NHS South Tyneside Clinical Commissioning Group

NHS Sunderland Clinical Commissioning Group

NHS South Tyneside Clinical Commissioning Group and NHS Sunderland Clinical Commissioning Group - 1st joint Annual Report on Learning Disability Mortality Review (LeDeR)
1st April 2019 - 31st March 2020

1. Introduction

Welcome to NHS South Tyneside Clinical Commissioning Group (STCCG) and NHS Sunderland Clinical Commissioning Group (SCCG) first annual report on learning disability mortality reviews (LeDeR) for 19/20. As the Local Area Contacts for both CCGs, we, the Executive Directors of Nursing, Quality and Safety, would like to begin this report with the same person centred narrative and focus as set out in the national programmes annual report.

'This report is about people who have died. They were people who were loved and cherished, and whose deaths have been heart breaking for their family and those who loved them. Sometimes when we read reports such as this, we can forget that there are people at the heart of it.' [Learning Disability Mortality review programme Annual report 2018: Bristol University]

To support this narrative and maintain a person centred focus, we are sharing some brief glimpses of the people whose deaths have been reviewed across South Tyneside and Sunderland.

'He enjoyed watching films on television and going to the local pub with a friend for a drink'

'She went on holiday with staff at least once a year, she loved to go to places which reminded her of holidays with her parent'

' As a younger man he had enjoyed attending fitness classes'

'He was well known in his local community and would speak to the local shop owners'

'She was a determined lady and she knew what she wanted, she liked to be in control of her life'

'She was unable to communicate her needs in any way however familiar voices appeared to have a calming influence on her'

'He enjoyed Rock music and loved to watch TV and the soaps'

' He was said to be very funny and sociable and a larger than life character, if he wanted to do something he did it, he did things his way and would not be swayed and was extremely independent'

'She appeared to enjoy visits from the local preacher and enjoy listening to songs of prayer on a Sunday.'

As continually learning organisations, STCCG and SCCG will ensure that the learning gained from reviews of the deaths of people with learning disability in our communities, will be shared across our health and social care services and have a positive impact on practice and service delivery. We will ensure that the findings inform our commissioning decisions and affect positive developments and sustainable change, where required.

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.

'All people should be given the same respect, value, access to treatment and rights. Our lives are not valued as much as other people's. This has to change and it starts with you. 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. Information, information, information - make it Easy Read and doesn't use jargon. Don't let us die too young'.

Jeanette Scott

STCCG Executive Director of Nursing Quality and Safety.

Ann Fox

SCCG Executive Director of Nursing Quality and Safety.

2. Summary

This first annual report presents an overview of the LeDeR work across South Tyneside and Sunderland, during 2019/2020. The report is intended to describe how STCCG and SCCG 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 in the area.

It sets out:

- The background to LeDeR;
- Local arrangements and governance regarding how reviews are undertaken and the engagement of partners in this;
- The number of reviews and relevant data;
- Performance against the timescales set out in the NHS Operational Planning and Contracting Guidance 2019/20;
- 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;
- Improvement outcomes;
- Intentions going forward.

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. 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.

The LeDeR programme is delivered by the University of Bristol. It is 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. The contract has since been extended until the end of May 2021. The programme is the first national programme of its kind in the world. Its overall aims are 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 LeDeR 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 has 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. There are priority review themes of cases aged 18-24 years or from a black or minority ethnic background. These receive multi-agency review and expert panel scrutiny. At the completion of the review, outcomes and recommendations are made by the reviewer and these are shared with each CCG's commissioning teams for services for people with learning disability. Commissioning teams consider the information within the 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), where the criteria is met for a Serious Case 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 STCCG and SCCG

South Tyneside and Sunderland CCGs work 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 – the Designated Nurse for Safeguarding Adults in STCCG and the Head of Quality and Safety in SCCG. As a result of the retirement of the deputy LAC in SCCG, the deputy LAC from STCCG undertook the role for both CCGs, from December 2019.

A joint CCG LeDeR Assurance Panel has been established and undertaken in collaboration with healthcare providers, reviewers and commissioners. The purpose of this Panel is to ensure that the Clinical Commissioning Groups 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 sub group of the STCCG's Quality and Patient Safety Committee (QPSC) and SCCG's Quality and Safety Committee (QSC), who receive regular updates on progress and outcomes.

This annual report will be shared with the respective CCG's Governing Body and the local Health and Wellbeing Boards.

6. NHS Backlog project

The NHS Backlog project is a national funded project from NHS England (NHSE) to support CCGs to complete outstanding LeDeR reviews. It is co-ordinated nationally by the North of England Commissioning Support Unit (NECS) and aims to complete all LeDeR reviews that have not yet been allocated and started up to the 31st

December 2018. CCGs identified as having a backlog were opted in and NECS were commissioned to complete reviews on the CCGs' behalf.

Sunderland CCG has 16 historical cases that are now to be reviewed within the Backlog project. This includes 3 cases of people who died aged 80 or over. These reviews were not initially prioritised as the age at death was higher than the local normal life expectancy and due to the limited availability of reviewers. However, now there is a dedicated resource, those reviews will be undertaken and positive learning gained from their long life.

South Tyneside CCG did not hold a back log of cases and therefore did not gain any additional resource and support from the Backlog project.

7. Reviewers

There are a number of professionals trained in completing LeDeR reviews across the health and social care economy, for both STCCG and SCCG. The current reviewers are from a variety of disciplines and organisations e.g. Acute and Mental Health Foundation Trusts, Local Authorities, General Practice and CCGs. Not all reviewers are able to actively undertake review of cases due to changes in clinical priorities or having trained primarily to gain understanding of the system. Engagement from the different organisations supporting the LeDeR programme has varied across the two CCG areas; however, both areas experience the challenge of a lack of dedicated reviewer resource to meet completion of reviews, within expected timescales.

To address this lack of capacity to manage the number of reviews, SCCG committed funding to employ an additional three reviewers on a sessional basis. The posts were hosted by the NECS. In December 2019, STCCG was successful in gaining funding from NHSE to support the LeDeR process. They joined with SCCG to access the NECS reviewers on a sessional basis. This enabled both CCGs to complete all outstanding reviews that were notified by the 30th September 2019, in the expected 6 month timescale to March 31st 2020.

Peer support sessions are in place to allow reviewers to meet to discuss challenges and solutions to completing reviews. This is a valuable opportunity for reviewers to share experiences and learning. The CCGs continue to support the training of reviewers to ensure reviews are completed within timeframe are of good standard and fully capture the learning.

8. Number of deaths and demographics

Sunderland CCG

During the period April 1st 2019 to March 31st 2020, SCCG had **19 deaths** notified on to the system. One of the cases was reviewed via the chid death overview panel (CDOP). One was removed, as found not to have a learning disability.

At end of year, 6 cases were complete and 12 were in progress.

There were 5 cases from the year 18/19 that had been delayed in completion and sign off. These were managed to completion in the period of this report and therefore the outcomes and learning gained is included.

South Tyneside CCG

For the same period, STCCG had **13 deaths** notified on to the system. One of the cases was reviewed via the chid death overview panel (CDOP). One was removed as found not to have a learning disability.

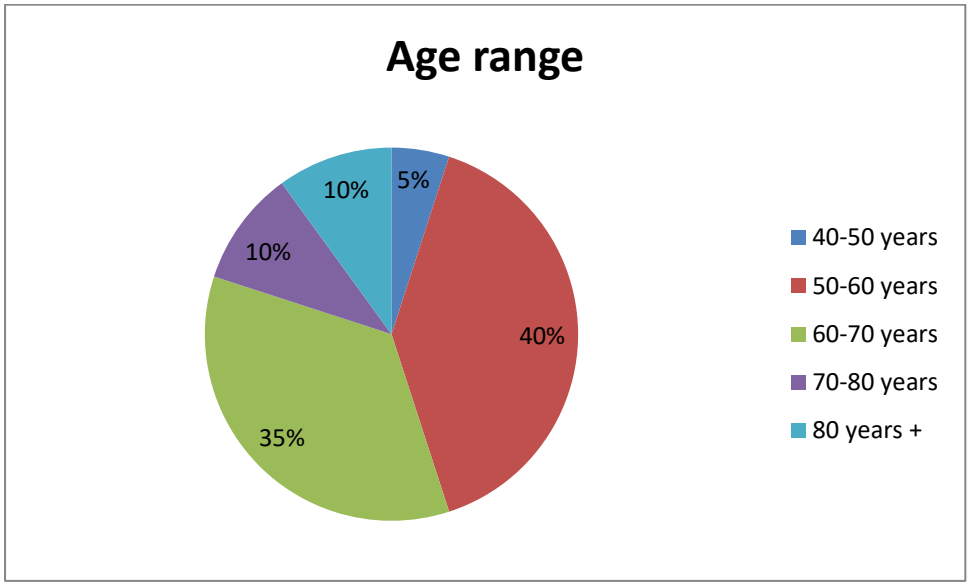
At end of year, 4 were complete and 7 in progress.

There were 12 cases from the year 18/19 that had been delayed in completion and sign off. These were managed to completion in the period of this report and therefore, the outcomes and learning gained is included.

Demographics

Of the deaths notified on to the system in 19/20, apart from the 2 child deaths, all were above 40 years of age and 75% were in the 50-70 years of age range, which aligns with the national findings of people with a learning disability dying approximately 20 years younger than the general population. 10% of deaths notified were for people aged 80 years or above. See figure 1.

Figure 1.



Gender

There have been more males than females notified on to the system.

Ethnicity and marital status

All adult cases notified where ethnicity is known have been people of white British background. A CDOP case was of a child with Asian ethnicity. The majority of people were recorded as having single status; however, a small number had longstanding relationships.

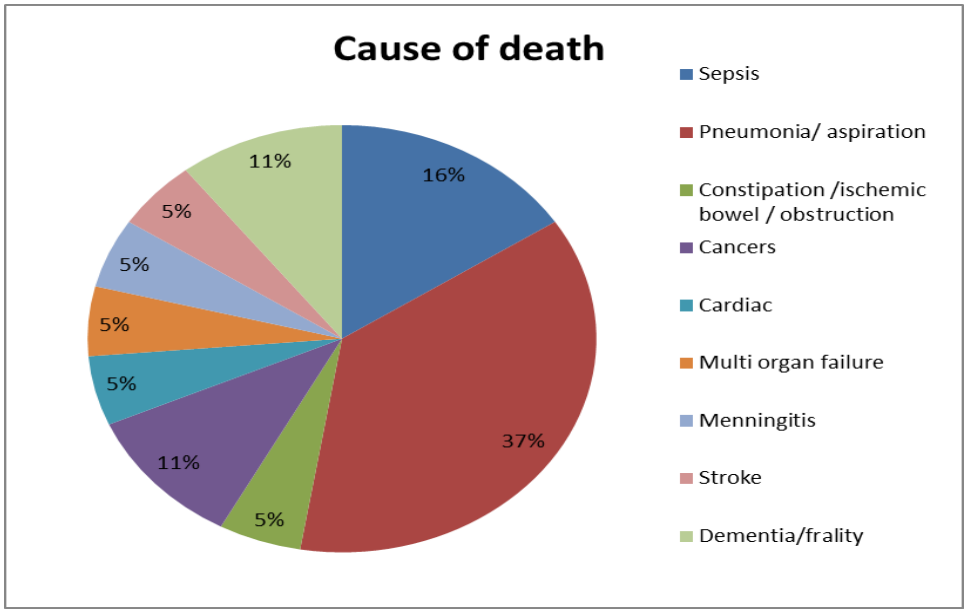
Place of death

Approximately 85% of people died in hospital with only a small number recoded as dying at home or a hospice.

Cause of death

In line with national findings, the greatest cause of death for people with learning disability in our communities is pneumonia and aspiration pneumonia at 37%. This is followed by sepsis at 16% and then cancers and dementia and frailty both at 11%. Other causes of death can be seen at figure 2.

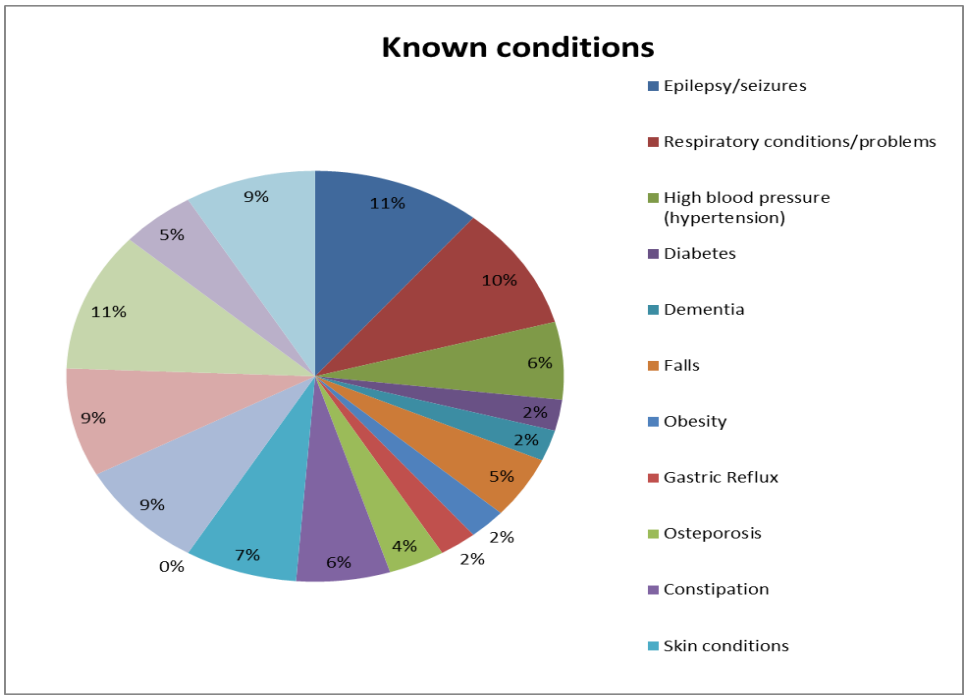
Figure 2.



Known conditions

The cases reviewed evidenced a wide range of conditions that individuals lived with. Many had multiple conditions with the most common being epilepsy and respiratory problems. See figure 3.

Figure 3.



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. Where information on a prescription was evident in the records, in approximately 30% of cases information on whether attempts to reduce or stop this, was not seen. This does not mean that medication was not reviewed, only that within the limited records seen the information was not always evident. **This may indicate an area for future focus.**

Annual health checks and health screening

Not all reviews included records that could evidence an annual health check (AHC) had been carried out in the last year or whether a health action plan had been made after this. AHC information was not evident in 35% of SCCG reviews and 28% of STCCG reviews. Similarly, not all cases could evidence expected health screening for age and condition had been carried out or offered. **This may indicate an area for future focus.**

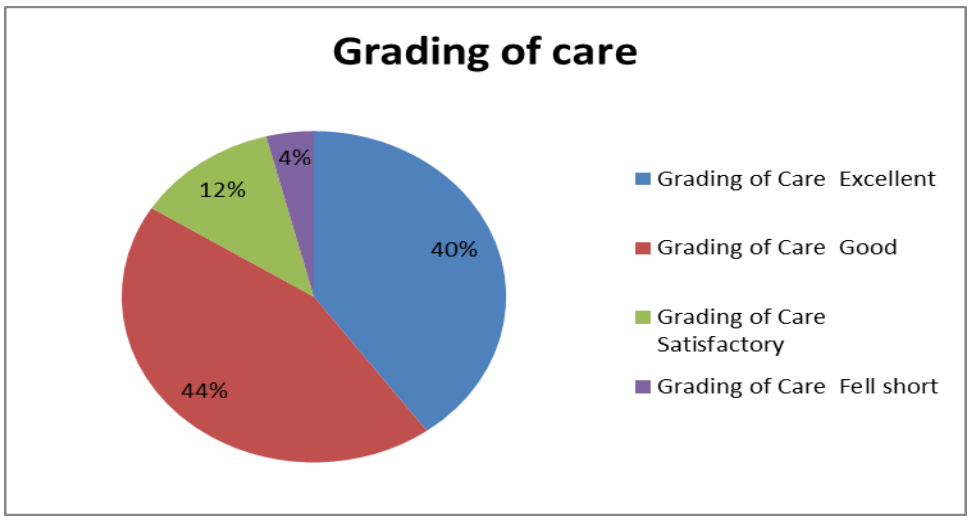
Family engagement in reviews

Where family information was known, just over 50% engaged in the review process. 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 contact made or did not feel it was the right time for them to meet with a reviewer. 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 reviewers graded the care received as being excellent or good. Of the small number graded satisfactory or falling short of satisfactory care, one case was considered to require a multi-agency review to gain additional learning. Where family concerns indicate an area of complaint they are directed to the appropriate process within the organisation. See Figure 4.

Figure 4.



9. Learning Themes

Positive Findings	
Reasonable adjustments	• Use of hospital passports. • Additional support with meals for family and sleeping (family to stay over). • Single rooms for individual. • Transport for family. • Additional support regarding mobility from physio and OT. • Open access to GP seen without appointment. • Use of a social story. • Home visits by primary care for flu vac. • Home visit by Speech and Language Therapy. • Care at Home team and Learning Disability liaison nurses support with hospital appointments and hospital stay. • Support to attend community health appointments and GP practice. • Advocacy offered. • Double appointment provided for scan and at outpatient appointments. • Given open access to hospital unit in the event of deterioration. • Reasonable adjustments at GP practice when doing Annual Health Check. • Used drawings and simple language.
Mental Capacity	• Assessment and Best Interests for central line insertion. • Best Interests on End of Life care discussed with family. • Mental Capacity Assessment evident for decisions for modified diet. • Mental Capacity Assessment re insertion of Nasal Gastric tube and Do Not Attempt CPR. • Best Interest consulted with friend. • Independent Mental Capacity Advocate referral. • Assessment of capacity for major surgery.
Best practice	• Excellent care by the surgical team. • Hospital Health action plan and pathway was available. • Excellent Multi-disciplinary Team working. • Shared End of Life care, by hospital and care home staff. • Excellent support from Community Learning Disability team. • Community decisions regarding feeding at risk in best interest. • Excellent communication between services and use of hospital passport. • Excellent care from hospital and excellent support from Community Learning Disability team. • Good practice from Learning Disability team, identifying need for additional support.
Area for of Learning	

Primary Care	• GP didn't offer to follow up on condition. • Found communication needs to be clearer. • Practice didn't routinely offer appointments. • Confusion with medications for multiple prescriptions for bowel management and anticipatory medication in End of Life care. • Improvement in GP recording. • GP records not shared appropriately. • Input from primary care on discharge was lacking. • Lack of reasonable adjustment of staff taking patient to health assessment. • Not recorded on GP system as Learning Disability. • Screening offered but not taken up and not followed up. • Poor understanding of Mental Capacity Act. • No evidence of Mental Capacity Act assessments or best interests seen in record.
Hospital Care	• On admission, poor coordination of care. • Concerns of care at hospital regarding feeding. • Delays of assessment from spinal team. • Delays for examinations causing stress with food and fluid (nil by mouth not co-ordinated with scan). • No Structured Judgement review as not flagged as having LD in hospital system. • Hospital didn't have passport which recommended routine contact to Learning Disability team, for support. • More training on Mental Capacity Act needed. • Delay in cardiac consultation. • Delays in falls service appointment.
Family view	• Felt there was a lack of dignity. • Felt looking for care homes quite stressful. • Not enough care regarding nutritional feeds in hospital.
Reviewers Recommendations	• Standard Operational Policy for GP & Pharmacy regarding repeat prescriptions. • Better recording of events in hospital. • Records don't always reflect Best Interests Decisions. • Improve record keeping for complex needs. • That the Learning Disability community team is involved with all people with a Learning Disability. • A process which identifies patients with complex needs, to facilitate regular health checks. • Primary care to be reminded of the need for reasonable adjustments, in particular regarding home visits. • Documentation for Mental Capacity assessments to be reviewed.

Outcomes	• Quality issues regarding prescriptions have been shared with medications management teams for consideration within wider service improvements. • Mental Capacity Act practice and training has been a focus for heath Trusts. Safeguarding assurance to the CCGs has shown improved levels of mandatory training and quality outcomes of Mental Capacity audits. • Improvements in ways of recording regard for the Mental Capacity Act in practice have been developed and in particular with those aged 16-17 years of age. • Awareness raising sessions have been provided to primary care on Learning Disability and reasonable adjustments. • Outcomes for AHC, the identification of individuals within the GP register and any complex needs has been progressed.

10. Performance against national targets

The NHS Operational Planning and Contracting Guidance 2019/20 sets out the expectation on CCGs and the system, with regard to LeDeR:

- 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 STCCG and SCCG are members of the regional steering group and achieve regular attendance from the Director of Nursing as responsible lead and LAC or the Deputy LAC.

Availability of reviewers has been a challenge, with regard to the timeliness of review completion for cases notified within the year 19/20. Sunderland achieved 50% of cases allocated in 3 months and 81% cases completed within 6 months.

South Tyneside achieved 46% allocated 3 months and 31% completed 6 months. This performance was significantly impacted upon by the number of reviews being notified in quarter 4 and then being placed on hold, due to the pandemic.

Assurance Panels are scheduled monthly to reduce delay in approval and completion of reviews.

Progress on reviews is monitored and discussed at each LeDeR assurance panel and highlighted by exception to the respective QSP and QPSC.

All key themes, trends and lessons learnt are shared with Learning Disabilities Strategic Alliance and Joint commissioning team in South Tyneside and the Learning Disabilities commissioning team in Sunderland.

A joint tracker for both CCGs is established which will enable best practice and learning to be easily extracted.

Peer support sessions are in place to allow reviewers to meet to discuss challenges and solutions to completing reviews and share experiences and learning.

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

This is the first annual report for STCCG and SCCG areas that will be presented through the quality governance and to the Governing body. It will then be published on the CCGs web site.

11. Impact of COVID 19

The COVID 19 pandemic has impacted across all health and social care, including the local LeDeR programme. It has undoubtedly been a factor in the CCGs being unable to meet the expectation of allocation of reviews within 3 months and completion within 6 months. Winter pressures during quarter 3 and 4 placed significant challenges on the availability of reviewers, many being unable to allocate time away from current clinical duties, to review deaths.

From March 2020, the local Foundation Trusts stepped back from LeDeR completely and placed structured judgment mortality reviews on hold. Reviewers were redeployed into clinical priority areas which also had a significant impact on the overall reviewer capacity.

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

The recovery planning for LeDeR will be considered within the context of local and national priorities and going forward reviews will indicate whether COVID 19 was indicated as a cause or contribution to the person's death.

12. Provider response to LeDeR findings by CCG area

South Tyneside

South Tyneside Community Learning Disability Team (CLDT) have promoted the service to improve the health outcomes for adults with Learning Disability living in South Tyneside.

This has been delivered by direct face to face visits with individuals and also within the forum of a Health Focus Group (membership comprises of people with a Learning Disability, Advocacy and Community Nursing), also information sharing with Care Providers and external agencies.

Examples include:

- The promotion of the Florence text messaging service which includes interventions offering advice and strategies to support awareness, for example, with medication compliance, engaging with mindfulness techniques and strategies to help reduce anxiety;

- Information sharing with care providers and service users –such as The Stop and Watch National Campaign –Recognising signs of deteriorating patients;
- Support to Primary Care – proving examples of 'easy read' accessible information letters to increase the engagement and uptake of people with a Learning Disability to have flu immunisation, an Annual Health Check and the offer of Community Learning Disabilities Team (CLDT) involvement;
- Participation of a CLTD Speech and Language Therapist to attend a regional Dysphagia event to look at what is currently happening across the North East and Cumbria and specifically what are the challenges in the region around Learning Disability and Dysphagia and the development of a Pathway.
- Involvement in designing a Sepsis awareness leaflet;
- Organising and delivering sessions in the community targeting people with a Learning Disability to provide information about cancer screening;
- Designing an 'easy read 'Safeguarding leaflet to provide information about understanding what abuse is and what advice and support is available;
- Providing information awareness sessions to GP practices.

Sunderland

Over the last 12 months in Sunderland, the Community Learning Disabilities Team (CLDT) has continued to work closely with GP practices on several health issues:

- A flu protocol that enables the health promotion team to support hard to reach individuals who typically do not attend their practice for their annual flu vaccine, or those with needle phobias where the health promotion team attend to undertake desensitisation. This has helped us to increase the amount of flu vaccines administered in Sunderland; we will also be offering flu vaccines pop up clinics in the day resource centres in 2020/21.
- Sunderland have applied for the Annual Health Check (AHC) Expression of Interest (EOI) Exemplar site status with NHS England & Improvement, if we are successful the funding will be utilised to make a greater impact locally with regards to AHCs and flu immunisations.
- We have an AHC quality framework that the practices work towards to drive up the quality of the annual health checks that they provide. In 2018/2019 this framework was rolled out across Sunderland and by the end of the year all practices across Sunderland were awarded bronze status. This quality improvement work has continued during 2019/20 and all practices attained silver status. Practices now have until March 2022 to achieve gold status.
- As part of this quality framework we have assurances that all practices have personal profiles for all patients in place, these indicate what reasonable adjustments are required thus ensuring they know all of their patients' needs and this promotes good access to primary care.
- Key objectives of the framework include; ensuring all patients engage in the screening programmes which they are eligible for, identify if a person is on the palliative care register (so a referral to the community learning disability team can be made to support the person) and referrals to health promotion team are actively made, where a person needs support to health appointment where it is difficult for them to access health appointments without support.
- Sunderland has a dedicated Sunderland Action for Health website which primary care utilise to obtain standardised easy read templates for patients which help practices communicate more effectively to its patients.

- As a direct response to LeDeR reviews, the health promotion team now check that a patient is on the GP learning disability register when the team begin supporting them. If there is any discrepancy with this, it will be further discussed with the practice manager to determine if they need to be added or not.

13. Commissioner response and future plans

South Tyneside

As part of the South Tyneside Alliance, South Tyneside CCG continues to work with partners from across health, social care and voluntary services, to ensure that there is a circle of learning and improvement.

A health focus sub group has been reinstated with partners, with the primary function of improving the health outcomes for the residents of South Tyneside. The group has been tasked with taking both the Local and National LeDeR themes and translating them into tangible actions. The health sub group are now responsible for ensuring that the South Tyneside Learning Disabilities/Autism Alliance receive a report on a quarterly basis, highlighting progress against priorities.

Given the importance of the getting this right, in 2019, a new physical health hub was commissioned, which went live at the end of 2019. The focus of the physical health hub is to develop; through a coaching relationship:

- Increased awareness of the impact of inequalities;
- Improve health outcomes;
- Support those who find it most difficult to access services;
- Access interventions in a person focused manner.

The hub works alongside the GP practices, with people who are aligned on the register and also proactively ensures that the right people are on the relevant register.

The hub consists of a pharmacist, learning disabilities nurses, health facilitators and data analysist. The 3 Primary Care Networks are committed, with the support of the hub, to ensure that all people with a learning disability, who agree to have an annual health check, can access one in a way that meets their needs. More importantly, that information is then used to support people with their own health plans.

Going forward in 2020/2021, the hub will support in the completion of LeDeR reviews, in conjunction with GP practice, local authority and health records. The new pharmacist will be leading on ensuring that the STOMP and STAMP agenda is fully implemented across the borough. This work will initially feed back into the health focus group, with themes and future actions being highlighted for action at the Learning Disabilities and Autism Alliance. As part of this role, there is also a strong emphasis on knowledge transfer and supporting professionals, families and individuals, to make informed decisions.

In addition, an enabler service has been commissioned to work with people who need additional support (predominantly individuals with a learning disabilities), to highlight opportunities to make informed health changes, through the development of new skills, including self-care skills. The outcomes achieved are feedback to the alliance, to ensure that any changes that are required can be implemented.

As part of the response to Covid 19, the alliance has worked with partners across the system to develop easy read self-management information, to support people to self-manage their health needs.

Sunderland

Sunderland CCG continues to work across the health system to improve the quality of care for those with a learning disability and/or autism. Sunderland CCG has a dedicated Senior Commissioner who leads this agenda; working collaboratively with Social Care colleagues and the All Together Better (ATB) where there is a dedicated programme around Mental Health, Learning Disabilities and Autism. The Senior Commissioner sits on the ATB programme to ensure the work they lead is integrated into the overall outcome programme.

There has been significant work with practices over the past 4 years focussed on those with a learning disability and/or autism; these primary care plans help the CCG to deliver the overarching Transforming Care Agenda.

Future plans include:

- Working towards practices achieving Gold status for the AHC quality framework;
- Influencing the national AHC template to ensure the hearing part of AHCs is scientific and a valid part of the overall AHC;
- Working with those learning disability and/or autism patients who also have epilepsy to ensure those on rescue medications have a timely and effective care plan review;
- Ensuring all our learning disability and/or autism patients have a care passport in place across Sunderland as well as a summarised Covid-19 passport to support any hospital admissions;
- Reinitiate the STOMP / STAMP project work across Sunderland to ensure those with a learning disability and/or autism have all psychotropic medication reviewed to ensure use only where appropriate;
- Continue with bespoke practice training for clinicians around their patients with a learning disability and/or autism;
- Continue the Point of Care Testing project evaluation and options appraisal to influence future commissioning;
- Continue to deliver quality community and inpatient Care (Education) Treatment Reviews for children and adults across Sunderland in line with statutory requirements;
- To work with local hospitals around the quality of care and support given to those individuals accessing secondary care who have a learning disability and/or autism.

If Sunderland are successful in their expression of interest to become the exemplar AHC site we plan to use some of the funding allocated to:

- Fund time and experience from local self-advocates to us help shape the work needed to achieve our outcomes;
- Work with people with a learning disability on a sessional basis and carry out secret shopper activity to ensure reasonable adjustments are being made;
- Further develop accessible information for the BAME community in regards to flu, annual health checks and reasonable adjustments as we are aware

currently the website does not accommodate people who do not speak English;
- Work with BAME community to develop accessible information and to raise awareness and increase identification on the learning disability register;
- Support funding materials for the various workshops, roadshows and campaigns we intend to run in the course of this project;
- Undertake a 'find your missing patient' exercise; this will involve using the NHSE guidance to improve identification of people with learning disabilities in general practice. The NHS Long term Plan commits to increasing the number of annual health checks but we can only achieve this if we work hard to identify the missing group of patients;
- Undertake focussed work with individuals from the age of 14 years to communicate and educate around their eligibility for the annual health check;
- Ensure communication is disseminated about the flu program in schools and offering interactive sessions on flu using easy read materials and the animated videos that have been produced to aid understanding;
- Support patients to complete their pre health check questionnaires so the practice can determine if they need to be seen face to face or by virtual consultation in the interim period as part of the risk stratification work linked to AHCs recovery from Covid-19;
- Work with local day resources, schools and colleges to provide roadshows to increase awareness and gather reasonable adjustments.

14. Conclusion

Both STCCG and SCCG are committed to delivering the LeDeR programme and focussed on delivering quality care and support to those with learning disabilities and/or autism. Progress has been made on the completion of reviews, despite the challenges of lack of reviewers and sustained/recurrent resources. The assurance panel has been strengthened over the year regarding identification of learning and links with commissioning.

The CCGs will work with local partners and 3rd sector organisations to ensure that deaths of our Learning Disability residents are prioritised for mortality review.

The annual report will be uploaded on to the CCGs website.

15. Recommendations

The STCCG and SCCG Governing Bodies are asked to note the content of this report and agree that health outcomes for people with a Learning disability will be of strong focus in the coming year, recognising the need to engage people with a learning disability in the LeDeR process and ensure that their voice is embedded in all of our commissioning processes.

Sharon Thompson

STCCG Designated Nurse Safeguarding Adults

September 2020.