was recorded that the AHC had not been undertaken due to Covid-19 and in 3 cases it was recorded as not known.

Similarly, the uptake of health screening has improved with 83% of people being recorded as provided with all or some of the appropriate screening for their age.

Family engagement in reviews

Family members were known in 53% of the cases and of those 63% engaged with the review. This was an increase on last year. It is recognised that engaging with family at the time of a loved one's death is sensitive and may present challenges.

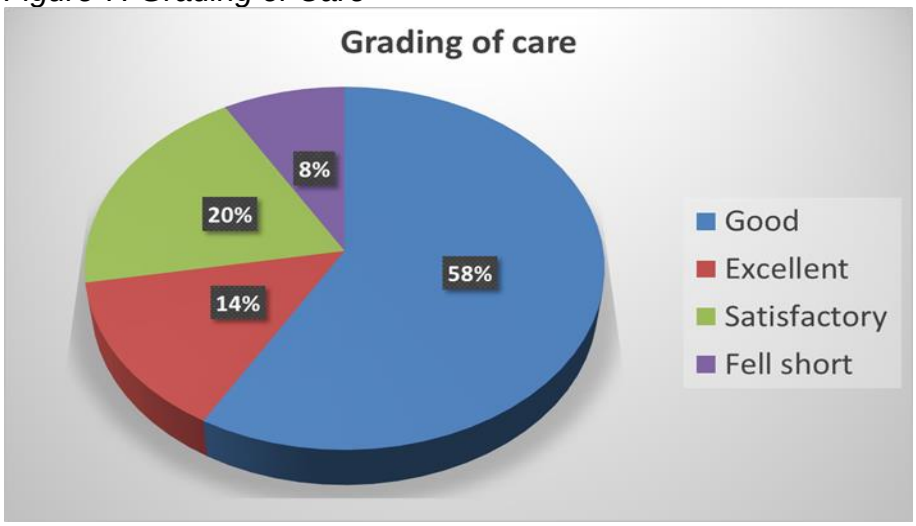
Opportunity for family engagement in the LeDeR process is available to all. However, a number of relatives did not respond to the reviewers attempt to make contact or feel that it was the right time for them to meet to discuss their relative. The ability to liaise with families at such a sensitive time is a recognised quality of South Tyneside and Sunderland's reviewers.

Grading of care

In the majority of cases, the LEDER reviewers graded the quality of care received as being either excellent or good (see Figure 7). A small number were graded satisfactory or falling short of satisfactory care, however no cases were assessed as requiring a multi-agency review, to gain additional learning.

Cases where care fell short of expected standards are shared with the Learning Disability service commissioners to address any immediate concerns. Where family concerns indicate an area of complaint they are directed to the appropriate process within the organisation.

Figure 7: Grading of Care



8. Learning Themes

Positive Findings	
Reasonable adjustments	• During Covid all reasonable adjustments were risk assessed. • Use of drawings and simple language. • Personal books and activities made available to people on wards. Due to Covid, all magazines and activities had been removed for infection prevention and control. • Primary health care assessments and annual health care checks booked in the persons own homes with carers and have a relative present. • Longer appointments at GP practice and flexible GP appointments. • Speech and language therapy (SALT) assessments arranged at residential care homes with an appropriate level of time and instruction. • Use of hospital passports.

	• Home visits by primary care for flu vaccination. • Care at Home team and Learning Disability liaison nurses provide support with hospital appointments and hospital stay. • Support to attend community health appointments and GP practice. • Helping families to understand complex medical terminology. • Availability of a person on the Ward who had the same first language as persons mother • Reasonable adjustments at GP practice when doing Annual Health Checks. • Use of the carers passport to identify carers and alter the visiting times. • Cancer services appointments offered to accommodate need and provide special provision. • Health Action Plan was completed in 2 appointments to meet persons need. • Family supported Xray appointment and there was flexibility with Covid restrictions. • Side room available for family to stay.
Mental Capacity	• Good records of Assessment and Best Interests. • Best Interests on End-of-Life care discussed with family. • Best Interest consulted with friend.
Best practice	• GP ensured access annual health checks and long-term conditions monitoring by telephone when unable to access the surgery due to Covid-19 restrictions. • Accessible easy read information about breast cancer awareness. • Reasonable adjustments were clearly documented in the GP Record. • Use of Enhanced Care Risk Assessment Tool to identify reasonable adjustments that were needed. • Hospital Health Action Plan and pathway was available. • Excellent Multi-disciplinary Team working. • Excellent support from Community Learning Disability team. • Mental capacity documented on every visit District Nursing visit. • Joint visit with learning disability nurse and district nurse on first visit to hand over and get to know person. • Care home used pictures to identify emotions and support meal choices. • Staff team supporting within own home understood the importance of using nonverbal communication to promote positive interactions and to ensure communication was effective. • Risk management plan to identify signs of silent aspiration and first aid.

	• Social care reassessed person on deterioration in health and difficulty managing stairs. The person was transferred to accommodation with ground floor access with two members of their care team transferred to ensure continuity of care. • At the end of life there is clear evidence that the hospital medics listened to the primary caregivers with a focus on palliative care. Primary caregiver (mother) was trained to monitor blood sugars and give insulin. • Excellent liaison between Diabetes Specialist Nurse and acute services.
Areas of Learning	
Primary Care	• Annual reviews should provide a holistic review of a patient's needs. • Needs were not reviewed timely due to pandemic. • No best interest meeting held to decide on taking blood to consider distress to person. • Out of hours staff should be encouraged to look at most recent reports from relevant professionals when visiting patients for a particular issue. • The importance of having a comprehensive EHCP to plan care considering patients and families wishes. • Not recorded on GP system as Learning Disability. • Screening offered but not taken up and not followed up. • No evidence of Mental Capacity Act assessments or best interests seen in record. • Death Certificates do not appear to have been provided in a timely and appropriate manner.
Care home	• Care staff delayed in contacting speech and language therapy when patient had issues with swallow. • Lack of knowledge of care staff regarding deprivation of Liberty safeguards (DoLS) application and time delay.
Hospital Care and community	• Healthcare provider should ensure that all staff are trained in the mental capacity act and that this is properly applied and documented in practice. • There is no evidence of a capacity assessment in the decision making around DNACPR and ceiling of care. • Earlier flagging of patients with LD to ensure support is made available at the earliest opportunity. • No care plan was completed prior to admission and the care plan put in place was in the last days of life. • Staff had to be prompted to refer to his Hospital Passport on several admissions. • Review and management of PEG /Feeding/Hydration regime was not evident following hospital discharge. • Review of nursing or residential need not considered in discharge. • Checks to be made on DNACPR and added to record.

Family view	• The family report the residential care home provided a lovely experience and family cannot fault the care given they remain in contact with the carers to date. • Care was not seamless in moving through hospital departments and there were delays in medication and feeds. • There is no evidence of a best interest's discussion or involvement from family for the decision not to resuscitate. • The GP went out of their way to see person at home. • The hospital treated person like they were family.
Reviewers Recommendations	• To improve systems in GP surgery for staff when managing end of life care and develop a process for managing relative phone calls in expected deaths. • Development of shared assessment and care planning for complex need and anticipatory planning. • Awareness raising for carers on dysphasia and speech and language therapy outcomes. • Swallowing should be assessed by a practitioner qualified in dysphagia management. • Improve understanding of prescribing thickener to "reduce aspiration" and the need for assessment. • Best practice to involve people who knew the person well in best interests decisions. • The CCG should ensure that GP practices provide a complete set of records relating to the period of review, including correspondence from other providers. • Ensure appropriate follow-up and review of feeding/hydration regimes with necessary health professionals to ensure needs are fully met in the community when there are identified issues relating to nutrition/hydration during that admission. • Hospital/Communication Passport is located/obtained for any patient admitted who has a Learning Disability and is available visibly at their bedside for any staff caring for them to view. • GP and care home staff should be made aware of process of escalation if unable to get in contact with assigned social worker. • Trust Mortality Review process to include deaths that occur within Emergency Department. • Share Public Health guidance to help health professionals when taking blood from a person with learning disability. • Reminder to prescribers that medications should be regularly reviewed to determine whether they are still necessary and effective. • Trust to review recording on Meditech of learning difficulty and learning disability to ensure correct diagnostic terms.

	• Medical staff to be reminded on record keeping standards on the cause of death. • Consider the broader impacts of the COVID-19 pandemic e.g., the closure of day services, delays to existing plans, changes to service delivery models, the isolation of people with learning disabilities, and an increase in clinical responsibilities for carers. • Constipation should be treated as a condition. • Access to advocacy should be available at all reviews. • All health professionals raise a safeguarding alert when there are concerns about risk to a vulnerable adult's health and wellbeing. • Abbreviations should be clarified to prevent confusion. E.G EHCP as either emergency health care plan or education health care plan. • Increase awareness of services across different communities and ethnic groups
Outcomes	• Dysphagia awareness training has been offered to all paid care staff in the area - recommend staff at home attend this training as soon as possible (currently on hold due to COVID-19). Interim video link training provided. • Commissioner and provider outcomes and response is set out in section 11.

9. Performance against national targets

The NHS Operational Planning and Contracting Guidance 2020/21 sets out the expectation on CCGs and the system, about LeDeR, which are:

- CCGs are a member of a Learning from Deaths report (LeDeR) steering group and have a named person with lead responsibility;
- There is a robust CCG plan in place to ensure that LeDeR reviews are undertaken within 6 months of the notification of death to the local area;
- CCGs have systems in place to analyse and address the themes and recommendations from completed LeDeR reviews;
- An annual report is submitted to the appropriate board/committee for all statutory partners, demonstrating action taken and outcomes from LeDeR reviews.

Both SCCG and STCCG are members of the regional steering group and the Deputy LACs regularly attend.

CCG assurance panels are scheduled monthly to prevent delays in the approval and completion of reviews, however during the pandemic LeDeR activity was stepped back due to clinical priorities. Virtual panels commenced via TEAMS and were increased where possible to twice a month in quarter 3 to meet the timeframes set down by NHSE&I for the completion of all delayed reviews by December 2020.

A joint tracker is in place for both CCGs which enables best practice and learning to be easily extracted. All key themes, trends and lessons learnt are shared with the respective commissioning teams.

Peer support sessions were postponed due to the pandemic however support from the deputy LACs was available to all reviewers. Reviewers have continued to attend panels to present their cases via TEAMS when able.

LeDeR continues to be an agenda item on the Learning and Improvement in Practice sub-Committee in both respective areas, which reports to the Local Safeguarding Adults Board.

This second annual report for SCCG and STCCG will be presented to the Joint Quality and Safety Committee and to each Governing Body. It will then be published on the CCGs web site alongside an easy read version.

The impact of the pandemic was recognised by NHSE&I, and an accepted delay of 3 months, in completion of cases was put in place, which extended the review completion date to the end of December 2020.Both SCCG and STCCG achieved completion of all reviews expected by this date.

Against the NHS Operational Planning and Contracting Guidance 2020/21 standards set out above, of the cases notified within the year, South Tyneside completed 81% of reviews within 6 months, with 56% of these being allocated within 3 months. 18% of the reviews were not allocated within 3 months or completed in 6. This was a significant improvement on last year's data due to the number of reviews notified in quarter 4 of 19/20 being placed on hold, due to the pandemic which significantly impacted upon performance.

Sunderland completed 50% of cases within 6 months with 30% of these being allocated within 3 months of notification. The remaining 50% were not allocated within 3 months or completed in 6. There were a number of deaths within quarter 1 which coincided with suspension of LeDeR activity and availability of reviewers, all being stepped back, and this significantly impacted this performance. All reviews, however, were completed within the 3-month extension period.

10. Impact of COVID-19

The COVID-19 pandemic has been and still is, a difficult and distressing time for us all. People with learning disability have raised their national voice to the inequalities they see regarding decisions made on end-of-life care and poor practice with blanket approaches to Do Not Attempt Cardiopulmonary resuscitation (DNACPR). The vaccination programme timings and the availability of information has left some people feeling forgotten about when the numbers of deaths of people with learning disability from COVID 19 increased.

Locally we have sought the views of people across our area on their reflections during the height of the pandemic. Equal People from Your Voice Counts (YVC) gave these views.

In response to Covid Vaccine roll out, one member of Equal People was pleased to get her vaccine early as she was YVC staff (this was excellent as although she has various health conditions including breathing problems, she would have had to have waited a further 2 months for her vaccine).

One member of Equal People said they were regularly tested where they lived. Another member was tested at regular health appointments. People were impressed that they were offered the vaccine so soon after the prioritising of people with

learning disabilities was announced by the government. However, it was mentioned that people with learning disabilities should have been a priority group for the vaccine in the first place.

People would have preferred the vaccine invitation letters in Easy Read.

Also, people mentioned that they were impressed with the support from YVC in arranging convenient appointments.

In general people were impressed with the local response and support with vaccine roll out and no one had issues with DNACPR.

The LeDeR programme across STCCG and SCCG will continue to seek to hear peoples voice and reflections on the pandemic and its impact on them and across all health and social care.

The local LeDeR programme was also affected with both CCG areas experiencing challenges on performance against national targets at differing times. STCCG saw most impact in the last quarter of 19/20 which lowered performance against the standards and was reported in last year's report.

From March to July 2020, in the first wave of the pandemic, the local Acute Foundation Trust stepped their reviewers back from the LeDeR process completely and placed structured judgment mortality reviews on hold. Some reviewers were redeployed into clinical priority areas and this impacted on our overall reviewer capacity.

In addition, across the system, there was reduced access to records, health and social care professionals who knew the person well and family members, for any outstanding or new reviews.

In quarter 3, in support of the CCGs and the system expectation from NHSE&I, the Acute Foundation Trust made available a number of senior staff to complete the LeDeR training and support reviews. This along with the return of the Learning Disability Liaison Nurse from re-deployment and an additional reviewer within South Tyneside Joint Commissioning Continuing Health Care team, enabled the cases delayed during the first half of the year to be reviewed to timescale.

Additional support was also created by NHSE&I commissioning the North East Commissioning Support Unit (NECS) to allocate two additional reviewers to the South Tyneside and Sunderland system.

This enabled both CCGs to meet the extended deadline of December 2020 for completion of the reviews delayed within the 1st wave of the pandemic.

11. Provider and Commissioner Response

South Tyneside

In 20/21, the physically health hub became fully operational in South Tyneside, providing additional support to people who had an identified learning disability to access full annual health checks and the development of health action plans. For some people the level of support involved providing outreach support into people's own home. In 20/21, 86% of people with a learning disability were able to access a full annual health check, resulting in a number of people with significant undetected

health needs being able to receive the appropriate treatment. This includes people receiving treatment for cancerous skin lesion. Work has commenced, to increase uptake further in collaboration with our 3rd sector providers.

People have also been supported to access desensitisation programmes, making access to vaccination and also health investigations. The team also has a pharmacist as a key member, who continues to support practitioners and individuals around medication management, and alternative options.

In addition, the Community Learning Disability Team (CLDT) have continued to provide support to people in South Tyneside who have a Learning Disability and are known to service.

The impact of covid and deterioration in respect to mental wellbeing over 2020 has been well documented, with people with learning disabilities reporting feeling isolated and lonely, which has also impacted on physical health as well as increasing the health inequalities. Therefore, work has commenced with IAPT service to increase accessibility for people with learning disabilities.

Welfare checks via telephone contact and home visits have continued with precautionary measures in place following Trust guidance. In addition, a link worker role has been developed across the Primary Care Networks (PCN's) to support people with learning disabilities and autism access the right support, at the right time.

Information such as Covid passport grab sheets and easy read accessible information from the Keeping Well for Winter and Keeping People Connected bulletins have been promoted and shared with service users, carers, and professionals.

Throughout 2020, both the memberships and focus of the health subgroup has been reviewed, to ensure that it covered the lifespan and to ensure representation across partners. The health subgroup have also developed a health dashboard to track health conditions.

The Acute Learning Disability Liaison Nurses have continued to support patients with a Learning Disability on admission to hospital and act as a point of contact for staff.

In 2020, Learning Disabilities Quality Checkers was introduced across all GP practices, with over 50% of the GP practices now having an active action plan to improve the experience for people with learning disabilities and ensure reasonable adjustment are in place.

The North East and Cumbria Learning Disability Network and the Access to Acute (A2A) Network have worked together to develop a learning disability awareness e-learning package for all staff in South Tyneside and Sunderland NHS Foundation Trust and revise care pathways. The Learning Disability Diamond Acute Care Pathways will be implemented across all Trusts in the North East and Cumbria which will support hospitals to deliver high quality, reasonably adjusted care, and treatment to people with learning disability.

Sunderland

Over the last 12 months in Sunderland the CCG has continued to work closely with health and social care partners on several health issues:

We have delivered an increased number of flu vaccines between September 2020 to March 2021, the end of year achievement was 71.8% across Sunderland for people with a learning disability. This is the highest number of flu immunisations delivered to this patient cohort over a 1 year period in Sunderland so far, and was achieved through a collaborative approach between GP practices, Health Promotion Team and Community Treatment Team within Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust (CNTW) and NHS Sunderland Clinical Commissioning Group (CCG).

Special arrangements were put in place for GP practices to identify those patients with a learning disability who required reasonable adjustments or required the vaccination to be delivered in their own home environment. Those patients were then passed over to the Specialist Learning Disability Nurses who could make the appropriate adjustments to deliver that vaccine or provide access to a nasal spray as an alternative. This nasal alternative helped to reduce anxiety and increase willingness to agree to the flu vaccine.

Sunderland were also successful in their application to become an exemplar site through NHS England & Improvement and were 1 of only 7 areas throughout the whole of the UK to receive this status. This was an exciting opportunity which has enabled us to work closely with primary care, local specialist schools, the BAME community and others to deliver a number of key projects as part of this exemplar site status.

The funding received made it possible to employ a Primary Care Practice Nurse for the period of this project (until September 2021) to work to deliver our exemplar site objectives. This included the further increase and uptake of annual health checks (AHCs) whilst ensuring the quality of these remains in line with our local quality framework. We agreed that by the end of the exemplar site status we would reach a target of 75% uptake of AHCs across Sunderland, by the end of March 2021 we achieved 78.2% which is a tremendous achievement especially during the Covid-19 pandemic.

There are a number of other areas delivered as part of our exemplar site status including working closely with our local specialist schools to design a birthday card that will be distributed to younger adults with a learning disability. This birthday card is to remind them of the importance of attending their AHC as we aim to increase the number of individuals aged 14 – 17 receiving AHCs. We have also been sharing our achievements, journey so far and best practice nationally via a number of webinars which were received well. Following this we have been approached by other CCG areas asking for us to mentor them this year to make similar improvements in their own area.

We continue to use our local AHC quality framework to support GP Practices to improve the quality of AHCs to those with a learning disability across Sunderland. This framework was rolled out in 2018/19 across Sunderland and by the end of March 2019 all practices were awarded bronze status. This quality improvement work has continued since and during 2019/20 all practices achieved silver status.

Practices have an action plan which outlines what they need to do to achieve gold status by March 2022, some of the areas practices are working on include:

awareness and completion of care passports for patients with a learning disability, ensuring all over 55 year olds are routinely referred for hearing screening and audit completion of health action plans to ensure they are of a high quality. As part of this quality framework we have assurances that practices have personal profiles for patients with a learning disability in place, these indicate what reasonable adjustments are required to ensure primary care know their patients' needs and promotes good access to primary care. Our Exemplar Site Practice Nurse is working closely with all practices to ensure updated reasonable adjustment information is collected and recorded correctly on GP systems in order to share that information on summary care records enabling other health services to view patients individual requirements.

As a direct response to LeDeR reviews, we continue to ensure the correct people remain or are added onto practices learning disability registers, this is extremely important to ensure they receive an annual health check, flu immunisation and to ensure reasonable adjustments are collected and added to their practice profiles to ensure easier access to healthcare services. We continue to make improvements to local registers via our exemplar site plans - one of our projects is around improving the registers and finding those missing patients. Our local team work to ensure any outcomes or lessons learned from LeDeR reviews are reflected in the next years plans to ensure any areas of concern are addressed as part of their continuous improvement plan.

Finally, we have received positive feedback from patients, families, and carers around our flexible and adjusted approach to delivering the Covid-19 vaccination programme to individuals with a learning disability and / or autism across Sunderland. All our learning from delivering flu vaccinations across the city has enabled us to ensure those individuals who have needle phobias or are anxious have bene supported by our learning disability specialist nurses to receive their vaccine in the most appropriate environment.

12. Change to National Policy 2021

The Learning from Deaths Review Programme (LeDeR) has been renamed 'The Learning from lives and deaths - People with a learning disability and autistic people' programme. This followed the publication of a new LeDeR policy on the 23rd March 2021 which now includes people with autism and is focused at driving improvements in care.

The responsibility for ensuring the delivery of LeDeR reviews will move to the integrated care systems (ICSs). This includes the responsibility for ensuring actions are implemented to improve the quality of services for people with a learning disability and autistic people and reducing health inequalities and premature mortality.

The LeDeR Programme was initially led by the University of Bristol which included overall responsibility for the direction of any reviews, operation of the web platform and analysis of LeDeR data; this contract closed in May 2021.

In response to the limitations of the web platform NHSE&I have led on the development of a new web-based platform which will help streamline reviews. A

consistent theme over the years since the LeDeR programme launched has been delays in accessing records, resulting inevitably in delays in reviews being completed to timescale. NHSE&I has therefore recommended that going forward that all reviewers are provided with smart card access to clinical records to speed up access to the right notes at the right time, and reduce unnecessary burden on clinical teams, especially primary care.

Reviewer training is being improved and will include annual refresher sessions, so that reviewers are equipped and supported to consistently deliver high-quality reviews in a timely manner, and to influence the development of actions to drive improvement.

There is an expectation is that reviewers will work in larger teams, with regular supervision and support including administrative support which will promote consistency in the quality of reviews.

Key timescales for implementation of the new policy arrangements are as follows:

- The new web-based platform will go live on 1 June 2021.
- ICSs should have a clear plan in place by 30 September 2021 for the new quality assurance structures and processes which will be implemented for LeDeR and fully operational from 1 April 2022.
- By 1 April 2022 all changes within the new policy must be implemented by ICSs, subject to legislative changes

To support this -

- Staffing models and local governance arrangements will be required to change in line with the development of ICSs and relevant human resources processes.
- Further advice is to be published in coming months on the process for adults who have a diagnosis of autism without a learning disability.
- Everyone with a learning disability aged four and above who dies and every adult (aged 18 and over) with a diagnosis of autism will be eligible for a LeDeR review.
- The child death review (CDR) process will be the primary review process for children (4-17) with learning disabilities and autistic children; the results of reviews will be shared with the LeDeR Programme. Further guidance on how the two processes will engage is pending.
- ICSs are expected to complete 100% of all their reviews within six months of them being notified on the LeDeR web platform. Unless statutory processes prevent that being possible or family members of those bereaved have asked for the review to be delayed.
- All eligible people from an ethnic minority background will receive a focused review and the families of anyone aged four and over with a learning disability or autism can request one.
- Reviewers will no longer make recommendations for each review, instead they will present areas of learning, good practice and areas of concern to the local governance group/panel.
- ICSs will need to establish a local governance group/panel, which as well as signing off the quality of focused reviews will, together with the reviewer,

agree specific, measurable, achievable, realistic and timebound actions which feed in to, and are cognisant of the strategic plan for the local area.
- The governance group/panel must include people with lived experience

Both CCGs are engaged in the work that is underway with the regional steering group and NHSE&I to develop plans to meet the changes set out in the new policy.

13. Conclusion

Within the context of a pandemic, throughout 2020/21 both South Tyneside and Sunderland CCGs have remained committed to delivery of the LeDeR programme, with a focus on delivering quality care and supporting those with learning disabilities and/or autism at this most challenging of times.

14. Recommendations

The Quality Safety Committee is asked to note the content of this report for assurance and information.

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May 2021