How Findings from the Learning Disability Review of Mortality (LeDeR) are Influencing the Reduction of Health Inequalities in Hertfordshire

LeDeR Annual Report 2021/2022

Prepared by: Nicola Conlin

On behalf of: The Hertfordshire LeDeR Leadership Group.

Contents:

	Page number
Foreword	3
Executive Summary	5
Introduction	7
Section 1: Background	8
Section 2: Learning from reviews: data and themes	13
Section 3: Action from Learning	21
Section 4: The year ahead – Key priorities	50

Appendices:

Appendix 1: Governance Chart	51
Appendix 2: Glossary of terms	52
Appendix 3: Acknowledgements	53
Appendix 4: References	54

NOTE: An easy read version of this report is available at: (to be added in)

Foreword

**Mark Harvey Operations Director Adult Disability and Mental Health Services,
Adult Care Services, Hertfordshire County Council. Chair of Herts LeDeR Leadership Group.**

This year's annual LeDeR report is published following some of the most difficult years many people will have experienced in recent times. For people with a learning disability and autistic children, adults and Carers, the impact of COVID will have been more acutely felt. Access to services, both health and social care, as well as the things that we all take for granted in our everyday lives were severely impacted.

In such times our response to LeDeR must not wain. Our ambition to make change now and for the future must be paramount. Over the last year we have changed the way we review and respond to the findings of these reviews. Our new Leadership Group is attended by senior representatives from all our key NHS and Social Care partners to ensure that learning is shared quickly and that actions are agreed and put into place as soon as is possible. Ensuring that we respond collectively and with a common understanding and purpose is vital.

We have also developed a number of posts to look at and address the issue of the social determinants of health inequalities that are often noted in our reviews. These posts will work closely with wider health inequality projects and ensure that we start to embed good practice into our social care and health assessments, care and support. We have also ensured that the voice of carers and people who may use social and health care services are helping to shape our LeDeR work, although we can always do more.

This year's report continues to highlight the impact of inequalities on people's experiences and their health. Our new approaches to learning and responding quickly, together with a joint approach is an improved response to these issues and we hope will have a positive effect. The reality however is that people will have faced many years of social and health inequality and the consequences of this will have had an impact. It may therefore take a number of years to see the positive outcomes of the work we do today, but we must ensure we do it and do it well. We must also understand that there are things we can do now that will benefit people today both in terms of how we provide care and support but also our need to ensure that people with a learning disability and Autistic children and adults are as valued and have the same equality of access to care and support as everyone else in Hertfordshire.

Marie Scales – Expert by Experience (Family Carer), LeDeR Leadership Group

The last year has gone so quickly, following the changes made to LeDeR. I was very pleased to have been asked to continue as a representative who had a relative with a learning disability who unfortunately had died.

To me LeDeR is so important because by reviewing the individual's death it shows whether the individual who had a learning disability had lived a good life to the best of their abilities and to have received good standards of healthcare.

We continue to see the same reasons for why the individual had died, we now include questions about Covid and how this effected the individual.

To me the importance of LeDeR is to show that we are improving health outcomes for people with learning disabilities and autism. By improving the health outcomes this will hopefully reduce the premature death of a person with a learning disability.

Sam Prowse – Expert by Experience Adviser representative on the LeDeR Leadership Group

As we see the world open again following the Covid-19 pandemic, along with people having vaccinations, people are adapting and getting used to what we call the new normal. It's lovely to see the enjoyment back on people's faces after such a difficult time. But equally there are a lot of people that are still worried about Covid-19 and rightly so. Everyone needs to find what they are comfortable with and how they control that.

There now a blend of online and face to face things in life. On a personal note, I'm a massive technology fan but I also really like face to face interactions with people. It makes such a difference. There is still some way to go to bridge the inequalities that people have with the use of technology and other aspects of life. Lots of amazing work took place during the pandemic, and we must continue to build on this because we can't let this good work go to waste.

In life we must look after all aspects of our health, whether that be mental health or physical health or them both linked together. LeDeR has changed a lot over the last year with policy changes and we really need to focus on the quality of people's lives. What outcomes do they need and want, at the same time realising that this can change throughout someone's life.

Over the next year we really need to work on involving more people in our learning from LeDeR and other areas of work so that people can have the best life possible.

Executive summary

This is the fifth annual report of the Hertfordshire Learning Disabilities Mortality Review (LeDeR) programme. LeDeR is an improvement programme that has been developed as a result of numerous reports over the last 15 years indicating that people with a learning disability die significantly younger than the general population.

The purpose of this report is to provide an account of the Hertfordshire LeDeR programme for 2021-22, describing both the learning from reviews and the actions taken to improve services as a result.

This report presents information about the deaths of people with a learning disability living in Hertfordshire aged 4 years and over notified to the LeDeR programme from 1st April 2021 – 31st March 2022. The report includes a collection and analysis of quantitative data from notifications of deaths from this period and describes how Hertfordshire is implementing Action from Learning.

New LeDeR policy

In 2021 a new LeDeR policy was introduced which changed many aspects of the programme. This reports details some of the key changes and the implementation of the new policy in Hertfordshire.

The new policy required changes to local governance structures, resulting in the formation of a new Hertfordshire LeDeR Leadership Group and strengthened accountability for LeDeR at senior leadership level across the Hertfordshire Integrated Care System.

Reviewing the deaths of autistic people without a learning disability was introduced as part of the new policy in early 2022. However, in 2021-22 there were no notifications of deaths of autistic people in Hertfordshire.

2021-22 - Key Information

- The total number of LeDeR notifications of death in Hertfordshire from April 2017 - March 2022 is **335**
- The number of notifications of death (**56**) in 2021-22 **decreased by 42%** returning to a similar level of notifications seen in 2018-19. This is reflected in the reduction of deaths from Covid 19 (2020-21 41%, 2021-22 4%)
- The median age of death of adults and children was 57.5 years, **adults only was 58. This has reduced from 2021-22,** however due to the small data set national trends will be a more representative reflection of this indicator. The LeDeR national report for 2021 has not yet been published at the time of writing this report (June 2022).
- The most frequently reported ICD-10 chapter for **underlying causes of death have remained the same for the last 3 years, being disorders of the respiratory system**. In 2021-2022 **41%** (n=18) of the deaths of people with a learning disability were due to disorders of the respiratory system. This would be 45% (n=20) if COVID 19 is included.
- For 2021-2022 **the leading causes of death were aspiration pneumonia** (20%, n=9), **pneumonia (community acquired)/lower respiratory tract infection** (16%, n=7) and then **sepsis** and **bowel cancer** were both third with 7% (n=3).
- Just over **half of the individuals died in hospital** (55%, n=31), a reduction from 2020-21 (70%) and a return to the levels seen prior to Covid 19 (54%).
- **GP LD Registers increased in size** over 2021-22 from 2020-21 (ENHCCG 4.5% increase, HVCCG 9% increase).

- National NHSE data for 2021-22 shows that **Herts and West Essex ICS achieved 72% uptake of Annual Health Checks (AHC)**. (Breakdown by CCG ENH 69.3%, HV 76.5%, WE 66.5%.) As a comparison the national uptake for 2021-22 was 71.3% and East of England 70%. The national target for 2021-22 was 75%.
- Evidence from reviews indicated that **some annual health checks (AHC) were delayed or carried out remotely due to Covid,** usually via telephone. There were also concerns raised about the quality of some checks, and not all health checks resulted in a clear and implemented Health Action Plan. Whilst there have also been examples of timely and thorough GP support with good reasonable adjustments, r**egular communication has been sent to practices to highlight these issues** and the importance of offering a range of clinically appropriate options. The **new Enhanced Commissioning Framework** includes practices **auditing their AHC Action plans** and assessing how well they are at arranging and supporting the uptake of follow up action to support a high-quality check, effective health interventions and awareness of health monitoring throughout the year.

In part this report reflects the ongoing response of health and social care services to the continued challenge of Covid 19. **A major success of this has been the Hertfordshire vaccination programme for people with a learning disability** (94% first dose, 91% second dose, 89% booster dose) which is evidenced by the significantly lower number of notifications of deaths in 2021-22 (56), back to a pre Covid level.

However, data from reviews continues to show the enduring health inequalities that people with a learning disability face. An important part of the solution is ensuring that **reasonable adjustments** under the Equality Act (2010) are provided by all health and social care organisations. This report gives examples of the **sometimes creative and imaginative ways that partner organisations across Hertfordshire are including the needs of people with a learning disability in the delivery of services and development of pathways.** In addition, a comprehensive suite of resources supporting **Principles and Pledges for Health Professionals in Making Reasonable Adjustments** have been developed by the Learning Disability Nursing Service to progress this further.

Alongside this, partners continue to work on **delivering targeted approaches** to reduce health inequalities. Examples of innovations include the development of a **tool identifying the risk of frailty**; the development of accessible resources to support **increased uptake of cancer screening**; a **new Annual Health Check preparation tool and Health Action Plan resources**; and the delivery of a **specialist physiotherapy pilot**.

Finally, the new Herts LeDeR Health Inequalities Plan includes 5 priority outcome areas, based on learning from reviews. Although LeDeR has historically focused on health outcomes, for the first time the Hertfordshire LeDeR Health Inequalities plan **recognises the impact of social inequalities on health equality.** Key national reports have highlighted the life events and experiences that impact on health inequality for the general population, and for people with a learning disability this is no different. **Social Care Advanced Practitioners** have been recruited in 2021-22 to **improve practice and awareness of the impact of social injustice** that people with disabilities experience.

Introduction

This is the fifth annual report of Hertfordshire Learning Disabilities Mortality Review (LeDeR) programme. LeDeR has been developed as a result of numerous reports over last past 15 years indicating that people with a learning disability die significantly younger than the general population. This report presents information about the deaths of people with a learning disability living in Hertfordshire aged 4 years and over notified to the LeDeR programme from 1st April 2021 – 31st March 2022. The report includes a collection and analysis of quantitative data from notifications of deaths from this period and describes how Hertfordshire is implementing Action from Learning.

This report has been written prior to release of the National LeDeR report for 2021, and the NHSE Action from Learning report. Therefore, no comparison can be made.

This year's report shows a significant reduction in the number of notifications of deaths in comparison to 2020-21, reflecting the lower numbers of death from Covid 19. The incredible health and social care response to the unprecedented challenge of a global pandemic was noted in the last report. This year, a continued drive for collaboration and innovation resulted in an outstanding effort between local partners to support the roll out of the Covid vaccination for people with a learning disability, the success of which is in part reflected by the lower number of deaths.

Nevertheless, this year's report continues to evidence that people with a learning disability are dying prematurely from things that can be prevented. The data shows a concerning reduction in the median age of death; however, caution is needed in interpretation of the relatively small data set and national trends will be a more representative reflection of this indicator. Locally we are analysing the cause of death for any specific cause of this reduction, and as yet this has not shown any notable explanations.

In line with the national LeDeR report (2020) respiratory conditions continue to be one of the leading causes of death. Coordinated efforts on a national, regional and local level are needed to tackle this enduring issue, ensuring that it is a priority for both mainstream and specialist services.

This year saw the introduction of the new LeDeR policy (2021), Learning from Lives and Deaths - people with a learning disability and autistic people. Locally this has enabled significant changes in the leadership and oversight of the programme, and in particular has led to a clear outcomes focused LeDeR Health Inequalities plan based on 5 priority outcome areas. For the first time our plan acknowledges the reality that social inequalities play a huge part in the health inequalities people experience, and endeavours to find ways of identifying and preventing issues at an earlier stage.

The newly established local Leadership Group has a broad range of members, including senior leaders and experts by experience working together to implement learning into action and be accountable for change. The programme continues to be supported by a committed and passionate community of practice through the Improving Health Outcomes Group (IHOG), and section 3 includes the extensive activity being delivered by these partners towards achieving the ambitions of the plan.

Finally, the Hertfordshire LeDeR Leadership Group are extremely grateful for the contribution that families and/or people who knew the individual well, have made to the review process. Each review is considered carefully for what it can show us about what is working well and what needs to change across our system, and we are committed to implementing service improvements and initiatives as a result.

1. Background

The Learning from Lives and Deaths programme (LeDeR) was established in 2016. It is a non-statutory process set up to contribute to improvements in the quality of health and social care of people with a learning disability. All deaths of people with learning disability over the age of 4 years are subject to a Learning Disability Mortality Review and since 2021, the programme has included adults with a clinical diagnosis of autism.

The ultimate purpose of the LeDeR programme is to reduce the ongoing and significant health inequalities that people with a learning disability and autistic people face. The 2019 NHS England Long Term Plan recognises that this needs to be addressed.

- Action will be taken to tackle the causes of morbidity and preventable deaths in people with a learning disability.
- The whole NHS will improve its understanding of the needs of people with learning disabilities and autism and work together to improve their health and wellbeing.

NHS Long Term Plan (2019)

Overview of the Programme

The function of the LeDeR review is to identify learning from the lives and deaths of people with a learning disability and autistic people and create actions from learning that achieve service improvements across health and social care. Reviews identify issues and areas where services fell short, alongside examples of good practice to learn from. The review process is not intended as an investigation, and there is a requirement that LeDeR works alongside other processes for example, safeguarding, police investigations and the coroner, and takes account of any mortality review that may have taken place after an individual's death.

In March 2021 a new NHSE policy Learning from Lives and Deaths – LeDeR (2021) was published. This policy described the core aims and values of the LeDeR programme and the expectations placed on different parts of the health and social care system in delivering the programme.

Learning from lives and deaths - People with a learning disability and autistic people (LeDeR) 2021

The policy set out the requirements of Clinical Commissioning Groups (CCG) and subsequently formed Integrated Care Systems (ICS) to implement a number of key changes in the delivery of the programme. These include a new review model, a new web-based platform and changes to workforce and governance. The policy was to be fully implemented by systems by 1st April 2022.

New reviewing model

The new reviewing model now includes two distinct review processes: initial and focused reviews. The reviews include a pen portrait describing who the person was, important events in their life, their likes and personality, followed by a review of any medical and social care the person received. Involvement of family members and/or people that knew the person well is key to the development of the pen portrait and building an understanding of their experiences.

Whilst every notification of death is progressed to an initial review, the criteria for a focused review includes,

- Where the individual is from a Black, Asian or Minority Ethnic background, due to significant under reporting and increased health inequalities in these communities.
- Where in the professional judgement of the reviewer there is likely to be significant learning for the ICS from carrying out a focused review.
- If there are concerns about the quality of care provided to the person by one or more providers, or there is evidence of lack of integrated or co-ordinated care.
- Where a family member requests a focused review to be completed.
- In the years 2021-2023, all deaths of adults who have a diagnosis of autism but who do not have a learning disability will have a focused review.

Implementation of the LeDeR programme in Hertfordshire

In Hertfordshire LeDeR has historically been delivered on the 'Transforming Care Programme' (TCP) partnership footprint, and since 2017 the CCGs in East and North Herts (ENH) and Herts Valleys (HV) have been responsible for ensuring the programme is delivered locally. From July 2022 with the formation of Integrated Care Systems (ICS), the local Hertfordshire and West Essex ICS will become responsible for delivery of the programme.

These new arrangements align West Essex under the new ICS footprint. However, LeDeR for West Essex will continue to be delivered under the Southend, Essex and Thurrock programme by the Learning Disabilities Health Inequalities Team hosted by Essex County Council, which has its own LeDeR steering group for oversight of the programme. Both Local Area Contacts (LAC) for Herts and West Essex share updates and reports to the Hertfordshire and West Essex ICS quality groups to ensure system wide accountability.

Governance

Following the introduction of the Learning from Lives and Deaths policy in 2021 and in line with governance requirements, a Leadership Group was formed in Hertfordshire to oversee the programme. Representation for this group includes the following,

- Operations Director Adult Disability and Mental Health Services, Herts County Council (Chair)
- ICS Director of Nursing and Quality
- ICS Associate Director- Quality Improvement and Patient Safety
- ICS Director of System Transformation & Integration
- ICS Associate Director - Adult Safeguarding
- Director of Nursing and Patient Experience (East Herts Health Trust)
- Chief Nurse and Director of Infection Prevention and Control (West Herts Health Trust)
- Lead Nurse for Safeguarding (West Herts Health Trust)
- Deputy Director of Nursing and Partnerships (Herts Partnership University NHS Foundation Trust)
- Chief Nurse (Central London Community Healthcare Trust)
- Deputy Director of Nursing and Quality (Herts Community Trust)
- ICS Director of Primary Care Transformation
- Learning Disability GP Clinical Leads
- Head of Community Commissioning (Adult Care Services)
- Head of Service, Adult Disability Service (East and North Herts, Adult Care Services)
- Head of Service, Adult Disability Service (West Herts, Adult Care Services)
- Head of Service, 0-25 Together (Herts County Council)
- Parent/Carer Representative

- Expert by Experience

The group reports to the local Learning Disability and Autism Strategic Partnership Board. This board is a sub board of the Hertfordshire Mental Health, Learning Disability and Autism Collaborative. (See Appendix 1 for further information on governance arrangements).

The purpose of the Leadership Group is to review key learning and agree strategic actions from reviews; develop and monitor the local LeDeR Health Inequalities plan in line with emerging themes and actions; provide assurance to the Learning Disability and Autism Strategic Partnership Board about the implementation of the Learning from Lives and Deaths programme; support greater collaboration across the Integrated Care System to promote and support action as a result of learning from LeDeR reviews; and ensure relevant information is shared with local quality groups and health and wellbeing board, to ensure the people who can affect the necessary improvements understand the issues that need to be addressed.

Information and Assurance Panel

To support the work of the Leadership Group an Information and Assurance Panel meets to provide quality assurance of reviews, and to ensure learning and information from reviews can be used efficiently and effectively by the Leadership Group. This includes checking reviews for quality issues; agreeing and signing off initial reviews; identify learning and making recommendations for strategic action from focused reviews for the Leadership Group; and cross-referencing actions with ongoing programmes of work to address themes.

Completion of reviews

Historically in Hertfordshire reviews were carried out by either clinically, or social care trained professionals working in Hertfordshire, or independent reviewers. The in-house model of reviewing created some challenges due to limited capacity of colleagues across the system to complete reviews. This led to a backlog of reviews in 2020-21. A small team of independent reviewers was established, and the programme was then well supported by experienced and skilled reviewers.

However, to meet the requirements of the new national policy and to provide business resilience for reviewing activity, from April 2022 completion of reviews has been commissioned out to an external provider, the North East Commissioning Support Unit (NECs). NECs have completed reviews on behalf of the national NHSE team and have subsequently developed extensive experience and knowledge of reviewing. In addition, NECs provides a multi-disciplinary reviewing team, separate from the Local Area Contact to ensure a supportive and high-quality delivery model for local reviews.

Children and Young People

Child Death Overview Panels (CDOP) are a statutory NHSE process which involves reviewing the death of anyone under the age of 18 years.

With the introduction of the new policy there is an ambition to better align the process of LeDeR with the CDOP process. Currently NHSE national leads for the LeDeR programme are working with the national Child Death Review team to explore the most effective ways to extract learning from Child Death Reviews, rather than replicate processes.

In the meantime, an interim process for collecting information about the deaths of children with a learning disability is in place. Locally the Local Area Contact (LAC) attends CDOP meetings where

deaths of children or young people with a learning disability are discussed. Relevant learning from Child Death Reviews is incorporated into the LeDeR Leadership Group meetings.

Coproduction

Coproduction and the voices of experts by experience and families/carers is a central part of the Learning from Lives and Deaths programme. The national programme is built on a history of people themselves and their families/carers speaking up about the health inequalities they experienced and highlighting the need for change.

The new LeDeR policy emphasises that local governance arrangements must 'promote meaningful co-production with people with lived experience'. There is currently representation from Experts by Experience and carers on the Herts LeDeR Leadership Group. In addition, funding has been allocated by the CCGs to enable further work to develop options for greater coproduction in 2022-23.

Action from Learning

A good LeDeR review takes considerable resources to complete. Professionals from across the system, family members, carers and people that knew the person well invest their time and emotional energy in contributing to reviews in order to produce a thorough reflection on a person's life and identify important learning about things that went well and things that could have been done better.

In order to validate this process, equal attention must be paid to ensuring a robust system of sharing learning from reviews and action from learning is in place.

Locally, learning is discussed at both the Information and Assurance Panel and the Leadership Group and appropriate actions agreed. This could include,

- A one-off focused action to address specific issues, or highlight learning to a team or organisation
- Aligning learning with an existing workstream, priority area or project and ensuring any relevant issues are combined into standing work plans
- The development of a new area of strategic work/priority

In addition, in 2022-23 learning from LeDeR reviews will be shared at the ICS System Quality Group where there is cross system representation.

The LeDeR policy sets out the intention for completed redacted reviews to be shared with everyone involved in the person's care and support. However, at the time of this report (June 2022) there are some ongoing quality issues with the redacted reviews from the national platform. This has led to a delay in sending out copies of reviews.

Options for sending out summaries of learning from reviews is currently being considered within Hertfordshire, although this may take significant resource to implement.

Monitoring

Performance is monitored by the national and regional NHSE teams against a Key Performance Indicator (KPI) of 100% completion of reviews within 6 months of notification. Data from May 2022

shows completion of 98% of reviews across both HVCCG and ENHCCG for this KPI. The remaining 2% of reviews that are older than 6 months since notification have been completed and are awaiting discussion at the next Leadership Group meeting.

Response to the Independent Review into Thomas Oliver McGowan's LeDeR Process

In October 2020 the findings of an independent review into the death of Thomas Oliver McGowan's (known as Oliver), LeDeR process was published. The review was commissioned in response to a number of inconsistencies in the local quality assurance processes of the LeDeR programme responsible for carrying out the review. The report identifies a number of recommendations for CCGs as a result of the learning from the review.

The new LeDeR processes have been implemented in Hertfordshire as a result of the new Learning from Lives and Deaths policy (2021) which reflects the recommendations of the Oliver McGowan review. However, due to quality issues with the redaction of reviews on the national LeDeR platform, locally there has been a delay in establishing a process for sharing redacted reviews with all who were involved in the care of the individuals, including the person's family or other loved ones, their GP, relevant health and care providers.

Local arrangements are being established which will resolve this issue by the end of Q2 2022-23 for all reviews completed under the new processes.

Section 2. Learning from reviews: Data and Themes

Section two of this report presents a range of quantitative data based on notifications made to the national LeDeR platform between 1st April 2021 – 31st March 2022. Anyone who is aware of a death of an individual with a learning disability, or an autistic person can make a notification to the platform. This annual report data refers to notifications of death for individuals registered with a GP practice within HVCCG or ENHCCG who died during this period.

At the time of writing this report (June 2022), the national LeDeR online platform does not enable data to be extracted for reporting purposes. Therefore, the following information is based on information recorded from reviews at a local level.

Number of notifications

Table 1 (below) shows the number of notifications of deaths per year in Hertfordshire since 2017. There were 56 notifications of death in 2021-22. All notifications were for people with a learning disability, and none for autistic people only.

The function to be able to complete reviews for autistic people (without a learning disability) aged 18yrs and over was introduced in January 2022 via the national LeDeR platform. However, given the lack of notifications from January to March 2022, more work needs to be done both locally and nationally to raise greater awareness of this. It is important to note that reviews are only for adults with a clinical diagnosis of autism. A lack of timely and clear diagnostic assessments routes and barriers to autism diagnosis for women may impact on the number of notifications of death. In addition, autistic people are often identified through Mental Health Services where the LeDeR programme and notification process is perhaps less well embedded than in Learning Disability Services where the programme is well established. Locally Autism Bedfordshire are delivering a workshop to raise awareness of the programme and the heath inequalities experienced by autistic people.

In 2021-22 there was a 42% decrease in the number of notifications of deaths from 2020-21 and a return to a similar level of notifications seen in 2018-19. This is due to the increase in deaths from Covid 19 notified in Q4 of 2019-20 and throughout 2020-21.

The Herts LeDeR Annual Report 2020-21 noted that the total deaths from Covid-19 or Covid-19 related causes represented 41% of total deaths. Deaths from Covid 19 in 2021-2022 was 4% (see data on Cause of Death).

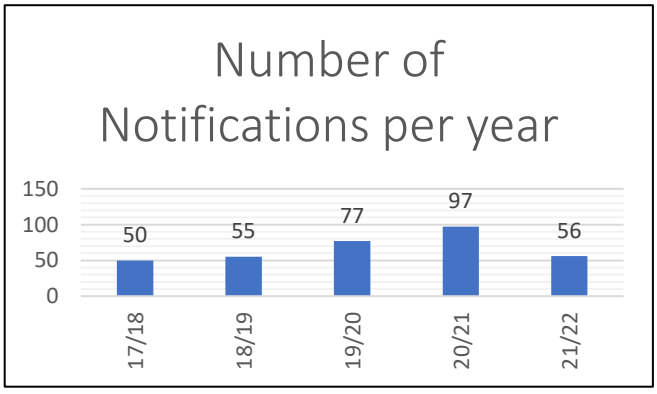


Table 1

The total number of LeDeR notifications of deaths in Hertfordshire since the beginning of the programme in April 2017 to March 2022 is 335.

Deaths by month

Table 2 shows the breakdown of deaths by month and indicates a peak of deaths in Autumn 2021.

Analysis of the available data has not indicated any specific cause for this peak. Only 1 death is attributable to Covid-19, although 1 is awaiting a coroner report.

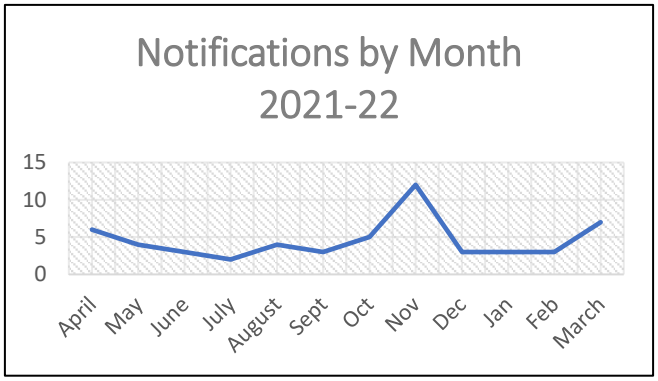


Table 2

Notifications by CCG

There is an even split of notifications between CCGs.

CCG	GP LD Register	Total Notifications	0-18	18+	% of GP LD Register
ENHCCG	2976	28	2	26	0.94%
HVCCG	3135	28	2	26	0.89%

Notifications represent approximately 0.9% of the total GP Learning Disability Quality Outcomes Framework (QOF) registers in Herts. Using national guidance ongoing work across both CCGs has focused on increasing the number of people identified as having a learning disability and ensuring GP Learning Disability registers are accurate.

Adult age range at death

In 2021-22 overall in Hertfordshire the median age of death for adults and children was 57.5 years, and adults only was 58 (adult male 60 and adult female 58). This is a decrease from 2020-21 (64.5 adults and children). In 19/20 overall in Hertfordshire the median age of death was 61 years.

In the last national LeDeR report (2020) the median age of death for adults and children was 61, median age of death adults only 62. The national report for 2021 has not yet been published.

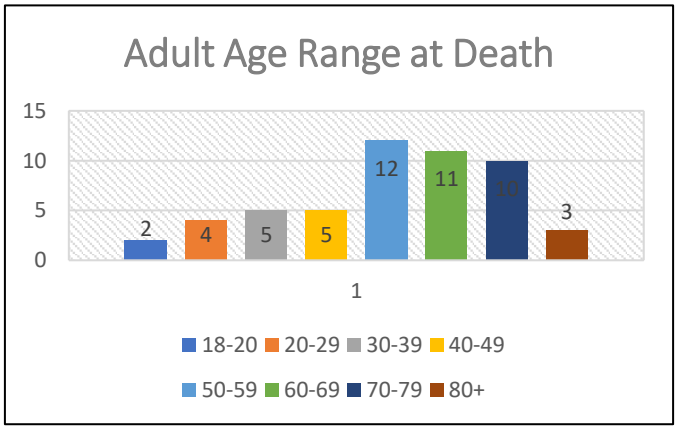


Table 3

Whilst the national LeDeR data (2020) reflects only a slight increase in life expectancy, it is concerning that the Hertfordshire data shows a reduction in median age of death of 7 years since 2020-21, and more than 3 years since 2019-20. More analysis is needed to understand any specific reasons for this, in particular where the cause of death is still unconfirmed and awaiting a coroner report (12 cases).

It is also concerning that the data continues to reflect the massive health inequalities that people with a learning disability face, when compared with the general population which, prior to Covid-19 had a median age of death of 82.3 years for males and 85.8 years for females. There is currently no consistent reporting on level of learning disability. However, extracts from the free text pen portraits indicate the following breakdown of level of learning disability.

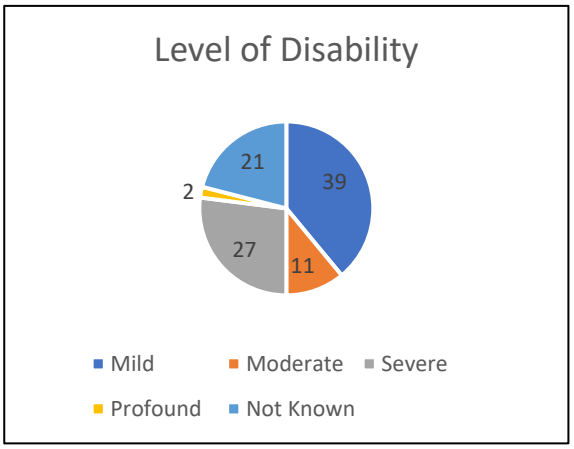


Table 4

Notifications by gender

There is a higher ratio of female to male notifications of deaths for the first time since the programme began. There was a higher number of female deaths between the ages of 50-59.

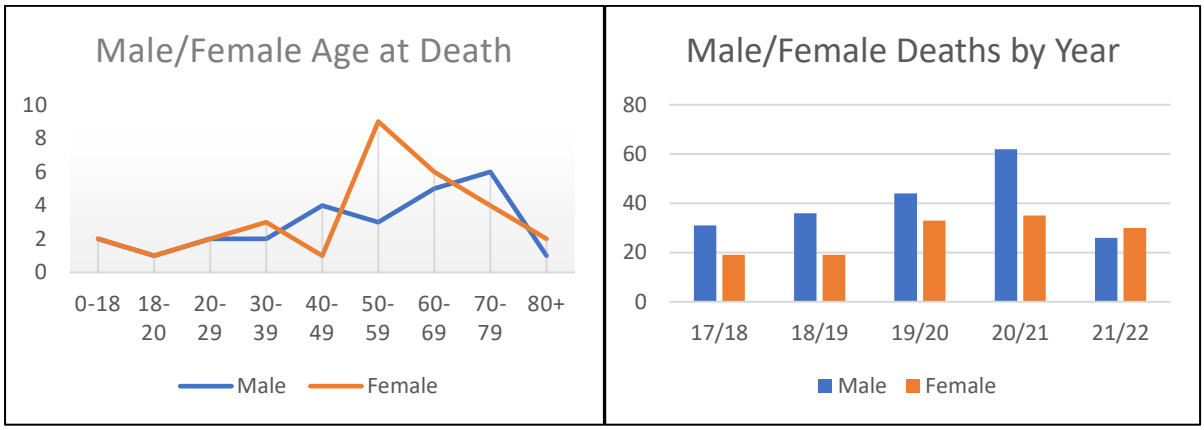


Table 5

People from minority ethnic groups

As has been the case in previous years, there were a low number of notifications of people from minority ethnic groups (n=2, 4%). However, given the lower number of total notifications in the year, this represents a greater percentage of the population. This data should be interpreted with caution due to the small data size, lack of clarity regarding the classification of Black Asian and Minority Ethnic (BAME) with the initial phases of the new LeDeR platform and the potential for errors when recording ethnicity in notifications.

Place of death

Just over half of the individuals died in hospital (55%, n=31), a reduction from 2020-21 (70%) and a return to the levels seen prior to Covid 19 (54%).

However, we also know from local reviews that End-of-Life planning is not in always in place. More work is needed to develop understanding and improve approaches to advance care planning for people with a learning disability locally.

Causes of Death

Of the 56 notifications made in 2021-22, 12 cases remain on hold for other investigations. The cause of death of these cases on hold is either not known or not confirmed, and therefore will not be included in this section. Three of these cases are child deaths and are awaiting Child Death Overview Panels (CDOP), six are waiting review by the coroner, two are waiting safeguarding review and one is being reviewed by the police.

Therefore, the cause of death is known for 44 people and will be discussed further below.

Underlying cause of death by ICD-10 chapter

The International Statistical Classification of Diseases and Related Health Problems (ICD-10) is a comprehensive classification of causes of morbidity and mortality and is published by the World Health Organization (WHO). It contains codes for diseases, signs and symptoms, abnormal findings, complaints, social circumstances, and external causes of injury or diseases. SCCI0021: International Statistical Classification of Diseases and Health Related Problems (ICD-10) 5th Edition - NHS Digital

From our local LeDeR data the most frequently reported ICD-10 chapter for underlying causes of death have remained the same for the last 3 years, being disorders of the respiratory system. In 2021-2022 41% (n=18) of the deaths of people with a learning disability were due to disorders of the respiratory system. This would be 45% (n=20) if COVID 19 is included.

The second most frequently reported underlying causes of death in 2021-2022 were in the ICD-10 chapter of disorders of neoplasms/cancer. 16% (n=7) of the deaths of people with a learning disability were due to cancer.

The third most frequently reported underlying causes of death in 2021-2022 were in the ICD-10 chapter of disorders of the circulatory system. 11% (n=5) of the deaths of people with a learning disability were due to disorders of the circulatory system.

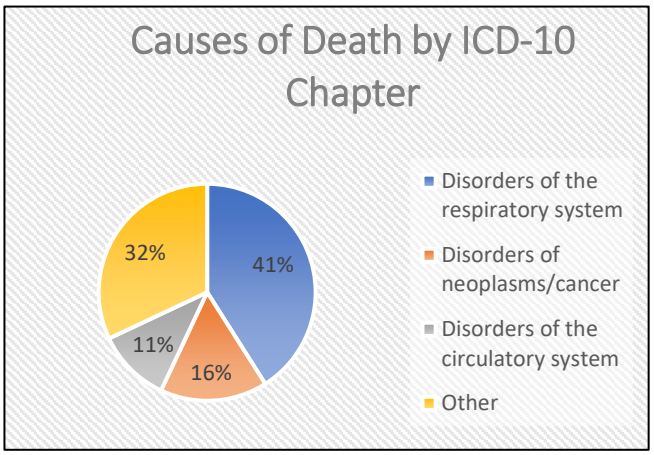


Table 6

Most frequently reported cause of death as per Part I of Medical Certificate of Cause of Death (MCCD)

For 2021-2022 the leading causes of death were aspiration pneumonia (20%, n=9), pneumonia (community acquired)/lower respiratory tract infection (16%, n=7) and then sepsis and bowel cancer were both third with 7% (n=3).

Last year, 2020-2021, the leading causes of death were COVID 19 (15%), aspiration pneumonia (10%) and COVID 19 pneumonia (9%). In 2019-2020 the top three causes of deaths were pneumonia (13%), cancer (12%) and sepsis (10%).

Life limiting Genetic Disorders

Only two people had a life limiting genetic disorder. These included Alexander Disease and Atypical Rett Syndrome. The causes of death for these adults were aspiration pneumonia and pneumonia. The average age of death was 32 years old.

Avoidable Mortality

Avoidable mortality is used as an indicator to measure the contribution of healthcare to improvements in population health. It is based on the concept that premature deaths for certain conditions should be infrequent and if in the presence of effective and timely healthcare, should not occur.

In 2020 a new avoidable mortality definition was created by OECD (Organisation for Economic Co-operation and Development). Avoidable causes of deaths are all those defined as preventable or treatable. Preventable and treatable causes of mortality are defined as follows,

Avoidable mortality: OECD/Eurostat lists of preventable and treatable causes of death (January 2022 version)

- **Preventable mortality**: Causes of death that can be mainly avoided through effective public health and primary prevention interventions (i.e., before the onset of diseases/injuries, to reduce incidence).

- **Treatable (or amenable) mortality**: Causes of death that can be mainly avoided through timely and effective health care interventions, including secondary prevention and treatment (i.e., after the onset of diseases, to reduce case-fatality).

In 2020, **22.8%** of all deaths in Great Britain (GB) were considered avoidable. Of the avoidable deaths in 2020, 68.6% were attributed to conditions considered preventable and 31.4% were attributed to treatable conditions. Neoplasms (cancers) contributed to the largest cause of avoidable mortality (35%), followed by cardiovascular disease (20.5%)

In Hertfordshire for 2021/2022, 59**%** (n=26) of the causes of death of people with a learning disability would be defined as avoidable causes of death. NOTE: of the total notifications (56) this represents 47%, although of the currently unknown or unconfirmed causes of deaths some will likely also be classed as avoidable. Of these 11.5% (n=3) would be considered preventable, 77% (n=20) would be considered treatable and 11.5% (n=3) would be classified as 50% preventable and 50% treatable as per OECD.

The most frequently recorded preventable medical cause of death in adults with a learning disability in Hertfordshire for 2021/2022 was aspiration pneumonia (23%, n=7). The most frequently recorded treatable medical cause of death among adults with learning disability in Hertfordshire for 2021/2022 was pneumonia/ lower respiratory tract infection (17%, n=5). This is much greater than the general population where only 8% of the avoidable deaths in 2020 were due to disorders of the respiratory system. Data taken from Fingertips - Public Health Data

Further Information about the causes of death per ICD 10 Classification

Respiratory diseases

Of the 44 notifications, 20 deaths were due to respiratory disease (45%) and 9 were due to aspiration pneumonia. Other conditions leading to aspiration pneumonia as per part 1b of the MCCD included spontaneous pseudo-obstruction, stroke (CVA), vascular dementia, intestinal obstruction due to volvulus, frailty of old age and cerebral palsy. The average age of death from aspiration pneumonia was 63 years old. Gender and ethnicity data shows that 6 people were female, 3 were male, 7 people were from white British background and 2 were black Caribbean.

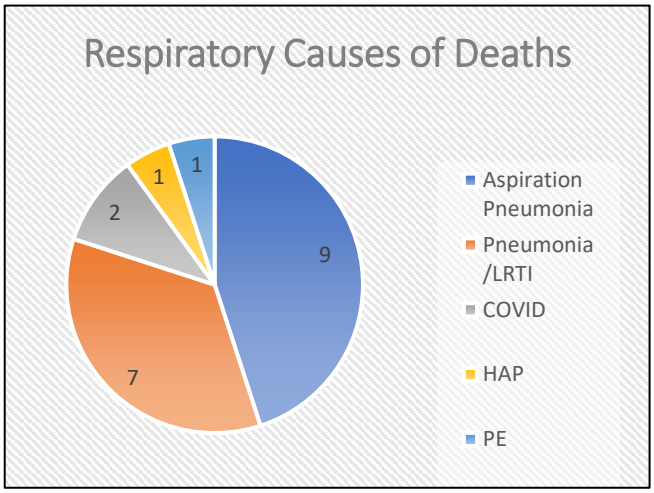


Table 7

A further 7 deaths from respiratory diseases were due to pneumonia/lower respiratory tract infection. Three of these had another condition listed as a contributing cause of death, in part 1b of the MCCD. These were pulmonary fibrosis, Alzheimer's dementia and Atypical Rett Syndrome. The average age of death from pneumonia was 62 years old. Gender and ethnicity data shows that 6 people were female, 1 was male and all 7 were white British.

Other causes of respiratory deaths were COVID 19 (n=2), hospital acquired pneumonia (HAP) (n=1) and pulmonary embolism (PE) (n=1).

Neoplasms/Cancer

7 deaths were due to cancer (16%). The average age of death from all types of cancer was 61 years old. 5 were female and 2 were male. All 7 were white British.

3 of these deaths were due to bowel cancer. The average age of death from bowel cancer was 64 years old. One person would have been too young to access bowel cancer screening, and another was just 60 years old, the age the bowel cancer screening programme starts in the UK. 6 were female and 3 were male. 7 were white British and 2 were black Caribbean.

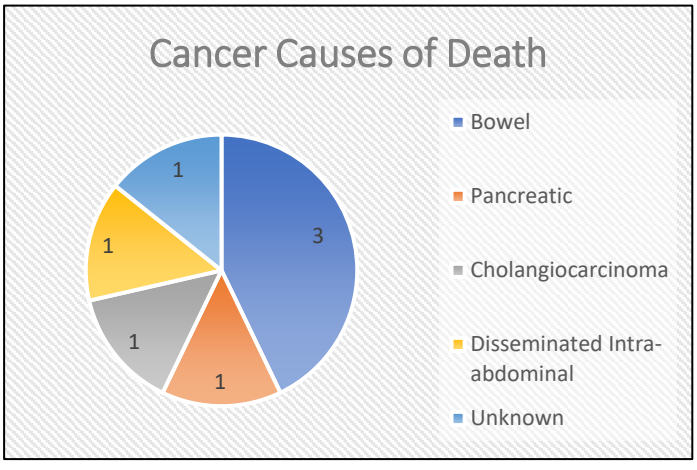


Table 8

Other causes of cancer deaths included pancreatic cancer (n=1), cholangiocarcinoma (n=1), disseminated intra-abdominal malignancy (n=1) and cancer of unknown origin (n=1).

Circulatory System

5 deaths were due to conditions in the ICD 10 Chapter of the Circulatory System (11%). The average age of death from conditions of the circulatory system was 60 years old. 2 were female and 3 were male. All 5 were white British.

The specific cause of death as per part 1 of the MCCD was myocardial infarction (n=2), heart failure (n=2) and cardiomyopathy (n=1).

Sepsis

3 deaths were due to sepsis (7%). Two of these were secondary to pneumonia, one was secondary to urinary tract infection. The average age of death from sepsis was 65 years old. 1 was female and 2 were male. All 3 were white British.

Chronic Liver Disease

2 deaths were due to chronic liver disease. One was due to alcoholic liver disease and one was due to non-alcoholic fatty liver disease. The average age of death was 58 years old. Both were female and white British.

Other causes of death

Other causes of death included frailty (n=2), dementia (n=1), small bowel obstruction (n=1), renal failure (n=1), spontaneous subarachnoid haemorrhage (n=1) and osteomyelitis of the sacrum (n=1).

Additional Information from reviews

Annual Health Checks

Data regarding annual health checks (AHC) is not included within the questions of an initial review. This has impacted on the ability to compare data from previous years.

Data shows that 54% (n=30) of reviews indicated an annual health check had been completed in the 12 months before death. However, 21% of reviews (n=12) are on hold and so the information is not yet available. Of the 14% (n=8) where the information was not known, this is either due to the reviewer not including the information in the review, or it was not clear from the records. 11% (n=6) did not have an annual health check either this did not appear to have been offered or was declined.

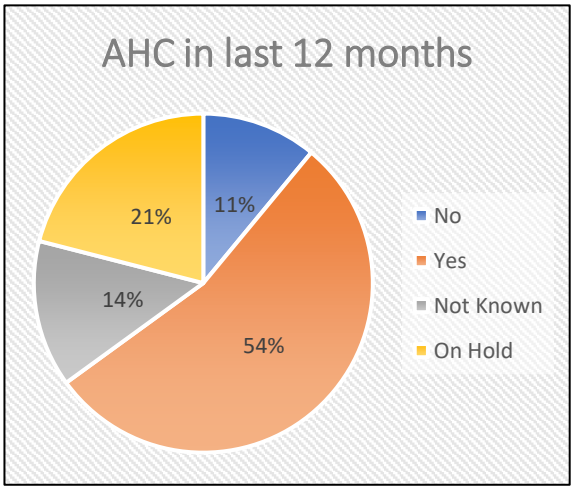


Table 9

Reviewers completing reviews on behalf of Hertfordshire have now been requested to record in the free text sections of the initial reviews whether an annual health check has taken place or been offered to ensure improved consistency in this data going forward.

Whilst there have been examples of timely and thorough GP support with good reasonable adjustments, there is evidence that some annual health checks were delayed or carried out remotely due to Covid, usually via telephone. There were also concerns raised about the quality of some annual health checks, and not all health checks resulted in a clear and implemented Health Action Plan.

Long Term Conditions

The current format of reviews and the functionality of the national platform does not yet provide a robust way of collecting and analysing data about long term conditions. However, from local data collection the following long-term conditions were noted in a significant number of completed reviews; Epilepsy 36% (n=16), Dysphagia 32% (n=14), Constipation 23% (n=10), Heart Condition 18% (n=8).

Initial and Focused Reviews

Where a notification meets the national criteria for focused reviews this is progressed. In the case of initial reviews, discussions take place between review and senior reviewer, and the Hertfordshire Local Area Contact (LAC) where needed, to agree whether to progress an initial review to a focused review. This may be in the case of new and/or significant learning for the ICS, or where there is a particular complexity to the case.

NHSE has anticipated that approximately 25-33% of reviews will be focused reviews.

Of the 56 notifications, 11% were completed as focused reviews and 68% initial reviews. The remaining 21% are currently on hold and therefore not yet known. It is reasonable to assume that a considerable amount of the 'on hold' reviews will progress to focused due to the level of complexity involved in the case.

Quality of Care

Unlike the previous review process, the new LeDeR reviews do not grade care in initial reviews. Instead, grades are only required in focused reviews for the Quality of Care and Availability of Services. As a result, comparison cannot be made with previous annual report data, and does not reflect the range of provision as often focused reviews are those where there have been significant issues. From 2022-23 the Information and Assurance Panel have introduced the grading of initial reviews to provide a wider reflection of quality of care.

Section 3: Action from Learning

'Action from Learning' is a critical element of the LeDeR programme and the new policy (2021) highlights the responsibility of the ICS to ensure that information from reviews results in activities and interventions that effect positive change across the system. Local areas must identify 'evidence of service improvement actions as a result of learning from reviews.'

As a result, a Hertfordshire LeDeR Health Inequalities Plan was developed based on learning from reviews since the start of the programme and which builds on the work of the previous Herts LeDeR steering group and the Improving Health Outcomes Group (IHOG).

Reducing health inequalities for people with a learning disability and autistic people is a complex task that will require multiple levels of thinking and action across diverse health and social care organisations. One of the key challenges of the LeDeR programme so far has been how to effectively connect the individual actions that a review may highlight with the broader strategic changes needed to address priority themes.

Our action from learning plan is therefore based on features of a Logic Model in order to begin to connect the relationship between cross system activities with the intended outcomes of the LeDeR programme. A Logic Model is described as,

"simply diagrams or flow charts that convey relationships between: the resources being put into a programme; the interventions, activities and processes planned; the outputs from these; and the short-term, intermediate and longer-term outcomes. Logic models provide a visual means of showing complex chains of reasoning."

NHSE, 2015

Logic Models lend themselves to be dynamic plans that describe the priority areas for action and are updated as things are achieved, and new learning is identified. For more information on Logic Models see Using Logic Models in Evaluation- Jul16.pdf (strategyunitwm.nhs.uk)

The Herts LeDeR Health Inequalities plan is structured around 5 key long term outcome areas which are then broken into short- and medium-term outcomes. The term 'people' in the plan is used to refer to people with a learning disability as these outcomes have been based on learning from reviews of people with a learning disability. Although there is likely to be some overlap of barriers, specific reference is made in the plan to developing a greater understanding of the health inequalities experienced by autistic people, as this is a new element of the LeDeR programme.

The 5 outcome areas are,

1.	**More people live longer and healthier lives**
2.	**Earlier identification and better treatment of health conditions**
3.	**More people have choice and control over their health treatment and support**
4.	**People experience more social equality in their lives which leads to better health outcomes**
5.	**Effective systems of information sharing and communication ensure good health outcomes for people**

In addition, work is ongoing to ensure that individual and strategic actions from reviews of the lives and deaths of autistic people are aligned with wider ICS strategic planning. The Herts LeDeR Health Inequalities plan is monitored by the Leadership Group.

Action from Learning - by outcome area

The following section gives details on the activities, outputs and outcomes that have been achieved by partner organisations across the ICS by the 5 priority areas in 2021-22.

Following the logic model framework each long-term outcome area is broken down into medium and short-term outcomes, showing a logical progression to achieve the overall programme goal. Medium term outcomes are described as 'what we want to see happening' and short-term outcomes as 'what we are focusing on now and in the year ahead'.

The LeDeR health Inequalities plan was developed in 2021 and the short-term outcome areas will continue to be the focus through 2022-23.

Long Term Outcome 1: More people live longer and healthier lives

One of the ultimate aims of the LeDeR programme is that more people with a learning disability live longer and healthier lives. However, since the programme was established in 2016, national data indicates that there has only been a slight increase in the median age of death, and local data has shown a decrease in median age in 2021-22.

Understanding the reasons for these statistics is complex and we do not yet have adequate systems of data analysis to understand the causes of this in greater depth. The data set for Hertfordshire is relatively small and the national report for 2021 has not yet been published for comparison. Nevertheless, it is continued evidence of the significant and enduring health inequalities people with a learning disability face.

Achieving a reduction in health inequalities will take a focus on ensuring that mainstream health care pathways are fully accessible and inclusive of the needs of people with a learning disability. Improving Health Outcomes Group (IHOG) partners are working collectively and across individual services to develop a greater understanding of reasonable adjustments, and how to provide them for people with a learning disability.

What we want to see happening:

Fewer people die of preventable or treatable causes.

All mainstream health pathways and services are fully accessible to people and are able to accommodate a wide range of reasonable adjustments.

There are effective specialist pathways which compliment mainstream pathways where needed e.g. epilepsy, dementia, frailty.

What we are focusing on now and in the year ahead:

- There is increased understanding and awareness across the system of the health and social inequalities people face through the LeDeR programme
- A review of transition experiences of physical health needs of young people will inform plans for service development/delivery.
- Examples of people that have 'fallen between services' will be identified from focused reviews and a plan developed to resolve any gaps in services or pathways.
- Information from LeDeR is used to take actions to improve services and support.
- The needs of people are included in all public health initiatives.
- More people attend cancer screening appointments. Greater awareness of the barriers and solutions to access.
- There is an effective tool to identify frailty needs and people are referred and receive appropriate support for their needs.
- There is increased awareness in Primary, Acute and Community Health services of reasonable adjustments and how to make their services more accessible.
- The epilepsy and dementia pathways are fully developed, embedded and effective.
- More people from BAME backgrounds access good quality health and social care support

Activities, outputs and outcomes achieved so far

The LeDeR Programme

A significant focus for the year 2021-22 has been the implementation of the new Learning from Lives and Deaths policy (2021). This has involved substantial changes as described previously and has taken time and resources to achieve. The arrangements in Herts are now fully compliant with national policy.

Changes to the leadership and governance of the programme has enabled better engagement in the programme from both health and social care and has resulted in new conversations and new areas of work. The Leadership Group is currently identifying the most effective opportunities to share learning from reviews across the system, and as mentioned previously, will include updates from the Leadership Group to the ICS System Quality Group on gaps, issues and good practice.

Two specific new areas of learning have been identified in the Herts LeDeR Health Inequalities Plan, 'transition experiences' and where individuals may have 'fallen between the gaps' of services or pathways. In the coming year cases where these issues have been highlighted will be reviewed to identify key themes and learning.

Action from learning continues to be supported through the local Improving Health Outcomes Group (IHOG). This group is made up of a wide range of professionals and organisations across Hertfordshire. Together they work creatively, and collaboratively around key themes identified from the reviews and take action to address local issues. The Leadership Group delegates specific actions to IHOG where appropriate. In addition, working groups are established to address particular issues where needed, for example End of Life Care.

All partner organisations have mechanisms in place to share learning from LeDeR. For example, in East Herts Heath Trust (EHHT) learning from LeDeR reviews is shared amongst individual teams and reflected in the revisions of Trust policies. This informs training which is delivered to staff and when services are redesigned.

In Hertfordshire Partnership NHS Trust (HPFT) a physical health oversight group for learning disability, forensic and rehabilitation services continues to meet monthly with representation from all clinical areas. Agenda items includes learning from LeDeR, serious incidents and Prevention of Future Deaths reports, as well as dedicated time to discuss national reports and local initiatives. In addition, local Physical Health groups have been set up in 2022 involving clinicians from all teams to take forward any learning and to identify and action local priorities around physical health for service users open to HPFT. Priority areas currently being discussed include the use of a physical health RAG rating tool, physical health training and staff competencies and physical health documentation.

Public Health

The Obesity Service Management task and finish group for the ICS identified a gap for people with physical or learning disabilities in accessing support for weight management. Funding was agreed from Public Health England for 1 year (until September 2022) to offer a focused programme called 'Shape up Together', a 12-week weight loss programme for those with physical disabilities, mental health conditions and learning disabilities. This started in January 2022 and has been well attended, mainly with referrals from day centres. Feedback from attendees has been very positive.

Cancer Screening

New Health Inequalities Nursing (HEN) posts within the Learning Disability Nursing Service (LDNS) have focused on key areas of health inequalities, with a post specifically assigned to supporting greater uptake of cancer screening appointments. Over the year the HEN has been working with GP practices raising awareness of access to cancer screening programmes in patients with a learning disability and helping to overcome barriers.

Activities have included work in HVCCG to establish searches in practices to identify patients with a learning disability entering a cancer screening programme. More work is needed to raise awareness and widen this out across the county. So far 66% of Hertfordshire GP practices have responded to the HEN's request for the names of learning disability patients entering the cancer screening programme in 2021-22.

Outputs of this work include accessible resources to help explain the processes involved in screening for people and those supporting them.

1) Bowel Screening 'Walk Through' Video

Supporting someone with a learning disability to complete bowel screening.

2) Cervical Screening 'Walk Through' Video

Cervical Screening Test for people with Learning Disabilities

3) Cartoon Story Board on Cervical Screening

paulas-smear-test-pdf-1.9mb.pdf

So far, the HEN for this area of work has undertaken approximately 7 months of active case work in 2021-22. Over this time data shows that more people completed screening as a result of involvement from the HEN. Of the patients identified as eligible for breast, bowel or cervical screening programmes, 18% (n=17) attended without any involvement. **A further 29% (n=28) completed screening programmes with the HEN involved.** The nurse continues to work with 26 patients to support completion of their screening.

See Table 9. Note **This includes those individuals where capacity assessment completed, non-attender/non-responsive, capacity assessment completed, and exception code assigned.

A very successful outcome of the involvement of the HEN has been the significant increase in engagement with bowel screening. Through

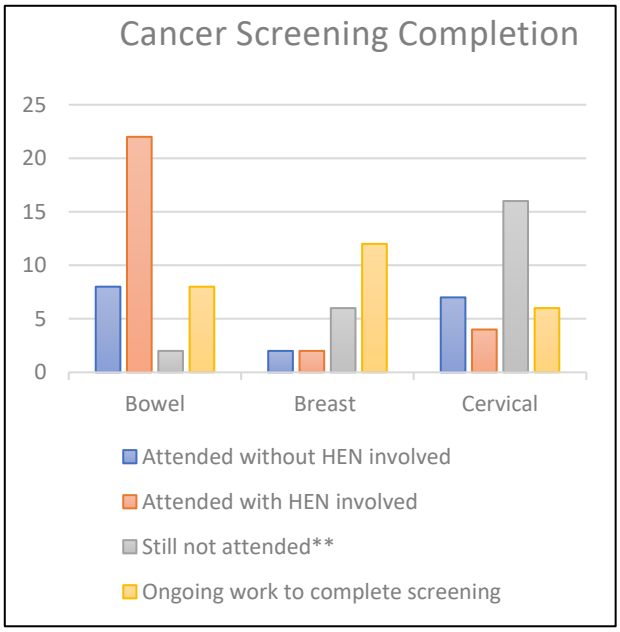


Table 10

home visit support or telephone support by the HEN 54% (n=22) completed screening, with ongoing work with a further 8 people who are all anticipated to complete.

The work has also involved ensuring that people can understand the purpose and process of screening through accessible information. The HEN offers home visits to spend time going through the processes in detail using easy read guides and models with opportunities for people to ask questions.

At times people are assessed as having capacity to make an informed decision once they have been given information in a format they can understand, and subsequently decide against having the screening done for their own individual reasons. In these cases, there is confidence that they have understood the risks to their health but have been empowered to make informed decisions about their health care.

The team have developed resources including capacity assessment and best interest tools that also highlight the least restrictive approach agreed, made links with local and regional screening services and developed a range of easy read resources to support this work. In the year ahead more targeted work at specific ages is planned to maximise the effectiveness of the intervention from the nurse.

In addition to the HEN, the Community Learning Disability Nurses also provide direct support for screening through referrals to the team. As an example of this work a Learning Disability Nurse supported a service user to attend a breast screening by identifying that she required wheelchair access as a reasonable adjustment. By overcoming this barrier, the individual was able to have a successful breast screening that they otherwise would not have had.

This work also extends across other services. For example, in East Herts Health Trust (EHHT) patients that are referred to cancer screening services by their GP are supported by members of the Acute Health Liaison Team (AHLT) during appointments or when accessing inpatient services.

Frailty

Frailty has continued to be a priority following work completed in 2020-21 by the Acute Health Liaison Team to understand the use of the Rockwood Clinical Frailty Scale (CFS) for assessing frailty risks in service users growing older and the application of this for individuals with stable long-term conditions. It was not evident how these changes in frailty risk would be accounted for in people with Downs Syndrome, Epilepsy, Stable Long-term disability, neurological conditions, multi-morbidities, self-neglect and non-engaging service users.

In addition, the identified age for looking into frailty needs typically starts from 65 years for the general population. Given that the median age at death for people who have learning disabilities is 61 years, and 40 years for people with profound learning disabilities, assessing frailty at age 65 for this population could result in significant delays to accessing proactive management.

This work became even more important when concerns were raised nationally about the use of the Rockwood Clinical Frailty Scale (CFS) in assessing treatment options for Covid-19, and locally the use of this tool for people with learning disabilities was suspended in acute settings in 2020-21.

The LeDeR Annual Report 2020-21 advised the pilot of the Frail + LD assessment tool would commence in Spring 2021; this was delayed until Spring 2022. The delay was in part due to the ongoing Covid-19 pandemic but also due to Adult Care Services receiving an offer of funding from

the Eastern Academic Health Science Network (Eastern AHSN) to support an external evaluation of the Frail + LD assessment tool's effectiveness in identifying the risk of frailty developing in people with Learning Disabilities.

The initial phase of the pilot has taken place with evaluation partners, the University of Hertfordshire (UH) reviewing the data collected and undertaking focus groups to help determine the effectiveness of the tool. Several training sessions have been held with clinicians during Q4 2021 and Q1 2022.

Coproduction work has included working in partnership with experts by experience to develop information sheets for engaging with service users and arrangements are in place for engaging with Carers.

Aims of the pilot:

- Provide an indication of the clinical utility of the scale in terms of its accuracy in identifying the risk of frailty in the target group
- Provide an indication of the thresholds for identification of frailty risk against clinical judgement
- Obtain feedback regarding use of the tool in practice and any modifications to be made

A further phase of the pilot is planned which will build on the findings from the initial pilot, provide information around any adaptations that need to be made to the tool, associated materials, and training for future larger scale studies.

Reasonable Adjustments

Reasonable adjustments are a legal requirement under the Equality Act (2010) to make sure health services are accessible to all disabled people. Our plan identifies this as a significant area of work for all services and this section gives an overview of considerable activities underway to address this and some examples of good practice.

In Primary Care awareness of reasonable adjustments has been raised through communication bulletins and delivery of a webinar for primary care staff and Covid 19 vaccinators. A new Enhanced Commissioning Framework (ECF) launching in October 2022 includes as a service outcome that practices recognise and record reasonable adjustments for patients with a learning disability using the appropriate codes.

The Learning Disability Nursing Service (LDNS) has developed a range of resources to support health professionals including bitesize training for GP practices to give a variety of options for education where time may be a limiting factor. Bitesize Learning Disability Awareness for Health Professionals

The Community Learning Disability Nurses (CLDN) work alongside Primary Care to support individuals with reasonable adjustments. Some examples include,

- One GP practice has a fortnightly virtual meeting between the GP/ CLDN to discuss all patients with a learning disability open to the nursing team to promote joint working and achieve better outcomes. This work resulted in a reasonable adjustment being provided for a patient to have an Utra Sound Scan at a satellite surgery and sitting upright due to their fear of lying horizontally. This enabled cancer to be ruled out.

- Blood test desensitisation work with a patient in her 40's who was afraid of blood tests and therefore had never had one before. The CLDN worked with practice nurses doing desensitisation visits and created a screen box. The patient visited during a quiet time, the nurse used numbing cream and music was played to help relax the patient. As a result of the blood test the patient was found to be deficient in Vitamin D.

Hertfordshire Community Trust (HCT) have introduced a reasonable adjustment flag for patients with a learning disability and autistic patients and raising awareness and understanding of what reasonable adjustments are is a continuing quality priority for the Trust for this coming year.

HCT have also been involved in creating a whiteboard animation which focused on raising awareness of the importance of reasonable adjustments. This was co-produced with input from experts by experience and involvement from a team at the Kings Fund. The white board animation has been widely shared. Herts Reasonable Adjustments 01.11.21

In West Herts Health Trust (WHHT) all patients who are known to have a learning disability have an electronic flag to alert staff that the patient has a learning disability. The Trust informatics team, generate a list of in patients with a learning disability and this is shared with the safeguarding team, carers lead, Named Consultant for safeguarding adults and Acute Health Liaison Team (AHLT) who visits all the patients daily (Mon- Friday).

The safeguarding team work collaboratively with the nurse consultant and consultant for dementia, including providing training on Mental Capacity, carers breakdown and reasonable adjustments.

Reasonable adjustment audits are undertaken monthly (dip dive audits) in addition to an annual Trust wide audit. These form part of the Trust safeguarding audit strategy. All audits are presented to the Trust safeguarding panel which has executive oversight.

Learning Disability awareness forms part of the mandatory training framework. Training is delivered to staff by the Acute Health Liaison Team (AHLT). Reasonable adjustment is taught using the TEACH model. Training compliance is monitored monthly by the Named Nurse for safeguarding and is presented to the Trust safeguarding panel. Training compliance for May 2022 was 93%.

The Named nurse for safeguarding has undertaken an NHS England "Ask, Listen, Do" project with support of the Health Facilitation Lead, the AHLT, experts by experience and carers to enable a more accessible feedback and complaints process for people with a learning disability/autism and their carer. This group meets every 6 weeks to discuss progress of project. Once embedded the overall aim is to be able to collate information and establish if there are any themes.

There are established "champions" for adults at risk. These staff are multidisciplinary and have nominated themselves to be champions. Training is delivered on a quarterly basis with support from AHLT and has included experts by experience, parents' perspective of being in an acute hospital with a child with a learning disability and end of life care for patients with a learning disability.

In East Herts Health Trust (EHHT) the AHLT also give advice and support to clinical areas on supporting people with a learning disability when accessing acute services. Carers and family members are routinely consulted on reasonable adjustments to optimise patient experience and enhance outcomes.

Good examples of reasonable adjustments noted in the Trust when accessing services in 2021-22 include:

(1) When managing people with a learning disability the endoscopy unit find out what kind of music the individual likes and will play the music of their choice in the endoscopy room. Positive feedback has been shared by carers, patients and AHLT nurses relating to this practice as it helps to ease anxiety.
(2) Critical care work very closely with carers and patients' families. A good example of a reasonable adjustment for a patient with a learning disability who was missing their dog was that the unit allowed the patients dog to visit and briefly to see their owner. This act helped to relieve the individual's anxiety.
(3) On occasions where people with a learning disability have accessed a service and required sedation for a procedure, if the individual also required bloods taken for another health issue this is also undertaken. There have been occasions where COVID testing was also undertaken in this manner where it was assessed that the individual lacked mental capacity for this decision and could not tolerate PCR testing. These actions helped to reduce distress and improve care co-ordination avoiding the need for multiple hospital attendances. This is a good example of secondary and primary health care services working well together.
(4) The Trust offer individuals who are flagged as having a learning disability on the Electronic Patient Record (EPR) easy read appointment letters to help facilitate their attendance.
(5) Flexible appointments are offered by many Trust services to facilitate attendance. For example, if the individual does not like crowded areas, appointments can be offered early morning or late afternoon when activity in the outpatient department is lower.
(6) A purple wrist band system is in place and used with the consent of patients with a learning disability. The wrist bands serve as a reminder to staff that the patient may need reasonable adjustments for how care is delivered and professional adjustment in communication styles.
(7) Since wave 1 of the Covid 19 pandemic the Trust has waved visiting restrictions for patients with a learning disability and/or autism to encourage carer and family visits. This helps reduce the stress on patients and encourages involvement in supporting care.
(8) The Trust Quickview system can be used to identify upcoming planned and clinic attendances for people with a learning disability. The AHLT and the safeguarding team can then plan the level of support required for the individual in advance of their attendance.
(9) The Trusts EPR includes a virtual ward for people with a learning disability so that the individuals can be better traced and located by the AHLT throughout the patients hospital stay.
(10) AHLT nurses attend the daily site safety huddle to communicate plans and concerns relating to patients with a learning disability. This facilitates the prompt resolution of concerns and enhances communication amongst the various Trust services.

EHHT has also reviewed the policy regarding the care of people with a learning disability. This now includes more robust advice and instruction on the importance of making reasonable adjustments and offers advice on the discharge processes in a manner which signposts clinical teams to access wider multi-disciplinary team members.

Finally, in April 2021, the EHHT introduced mandatory learning disability awareness training for all staff irrespective of role through the completion of an E-Learning module developed by Health Education England; currently 90% of Trust staff has completed the training. Feedback from participants has indicated that staff are clearer on the difference between a learning disability and learning difficulty and staff are also clearer on the concept and need to make reasonable adjustments.

Epilepsy

Data from 2021-22 notifications shows that 32% of people who died had epilepsy. This supports national data that shows people with a learning disability are more likely to have epilepsy than the general population.

Recent guidance in the Step Together report (2020) has supported the integration of care for people with epilepsy and a learning disability. This was developed with input from professional bodies, health care professionals, people with a learning disability and epilepsy, families, carers and third sector organisations and recommends more collaborative working between General Practice, Learning Disability Mental Health Services, Specialist Nursing Services and Neurology/Epileptology services

Step Together - Integrating care for children, young people and adults with epilepsy and learning disability.

Locally adults with a learning disability and epilepsy may either be known to a Consultant Learning Disability Psychiatrist or a Consultant Neurologist, or at times both. They would also receive care from their registered GP and may receive care from Out of Hour Services and acute care in A+E. The Consultant Learning Disability Psychiatrist (Hertfordshire Partnership NHS Foundation Trust) holds clinics within the community. There is also additional support from an Epilepsy Specialist Nurse (ESN) from the Community Learning Disability Nurse service with experience of working with patients with a learning disability, their families and/or carers.

In 2021-22 a new Epilepsy pathway has been drafted covering; first seizure pathway; transition pathway; and adults with known epilepsy, to ensure joint working with all teams for the best outcomes for the individual and in the ethos of Step Together report. Central to this is the role of an Epilepsy specialist nurses (ESN) both in the community and acute settings. Currently there is an ESN in EHHT, and a business case has been developed for a similar role for WHHT to ensure equity across Hertfordshire.

Hertfordshire Partnership NHS Foundation Trust (HPFT) have completed an audit of epilepsy care within the learning disability inpatient wards against NICE guidance. Results of the audit have been discussed at governance meetings and guidance on epilepsy care planning for inpatients has been disseminated along with an Epilepsy assessment and management toolkit developed by colleagues in HPFT Essex Learning Disability services.

Partners providing equipment for those with epilepsy have presented at the HPFT Learning Disability and Forensic Physical Health Oversight Group. The STEP Together paper has also been discussed and teams have assessed their skills levels around epilepsy identifying where further training is needed.

Dementia

People with a learning disability are at greater risk of developing dementia, especially young onset dementia (when dementia symptoms develop before the age of 65).

As a result of learning from LeDeR reviews a review of the dementia pathway and strategy is underway (June 2022). This work will include a review of opportunities for staff support, development and training in care and support of people with Learning Disabilities and dementia, including communication and pain awareness. A Task and Finish group has been identified to carry out the audit and report back to the LeDeR Leadership Group.

The Learning Disability Nursing Service (LDNS) has made changes to the criteria for achievement of the Purple Star Award for GP practices which now includes identifying eligible patients for proactive dementia baseline assessments.

A barrier for clinicians can be starting the conversation about dementia with people with a learning disability at a younger age and the reluctance of people to be assessed at that stage. In 2022-23 the LDNS will create a leaflet to explain how the Dementia Questionnaire for People with Learning Disabilities (DLD) helps with identifying early signs to ensure early treatment.

Within the LDNS, IT services are working in partnership with Pearson's publishers to enable an electronic copy of the DLD to be created on local IT systems.

In other practice across the ICS, in EHHT there is an admiral nurse in post that provides support to clinical areas for all patients with a diagnosis of an underlying dementia irrespective of whether the individual has an underlying learning disability.

STOMP and STAMP

STOMP stands for Stopping the Over Medication of People with a learning disability, autism or both with psychotropic medicines and STAMP stands for Supporting Treatment and Appropriate Medication in Paediatrics.

STOMP is an NHSE programme involving a range of key stakeholders to support individuals to ensure they are being medicated appropriately. Other therapies and support (including family support) may be effective as an alternative to the use of psychotropic medication.

In Hertfordshire there is a well-developed and resourced approach to supporting this programme of work through a dedicated STOMP nurse, and more recently Health Care Assistants, within the Learning Disability Nursing Service (LDNS). This team offers support to Primary Care to identify individuals eligible for a reduction in psychotropic medication, and a process to achieve meaningful outcomes. The ongoing aim is to establish a model that enables STOMP to be sustainably embedded across the system in the coming years.

The programme was impacted by Covid 19 during 2021-22, when face-to-face assessments were paused at times, alongside a consideration of the impact of medication changes at a time when people were experiencing significant lifestyle changes due to government restrictions.

Despite this, 2021-22 saw an additional 26 surgeries STOMP assessments complete (making 42 surgeries in total across Hertfordshire), 273 initial assessments carried out and 75 people had or having a reduction in medication as a result.

Work has progressed in developing a local approach to STAMP, and in 2021-22 Hertfordshire received funding from NHSE to carry out a small pilot to explore the prescribing of psychotropic medicines in children and young people (CYP) with Learning Disability (LD), autism or both to ensure that they are getting the right medicines, at the right time, for the right reason and for as short a time as possible. Hertfordshire Community Trust's Pharmacists conducted a review of GP records for 79 CYP who were prescribed psychotropic medicines. A report of the review identified a number of recommendations which will be considered by a Task and Finish group in 2022-23 and actions agreed for implementation across Hertfordshire.

Access to healthcare and support for people from BAME backgrounds

The LeDeR Annual Report 2020-21 highlighted that there was significant underrepresentation from Black, Asian and minority ethnic (BAME) communities within the notification of deaths (2 out of 97). The data from 2021-22 shows a continued low number of notifications (2), although as previously noted given the lower number of total notifications in the year, this represents a greater percentage.

Research has shown that people from ethnically diverse backgrounds have been disproportionately impacted by the effects of the Covid-19 pandemic. Both locally and nationally understanding the health inequalities for people with a learning disability from BAME backgrounds continues to be a priority area of work.

In 2021-22 a review of data from Adult Care Services (ACS) regarding ethnicity of both service users and known carers has been completed to further understand the numbers of people who have a learning disability, Physical Disability and/or Autism from a BAME background receiving support compared to the national averages. This analysis has confirmed that there are fewer people accessing services than could be expected based on disability prevalence in the general population.

Links have been made to local organisations already working with ethnically diverse communities to support engagement with people to understand and overcome barriers or issues in accessing services. A project plan is being developed to better understand the barriers to accessing services, to develop increased coproduction and to ensure the needs of people are reflected in planning and commissioning of services. This work will continue through 2022-23.

Priority Area 2: Earlier identification and better treatment of health conditions

A key national strategy in support of this priority is the Learning Disability Annual Health Check (AHC). The national target for 2021-22 was that 75% of people aged 14 and over with a learning disability on the GP learning disability register should have had an AHC.

National NHSE data for 2021-22 shows that Herts and West Essex ICS achieved 72% uptake of AHCs. Breakdown by CCG ENH 69.3%, HV 76.5%, WE 66.5%. As a comparison the national uptake for 2021-22 was 71.3% and East of England 70%.

This does not give a measure of the quality of AHCs, although the national data indicates a variation between the number of AHCs recorded and Heath Action Plans. Work is needed in 2022-23 to understand this discrepancy and ensure that AHCs are resulting in meaningful and clear Health Action Plans.

In Hertfordshire priority is being given to supporting practices to engage and support 'hard to reach' patients through 2022-23 and the new HWE ICS Primary Care Enhanced Commissioning Framework includes priority areas to support improved quality of checks.

What we want to see happening:

GP QOF register numbers accurately reflect the predicted population of people with a learning disability and/or autism.

100% of eligible people on GP LD registers have a high-quality Annual Health Check (or have made an informed choice not to have one).

More illnesses and diseases are identified early, and appropriate treatment accessed.

Fewer people die of respiratory conditions.

What we are focusing on now:

- All GP practices have identified and acted on increasing/accuracy of registers in line with QOF Improvement Domain for Learning Disabilities 2021/22.
- More children, young people and their families know about being on their GP register, having an Annual Health Check and the benefits.
- More GP practices have an effective embedded process for delivering high quality AHCs annually.
- More social care providers know their role in making sure good Annual Health Checks happen and how to help people with their Health Action Plans.
- There is a greater understanding of diagnostic overshadowing amongst health and social care professionals.
- More people, families and support workers have an increased understanding about early signs of health conditions and what to do to get advice, support and treatment.
- More people and paid/unpaid carers have flu/Covid vaccinations.
- GPs, paid and unpaid carers and other health professionals have greater knowledge of factors that increase the risk of respiratory conditions and what to do to prevent including postural support and oral health.

Activities, outputs, and outcomes achieved so far

Annual Health Checks - Children and Young People

The Quality and Outcomes (QOF) framework continues to include an indicator to ensure that GP practices have an accurate Learning Disability Register. (Quality and Outcomes Framework guidance for 2022/23). NHSE guidance has been produced to support practices to ensure that every patient with a learning disability registered with them is included.

GP practices are supported through a range of offers from the Learning Disability Nursing Service (LDNS) to implement national guidance. This can include cross checking patient records with Adult Care Services records, which often identifies errors where individuals have been wrongly included and are subsequently removed.

For individuals without a diagnosed learning disability, a national identification tool has been developed. Whilst this is not a formal diagnosis, GPs are encouraged to use the tool where it is recognised that the individual would benefit from being on the Learning Disability Register in order to receive further support to manage their health.

Training is provided to enable all practice staff to understand and recognise learning disabilities. This helps to develop opportunistic identification of people where the screening tool can then be completed to check eligibility for inclusion on the register. In some cases patients may not wish to have the label of a 'learning disability' attributed to them as they may perceive this as stigmatising. In this case the Community Learning Disability Nurses offered skilled and sensitive support to engage with patients that may be hard to reach, communicating the key benefits of the health checks. In addition, Community Learning Disability Nurses request that the screening tool is completed at the point of referral to the service.

Both Clinical Commissioning Groups (CCG) have a Learning Disability GP Lead. The GP leads have been instrumental in circulating information to practices improving the quality of registers and identification of people with a learning disability.

In Hertfordshire register sizes grew over 2021-22. National NHSE data shows the following increases,

CCG	Q4 2020-21	Q4 2021-22	% Increase
ENHCCG	2846	2976	4.5%
HVCCG	2870	3135	9%

For children and young people terminology can be a barrier to identification and inclusion on the GP Learning Disability register. Prior to a formal diagnosis being given, paediatricians use the term 'global developmental delay' and more commonly 'learning difficulty'. This coding is not recognised as being someone with a 'learning disability' and so there may be individuals not being included on the Learning Disability register who otherwise could be.

More work is needed with children's services to ensure correct coding. The LD GP Lead for HVCCG has been supporting this issue engaging with Children's Services colleagues to explore whether the Education Health and Care Plan process can include reference to the GP register and support more clarity of diagnostic codes.

The Learning Disability Nursing Service (LDNS) has been working in collaboration with Children's Services colleagues to ensure good health is promoted in 'Preparing for Adulthood'. This work has included understanding about annual health check and GP registers. A Preparing for Healthy Adulthood tool was created Caring for your health into adulthood (hertfordshire.gov.uk) to support young people with learning difficulties and learning disabilities to look after their health and understand the support that is available to them.

The tool has been promoted widely by the LDNS and 0-25 nurses, and across a number of events and to education settings. Further work in 2022-23 includes creating a school leaver pack on health and a pathway explaining the health services available.

High quality Annual Health Checks (AHC)

2021 – 22 saw the roll out of a new approach to supporting Primary Care with delivering high quality annual health checks (AHC) in Hertfordshire. This approach promotes a collaboration between the individual, their family members/carers or paid support and their GP. It introduced an AHC Preparation Form that people are requested to complete and return to their practice, with support if needed, before the AHC is booked in. This tool aims to raise awareness of how everyday support can help to reduce health inequalities when everyone acts together. A menu of Health Check Actions was created to help paid and unpaid carers to learn about the resources available on the Herts Learning Disability My Health website pages. www.hertfordshire.gov.uk/LDmyhealth

The Learning Disability Nursing offer includes the option for GP practices to highlight any social care providers that are reluctant to engage in the collaborative approach, and support and training is then provided. Communications and resources on this collaborative approach has been circulated to all practices and so far, 55% of GP practices have engaged with the lead nurse for this area.

The HEN leading on Annual Health Checks and the Purple Star lead nurse also contacted all practices with a tailored offer of support for patient who were not responding to contact. The nurses then worked with individuals to overcome barriers. In some cases, this simply involved finding their preferred means of communication and educating on the benefits of an annual health check. In other cases, this resulted in welfare issues being identified and either building a 'connected lives' support around them or where necessary raising a safeguarding concern or requesting social care assessments. In 2021-22 21 surgeries responded to this offer, and as a result 140 'hard to reach' people were contacted.

The LDNS also created a video resource to support GPs with 'How to do a High-Quality Annual Health Check' https://www.youtube.com/watch?v=lEEpias8OVA

As referred to in the data, there have been concerns raised in some LeDeR reviews regarding reduced access to face-to-face appointments in Primary care. For many people with a learning disability face-to-face appointments are vital. Communication may be more effective, there may be complex clinical needs, there may be concerns about the patient safety, capacity or safeguarding, or it may be hard to ensure, by remote means, that patient/carers have all the information they want and need about treatment options. Face-to-face appointments may also reduce the risk of diagnostic overshadowing.

However, the importance of choice, patient preference, versatility (if clinically appropriate) and reasonable adjustments is also paramount and was highlighted a 2021-22 'Check In' survey carried out on the Hertfordshire Learning Disability Joint Commissioning Strategy 2019-2024, The Big Plan.

This was completed in August/September 2021 and considered the different experiences over the previous 18 months in health and social care.

With regards to health care 53% of responses were from people with a learning disability, 28% were from family or unpaid carers, 12% from groups of people with a learning disability and 8% from paid carers.

- 6% of people explained they liked face-to-face appointments, but 30% described that they liked the choice of appointments being face-to-face, on the telephone or online.
- 20% of people explained that reasonable adjustments were important and what was good and bad.

Learning from the LeDeR reviews and the Big Plan Check In survey have been shared with Primary Care leads and communications are being developed to disseminate to practices to highlight these issues.

Finally, as mentioned previously an Enhanced Commissioning Framework (ECF) has been developed by Hertfordshire and West Essex Integrated Care System (ICS) as part of its strategy to improve the quality and outcomes of care delivered by GP practices (GP) in primary care for their registered patients. This framework includes the requirement for practices to audit their AHC Action plans and assess how well they are doing at arranging and supporting the uptake of follow up action. This aims to encourage a quality AHC, effective health interventions and awareness of health monitoring throughout the year.

Social Care Providers and Annual Health Checks

The LDNS work closely with Herts Care Providers Association (HCPA) to ensure that information about Annual Health Checks, Purple Folders and health promotion for people with a learning disability is embedded in the information they provide. Information is available via the HCPA Members Zone page for Adult Disability Services and targeted sessions are organised on specific themes or topics. Updates are also included in HCPA newsletters shared throughout the year. HCPA have been critical partners in supporting the increased uptake of vaccinations running a dedicated website and webinars reaching significant numbers of social care staff.

Learning Disability Care Coordinator Pilot

In 2021-22 Hertfordshire received funding from NHSE to implement quality improvement projects for implementation of Annual Health Checks. Based on the work of the Community Learning Disability Nurses and in partnership with the Learning Disability GP Leads, a pilot project was launched to assess the value of a Learning Disability Care Co-ordinator to help Primary Care Network's (PCN) deliver high numbers of high quality, focused annual health checks.

Care Coordinators have been working across two PCNs (one in HVCCG and one in ENHCCG) to carry out a number of key tasks in support of improved Annual Health Checks. This includes,

- identifying the population of people with Learning Disabilities across the practices within the PCN and ensuring accurate GP registers
- making contact with each patient/their carer and either checking or establishing their accessible information standard needs, their reasonable adjustment needs and the level of support they have in life
- sharing information with patients and/or their supporters regarding annual health checks and the local Annual Health Check Preparation Form

- encouraging individual/carers to complete the preparation tool and return it to the surgery
- working with practice managers/administrators with individual practices across the PCN to ensure information regarding reasonable adjustments is recorded on their systems and will be used to plan annual health checks
- making links with wider PCN/practice staff to ensure equitable access to Primary Care Services, for example, social prescribers and health and well-being coaches.

Ongoing support is provided by the HEN leading on AHCs, who is able to provide tailored support to engage those people that are 'hard to reach' and not engaging in Annual Health Checks as described above.

Initial outcomes of the project have been improved accuracy of the GP LD register, increased awareness and subsequent uptake of AHCs of some 'hard to reach' patients, increased use of Purple Folders and increased referrals to health and wellbeing coaches and social prescribers following the AHC. The project will continue to be monitored in 2022-23 and learning shared with Primary Care Learning Disability Leads.

Diagnostic Overshadowing

The General Medical Council defines diagnostic overshadowing in the context of learning disabilities as "symptoms of physical ill health that are mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person's learning disabilities". Learning disabilities - ethical topic - GMC (gmc-uk.org)

In Primary care information on diagnostic overshadowing and learning from LeDeR reviews has been shared through the GP bulletin and the LDNS delivered 237 training sessions across Primary care and Acute settings raising awareness of diagnostic overshadowing.

Within HCT there has been a focus on raising awareness of diagnostic over shadowing, with a video resource shared via the all-staff bulletin. Diagnostic overshadowing is also highlighted within the new HCT policy on delivering care for people with a learning disability and autistic people.

In WHHT the Named consultant for adults safeguarding is responsible for providing training to medical staff at Grand Rounds. Training has included reasonable adjustments, DNACPR and diagnostic overshadowing. The AHLT review all patients who have a LD/autism and who are inpatients daily (Mon- Fri). If there are any concerns relating to care staff escalate to the Named Nurse /Named Consultant safeguarding adults who will intervene and resolve any issues including providing training for individuals.

The Trust has a Learning Disability partnership group. This a multi-disciplinary group of senior staff, who meet quarterly. There is an associated work plan with actions aligned with Hospital Improvement standards (2018), and reflects the work of NHS England, the Care Quality Commission (CQC) and Health Education England (HEE) NHSE & NHSI Learning Disability Improvement Standards project the trust completed, Local Learning, and themes from LeDeR. This is updated monthly and minutes from this meeting are shared at the Trust safeguarding panel which has executive oversight. Diagnostic overshadowing case study has been shared and discussed in the meeting.

In EHHT the management of individuals with a learning disability and autism policy includes definitions and guidance on how to avoid diagnostic overshadowing. This topic is covered in staff training conducted by the ALHT who also review patients in a manner which highlight to the managing clinical team if there is a risk of overshadowing.

Early signs of deterioration

Training in recognising deterioration and soft signs has been delivered to families/carers and paid supporters by the Health Improvement and Prevention nurses (HIP) within the LDNS. The Purple All Stars (a creative arts group made up of people with learning disabilities) have also promoted this message via their performances and social media videos. A new Check it Out Video has been created to go alongside the Health Action Plan targeted Stay healthy at home checklist Check it out!

The collaborative AHC process as described above is designed to support recognition of early signs ill health, and a video resource was produced to support raising awareness for family members/carers and paid supporters Annual Health Check Preparation Tool

In WHHT the safeguarding team work closely with the Trust carers lead nurse, who is an active member of the Partnership. Her role involves supporting carers to gain access to support and advice. The carers lead nurse has worked closely with AHLT to update the safeguarding internet page to provide easy read material to guide carers and patients with learning disabilities (particularly regarding Covid-19).

Covid Vaccinations

The Covid-19 pandemic presented a massive challenge in protecting public health, no more so for the most vulnerable among our communities. Very early on in the pandemic, people with a learning disability (LD) were identified as being at increased risk from the virus. On average, people with a learning disability are six times as likely to die from COVID infection than the general population. It was vital that people with LD were encouraged and supported to have the COVID-19 vaccination as soon as it became available and could then benefit from the protection it provides.

Colleagues from health and care services and the voluntary sector worked together to set up a targeted vaccination programme for people with LD, which was overseen by the Hertfordshire Mental Health, Learning Disabilities and Autism Collaborative.

Primary Care Networks (PCN) led on making initial contact with people with LD and SMI at the start of the national vaccination programme. Health and social care staff provided detailed intelligence on people in health and care settings to help maximise uptake. Staff from across the Collaborative who have skills in supporting people with LD were deployed into dedicated vaccination teams which led the drive to vaccinate as many people as possible.

GP clinics were specially set up with the reasonable adjustments needed to ensure the vaccination process was as patient-friendly as possible, for example, providing longer appointments with dedicated support for people with needle phobia. Staff from a number of agencies helped trace people needing vaccinations whilst also working to reduce vaccine hesitancy through webinars and by providing key information to users and carers. Social media messages shared positive stories about vaccination, examples of which were picked up by the national media.

As a result, a very high proportion of people with LD in Hertfordshire have had first, second and booster COVID-19 vaccination doses, as detailed below:

	First dose	**Second dose**	**Booster dose**
People with LD	94%	91%	89%

The work we have undertaken during the programme to drive up vaccination rates remains in place and collaboration continues between social care, Primary Care Networks and GP practices to encourage even greater take-up. A strong platform has been built for the future around the issues of consent/capacity and in making reasonable adjustments.

While uptake of the COVID-19 vaccine in Hertfordshire is strong, there is still more work to do – some vulnerable people are not yet fully vaccinated. All health and care staff are encouraged to follow the ethos of *Making Every Contact Count*, supporting them to recognise their role in helping everyone they come into contact with to better understand the benefits of vaccination.

The success and speed of this programme was only possible through organisations working together as partners in a positive and collaborative way. It has been an outstanding example of joint working during the pandemic.

More work needs to be done to ensure greater uptake of the Flu Vaccination. Local data shows that HVCCG achieved 67.5% a similar percentage achieved for 2020/2021 with 67.8%.

Oral Health and Aspiration Pneumonia

Data from local and national LeDeR reviews shows that respiratory disease is the biggest cause of death in people with a learning disability and that aspiration pneumonia is one of the most common conditions.

In Hertfordshire there have been a number of initiatives directed at this issue including,

- Recruitment of specialist physiotherapist post within HPFT as a pilot to support service users with known respiratory disease or at high risk of respiratory disease within the dysphagia pathway.
- Virtual dysphagia awareness training package developed and being delivered to care providers, carers and the other health/social care professionals.
- 'Posture Friends', a programme of training and education on postural support for support providers has been developed by HCPA and key partners.

In 2021-22 further work was developed based on evidence-based literature that suggests aspiration pneumonia is a multifactorial disease with associated risk factors of poor oral health, reduced/poor swallow and poor posture. In addition, the LeDeR national report (2020) highlights the incidence of early death from aspiration pneumonia and links it with poor oral health.

The Learning Disability Mortality Review (LeDeR) programme Annual Report 2021

A strong partnership approach between SaLT and Physiotherapy in HPFT, SaLT and Dental in HCT and the IHOG has enabled a multipronged approach to be developed which aims to:

- Work closely with GPs to raise awareness of need for threefold approach.
- Develop a risk assessment tool to support GPs in onward referral
- Develop a pathway to refer to and between all 3 services: Physio, SaLT and Dental.
- Develop connections between this pathway and other supportive pathways such a frailty, risk feeding.
- Work closely with HCC to co-ordinate with other projects to enhance AHC.

This work and evaluation of the impact will continue throughout 2022-23.

In WHHT a sepsis nurse has recently been appointed, who has joined the LD partnership. There is a plan in place to review the easy read “sepsis” leaflet and ongoing collaborative work with the Clinical Nurse Specialist for Safeguarding and Speech and Language Therapy to distribute guidance/support materials for aspiration pneumonia for both staff and carers.

Priority Area 3: More people have choice and control over their health treatment and support

What we want to see happening:

Experiences of planned and emergency hospital admissions are appropriate, positive and meet people's needs.

More people have choice and control over their End of Life wishes.

- Purple Folders are used consistently to improve understanding of people's needs.
- There is a reduction of inappropriate hospital admissions and delayed discharges.
- There is increased knowledge and skills of *advance care planning* amongst social care professionals and families/carers.
- There is increased knowledge and skills of *End-of-Life planning* and support amongst social care professionals and families/carers.

Activities, outputs, and outcomes achieved so far

Purple Folders

My purple folder is a health passport that is offered to adults with learning disabilities living in Hertfordshire. Good use of the Purple Folder can reduce the risk of delays in diagnosis due to communication barriers or reluctance to accept investigations or treatment and is designed to be used by all health services in Hertfordshire when a patient attends an appointment.

The Purple Folder provides health professionals with a holistic overview of,

- The person's health and their baseline abilities
- Recent history of other health professional's involvement to help build a diagnostic picture
- The reasonable adjustments that need to be made to ensure equitable health outcomes are achieved
- The communication needs of the person to ensure they can understand and make informed choices. Also, to ensure health professionals know whether they are communicating pain or ill health
- The level of support the person needs to enable them to successfully access healthcare services
- The support level they would need with personal care, eating and drinking should they be admitted to hospital.

It is a tool that can support health professionals to confidently communicate and work with an individual in the most appropriate manner for them.

In 2021-22 the Purple Folder was reviewed, and views were obtained from professionals, people with LD and their carers and changes made to improve the consistency and effectiveness of its use. The updated version has been approved by the Hertfordshire Safeguarding Adults Board and is being prepared for launch, subject to confirmed funding. A Purple Card has also been created and is ready for launch with the new Purple Folder.

IHOG partners are all committed to ensuring Purple Folders are used across the relevant settings, and references are made to the folders within reasonable adjustments audits, staff training and service development meetings. In acute settings where eligible patients do not have a Purple Folder the AHLT will provide the individual with a folder and advise carers and clinical staff on how to use it effectively.

Reduction of hospital admissions

The Health Improvement and Prevention team (HIP) continue to work with care providers and professionals to reduce the risk of hospital admissions resulting from complex or unmanaged physical health needs for people who have learning disabilities.

During the pandemic the HIP team have played a critical role in supporting service providers and carers to reduce the impact of Covid-19 on people they support. The team is there to support the community nurses and social workers in Adult Social Care (ASC) in reducing the risks of hospital admissions.

The HIP team has delivered training and raised awareness in,

- Identifying Soft Signs of Deterioration – (including how to monitor client's temperature, blood pressure, pulse, respirations, oxygen saturation).
- Use of SBARD Communication Tool in giving vital information to health professionals e.g. GP.
- Infection Prevention and Control Training
- RESTORE2 Mini (NHS England) – Educating families and their carers about how to identify soft signs of deterioration and how to get help quickly.
- Skin Integrity -pressure area care
- Prevention of Urinary Tract Infection
- Falls
- Urine Colour and Hydration
- Nutrition Care Plan – (Malnutrition and Dehydration)

End of Life Care/Advance Care Planning

Health inequalities for people with a learning disability are also seen in palliative and end of life care and this has been noted in national guidance delivering-end-of-life-care-for-people-with-learning-disability.pdf (england.nhs.uk)

Local LeDeR reviews have highlighted some cases of excellent (advanced) care planning and End of Life care but also cases where this could be improved. As a result, a working group was established with the purpose of,

- Improving the experiences of End-of-Life Care for people with a learning disability, ensuring that care plans are made appropriately, timely and are followed as far as possible
- Increasing the appropriate utilisation of End-of-Life care pathways by people with a learning disability.

Tasks include ensuring that the needs of people with a learning disability are reflected in the new Herts and West Essex ICS Palliative and End of Life Care Strategy; auditing the number of patients with a learning disability on the GSF registers across the ICS; and identifying links between elements of Advanced Care Planning with AHC Health Action Plans.

The LDNS have delivered a number of training and awareness raising sessions including,

- Online training to care providers alongside the Peace Hospice trainer on bereavement in learning disabilities.
- Joint training sessions delivered by with Palliative care staff to the Adult Disability Team and via a webinar through Herts Care Providers Association
- Sessions to hospice staff on communication and learning disabilities.
- Sessions to Speech and Language Therapists on End of Life and Learning Disabilities

In addition, HCPA offer specific End of Life education packages for providers throughout Hertfordshire and recently launched an 'End of Life champion' course which focuses on Advanced Care Planning.

In WHHT the Trust has an end-of-life pathway for patients with an LD/autism. This was developed with support from the palliative care team and AHLT. This ensures that all patients who are considered end of life are referred to the palliative care team who will review the individual regardless of symptoms. This pathway is audited as part of the safeguarding audit strategy and presented to the Trust safeguarding panel.

In EHHT, guidance on the use of DNACPR (Do not attempt cardiopulmonary resuscitation) and Treatment Escalation Plans (TEP) relating to people with a learning disability has been given to clinical areas by members of the Resus team who also cover learning disability and DNACPR decisions in staff training.

For people nearing end of life with a learning disability they are reviewed by and referred to palliative care services. Decisions are made to reflect the wishes feelings and beliefs of individuals and opinions are sought from the individual's carers or next of kin.

Finally, due to ongoing examples of inappropriate DNACPRs for people with a learning disability during Covid, the Learning Disability Nursing Service (LDNS) have worked with safeguarding leads to create a DNACPR tool for clinicians and carers to help guide and improve practice in this area. This will be launched in 2022-23. In addition, the LDNS take a 'Making Every Contact Count' approach and always check the DNACPR for people referred to them and it has been added to the Primary Care Purple Star strategy criteria, for practices to review all active DNACPRs in order to fulfil the accreditation requirements.

Priority Area 4: People experience more social equality in their lives which leads to better health outcomes

Research based on the general population shows that health inequalities are not caused by one single issue, but by a mix of social, behavioural and genetic and biological factors. In 2010 The Marmot review 'Fair Society, Healthy Lives' set out the key policy recommendations on the social determinants of health throughout the life course:

1) Give every child the best start in life
2) Enable all children, young people and adults to maximise their capabilities and have control over their lives
3) Create fair employment and good work for all
4) Ensure a healthy standard of living for all
5) Create and develop healthy and sustainable places and communities
6) Strengthen the role and impact of ill-health prevention

Following this the focused report 'A Fair and Supportive Society' (2018) highlighted that people with a learning disability are more likely to experience worse social determinants of health than the general population. For people with a learning disability, as for the rest of the population, their health and wellbeing outcomes will be maximised when social conditions are favourable.

The LeDeR Health Inequalities plan recognises the need to consider social inequalities, and this priority area identifies a number of outcomes in relation to issues that impact on social equality for people with a learning disability. However, this is a relatively new area of work, and so activities, outputs and outcomes are limited at this time.

What we want to see happening:

Digital transformation of health and social care supports better health outcomes for people.

More people experience Personalisation in their social care support.

There are more examples of social care support that directly challenges and changes the social equalities people face.

- There is an increase in digital skills and knowledge amongst people, paid and unpaid carers.
- More social care providers are signed up to the Connected Lives Model.
- There is increased understanding of the impact of social inequalities on health outcomes amongst health and social care professionals.
- More people and families/carers know their rights about health and social care and what they can do to challenge and change things.
- All social care commissioning includes a consideration of reducing health and social inequalities.
- All social care monitoring teams ensure health and social inequalities are identified and acted on within monitoring frameworks.

Activities, outputs, and outcomes achieved so far

Digital Inclusion

In today's society, digital exclusion can be seen as a form of inequality. There is a close correlation between digital exclusion and social disadvantages including lower income, lower levels of education, and poor housing. NHS Digital acknowledges that 'in an increasingly digital world, people who are digitally excluded are at risk of worse access to services and worse health outcomes'.

People with a learning disability face significant barriers to digital inclusion, and in a world that experienced fast paced digital transformation through the Covid pandemic, there is a risk that people are left behind. In their work on digital equality, Digital Inclusion Leeds have highlighted that the barriers people with learning disabilities face when it comes to doing things online are often more pronounced than those without (Autism and Learning Disability Digital Inclusion Network).

In 2021-22, the My Health App {Maldaba}, a digital tool for recording and sharing information about care needs, was piloted in Hertfordshire through the Community Learning Disability Nurse (CLDN) team. However, there was limited uptake of the tool, and it was not deemed sustainable for ongoing funding via Adult Care Services. The tool continues to be promoted for self-funding as an option and is referenced in the new Purple Folder and Preparing for Healthy adulthood guide.

The CLDN team also launched an initiative to encourage people with a learning disability to record a 'me on my best day' video snippet to their phones to show health professionals what they usually look, act and communicate like. The Creative Practitioner along with The Purple All Stars created a video to demonstrate this and it is referenced at the beginning of the new Purple Folder Pages Me on my best day!

There is considerably more work to be done in this area in 2022-23, in particular in ensuring that people with a learning disability can access local digital inclusion initiatives aimed at the wider population, such as those described by New Leaf College. (Digital skills and inclusion)

In 2021-22 Herts Care Provider Association (HCPA) carried out a gap analysis to understand where Digital Care Records are being used in CQC registered providers across Hertfordshire (including those supporting people with a learning disability). Responses were received from 80% of providers. The results show that currently approximately 47% have a plan for digital records in place. In 2022-23 HCPA will explore opportunities for supporting social care providers to develop digital solutions and establish best practice for using digital records.

Connected Lives

Connected Lives is a model for social care in Hertfordshire that places more emphasis on prevention, enablement and community opportunities.

The model can be embedded in everything across social care, from assessments, commissioning and the delivery of care. It moves away from thinking about needs and services and focuses on what people want out of life and how they can be supported to live a full, active and independent life. Connected Lives isn't just about connecting people to other people, but about connecting people to things like equipment and technology, work and volunteering, access to local community groups and services and friends and family.

As part of the Hertfordshire Supported Living Framework and Community Opportunities Framework, it is clearly set out in provider service specifications and contracts that a Provider's service model, values and methodology should reflect and endorse the delivery of Connected Lives.

As part of the tender process to join Herts County Council Contractual Frameworks, providers are required to evidence their understanding, commitment and experience of delivering the Connected Lives ambitions.

Herts Care Provider Association (HCPA) and Adult Care Services are working collaboratively to support Connected Lives with providers. The approach is currently embedded through all HCPA training with two new courses on Connected Lives planned for 2022-23. One is aimed at care staff and Connected Lives in the work context, and the other aimed at managers and organisational change.

Knowledge, understanding and action about social inequalities

Social injustice has been acknowledged by Adult Care Services as an important area of work and as a result a number of new posts have been funded to support this. So far, two new Advanced Practitioner posts have been created and recruited to, whose focus is on improving practice and awareness of the impact of social injustice that people with disabilities experience and how the social determinants of health underly or are the drivers of health inequalities and poorer health outcomes. Planning is scheduled to scope out the key areas of focus and performance indicators for these roles and will be delivered across 2022-23.

The CLDN team have developed health protocols for social care providers and staff to follow for people with a learning disability that have complex health care needs requiring a multi-disciplinary approach to achieve best outcomes, for example service users with a diagnosis of both complex Diabetes and forensic needs. In addition, health protocols have been developed for mainstream care home providers that are supporting residents with a learning disability.

Herts Care Providers Association ran a webinar for social care providers to raise awareness of LeDeR and reducing health inequalities. Information is shared via the HCPA website on how providers can access resources and share with individuals they support. However, more work is needed in this area to ensure that social care providers recognise their role in acting on learning from LeDeR and implement changes to reduce health inequalities and premature mortality.

HCT have a health inequalities steering group chaired by the Clinical Lead for Learning disability and Autism with a focus on support for vulnerable groups. Plans are being developed to deliver targeted work with a strong emphasis on reaching out to the community, prevention and sharing examples of best practice.

In WHHT a "Celebration of life" was arranged for patients with a learning disability/Autism. Invites were sent to families, care providers and AHLT. A tree was planted in the Trust memorial garden to remember the patients with a learning disability/autism who died during the Covid pandemic. The Purple All Stars attended and did readings and sang and danced followed by tea and cake.

The named nurse for safeguarding undertook a review of the care of patients with a learning disability who died of Covid. This was completed in parallel of a review of Structured Judgement Reviews (SJRs) by the Named Consultant for safeguarding and the Director of Governance. This data analysis was completed to provide assurance that patients who were admitted to the Trust during the COVID-19 pandemic received the appropriate standards of care and treatment. The conclusion is

that the Trust provided good to excellent care to patients with a learning disability during the peak of Covid.

The trust has also undertaken reviews of the patients on surgical waiting lists based on clinical priorities. Every patient that has waited 48 weeks or longer are having harm reviews carried out by the relevant clinicians. This has included a review of our patients with a learning disability on the waiting list for surgery. Arrangements will be made to expediate surgery if required.

The safeguarding team took part in Mencap's "Rock your Socks" campaign to raise awareness of down syndrome. Staff from across the trust organised a variety of activities, which was shared in the Trust newsletter and raised money for Mencap. The Trust was nominated as supporters of the month.

Finally, Acute Liaison Nurses work with family/paid carers with each referral and work closely with Acute Trust Carers Leads and the Patient Advice and Liaison Service (PALs) to ensure people know how to raise concerns or make a formal complaint.

Commissioning and Monitoring

As part of the contractual tender application process to join HCC Frameworks, providers are required to explain and evidence how they will reduce health and social care inequalities. HCC quality assurance processes assess compliance with this expectation. For services contracted out of framework, for example residential and nursing care, the Community Solutions Team only broker services that have a 'Good' or above CQC rating and a 'Good' PAMMS (Provider Assessment and Market Management Solution) rating if more recent.

HCC has a large quality assurance monitoring resource and responsibilities, and remits are clearly defined. The Community Commissioning for Adults with Disabilities team monitor Supported Living and Community Opportunities. The Integrated Accommodation Commissioning Team monitor the quality of residential and nursing care. The Integrated Community Support Team monitor the quality of Home Care.

All services are assessed at a minimum annually. A PAMMS assessment takes approximately two days. Part of the monitoring assessment considers health and social inequalities. A robust risk assessment approach is in place to identify providers that are not meeting service users' health and social needs. HCC has a staged Safety and Improvement policy (SIP), entry is dependent on the risks to service users, identified by monitoring officers, operational colleagues, safeguarding colleagues and other stakeholders. The process is initiated via a Multi-agency Disciplinary Management Meeting. If a Provider is placed in Quality Monitoring (QUAM) as a part of the SIP improvement expectations are set and monitoring checks in at least monthly. If the Provider is deemed high risk monitoring colleagues will visit frequently, sometimes weekly, to check on improvement compliance, service user wellbeing and generally support provider managers to turn the service around.

Priority Area 5: Effective systems of information sharing and communication ensure good health outcomes for people

What we want to see happening:

Information about reasonable adjustments is available digitally and shared across ICS systems.

There is an ICS wide model of physical health risk stratification that is used to identify and support people most at risk.

- There is an increase in reasonable adjustments information recorded and shared across systems and providers.
- More information about people at risk of poor health outcomes is recorded and shared across systems and providers.
- There is an agreed cross system response to support those people identified most at risk.

Activities, outputs, and outcomes achieved so far

Digital Flag

Hertfordshire have been an early adopter site for the NHS Reasonable Adjustments Digital Flag. The Reasonable Adjustment Flag is a national record which indicates that reasonable adjustments are required for an individual and optionally includes details of their significant impairments and key adjustments that should be considered Reasonable Adjustments Flag. In 2021-22 local pilot work has included,

- Developing a template for recording reasonable adjustments
- Development of a Learning Disability Awareness whiteboard animation by HCT
- Development of a suite of Reasonable Adjustment videos created for Community Health providers and developed into Purple Principles training being launched in 22-23 Principles and Pledges for Health Professionals in Making Reasonable Adjustments

Through 2022-23 work will continue with partner organisations from IHOG to promote and embed these training resources.

In Primary care, searches for reasonable adjustment codes have shown that there is limited coding on primary care systems. In 2022-23 alongside the promotion of training resources, recording of reasonable adjustments has been included as part of the Enhanced Commissioning Framework (ECF). A rerun of the search is planned in Q4 2023 to evidence the impact of these activities in primary care.

In EHHT, the nature of reasonable adjustments required for individuals accessing Trust services is documented in patient records and our Electronic Patient Record. In 2022/23 the Trust will look to implement a flagging system which not only flags that a person has a learning disability but also includes details of the reasonable adjustments that the individual requires.

Physical Health Risk Stratification and Response

The benefit of an aligned approach to risk stratification of health and social inequalities and a partnership response to those identified as being at high risk has been highlighted as an area of development from local LeDeR reviews. Although there are significant considerations in achieving this outcome, an initial workshop is planned inn 2022-23 with representatives from primary care, social care and health to discuss current models being used across the system and consider options for greater alignment, development of a shared model and increased collaborative working.

At the start of the Covid pandemic, Hertfordshire Partnership NHS Foundation Trust (HPFT) learning disability services developed a tool to stratify risks regarding physical health and mental health needs of service users in an effort to prioritise care. The Physical Health RAG rating tool has since been refined to take into account of protective factors (such as good support networks) to enable staff to highlight those who need more intensive input from services. This, alongside similar resilience rating work done during Covid 19 by Adult Care Services, will help inform the development of a shared tool.

A positive outcome of the Covid pandemic has been greater information sharing across systems. The LDNS is now able to access the HPFT Paris records system, which has resulted in better partnership working and outcomes for individuals.

In WHHT, the Trust updates it EPR system with information provided by the Strategic lead nurse for AHLT regarding patients who have LD/ autism. The safeguarding team work closely with AHLT and community providers to share information regarding individuals at risk and attend MDT meeting to ensure appropriate plans are in place to support individuals.

The roll out of the Hertfordshire and West Essex Shared Care Record will also impact positively on people with a learning disability in this area. The record brings together information from electronic records held by different health and care providers. Once fully rolled out, the Shared Care Record will include information from hospitals, GPs, Out of Hours, NHS 111, Mental Health, Social Care, Community, and other healthcare providers within West Essex and Hertfordshire.

Section 4 – The Year Ahead, Key Priorities

The priority outcomes for the year ahead are already set out in the Herts LeDeR Health Inequalities plan. This year's annual report has given further evidence of the need to focus on these areas to produce sustained and long-term change.

It is particularly important that efforts are made to ensure that this plan is aligned with and supported by the wider health inequalities work across the ICS and included in the priorities of the newly formed Integrated Care Board and those set out in the Health and Wellbeing boards futures plan.

An ongoing area of focus is the prevention and management of respiratory conditions which continues to prevail as the leading cause of death. In addition, efforts must be sustained to ensure that people with a learning disability are prioritised in strategies to reduce the impact of Covid 19.

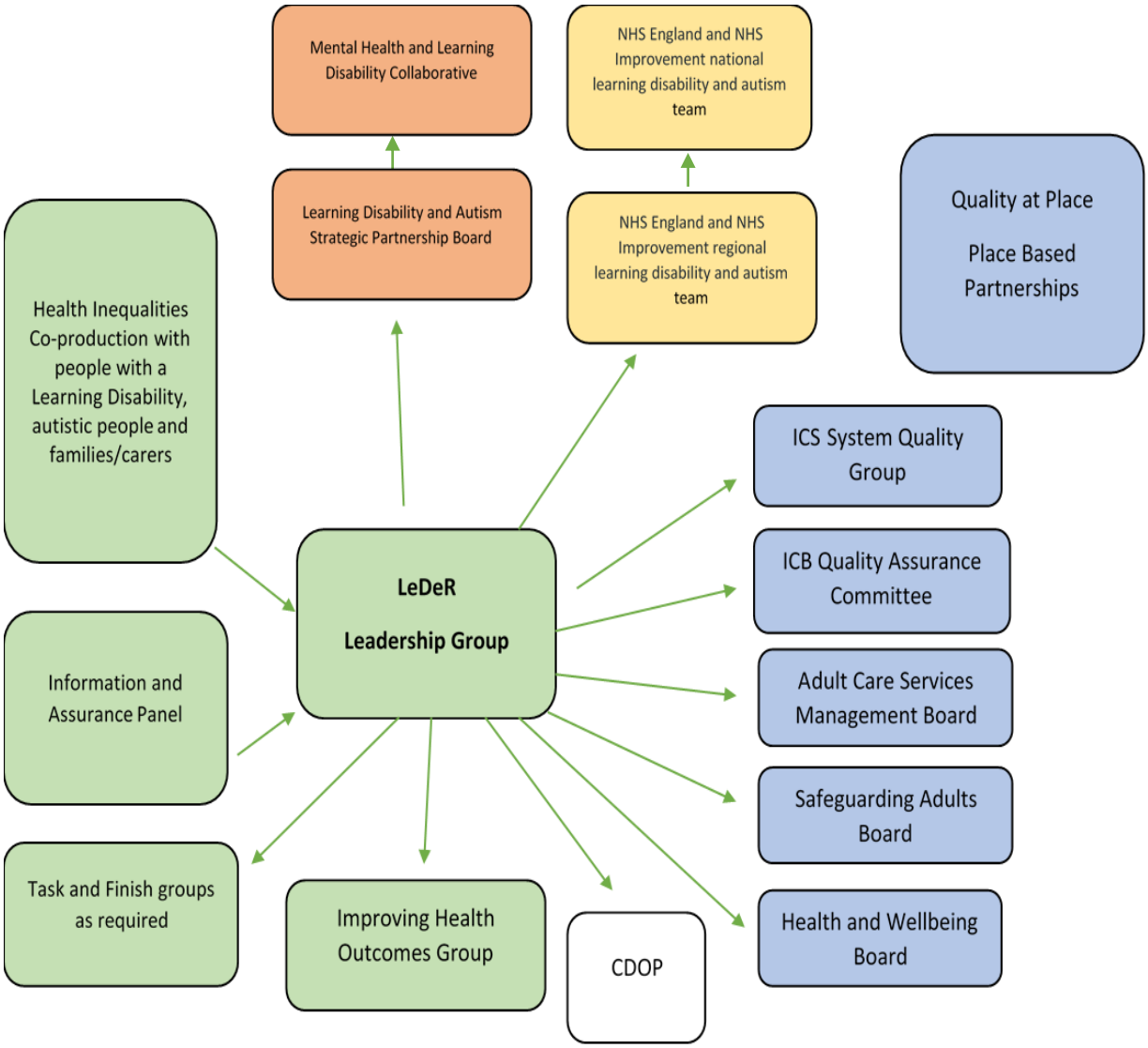
2021-22 saw a massive shift in the use of technology to support connection both in our social lives and in our access to health care. It is essential that barriers to digital inclusion that people with a learning disability face are considered as these shifts in our lives become embedded in the way we live, work and access the world around us. This is included in our priorities and work will be done over the year to link with digital transformation programmes across the ICS to raise awareness of these issues.

Evidence that social inequalities lead to poorer health outcomes will continue to drive our work and 2022-23 will include work to find better ways to identify people at risk of inequalities and create more integrated responses.

Finally, we will continue to build on our new processes and structures to ensure learning into action, and in particular focus on how learning from LeDeR can be shared across the ICS. An important aspect of development will be ensuring that notifications are made for deaths of autistic adults, and that the right partners are included within the Leadership Group to ensure accountability for Learning into Action. The year ahead will see developments in co-production of our programme, ensuring that the voices of people themselves and those closest to them are central to shaping priorities, finding solutions and creating change.

Appendix 1

Hertfordshire Learning from Lives and Deaths – People with a learning disability and autistic people, Governance Structure Overview



Appendix 2 Glossary of terms

ADS	Adult Disability Service
AHC	Annual Health Check
AHLT	Acute Health Liaison Team
BAME	Black Asian and Minority Ethnic
CCG	Clinical Commissioning Group
CDOP	Child Death Overview Panel
CFS	Clinical Frailty Score
CLCH	Central London Community Health Trust
CLDT	Community Learning Disability Team
CQC	Care Quality Commission
DNACPR	Do not attempt cardiopulmonary resuscitation order
ECF	Enhanced Commissioning Framework
ENHCCG	East and North Hertfordshire's Clinical Commissioning Group
EHHT	East and North Hertfordshire's NHS Trust
ESN	Epilepsy Specialist Nurse
HCC	Hertfordshire County Council
HCPA	Hertfordshire Care Providers Association
HCT	Hertfordshire Community Trust
HEE	Health Education England
HEN	Health Equalities Nurse
HIP	Health Improvement and Prevention (Nurse)
HLT	Health Liaison Team
HPFT	Hertfordshire Partnership Foundation Trust
HVCCG	Herts Valleys Clinical Commissioning Group
ICS	Integrated Care System
LAC	Local Area Contact
LD	Learning Disabilities
LDNS	Learning Disability Nursing Service
LeDeR	Learning Disability Review of Mortality
KPI	Key Performance Indicator
NECs	North East Commissioning Support Unit
NHSE	Nation Health Service (England)
QOF	Quality Outcomes Framework
PALs	Patient Advice and Liaison Service
PAMMS	Provider Assessment and Market Management Solution
PCN	Primary Care Network
STAMP	Supporting Treatment and Appropriate Medication in Paediatrics
STOMP	Stop the over medication of people with a learning disability, autism or both with psychotropic medicines
SJR	Structured Judgement Review
STP	Sustainability and Transformation Partnerships
TCP	Transforming Care Programme
TEP	Treatment Escalation Plan
WHHT	West Herts Hospital Trust

Appendix 3: Acknowledgements

With thanks to report contributors:

Adefunke Eriolu	Senior Commissioning Manager Learning Disabilities and Autism, Integrated Health & Care Commissioning Team, HCC
Dawn Bailey	Named Nurse for Safeguarding Adults, WHHT
Kate Barker	Practice Governance Lead, HPFT
Graham Duff	Strategic Lead Nurse, HCC
Dr Vicky McCulloch	Clinical Lead LD, HVCCG
Enda Gallagher	Adult Safeguarding Nurse for E&N Herts NHS Trust
Hilary Gardener	Strategic Liaison Nurse for Primary Care, HCC
Louise Jenkins	Strategic Liaison Nurse for Secondary and Tertiary care, HCC
Una Monaghan	Clinical Director, Herts Special Care Dental Service, HCT
Michelle Airey	Integration Manager, HCPA
Lucy Rush	Head of Service ADS West, HCC
Laura Gordon	Head of Community Commissioning for Adult with Disabilities (Interim), HCC
Jessica Shingler	Information Quality Officer, HCC
Nicky Vellacott	Named Nurse for Safeguarding, CLCH

Appendix 4: References

The Learning Disability Mortality Review (LeDeR) Programme Annual Report (2020), The University of Bristol. https://leder.nhs.uk/images/annual_reports/LeDeR-bristol-annual-report-2020.pdf

Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) policy (2021), NHSE https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf

The NHS Long Term Plan (2019), NHSE https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/

Step Together – Integrating care for children, young people and adults with epilepsy and learning disability (2020), Epilepsy Action. Step Together - Integrating care for children, young people and adults with epilepsy and learning disability.

The Forward View into Action: New Care Models: update and initial support, NHSE, 2015. ncm-support-package.pdf (england.nhs.uk)