# NOTTINGHAM & NOTTINGHAMSHIRE CCG LEARNING FROM LIFE & DEATH REVIEWS (LEDER) PROGRAMME

Annual Report 2021 -2022





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### **Annual Report 2021 – 2022**

# **Nottingham & Nottinghamshire CCG**

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# **Executive Summary**

People with a learning disability often have poorer physical and mental health than other people and may face barriers to accessing health and care to keep them healthy. Too many people with a learning disability are dying earlier than they should, many from things which could have been treated or prevented.

The learning from deaths of people with a learning disability (LEDER) programme was set up as a service improvement programme to look at why people are dying and what we can do to change services locally and nationally to improve the health of people with a learning disability, reduce health inequalities and prevent premature mortality of people with a learning disability and autistic people by reviewing information about the health and social care support people received. By finding out more about why people died we can understand what needs to be changed to make a difference to people's lives.

### It does this by:

- Delivering local service improvement, learning from LEDER reviews about good quality care and areas requiring improvement.
- Driving local service improvements based on themes emerging from LEDER reviews at a regional and national level.
- ➤ Influencing national service improvements via actions that respond to themes commonly arising from analysis of LEDER reviews.

The Learning Disabilities Death Review (LEDER) Programme is commissioned by NHS England and Improvement and managed locally by Nottingham & Nottinghamshire CCG. Responsibility for ensuring the delivery of LEDER reviews currently lies with clinical commissioning groups (CCGs). As we move into new arrangements in the NHS through 2022 and into 2023, local Integrated Care Boards (ICBs) will become responsible for ensuring that LEDER reviews are completed for their local area and that actions are implemented to improve the quality of services for people with a learning disability and autistic people to reduce health inequalities and premature mortality.

The age range of LEDER deaths for Nottingham and Nottinghamshire reflects the national trend for learning disability deaths with the average age of death in 2021/22 being 54 years which is lower than previous years and is considerably lower than the mortality rate within the whole population. Our work moving forward is focused on health inequality for people with a learning disability with alignment to other LD/ASD living and ageing well themes, including earlier diagnosis/detection of health conditions, increased delivery of GP annual health checks and the STOMP/STAMP programmes (stopping of overprescribing of medication to people with LD/ASD).

The ongoing analysis of the LEDER reviews has highlighted several key themes that need addressing as part of our 2022/23 programme plan.

- Transition from Children & Young people services to adult services
- Learning disabilities registers (Learning Disability verses Learning Difficulty)





- Common morbidities respiratory, cancer, gastro-intestinal related deaths
- Communication between primary care, secondary care and social care providers
- Communication with support and education for Carers/Families



### Introduction

The purpose of this report is to provide an oversight of the progress and impact of the learning within Nottingham & Nottinghamshire CCGs of the LEDER Programme from 1<sup>st</sup> April 2021 – 31<sup>st</sup> March 2022.

The LEDER programme was established in 2015 and was first introduced into Nottingham & Nottinghamshire in 2017. The programme was established to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and change and improve care and services as a result of this The aim being to enable people with learning disabilities to receive equitable health and social care to that of the general population and reduce the life expectancy gap.

The LEDER reviews focus on improving service delivery and system change and is not responsible for investigating the cause of death. If there were any issues from either a clinical, safeguarding, or legal perspective in relation to the death this would have been dealt with through the appropriate policies and procedures.

The report will go onto cover the key themes, challenges, achievements, and the learning from local reviews.

### **National LEDER Programme**

LEDER is a unique national service improvement programme that aims to improve care, reduce health inequalities, and prevent premature mortality of people with a learning disability and from January 2022 with include autistic people

The LEDER Programme supports reviews of deaths of people with learning disabilities and/or autism aged 4 years and over; and the Programme supports reviews of all deaths, irrespective of the cause of death or place of death. The LEDER programme was supported by the University of Bristol until May 2021 when its contract ceased and from June 2021 NHSE/I took it forward. The programme is a joint health and social care project, involving healthcare providers across the health economy, Local Authorities and Clinical Commissioning Groups until the implementation of Integrated Care Boards (ICB) from July 2022 whereby it will become the responsibility of the ICB.

A national LEDER policy was developed for the first time in March 2021, the key implications are:

There is a stronger emphasis on the delivery of the thematic actions coming out of the reviews and holding local systems to account for that delivery, to ensure that there is evidence of service improvement locally.

Launch of a new process for reviews to follow with 2 distinct levels of review, a new computer system ('web-based platform'), and new training for the LEDER workforce.





# Local Integrated Care Boards (ICBs) will become responsible from 1 July 2022 for ensuring:

- LEDER reviews are completed for their local area
- Actions are implemented to improve the quality of all mainstream services for people with a learning disability and to reduce health inequalities and premature mortality
- Recurrent themes and significant issues are identified and addressed at a more systematic level
- ICS reviewers will work in teams so that no reviewer will work alone, everyone will have the time they need to do reviews and support to do them.
- The policy introduced the need to commence reviewing the deaths of adults who have a diagnosis of autism but no learning disability.
- All reviews of people who are autistic without a learning disability will be focused reviews initially

# Overview of the LEDER programme within Nottingham & Nottinghamshire

The Learning from Life & Death Reviews (LEDER) programme is part of a national focus upon improving the lives and care of people with Learning Disabilities and Autistic people. It is an integral part of the Nottingham & Nottinghamshire LD&ASD Transformation Programme, and the learning contributes to the development and implementation of the Programme. LEDER sits within the LD&ASD 'Living & Ageing Well' work-stream which focuses on 3 key themes that address health inequality, morbidity and mortality, and aims to improve quality:

	Annual Health Checks
	LEDER (Learning Disabilities Mortality Reviews)
	STOMP/STAMP (Stopping the over prescribing of medication to adults, children and
young	people with a learning disability, autism or both and supporting treatment and
approp	riate medication in paediatrics)

Reviews are managed by the ICB LD&ASD Quality Team who are responsible for receiving referrals, coordinating reviews, quality assuring and disseminating the learning from the reviews across the system.

The reviews are completed by an external consultancy company and are quality assured by an internal CCG panel that compromises of the Local Area Contact (LAC), Senior Reviewer, ICB leads who are registered nurses from both LD and General Adult backgrounds as well as safeguarding leads

From January 2022 deaths of people with a known diagnosis of autism are notified and subject to the review process. As per the national picture, it is observed that notification levels were low for ASD deaths between Jan-March 2022, as knowledge and understanding of ASD notifications is still building.





# **Governance Structure - Steering Group and Clinical Quality Assurance Group**

### The LEDER Steering Group

The LEDER steering group provides oversight, support and governance to the local delivery of the programme.

The steering group meets quarterly and it has representation from the CCG, NHS (primary care, community and acute) organisations, local authorities, GPs, Clinical Directors, representatives from Public health, Medicines management, the Care Quality Commission and the Child Death Overview Panel as well as experts by experience including the My Life Choices group (MLC).

The steering group is facilitated by the CCG and Chaired by a Consultant Psychiatrist from the mental health NHS Trust. The steering group focuses on cascading the learning and themes arising from completed reviews across the system and is fundamental to cascading the purpose of LEDER and promoting referrals into the programme.

LEDER has also informed changes to organisational policies and practice when incidents have been reviewed and learning has been cascaded with a focus on quality improvement. Examples of this include increasing the use communication tools between primary and secondary care systems such as health passports, or challenging thinking among acute care systems regarding capacity and consent to treatment. Further work is on-going to ensure changes in practice are embedded well across the system and workforce.

During 2021/22 a subgroup of the steering group was formed to further examine evidence contained within LEDER reviews and indications of quality issues that may need further action or oversight within the ICS. The group included representation from acute and primary care liaison teams, safeguarding leads, CYP transitions leads, private providers and the two local authorities. The group also ensures that outputs from the steering group are aligned to wider system partners and process including safeguarding adult reviews, child death reviews, inquests and police/prison/probation ombudsman reporting. Reports are also submitted through the CCG Quality Governance Committee's to ensure that there is also CCG executive oversight of the programme. This is in addition to the system Learning Disability & Autism Board that over sees the transformation workstreams which LEDER is a part of.

The LEDER Quality Assurance Panel reviews and quality assures every completed review. They are there to identify themes, concerns, good practice and extract the learning along with actions that are then taken to the LEDER Steering Group for wider dissemination.



# Progress against recommendations from 2020/21 Annual Report

The section provides evidence of the difference the programme and reporting systems have made against last year's recommendations.

System ownership of the development of the LEDER plan to respond to the changes required to implement the new national LEDER policy, with a particular focus on the future of reviewing.

The ICB LD&ASD quality/transformation team considered how as an ICS we can ensure the timely completion of LEDER reviews. A number of options were presented to the LD&ASD Transformation Board, and it was agreed based upon the findings/data that we would spread the risk regarding resources and personnel whilst we are becoming clearer on the impact of ASD notifications and therefore the numbers of WTE staff required to complete reviews. We agreed to build internal capacity within the ICS for reviews and quality assurance, whilst continuing to commission external consultants for some reviews on a spot purchase basis. Five registered professionals from within the ICS have been identified and have completed reviewer training. System leads are actively taking part in internal quality assurance panels. as we were unaware of the impact of the reviews for deaths for those with autism it was difficult to forecast the total number of hours and whole-time equivalent posts that would be required and so we have started with a hybrid model, with the intention of increasing capacity in the future if needed.

Prioritisation of LEDER reviews from 1st June 2021 with support from all system partners, following the national pause in reviews due to changes with the review database

Despite the new platform posing a number of challenges nationally to all systems, Nottingham and Nottinghamshire prioritised 'stacked reviews 'in June 2021 and set out an action plan to show how Q4 and Q1 reviews could be undertaken and signed off within timescale, to prevent a negative impact on review timescales later in the year. End of year performance showed that as a system, reviews were generally completed and signed off within 6 months of notification unless there were legislative or statutory processes being completed.

Development of an outcomes dashboard with a focus on exploring underlying causes of ill health and preventable deaths to facilitate a system-wide quality improvement approach to reduce the number of preventable deaths. A continued focus on respiratory deaths and vaccine uptake

During 2021/22 specific clinical groups continued to focus on the most prevalent health conditions which LEDER identified including aspirational pneumonia, cancer and gastro-



intestinal conditions, and to agree cross-agency action to improve early detection and treatment, linked to the promotion of GP annual health checks. The programme has continued its focus on morbidities in which we are an outlier, or which are flagged as statistically significant. The all-cause mortality data sets presented within the national data are complicated in that there are separate categories for pneumonia, type A+B flu, CV19 related deaths and a separate category entitled 'respiratory' when these categories cannot be regarded as discrete entities and clearly overlap. The local system determined that there would be a focussed review on all respiratory related deaths which include CV19 to assess the system response, ensure that the system responded appropriately and fully to need, and to identify any gaps or areas for improvement. The data from these CV19 related deaths in 2021/22 reviews showed that the areas for improvement (better communication between providers and families, earlier identification by provider and assessment by primary care etc) were in line with other morbidities across the programme. Interviews with families concluded issues arose with national mandates relating to CV19 (less face to face contact with community-based professionals) as opposed to issues relating to CV19 as a presenting respiratory condition.

### Ensure that the LEDER Policy is embedded with the work plan.

The EDER policy has been embedded within our local strategy and Programme Plans with workstream 3 having oversight of performance, delivery of actions identified through reviews across the other workstreams within the Programme. We have recruited to specialist LEDER posts which sit within the wider LDA case management team and Transformation and Programme Team. This has strengthened the learning across the system and has been embedded within commissioning and transformation of services. This has also strengthened how case management and MDT meetings are run with new terms of reference and roles and responsibilities being made much clearer across the system. This has supported us to start to change culture within our system in how we support staff and patients. We have ensured that learning from LEDER is enhanced through the themes we pick up through MDT/case management meetings and the recent safe and well reviews.

### Clinical Quality Assurance Panel to take place monthly

Quality Assurance Panel are in place, and they scrutinise the quality and efficacy of reviews, provides constructive feedback to reviewers, ensures compliance with national policy is upheld, and gathers data on themes and areas of learning/improvement to assist with the prioritisation of resources.

# Create a LEDER communications strategy ensuring education and learning for those working with LD/A

We are yet to complete our LEDER communication strategy, but this is something we aim to complete in 2022/2023. However, we have undertaken the following actions to ensure that our workforce is aware of the learning that has come out of reviews:

We have ensured that the themes coming out of LEDER reviews are being captured through our local Sit reporting which is discussed at relevant workstreams and our Operational Delivery





### Transforming Care Partnership

Group (made up of Heads of Services of health and social care operational service across ICS)

Workstream 3 identifying key gaps and developing key actions to embed learning. For example, key gap was poor communication with trust/families and primary care from within the acute care systems. We have extended the acute LD Liaison Team with the addition of 1.5 WTE Speech and Language therapist post to primarily support the communication needs of IDD patients during their time in hospital through the use of reasonable adjustments and specialist accessible information. Specialist SLT advice and consultation will also be offered to support patients' staff and families as well as liaison with community IDD, SLT and CIDT teams

Themes identified by LEDER reviews are considered in the commissioning of services. For example, the expansion of our local epilepsy service and improvement in our reach in terms of BME communities accessing AHC's.

Raise awareness of the needs of people with complex needs and LD within primary care, and the need for this to be reflected clearly in health records. Raise the importance of professional and clinical judgement being utilised within GP practices when adjusting care and treatment to this complex cohort

Primary care Liaison Nurses are working with clusters of GP practices in order to ensure that that diagnosis is differentiated and recorded appropriately (i.e., learning disabilities and learning difficulties) and to ensure that the LD register is updated and accurate. Red flags regarding complex needs should therefore be noted by secondary care are outpatient and inpatient services. Improvements that have been made to the update of annual health checks will further embed the relationship between primary care services and the patient cohort, and lead to the earlier identification of serious conditions. Primary care liaison nurses are integral to supporting this process and are continuing to do build upon these relationships and enhance the service for people with a learning disability and autism.





# **LEDER Annual Report Data - Summary of performance for 2021/2022**



From 01/04/2021 to 31/03/2022 5.5 out of 10 deaths were female (54%) while 4.5 out of 10 were male (46%)

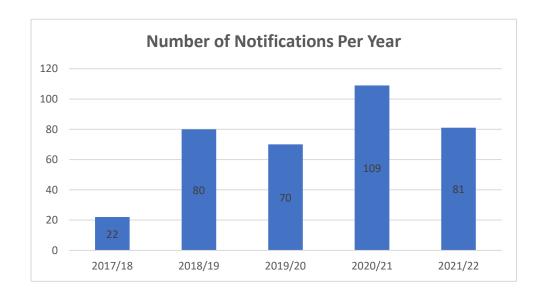
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Nationally 56.4% of deaths notified to LeDeR were for males and 42.6% for females. This split is reflected in Nottinghamshire's data.

35% of people died in Hospital
35% of people died in their usual place of residence
The National average of reported LeDeR deaths in hospital is 61%

### LeDeR reports to date - March 2022

The breakdown of data below shows the number of notifications to date and 2020/21 performance. 81 LeDeR notifications have been made in 2021-22 that were found to be in scope and went onto be reviewed.





### Transforming Care Partnership

There is variation within the number notifications received each year, with 2020/21 seeing an increase, and 2021/22 seeing a return to usual levels. It is likely that notifications levels will continue to rise due to the addition of ASD deaths and therefore widening the scope of the programme.

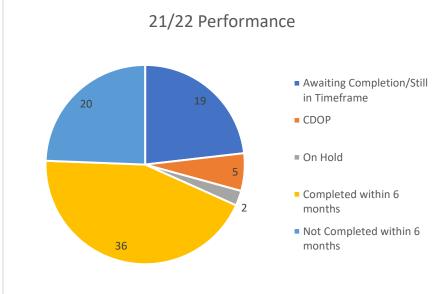
#### **LEDER Performance**

82 LEDER notifications were received during 2021-22

Of these so far 36 have been completed in the 6-month time frame.

20 have been completed but missed the 6-month deadline.

19 reviews are still ongoing with LEDER reviewers but are still within the completion

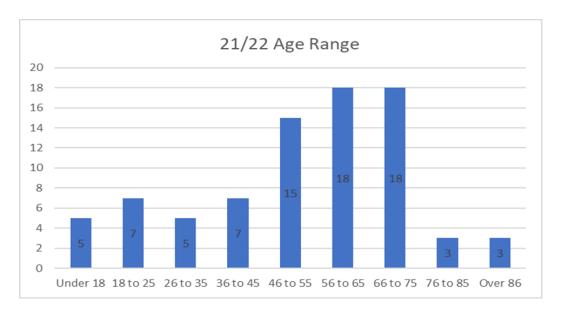


deadline.

2 reviews have been placed on hold awaiting coroner's inquest.

5 reviews were CDOP and are undergoing the CDOP review process.



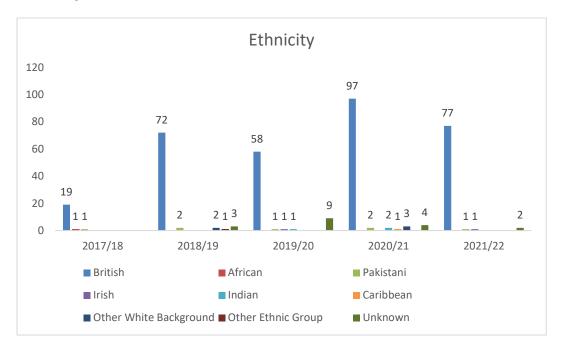


The 2021 Kings College LEDER report showed that nationally the average age of LEDER reviewed deaths was 61 which was the same as 2020. The average age of death for the general population is 83 for males and 86 for females although the general population age of death is lower in parts of Nottinghamshire then the national average.

With parts of Nottingham and Nottinghamshire having a lower average age of death within the general population in areas of higher deprivation, the average LEDER reviewed age at death is likely to be lower than the national average, but further work is needed to understand variation across PCN areas and a recommendation will be for the system to break average age down by area as opposed to only looking at average age across the system.

Reporting Period	Average age at death	These figures
2021/22	54	reflect the national
2020/21	59	picture
2019/20	56	during the
2018/19	57	same periods of time.
2017/18	62	of time.

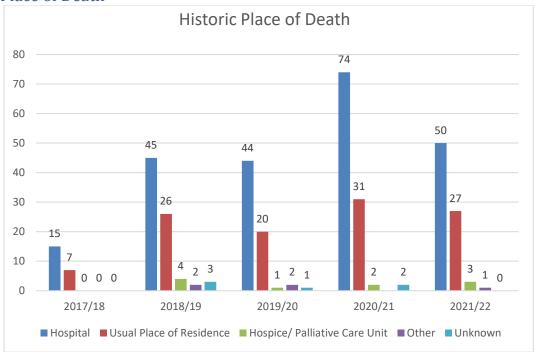




Black and minority ethnic (BME) deaths make up a small percentage of overall LEDER deaths and is in line with the national picture. Nationally, the vast majority (91%) of adults and children with learning disability who died in 2021 were denoted as white. This is the same as the overall percentage of people who died denoted as white between 2018 and 2021 (91%). In comparison, the proportion of people denoted as white in the general population is 85%<sup>5</sup>. This may be due to a difference in population structure of people with a learning disability (with fewer older people from ethnic minority groups), although an underreporting of deaths of people from ethnic minority backgrounds may also be possible. Although it is hard to draw conclusions from the low sample of BME deaths locally, we know that BME groups have low uptake levels of annual health checks and are over-represented for certain morbidities. Nottinghamshire has bid for and received funding for a BME AHC exemplar project which will target BME AHC uptake within a specific PCN area. Outcomes will be reported in 2022/23 and if successful will be rolled out wider within the system.



#### Place of Death

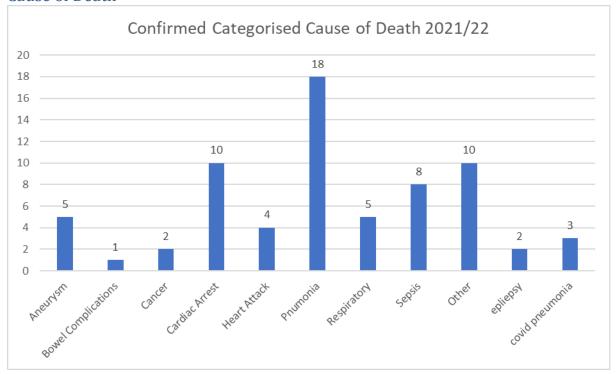


Hospital remains the most common place of death. Nationally the Kings College report showed that 61% of deaths took place in hospital which is higher than the general population. The trend is relatively stable however, during the first two quarters of 2021/22 there was an increase in hospital-based deaths versus community-based deaths -some of which were Covid-19 related.

During 2020/2021 3 reviews were not completed within the timeframe. The reasons for these were delays to completion of Coroners Report/Inquests, delays to completion of Serious Judgment Reports (SJRs) and delays in receiving GP records. Some of the delays, particularly in relation to GP records, were affected by the national decision to ask GPs/primary care to focus on an immunisation programme in November 2021 which pressure on the primary care system.



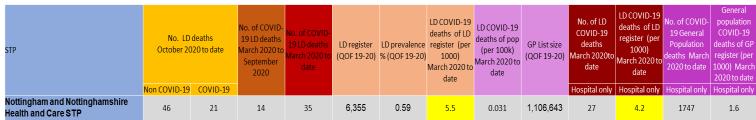
### Cause of Death

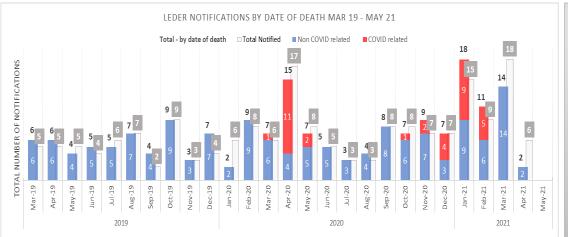


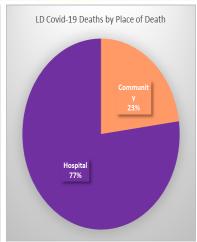
Overall, the most prevalent morbidities do reflect the national average for the most prevalent morbidities within this population. Reporting can sometimes be skewed by the order at which things are reported at the point of death such as being based on the 1a category on the death certificate sometimes people may have multiple comorbidities.



### Deaths related to Covid (positive test within 28 days prior to date of death)







DATA SOURCE – UNIVRSITY OF BRISTOL. DATA AS AT 05.05.21



In 2021/22, respiratory conditions still remain the highest cause of death within our LD/A population, Pneumonia, aspiration pneumonia and Covid 19 related deaths being the highest. Covid 19 associated Pneumonia is also identified for 5 people.

### COVID Data 2021/21

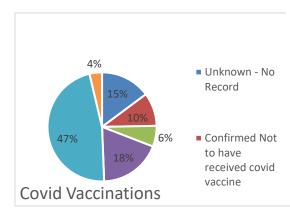


Chart shows available data from the LEDER reviews on covid vaccinations.

38 reviews (47%) confirmed that individuals had received both doses of the covid vaccine.

3 reviews (4%) showed that only one dose was given before death. 12 reviews (15%) had no recorded vaccine given on the LEDER initial review. Could not confirmed if vaccines had been given. 15 reviews (18%) are ongoing – no info on vaccines is available yet.

5 CDOP (6%) Vaccination status unknown.





## **Quality & Safeguarding**

### Quality of Care in Focused Reviews

Of the 81 reviews received in 2021-22 27 27 were found to be focused due to the cause of death falling into one of the local priority area categories.

Of the 27 focused reviews 15 were rated as rated as good care and 1 was rated excellent. 3 reviews found satisfactory care.

6 reviews found that care fell short of expected good practise. These reviews did not find that the care contributed to the cause of death. One review found that failings in the lack of provision of the covid vaccine is likely to have had a direct impact on the individual's death.



Evidence suggests that potentially a quarter of focused reviews identified less than satisfactory care – this will form part of a recommendation 2022 - 23



# **Learning Disabilities Register**

A key challenge with our local register has been flagged within reviews, particularly around the coding of people with learning difficulties versus learning disabilities. There has been a history of mixed messages in GP practices in regard to making referrals to LD services only when there is a clinical need for the patient and being discouraged to refer if there is no clinical need for a diagnosis. Some people have been coded as having 'learning difficulties' as opposed to learning disabilities particularly where there is no urgent clinical or behavioural need. Issues with the accuracy of primary care LD registers can result in people not receiving an annual health check and a GP Practice not being alerted if people are not accessing health care regularly.

GP practices are now auditing their coding system, to ensure that family members who have a caring role for other patients in a practice have their records linked. This will be a key area of focus over 21/22 to ensure correct coding and monitoring of individuals with a learning disability to ensure they get access to the support they need. The communication strategy for LEDER should include 'no wrong door' messaging for a carer seeking support from professionals.

### Key benefits of being on the Register are:

- Better information about the health needs of people with learning disabilities in a given locality.
- Better planning of health and care services for people with learning disabilities.
- An ability to anticipate an individual's needs before they attend health or care settings.
- Better understanding and integration of needs across health, care, education and employment.
- Better transition planning for young people with learning disabilities who are leaving school or college and approaching adulthood. If children and young people are on the register support and adjustments can be put in place before they transition
- If a child is on the Register, they will be invited for an Annual Health Check once they reach 14 years of age

### Reasonable Adjustments (RA)

A key project already underway within NHSE/I and NHS Digital before the pandemic is the Reasonable Adjustments (RA) Flag. The flag has been built into the NHS Spine to enable health and care professionals to record, share and view details of reasonable adjustments across the NHS, wherever the person is treated. Having been successfully piloted, the flag will be available for wider use from the end of 2020. Locally Nottingham & Nottinghamshire are investing into developing the digital systems to ensure reasonable adjustments flags are included.

Digital systems are being put in place to align with the national work that is being piloted. Primary Care IT is developing a clinical template for RA; this will act as a flag for someone to be able to see reasonable adjustments in a patient's clinical record. It will also provide a template to capture the detail of this RA which will have a list of common RAs to select but also a free text box to add any further context or detail. Primary Care Liaison and Acute Liaison Nurses have been involved with developing this common list. This will be shown in the patient

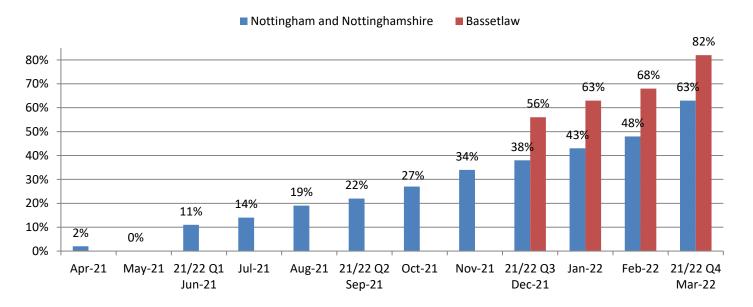


shared care record so will go through to Secondary Care to see the flag and then the detail needed. This is being kept as simple as possible to ensure consistency and minimise room for errors.

### **Annual Health Checks**

- As part of the national focus on LD/Autism within the NHS Long Term Plan it is the
  expectation that people aged 14 years and over with a learning disability are offered
  and assisted to attend an annual physical health check, with a commitment that at least
  75% of eligible people will receive an Annual Health Check (AHC) by the end of March
  2024.
- The LD AHCs are in recognition of the early mortality rate, as learning from reviews shows that a number of deaths were attributed to an undiagnosed treatable long-term condition, and/or related to issues with accessing primary care services. As a result of this each CCG/ICS area is performance measured on the numbers of people with LD accessing AHCs each year as a percentage of the estimated local LD population based on the GP's LD Registers.
- During 2021/22 NHSE confirmed the revised target for Notts ICS is 3,821 health checks, due to the impact of the Covid 19 vaccination programme that Primary Care was asked to prioritise.
- As of 29 March 22, 3,776 health checks completed in 21/22 which forecast missing our revised target by 45 health checks. However, NHSE noted the significant improvement during Q4 and Notts was one of the top performing areas in the region for improving AHC uptake.

### LD Annual Health Checks - 21/22 Performance (Target 75%)







### STOMP/STAMP

Work is underway to fund the PCN pharmacist to complete baseline searches on the GP patient records to identify children and young people with LD, autism or both prescribed psychotropic medicines. Initial searches will be carried out on the GP patient records system to identify patients aged up to 18 years of age with LD, autism or both that were prescribed psychotropic medicines.

## Objectives for 2022/23 and Beyond

- Nottingham and Nottinghamshire will develop outcomes dashboard with a focus on exploring underlying causes of ill health and preventable deaths to facilitate a system-wide quality improvement approach to reduce the number of preventable deaths.
- Review all recommendations within the LeDeR reviews at Quality Assurance Panel and Workstreams, to embed the learning across the system in a quality improvement approach to reduce the number of preventable deaths. Ensure that a sample of reviews that highlighted good quality and a sample showing poorer quality care are looked at by the system physical health steering group and comparison made to understand where high quality care is happening and focus on areas/examples that require improvement.
- ➤ We will break down the average age of death by locality area as well as take an average across the whole area, in order to understand if average LeDeR deaths are linked to variations in general population age of deaths which vary between differing areas.
- We will work towards achieving the national outcomes objectives in line with People with a learning disability and autistic people (LeDeR) policy (Version 1, 23 March 2021) during 2022/23 and review progress in 2023
- > Increase communication and education of LeDeR into the community and wider workforce with a focus on raising GP awareness.
- Work with NHSE regional team to ensure that we are supporting delivery of the Oliver McGowan training in conjunction with the Nottinghamshire Training Alliance Hub. Understand what the resource is and what the practical implications are for us as a system to ensure that the work is coordinated and is achievable within timescales.
  - Greater use of reasonable adjustments in health and care services for people with a learning disability and autistic people
- > Better outcomes for people as a result of local service improvement project
- > To complete LEDER reviews within timescales using reviewers with knowledge and expertise from across the system

