Annual Greater Manchester Learning from Lives and Deaths Review Programme Report (LeDeR) April 2022 – March 2023

Part of Greater Manchester Integrated Care Partnership

Acknowledgement

It is important that those reading the report are reminded that the learning comes from the lives and deaths of real people, who lived with their families or other support within Greater Manchester. This work could not happen without them, so we take time to remember all of them.

All the reviews include a pen portrait of the person who died. For each case we quality assure, we always start by reading aloud the pen portrait. These portraits help us connect to the person and remind us to consider whether the care and treatment they received would have been good enough if it was us or our relative.

We have learned of some amazing people within GM, each with their own individual personalities, likes and dislikes. We have heard some wonderful stories about people's lives and experiences, some which are sad and others which make us smile. We have also listened to close family members, carers and other people who knew the person well about their individual experiences within the health and social care setting and how they feel we can improve care. We understand that this may have been difficult and would like to express our gratitude.

We would like to thank everyone who provided us with information to make the reviews as thorough as possible. This is so we can identify the areas for development and work towards achieving achievements together. This includes NHS Trusts, hospices, GP surgeries, local authority teams and local care providers. Also, to former CCGs, their LACS and reviewers who led the LeDeR programme and contributed greatly from its inception in 2017.

Lastly, we would like to thank our LeDeR reviewers for providing the detailed reviews which have been written with compassion and care.

Contents

Acknowledgement 2
Contents 3
Table of abbreviations 6
Executive summary 7
Background 8
Other quality improvement frameworks 8
Impact of LeDeR 8
Change in focus 9
Change in eligibility 9
Change in workforce 9
Number of notifications 9
Coproduction and family involvement 10
Chapter 1: Demographics 11
Age at death 11
Ethnicity 12
Chapter 2: Long term health conditions 14
Chapter 3: Circumstances of death 16
Place of death 16
Deaths with DNACPR decisions 16
Causes of death 18
Chapter 4: Quality of care 20
Initial review 20
Focused review 20
Grading of care and services – focused reviews 21
Good practice 22

Thematic analysis for focused and initial reviews 24

Summary of quality of care 27

Chapter 5: Learning into Action and recommendations for 23/24 28

Autism learning 28

Annual Health Checks 28

Case study - Cornishway Group Practice, Wythenshawe 28

Cancer Screening Programmes 30

Respiratory conditions 32

Epilepsy 33

Inequalities for people from minority ethnic communities 33

Greater Manchester Hospital Directory/ Health equality for patients with a learning disability 34

Healthy Weight 35

Mental capacity Act and Best Interest 35

Support the development and sharing of best practice. 36

Constipation 36

Learning Disability Improvement Standards 36

Chapter 6: Summary 37

Appendix 1 – Case study bowel cancer screening pathway 38

What we tried 38

How we amended it 38

Next steps 38

Appendix 2 – Case study Bury man encourages people with learning disabilities to use bowel cancer home testing kit. 39

Appendix 3 – Why you need your flu jab poster. 41

Appendix 4 – Case study Pennine vaccine Jeremy 42

Appendix 5 – Greater Manchester Asian Family Right Day 44

Appendix 6 – References and links to further information. 45
Comments.. 45
Reference links 45

Table of abbreviations

Abbreviation	Term
BI	Best Interests
CCG	Clinical Commissioning Group
CDR	Child Death Review
DoLS	Deprivation of Liberty Safeguards
DNACPR	Do Not Attempt Cardio-Pulmonary Resuscitation
GM	Greater Manchester
GP	General Practitioner
ICB	Integrated Care Board
ICS	Integrated Care System
LeDeR	Learning from Lives and Deaths Review Programme
MCA	Mental Capacity Act
MCCD	Medical Certificate Cause of Death
MHA	Mental Health Act
NHS	National Health Service
NHSE	National Health Service England
PCN	Primary Care Network
SJR	Structured Judgement Review

Executive summary

The twelve months from April 2022 to March 2023 was spent consolidating and adapting to the changes required by the national LeDeR policy (2021) and the Health and Care Act (2022).

The former brought significant change in responsibility, workforce, and remit for the LeDeR programme, changing how LeDeR is done nationally and locally across Greater Manchester (GM). The latter introduced Integrated Care Systems (ICSs), with a requirement for system learning and working, and Integrated Care Boards (ICBs), with Greater Manchester's ICB (NHS GM) becoming responsible for LeDeR across Greater Manchester.

GM as a whole health and care system, with its ten individual localities, has worked hard to adapt to these changes, demonstrating an ongoing commitment to learn from LeDeR reviews and implement meaningful change and improvement initiatives to meet the aim of the LeDeR programme. The aim remains for people with a learning disability and autistic people across GM to enjoy good health and good care, and to no longer experience health inequalities or die from preventable causes.

This is the first GM wide LeDeR annual report since the inception of the ICS which really allows for wider and more detailed thematic analysis on which to base initiatives and outcomes. The purpose of the report is to share findings from the 164 completed LeDeR reviews in 2022/2023.

When reading the findings of this report it should be kept in mind that referral to the LeDeR programme, although strongly recommended, is not mandatory so does not have complete coverage of all deaths of people with a learning disability and autism. The benefit of a combined GM wide report has allowed for richer thematic analysis, however, the numbers in some subcategories are still small so must be interpreted with caution; findings and comparisons must be considered indicative rather than conclusive.

Background

Learning from lives and deaths - people with a learning disability and autistic people (LeDeR) is an NHS England (NHSE) service improvement programme.

Introduced in 2017, LeDeR's purpose is to improve the quality of health and social care for people with a learning disability and/or autism and autistic people. LeDeR requires a review of the care received after the death of every adult over 18 (under 18 years is the child death review process) with a learning disability and autistic people to identify what is working well and what still needs to change. Actions to grow good practice and achieve improvements where needed are agreed. Working together as one GM health and care system will provide more opportunities to achieve change and address the ongoing health inequalities and higher morbidity and mortality rates of people with a learning disability (compared to the general population).

Other quality improvement frameworks

LeDeR sits alongside existing coronial and safeguarding processes and is embodied in the NHS Long Term Plan . It is part of wider NHSE quality improvement frameworks, interlinked with the Learning from Deaths framework , an initiative to bring greater scrutiny of deaths and standardisation of mortality review processes. It links with the learning disability improvement standards that require NHS trusts to monitor and review the quality of care they provide to patients with a learning disability . It also connects to the Quality Outcome Framework in place for primary care .

LeDeR also sits alongside local government improvement initiatives, including the supporting adults with a learning disability to have better lives outcomes and improvement framework . The national medical examiner system is bringing a further layer of review, with independent scrutiny of all non-coronial deaths. All are gaining momentum since their inception.

Impact of LeDeR

The purpose of LeDeR is the learning from reviews to drive local and national service improvements, reducing health inequalities and premature death. Significant data about what is working well and where improvements are needed, have been and continue to be generated.

The challenge has been ensuring meaningful actions are embedded, sustained, and achieve the required outcomes. The evidence of ongoing health inequalities reflects the difficulties in achieving such change in isolation, without taking account of the interdependencies between health and social care systems.

The requirement for a new approach to LeDeR, recognising the need for system-wide oversight and governance was the rationale for the new national LeDeR policy.

Change in focus

Linked to this, the national LeDeR policy requires a shift in emphasis, from review completion to the delivery of change. ICSs must identify actions from LeDeR learning that will result in measurable improvements in the health outcomes of local people with a learning disability and autistic people, stopping reoccurring themes.

Change in eligibility

As noted, LeDeR has been widened to include autism. From 1 January 2022, the death of a person aged 18 years and above, with a formal clinical diagnosis of autism and no learning disability is eligible for a LeDeR review.

There are recognised similarities between health inequalities experienced by people with a learning disability, by people with a learning disability and autism, and by autistic people without a learning disability. The new national autism strategy aims to reduce the health and care inequalities faced by autistic people.

Change in workforce

The national LeDeR policy also requires a significant change to local LeDeR workforce models. Reviewers, previously working within individual CCGs, have come together as a discreet, standalone team within an ICS, supported by a new senior reviewer role and dedicated administrative staff. The LeDeR Local Area Contact (LAC) role, also previously within each CCG, has been replaced by a more independent role for greater scrutiny and oversight. This more structured and supported workforce model is in response to the recommendations of the Oliver McGowan review.

Number of notifications

The number of notifications to the LeDeR programme is increasing each year. This increase in notifications reflects the increased understanding about the programme rather than an increase in deaths. The number of notifications is expected to also increase given the inclusion of autism into the programme. The highest peak in notifications 2022/2023 has been in December, January, and February.

Table 1 GM notifications to the LeDeR programme 2017 to 2023

Year (1st April to 31st March)	Number of Notifications
2022 to 2023	224
2021 to 2022	207
2020 to 2021	205
2019 to 2020	180
2018 to 2019	177
2017 to 2018	108

Coproduction and family involvement

Co-production and working with people with lived experience are at the heart of our Learning Disability, Autism and LeDeR programmes within GM. We aim for every aspect of our work to be informed by people with a lived experience. A well informed Confirm and Challenge group exists within GM which involves a network of people with a learning disability and their families for whom we work in close partnership with.

Experts by experience are integral to our governance and are represented on our:

- Learning Disability and Autism Strategic Group
- Learning Disability and Autism Strategic Delivery Group
- Learning Disability Good Health Group

Chapter 1: Demographics

This section will focus on the 164 completed reviews between 1st April 2022 and 31st March 2022. The range of notification to the programme is 2021 with some reviews from 2020.

There were 81 females and 83 males. Of these reviews, there was one completed review with a diagnosis of autism only.

Age at death

The overall median age of death for the 164 completed reviews is 62 years which is comparable the NW average in 2021 of 61 years.

For the 81 females, the median age at death was 61 years and for the males, the median age at death was 63 years.

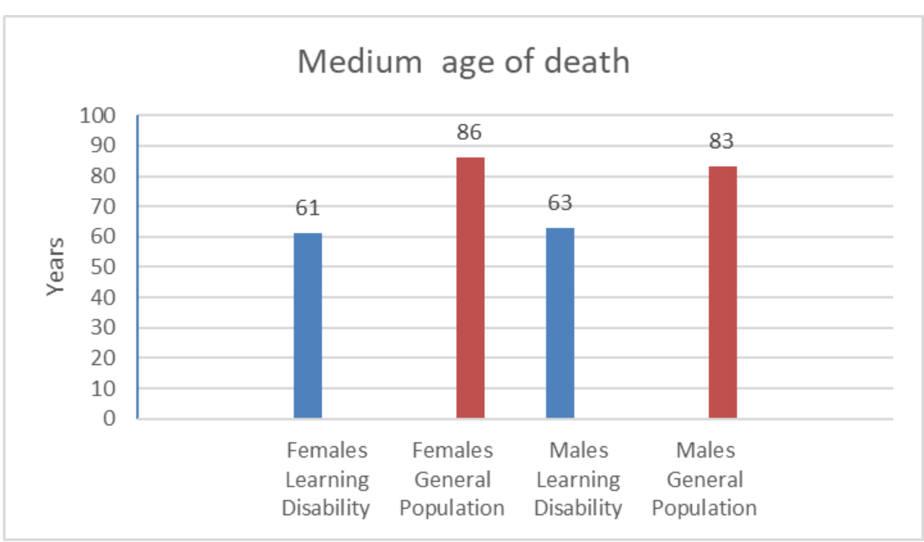


Figure 1 Graph showing Median age of death in years.

Comparisons with published data for the general population of England are indicative but not directly comparable, the deaths for the general population include 0–18-year-old data whilst LeDeR is 18 years and above.

In the general population of England from 2016-2018, the median age at death was 83 years for Males and 86 years for females. This gives a disparity of 20 years and 25 years respectively in comparison to those people with a learning disability.

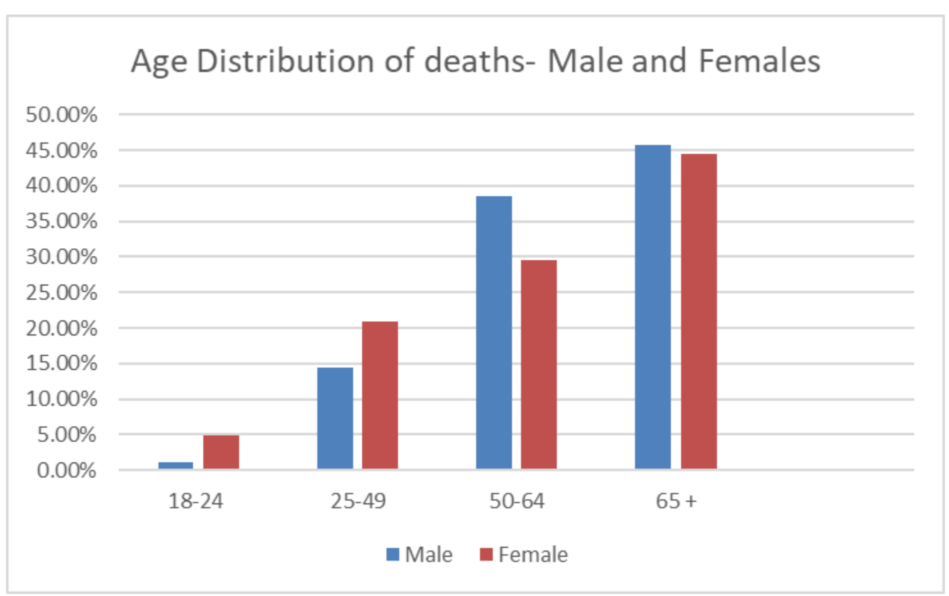


Figure 2 Age distribution of deaths for people with a learning disability.

In 2020, 85% of people in a general population died at age 65 or over. The percentage of people who died 65 years and over with a learning disability was 45.7 % for males and 44.4% for females.

Ethnicity

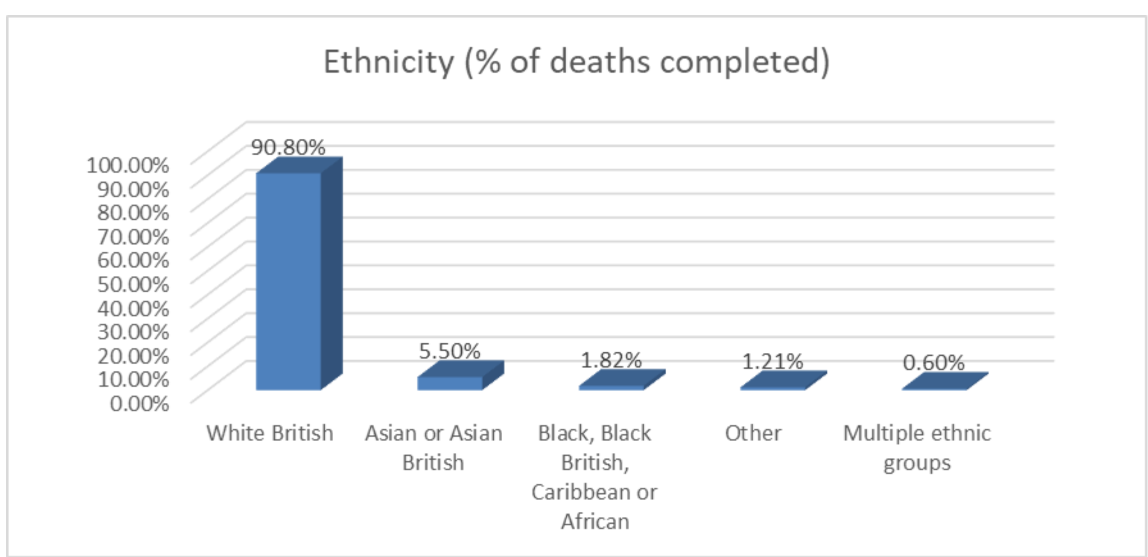


Figure 3 Completed cases by ethnicity.

Information about ethnicity was available for all the reviews completed in 2022/2023.

The majority of people who died were white (90.8%).

There were 5.5% of completed reviews that were Asian or Asian British.

1.82% of completed reviews were Black, Black British, Caribbean.

The general population of GM, there are 73.4% white and 23.6% from other minority ethnic groups. There are approximately 13,300 people with a learning disability who are white within GM and 2,700 from minority ethnic groups that are known. There is a concern nationally that people from ethnic minority communities are not accurately coded within primary care as having a learning disability and consequently not on the learning disability registers and being notified to the LeDeR programme.

Chapter 2: Long term health conditions

Information is collected during the review process regarding an individual's long-term conditions. Information is not always available to the reviewer and may only be present in the coded data from primary care where a reviewer has deemed this relevant to review. In essence, incidence of long-term health conditions may be higher/different than what has been collected within these closed reviews for this reason. Ten conditions are included in the definition of a long-term health condition for the purpose of this report.

Long term conditions data was available for 125 of the completed reviews. This was often within the narrative of the LeDeR review rather than pre-fixed boxes.

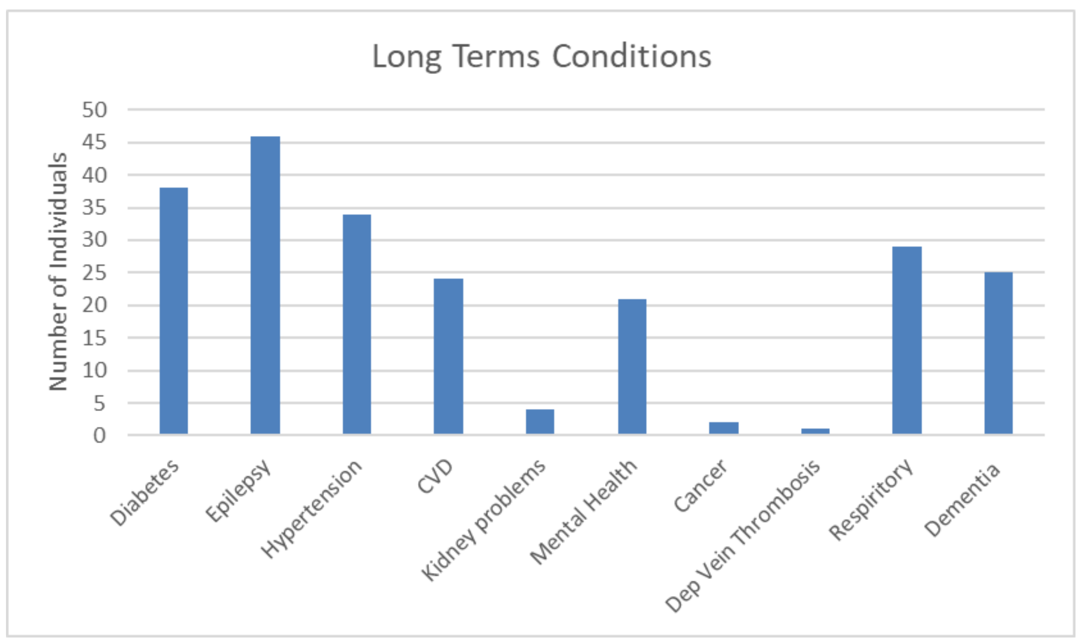


Figure 4 Long term health conditions in Greater Manchester.

Epilepsy was the most frequently reported long term condition which was cited in 46 reviews (28% of total reviews /36.8% of the reviews with long term conditions mentioned). The denominator is 185- the total number of completed reviews for 2022-2023. The denominator is 125- the number of reviews with long terms conditions mentioned.

Diabetes was the second most frequently reported condition with 38 cases cited within the reviews (23.1% of total reviews/30.4% of the reviews with long term conditions mentioned).

Hypertension was the third most frequently reported health condition with 34 cases cited in the reviews (20.7 of total reviews/ 27.2% of the reviews with long term conditions mentioned).

Respiratory conditions was the fourth most reported health condition with 29 cases cited in the reviews (17.6% of total reviews/23.2% of the reviews with long terms conditions mentioned.

Dementia was the fifth most reported health condition with 25 cases in the reviews.

Nationally, epilepsy was the most reported long-term condition with 33% reported to have the condition from the number of reviews that had a long-term condition mentioned. Nationally Diabetes and Hypertension were 8th and 10th respectively. Diabetes was present nationally in 15% of the reviews where this information was recorded compared 30.4% for GM. Direct comparisons are helpful but not conclusive due to different cohort ranges.

A raised BMI of over 30 was recorded in 26 reviews. Although reviewers are encouraged to gather this information, in some circumstances this is not available so this figure could be increased.

Multi-morbidity is defined as the presence of two or more long term conditions occurring at the same time. There were 33 people with two long term conditions and 29 people with three long term conditions recorded. 4 people had the presence of four long term conditions recorded. This was based on the ten long term conditions defined for this report only.

Chapter 3: Circumstances of death

This section reports the circumstances of the death of people with a learning disability. This includes where people have died, whether a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) was in place prior to death, and whether the DNACPR recommendation was followed correctly.

The medical certificates of cause of death (MCCD) have also been reviewed.

Place of death

Information about place of death was available for 161 people out of 164.

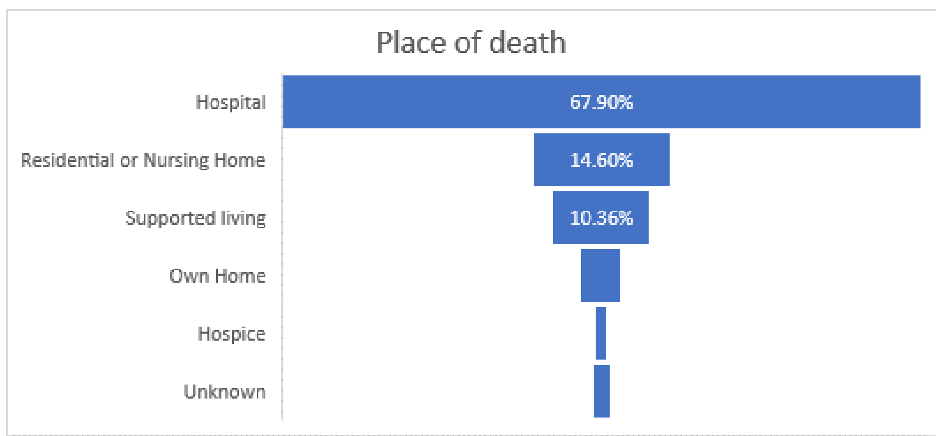


Figure 5 Place of death.

67.9% (n=111) of deaths in GM occurred in hospital. In comparison to deaths from the public, a greater proportion of people with a learning disability die in hospital compared to 42% of the general population in 2020.

14.6% (n=24) people died in a nursing or residential home, whilst 10.36% (n=17) died in supported living accommodation. 4.26 % died in their “own” home, often living with family.

The reasons why a higher proportion of people die in hospital with a learning disability compared to the general population are multifactorial. This may be due differences in age characteristics or causes of death or could be due to factors relating to living circumstances or palliative care services and discharge planning.

Deaths with DNACPR decisions

Information about DNACPR was available for 161 out of the 164 reviews.

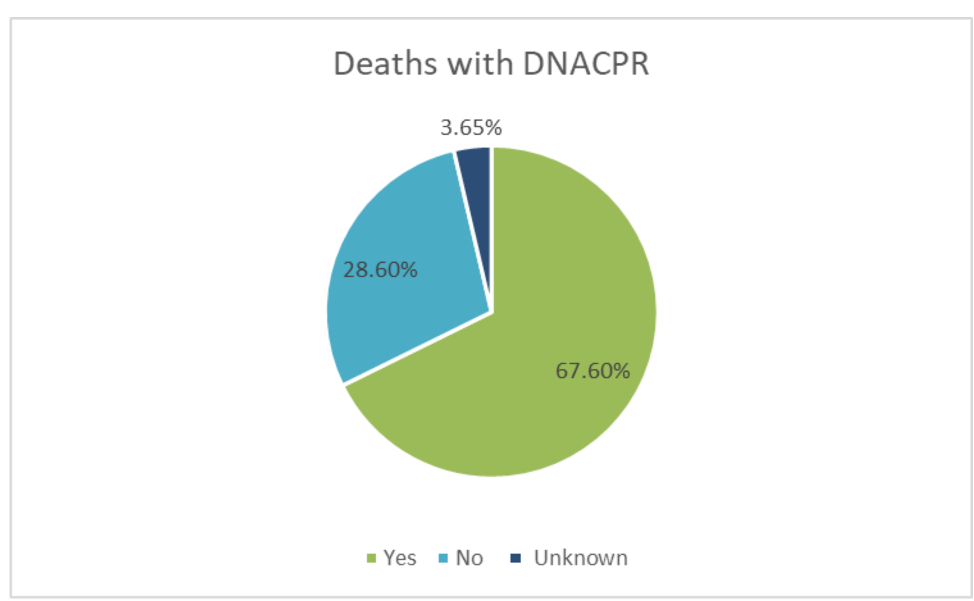


Figure 6 Percentage of adults with a DNACPR decision.

67.6% (N=111) had a DNACPR recommendation in place at the time of death. Of these 41.6%, (N=46) the DNACPR was not in place before the last episode of care leading to death. Nationally, 64% of people had a DNACPR decision in place at their time of death.

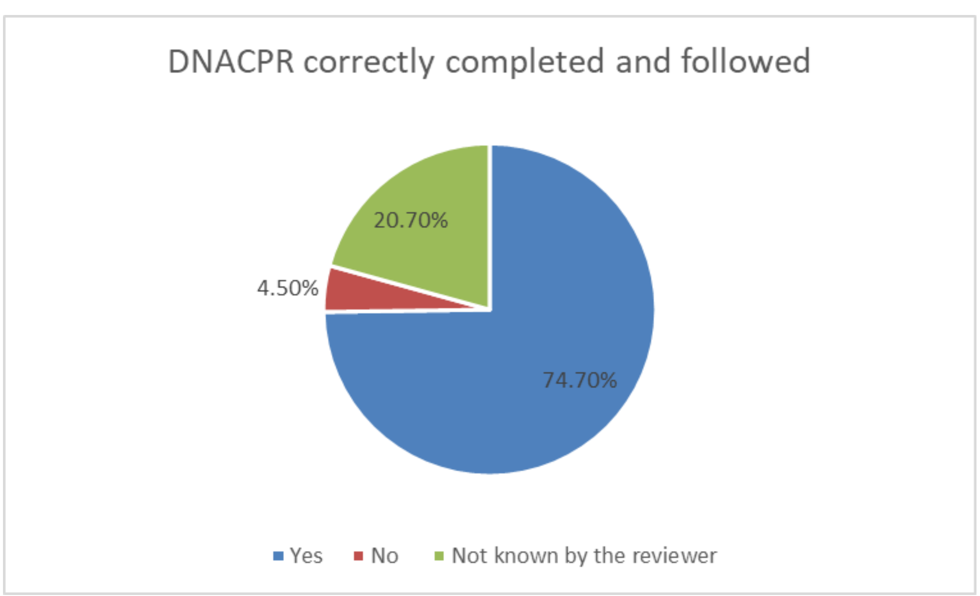


Figure 7 Percentage of adults who died with a DNACPR decision at their time of death, for whom documentation was completed and followed.

The reviewers determined that in 74.7% of the reviews (N=83) the DNACPR documentation was completed satisfactorily and followed. This compares to 63.8% nationally (2021). There were 4.5% of the reviews (N=5) that the reviewer felt that there was incomplete or incorrect documentation. In 20.7% (N=23), the reviewer was unable to determine whether the process for making a DNACPR decision had been correctly followed.

Causes of death

When someone dies, a doctor who was involved in the person's care completes a MCCD. This indicates the sequence of conditions which lead to death. This section reports the common causes of death of people with a learning disability. The reviewer was able to determine the cause of death in all but two reviews.

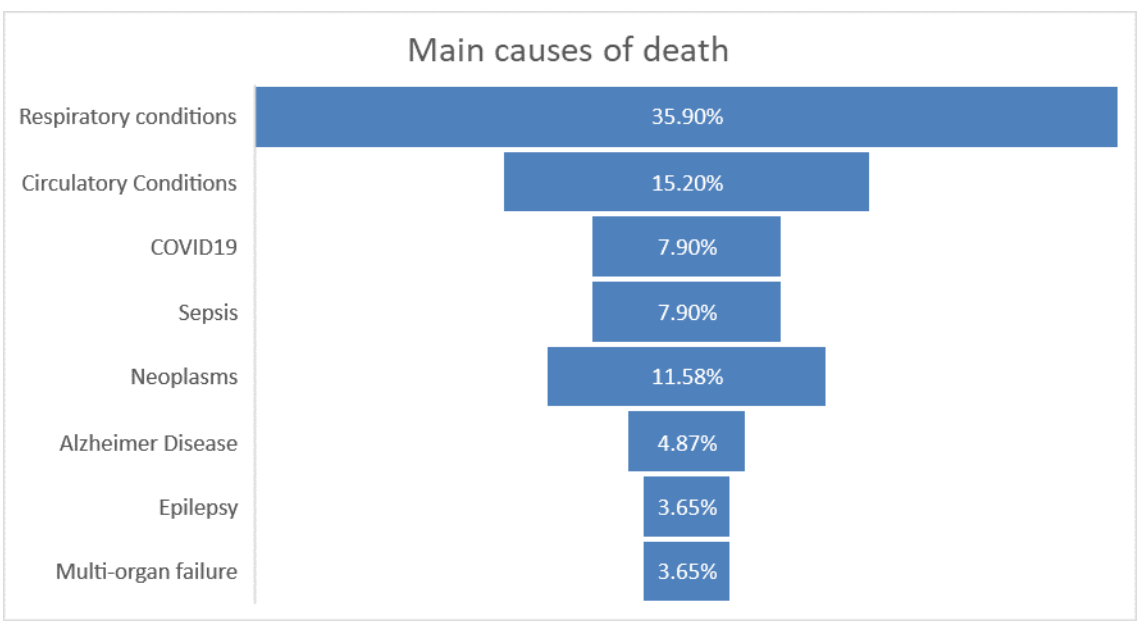


Figure 8 The 8 most recorded causes of death within GM

Respiratory conditions accounted for the most recorded causes of death within GM. Of these cases (N=59), 38.9% (N=23) were due to aspirational pneumonia with 49.1% (N=29) due to pneumonia (organism unspecified) including both hospital and community acquired. Nationally 12% of deaths in 2021 were due to diseases of the respiratory system which places GM significantly higher. Caution must ensure with direct comparisons due to clustering of conditions used for the purposes of reports and date range for completed reviews may be different.

Circulatory conditions accounted for the second highest cause at 15.2% (N=25). This included conditions such as Myocardial Infarction (Heart Attack), Cerebral Vascular Accidents (Stroke), Peripheral Arterial Disease and Aortic Disease. Nationally, diseases of the circulatory system accounted for 14.3% of total deaths.

Neoplasms accounted for the third highest cause of death at 11.58% (N=19). This is like the national percentage in 2021 at 11.4% of these cases, two were due to breast cancer and three due to bowel cancer.

COVID19 and Sepsis accounted for 7.9% respectively (N=13) of the total causes of death.

Epilepsy accounted for 3.65% (N=6) of the total causes of death. In all cases Status Epilepticus was recorded. This occurs when a seizure lasts more than 5 minutes or

when seizures occur very close together and the person doesn’t recover consciousness between them.

Chapter 4: Quality of care

Initial review

The reviewer will carry out an initial review using the new web platform to guide them through the process. The initial review will include a guided conversation with a family member or someone close to the person who died, a detailed conversation with the GP or review of the GP records and a conversation with at least one other person who knew the person well.

From the information gathered, the reviewer and the LAC will use their professional judgement to decide whether a focused review is required.

Focused review

Situations where a focused review will be conducted are:

- If the individual is from a Black, Asian or Minority Ethnic Group, a focused review will automatically be completed due to significant under reporting and increased health inequalities in these communities.
- All deaths of adults with a diagnosis of autism but do not have a learning disability.
- If in the professional judgment of the reviewer there is significant learning for the ICS. This includes 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 coordinated care. A family member can always request a focus review to be completed.

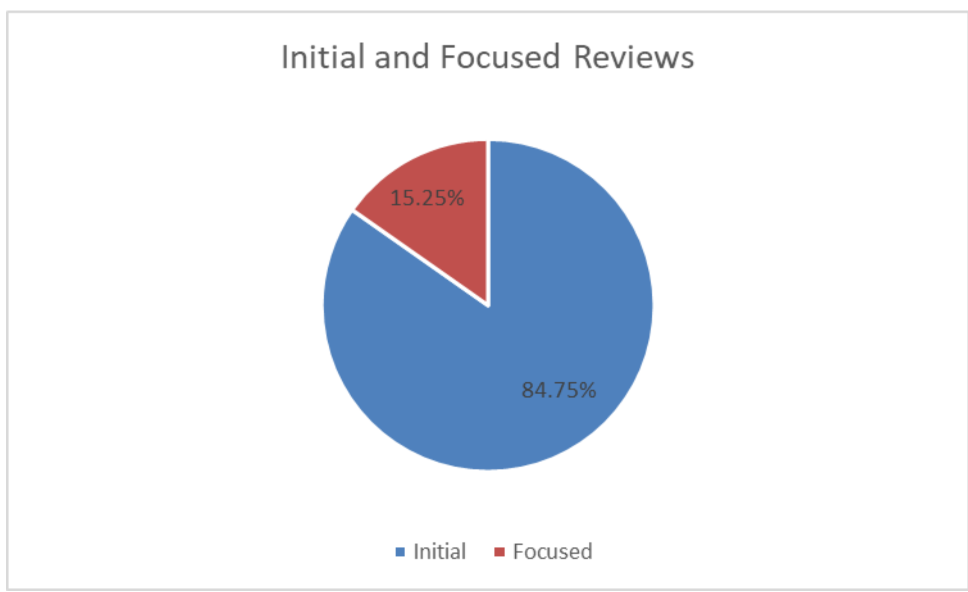


Figure 9 Initial and focused reviews closed in 2022/2023

GM completed and closed 139 initial reviews in 2022/2023. This is 84.75% of the total reviews closed.

GM completed and closed 25 focused reviews in 2023/2023. This is 15.25% of the total review closed.

A key priority for the ICS will be to increase to number of focused reviews to between 35 % of total reviews in line with national recommendations and expectations.

Grading of care and services – focused reviews

The LeDeR reviewer is asked to grade the overall quality of care and services provided. Quality of overall care and services are rated on a six-point scale. This is for focused reviews only:

1 = Care and services fell short of expected good practice and this contributed to the cause of death.

2 = Care and services fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.

3= Care and services fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death.

4= Satisfactory care/ availability of services (fell short of expected standards in some areas, but this did not significantly impact on the person's wellbeing).

5= Good care and availability and effectiveness of services was good.

6= Excellent care and availability and effectiveness of services was excellent.

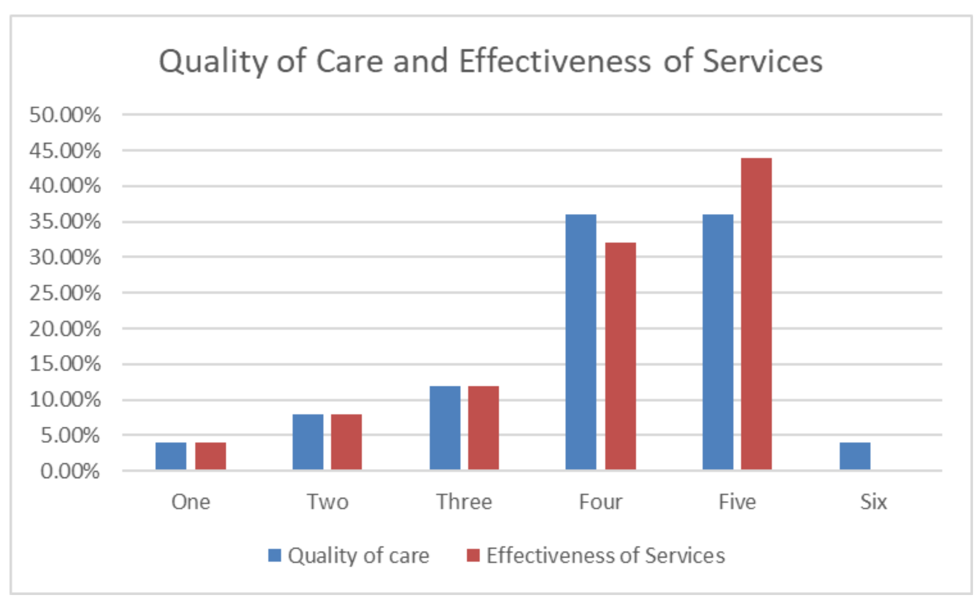


Figure 10 Quality of Care and Effectiveness of Services from focused reviews

Most of the care and services fell between rating four and five – satisfactory to good care and availability of services.

From the focused reviews, the services and care scored five and six respectively when there was positive evidence in relation to good care planning, with no evidence of gaps with recommended diagnostic and treatment guidelines met. There was good evidence of the application of the MCA/BI process in addition to effective joined up services that were proactive to the individual's needs and requirements.

Good practice

There were some excellent examples of good practice within both the initial and focused reviews. For the focused review, the reviewer is asked to describe this.

Good practice identified	Completed focused reviews 2022/2023
Yes	76% (N=19)
No	8% (N=2)
Unrecorded	16% (N=4)

Figure 11 Table showing good practice identified in completed focused reviews.

Excellent care with family supported by services and comprehensive psychatric care.

The person was supported to live a healthy life by the GP- she had all the necessary screening and immunisation and when unwell, the GP visited regularly. The practice was proactive and always kept the health action plan up to date.

The carers stayed when she was in hospital, round the clock, to ensure continuity of care.

The discharge process was seamless- this was due to the coordinated working between the hospital and community staff.

Care was excellent and this was graded as a six because it was totally person centred at all times. Clear evidence of an advanced care plan with excellent application of the Mental capacity Act and Best Interest.

Figure 12 Good practice comments.

There was evidence of comprehensive annual health checks that were followed by a detailed health action plan. In addition, there were some good examples how reasonable adjustments have been implemented in primary care for people, especially around attending routine appointments such as for immunisation.

The involvement of learning disability liaison nurses within the hospital setting, including at discharge level, led to positive outcomes and successful discharges. There were some excellent examples of how the MCA/BI has been applied with the

involvement and advice of the learning disability nurses in addition to good implementation of reasonable adjustments.

There were many reports of good practice in inpatient care primary and community care. Central to this was proactive and consistent staff who were well trained. Support packages that were person centred, flexible and adaptable and that promoted people's independence, were areas highlighted as good practice.

There were many examples of good communication between care professionals which was linked to timely intervention and improved outcomes. The presence of an assigned person who would take the lead in the coordination of care was recognised as being important to ensure a joined-up approach was implemented.

Thematic analysis for focused and initial reviews

The learning themes from the initial and focused reviews have been grouped into the following headings:

- Learning Disability Awareness
- DNA CPR recommendations and the end-of-life care
- Deterioration
- Care pathways
- Involving the coroner
- Family and carer awareness of available support
- Transition
- Safeguarding
- Training on specific conditions
- Professional Practice and the provision of care

The care settings where the themes have occurred are grouped under:

- Primary and community care
- Hospital in patient care
- Social Care
- End of life care

The most recurring themes from focused and initial reviews completed in 2022/2023.

Themes	Areas of concern and care setting
Professional practice and the provision of care.	• Inconsistent delivery of preventative screening in some cases and difficulties accessing appointments. (Primary and community care) • If not attended for appointments coded as “did not attend” – no evidence of follow up initiated or further appointments sent. (Primary and community care) • Inconsistent use of health action plans following on from annual health check. Incomplete or inadequate health checks in some circumstances. (Primary and community care)
Learning Disability awareness.	• Application of MCA and BI was inconsistent - this was sometimes not clearly discussed when decisions were made both in primary and secondary care. (Primary and community care and hospital inpatient)

Care pathways.	• Inconsistent use of reasonable adjustments – examples include not using reasonable adjustments during outpatient appointments and hospital stay. (Primary and community care and hospital inpatient) • Inconsistent use of reasonable adjustments within primary care- some people reported that they were invited to busy clinics which they found overwhelming. (Primary and community care and hospital inpatient) • Length of stay in hospital for some people was excessive due to difficulties with discharge planning and availability of relevant services required. (Primary and community care and hospital inpatient) • Inconsistent coordination when a person was under multiple services and consultants as an inpatient. (Primary and community care and hospital inpatient) • Inconsistent use of hospital passports. (Primary and community care and hospital inpatient) • Inconsistent involvement of specialist learning disability services when an inpatient. (Primary and community care and hospital inpatient) • Management of long-term conditions was inconsistent in some cases- especially weight management and constipation. (Primary and community care and hospital inpatient) • There have been several examples of the provider changing x 3/4 times due to re- commissioning of services and other reasons- when this has happened it has led to disjointed services delivered and unmet training needs in certain situations. (Primary and community care, hospital inpatient and social care)
Training on specific conditions.	• Poor management of certain conditions within social care settings. Most notably is management of constipation obesity and epilepsy. (Social care)

DNA CPR recommendations and the end-of-life care.	• In some circumstances, there was a lack of advocacy involvement cited in both general discussions and those decisions involving DNACPR. (Primary and community care and hospital inpatient)
Transition	• In some cases where this involved a young person, transition from children to adult services and subsequent lack of coordination and difficulties navigating through services was cited as being complex and disjointed. (Primary and community care and hospital inpatient)

Figure 13 Themes relating to areas of concern and the care setting.

Summary of quality of care

Although there were many initiatives associated with positive practice, implementation was not universal.

Several initiatives have been introduced nationally to improve outcomes for people with a learning disability including annual health checks, health action plans and hospital passports. Up to date annual health checks and health action plans were associated with positive practice but there is inconsistent quality around these. These initiatives are supported by legislation such as the Mental Capacity Act but there is evidence that these are still being inconsistently applied.

Chapter 5: Learning into Action and recommendations for 23/24

This section will focus on some of the activities that have been implemented based on the thematic learning from previous locality annual reports. Priorities for now and 2024/2025 have been indicated based on the learning from the completed reviews in 2022/2023. These will form part of the priority action plan for the GM Learning Disability Good Health Group.

Autism learning

For the first time, people over the 18 with a diagnosis of autism only are eligible for a LeDeR review from January 2022. At this point, GM has only one completed review and nine notifications. One of the key priorities is to improve the number of notifications that GM does receive to the programme for those people with autism only.

Annual Health Checks

2021/2022	2022/2023
66%	80%

Figure 14 Annual Health checks 2021/2022 and 2022/2023.

Clinical evidence shows that annual health checks can identify undetected health conditions early, ensure the appropriateness of ongoing treatments and promote health. Increasing the number of people who have had an annual health check has been a priority for GM and this has increased from 66% in 2021 to 80% in 2022/2023. There have been several initiatives ongoing which has also contributed to this difference. This includes the community learning disability teams working in partnership with primary care, training masterclasses and annual health check events.

Manchester have introduced two Primary Care Coordinators to work alongside primary care, and this has made a significant difference to annual health check uptake in addition to other health related goals.

Case study - Cornishway Group Practice, Wythenshawe

“While embarking upon our annual health check pilot, a gap was identified for the provision of hand on support to the person with a learning disability to achieve health goals specified on their health action plan as well as any other identified support needs. There also needed to be a person who would have knowledge of local services and resources and be the “go to person” for practical queries. This presented an ideal opportunity to utilise some of our additional roles reimbursement scheme (ARRS) funds to create this role.

The care coordinators have been in post for just over a year and made a difference to the PCN learning disability population. They have contacted harder to reach patients and supported them to get their annual health checks.

One PCN has now has over a 90% uptake when previously this was much lower. All patients are supported to achieve their health goals by receiving practical and reasonably adjusted access to services they require.

The care coordinators have looked after carers by providing additional support for their health and wellbeing needs. They also work alongside prescribers and voluntary and community organisations. They are raising awareness of the importance of annual health checks in schools and colleges, supporting families so we can achieve our aim of "starting as early as possible". The care coordinators are fully embedded in our networks."

Dr Geeta Wadhwa, Partner and Speciality Trainer, Cornishway Group Practice, Wythenshawe, Clinical Lead for Learning Disability and Autism.

There are still annual health checks that don't result in a Health Action Plan - the health goals the GP agrees with their patient. This diminishes the likelihood of health improvement in the patient. There is an array of Health Action Plan templates used by GPs currently; these will be reviewed in conjunction with people with lived experience.

Priorities for 23/24

There are still over 2000 people that have not had an annual health check within GM and there may be more who are not known to services or on the GP register. All localities to prioritise those who didn't have an annual health check in 22/23.

Introduce quality audit cycle to ensure both quality and impact of annual health checks and completeness of health action plans.

Primary Care Assistant Practitioners

From October 2023, there will be a pilot implementation of 5 Primary Care Assistant Practitioners for 12 months, who will work across 5 localities and be hosted by Pennine Care NHS Foundation Trust.

We know from the LeDeR reviews that people with learning disabilities are not always receiving their annual health check with the GP and receiving a health action plan, despite their higher risk of poor physical health. They are also not being supported to attend for health preventative services such as screening and immunisation.

By supporting people to access their appointments, this proposal supports the work across primary care and community learning disability services. It will complement existing and emerging pathways for long term conditions. The role of Primary Assistant Practitioner will work alongside Primary Care Networks (PCNs) and other

connectors, including learning disability community teams to focus on support for people to overcome barriers to accessing primary care and other long term condition pathways.

The team is being implemented to reduce the barriers that patients who have a learning disability and or autism face in accessing physical health care in the right place and supporting them if they are unable to do so independently. This will be fully evaluated for effectiveness, impact, and outcome from qualitative and quantitative perspective.

Cancer Screening Programmes

Reviewers check that people with learning disabilities and those with autism have been invited and supported to attend screening appointments. The evidence in the reviews demonstrates that some people are supported very well to attend, and others do not attend.

A significantly smaller proportion of people with a learning disability had a breast, cervical and colorectal screening test in 2020 compared to those without a learning disability. NHS Digital breast screening data for England demonstrates there is a 15% difference in breast screening in GM compared to the rest of the population. For cervical the difference is over 30% and bowel screening the difference is around 10-12% compared to the general population. This is line with the national trend. Caution must ensue as the data with NHS Digital is still classed as experimental.

Pathways associates have undertaken focus groups with people with lived experiences to explore key themes to improve screening uptake. As an outcome from this, screening pathways have been developed for those with a learning disability.

Improving the uptake of breast and cervical cancer screening for women with learning disabilities.

Thematic Analysis of the learning from engagement carried out between March and July 2022 by Pathways Associates CIC

A bowel cancer screening pathway was initiated with the Northwest Bowel Screening Hub which demonstrated significant improvements in participation (Appendix one). This is evidenced by the support as described by Stephen in appendix two. Localities have agreed to further pilots to further test the model in 2023/2024.

GM has recently formed a Learning Disability and Autism Cancer Network with task and finish groups for each screening programme with the overall ambition to improve cancer screening uptake and improve pathways.

Ansar Projects (Bury) have created a series of accessible resources to support people with a learning disability to know their body. The resources are unique and include breast and testicular cancer symptom guides, self-checking social stories and information on what to expect if you notice a change. Because of this work, Ansar projects were in the national learning disability and autism awards and were runners up receiving highly commended.

Key actions for 2023/2024

To work with people with lived experience and introduce further cancer screening pathway pilots for people with a learning disability and autism across GM. These will be fully evaluated to inform future plans.

A focus on early intervention and prevention, which recognises the impact of intersectionality, including how people will be supported to access screening and immunisation.

Respiratory conditions

Respiratory infections are a leading cause of death nationally and within GM and the risk is increased in those with dysphagia (swallowing difficulties). Preventing, diagnosing, and managing dysphagia remains a key priority. We will work with our partners from provider services to deliver "learning into action" workshops for managing dysphagia and identify any barriers and good practice. This will be used to improve care pathways as necessary across health and social care.

Bacterial pneumonia was the stated cause of death in 29 cases of closed LeDeR cases in 2022/2023. Flu, COVID19 and Pneumonia vaccinations are important for those with a learning disability as they are identified as a clinically "at risk group".

GM worked in collaboration with the 'Staying Healthy Group' who all have lived experience, to gain their insights on how to improve flu uptake and communication. This consisted of holding several focus groups. The insight was incorporated into co-designed flu information. An example of this is within appendix three.

A learning disability flu toolkit was developed to support primary care with delivery of flu vaccination with an array of easy read flu information to support the campaign. In addition, flu webinars were held to provide additional support. Primary care were encouraged to offer flu/COVID19 vaccination when they attended the surgery for their annual health check.

The Community Learning Disability Teams across Greater Manchester supported people with a learning disability with positive effect. Appendix four describes a case study which demonstrates how support and appropriate reasonable adjustments has a positive effect on outcome.

NHSE have commissioned guidance on pneumonia and aspiration pneumonia from the British Thoracic Society (BTS). In addition, RightCare scenarios have been developed by NHSE as an education guide which put the person at the centre of a scenario to show the difference between an optimal and suboptimal pathway of care. These will support local systems to develop optimum pathways.

Supporting people and promoting uptake of the Pneumonia, Influenza and COVID 19 vaccinations are important priorities for GM.

Key actions for 2023/2024

We will work with partners for the health and social care setting to deliver workshops to raise awareness of dysphagia and the risk of aspirational pneumonia.

We will work with our partners to scope out dysphagia pathways considering the new clinical guidance from the BTS and utilising RightCare scenarios.

We will work with partners across the health and care setting to maximise Pneumonia, Flu and COVID19 vaccine uptake for people with a learning disability.

Epilepsy

Epilepsy is a condition that effects electrical activity in the brain causing seizures. It was the most reported long-term condition in GM with 28% of people having this condition from the completed reviews. This is in comparison to around one in one hundred of the general population.

Six people in Greater Manchester died of Sudden Unexpected Death in Epilepsy (SUDEP). Warning signs are seen in 90% of people who have a diagnosis of epilepsy and die suddenly. It is important that people with epilepsy have a care plan and are aware of the risks of SUDEP. There was a theme relating to care providers knowledge and understanding around epilepsy in addition to other long term condition management. SUDEP action – My Life with Epilepsy have developed a toolkit which will be utilised across GM.

Priorities for 2023/2024

To scope available training resources and work with localities to ensure care providers have up to date knowledge on the management of epilepsy and are aware of the importance of maintaining up to date epilepsy care plans.

Inequalities for people from minority ethnic communities

There is a requirement to carry out a focused review for every person from a minority ethnic community. The 2021 national LeDeR report found 42% of white British people died aged 65 years and over compared to 7% of people from Asian British ethnic groups and 5% of people from Black/African/Caribbean Black British Ethnicity. Adults with the lowest median age of death (30 years of age) were males of Asian/Asian British.

A greater proportion of deaths of people with a learning disability both nationally and within GM were White British (90.8%). There is a concern that people from ethnic minority communities are not accurately coded within primary care and consequently not on the learning disability registers and notified to the LeDeR programme.

In recognition of the health inequalities that exist for people from minority ethnic communities, Manchester locality has undertaken a project with those with lived experience, to find out more about the views and experiences, facilitated by Black Health Agency (BHA) for equality with advice from Breakthrough UK. Learning from the project will be used to help raise awareness and reduce health inequalities.

An Asian family right day was arranged by the wrap around partnership in which there was engagement, co-production and health related themes (appendix five). This will be further developed in collaboration with the British Muslim Heritage society.

There has been significant work to improve ethnicity data reporting and uptake of health initiatives including annual health checks and immunisation on tableau. This will be further improved in collaboration with business intelligence.

Following the publication of We Deserve Better there are important priorities for the ICB.

Priorities for 2023/2024

Ensure the number of LeDeR reviews notified within the ICB reflect the demographics of the local population and take action to raise awareness of LeDeR within these communities.

LeDeR reviewers should ensure they accurately record in the LeDeR review the ethnicity of the person whose death they are reviewing.

ICB will ensure the quality (completeness, validity, and accuracy) of ethnicity coding for people with a learning disability. All NHS care providers should routinely and accurately collect ethnicity data relating to people with a learning disability.

Greater Manchester Hospital Directory/ Health equality for patients with a learning disability

People with learning disabilities and autistic people report that needing access to acute hospital services can be anxiety provoking, be confusing and there is often a lack of information about what can be done to help. There can be a lack of reasonable adjustments and of easy read and accessible information.

One of the priorities for GM confirm and challenge and in response to the outcomes from the LeDeR reviews, will be the development of a co-produced GM directory of all the acute settings, identifying acute liaison teams, community support available and pathways to access high quality and person-centred care in acute settings. This has been scoped and will be brought together is an accessible format.

The aim and outcome from this will be to ensure any individual with a learning disability or autism and their carers are better able to navigate complex acute and planned services by having access to information and guidance in an easy read format.

Learning Disability teams across GM are working to ensure reasonable adjustments are made for individuals with a learning disability or who are autistic. One example of this is a pathway that was launched by Bolton NHS Foundation Trust. This allows complex patients who experience anxiety, stress, or needle phobia to be placed under sedation to progress routine diagnostic tests such as blood tests or extras which were previously impossible to undertake.

This was implemented because of LeDeR learning and the difficulties experienced by complex patients. The importance and impact of specialist learning disability liaison nurses was highlighted by the national press using this example in Bolton.

Healthy Weight

It has been recognised for many years that people with a learning disability are at an increased risk of being overweight or obese compared to the general population. There are higher proportions in the more severe category of obese nationally compared to the general populations. There were 26 instances within the reviews that a BMI over 30 was mentioned which can have an impact on other long-term conditions such a hypertension and cardiovascular disease.

GM is currently undertaking a scoping to identify healthy weight services across GM which are accessible to people with a learning disability. From this, we will identify potential service gaps and ensure any mainstream services are accessible.

Actions for 2023/2024

Focused reviews will be undertaken on people with a BMI over 30. This to identify a holistic overview of potential contributory factors and evidence of appropriate programmes.

Complete the healthy weight scoping across GM and work collaboratively with partners to ensure mainstream services are accessible for people with a learning disability.

Mental capacity Act and Best Interest

This annual report has highlighted the need for a more consistent application of the MCA and BI. Reviewers highlighted areas where the level of knowledge about the MCA amongst professionals, as well as concerns about capacity assessments not being undertaken and best interest processes not being followed. This is particularly relevant within preventative interventions like immunisation and screening where it is documented that there is a refusal, but this is not underpinned by MCA or BI.

Priorities for 2023/2024

Raise the profile of the MCA and BI within primary and secondary and social care providers.

Work with our partners to increase healthcare workers confidence and competence in using the MCA/BI.

Support the development and sharing of best practice.

Work with primary care to scope out and develop prevention of adult not brought- Learning Disability and or Autistic People. This is aimed at adults without capacity and primary care appointments.

Constipation

People with a learning disability are at greater risk of constipation 10% of the general population and 20-50% of people with a learning disability are affected. It can be very difficult to diagnose. Constipation can be exacerbated when people find it difficult to communicate to others that they are constipated. Constipation can cause pain, distress and even death; effective monitoring is essential to maintain wellbeing.

From the LeDeR reviews, chronic constipation was cited within a significant number of reviews. There was inconsistent management of this with little reference to underlying cause and prevention.

Family members, carers and paid support have a key role in the early recognition of this. It is a condition that benefits from a holistic approach with multi-disciplinary input. The management of constipation has been a national priority and work was commissioned to review the management. One key finding was that better recognition and management of constipation may reduce hospital admission and improve quality of life.

Bolton are planning to introduce a total bowel management approach across all community learning disability teams for which will provide learning within GM.

Actions for 2023/2024

We will have a focus on constipation within LeDeR reviews and other routes to understand the prevalence, causes and management.

Working with our health and social care partners, we will raise awareness regarding the importance of early recognition and correct management.

Learning Disability Improvement Standards

The learning disability improvement standards have been developed to help NHS trusts measure the quality of care they provide to people with a learning disability, autism or both. The standards have been developed with number of outcomes created by people and families which are expected from the NHS. Compliance with these standards requires Trusts to assure themselves that they have the necessary structures and processes to deliver the outcomes for people with a learning disability and/or autism. The performance against these standards will be triangulated with outcomes from the LeDeR reviews to provide assurance regarding compliance and where improvement may be required.

Chapter 6: Summary

This is the first combined GM LeDeR report which focused on findings from the closed reviews of the deaths of people with a learning disability and those with autism in 2022/2023. These, mainly occurred in the calendar years 2020/2021, identifying any trends and considering priorities for service improvement in 2023/2024.

The LeDeR programme continues to grow in scope, including the addition for reviews of deaths of autistic adults. As the LeDeR dataset grows across GM, so will the opportunities for further statistical analysis across the years. This will allow us to demonstrate change over time, understand where initiatives have been effective and target areas where more needs to be done. The new focused review (conducted on selected cases) contains quality care indicators which will in the future allow for more direct comparisons to monitor progress and outcome. These reports will be further enhanced as we engage with stakeholders and explore areas of key lines of enquiry that are relevant to our population such as constipation and healthy weight.

The findings, key recommendations and priorities from this report will be agreed, co-produced and implemented with agreed deliverables in conjunction with people with lived experience and our health and social care partners across GM. This will form part of the GM Learning Disability and Autism Good Health work priorities for 2024.

Appendix 1 – Case study bowel cancer screening pathway

What we tried

The Northwest Bowel Screening Hub contacted the coordinating Nurse Specialist from the Bury Community Learning Disability Team (CLDT) with a list of adults who are going to be contacted to receive a bowel cancer screening kit.

People known to the team and their carers contacted to offer guidance, support and reasonably adjusted and accessible information on completing the kit.

The project yielded positives outcomes with a significant increase in participants completing the kit, evidencing that additional support and reasonable adjustments increases participation in the bowel cancer screening programme.

How we amended it

The original list 35% were not known to the service so did not receive any additional support. This led to a change in the pathway, and the Cancer Screening Improvement Team now contacts those not known to the service.

Joint working between the Cancer Screening Improvement Lead from the Pennine Bowel Cancer Screening Programme and the local CLDT was pertinent to the success of the pilot.

Next steps

With the recent inception of the GM Learning Disability Cancer Network the new pathways are to be tested in the other 9 localities of Greater Manchester.

All 10 localities have signed up to the pilot with a plan to stress test the model in September, October, and November to evaluate in December.

Appendix 2 – Case study Bury man encourages people with learning disabilities to use bowel cancer home testing kit.

Screening is vital to detect bowel cancer at the earliest stage when it is more likely to be successfully treated and home testing kits are making it easier for people to do this in the privacy of their homes.

Stephen Owen is encouraging others to use the home testing kit.

A Bury man with a learning disability is supporting a campaign to urge others with similar conditions to use their bowel cancer home testing kit.

Each month, the NHS posts out more than half a million free Faecal Immunochemical Test kits (FIT) for people to use in the privacy of their homes. The test can detect early signs of bowel cancer.

Stephen Owen, 64, from Whitefield, Bury, completed his screening with the help of the Learning Disability Flagging Project which helps people with learning disabilities take part in the national bowel cancer screening programme. Now, he's hoping that his story will encourage other people who live in Greater Manchester to do the same.

Community learning disability teams are notified in advance when a patient with a learning disability in their care is due to be invited for their bowel screening kit. They then help and support the patient to complete the test.

Caroline Mattinson, cancer screening improvement lead from the Pennine bowel cancer screening programme, part of the Northern Care Alliance NHS Foundation Trust, said:

"Our team helps and encourages the patient to do the FIT test. The project has had a positive outcome on the adults with a learning disability who have taken part. This is helping to reduce health inequalities and ensure that people with learning disabilities can access bowel cancer screening."

Nicky Bennett is a specialist nurse for the Bury community learning disability team, provided by Pennine Care NHS Foundation Trust. She said:

"It's great to be working with cancer screening colleagues to make sure people with a learning disability are supported to spot the early signs of bowel cancer.

Providing reassurance, or more accessible information can significantly improve the likelihood of them completing the kit. And we're also able to offer extra support if they need follow-up tests or treatment."

Stephen said:

"My bowel cancer screening kit arrived through the post. My support worker helped me to understand the test, and I agreed to do it. Then, I signed a consent form. I needed help to use the kit and send back the sample. The results came back quickly. My support worker explained my results."

Stephen's test did not spot cancer but did find he had an infection. He is now having some further treatment.

Screening is vital in helping the NHS detect bowel cancer at the earliest stage when it is more likely to be successfully treated.

Stephen said it is important that people do the test. He commented:

"Always do the bowel screening sample and send it off. If you don't understand, ask for information about the test. Easy read information is available, and you can read this with your support worker."

Roger Prudham, clinical lead for bowel cancer at the Greater Manchester Cancer Alliance, said:

"Bowel cancer is the fourth most common cancer in the UK, but we know that screening increases the chances of early diagnosis which can prevent deaths from this devastating disease. This is an inspirational example of how the bowel cancer screening programme is impacting lives through inclusivity."

For more information about the Northern Care Alliance's Bowel Cancer Screening service, visit the website.

Appendix 3 – Why you need your flu jab poster.

Appendix 4 – Case study Pennine vaccine Jeremy

Jeremy is a 57-year-old gentleman with downs syndrome and learning disabilities. Historically, he lived alone with outreach support and engaged very little with any services. He refused to attend GP appointments and often refused entry to support staff and health professionals. He had a number of unmet health needs and, as a result, he was supported to move into a supported living tenancy just prior to the pandemic.

Living in a supported living environment made it much easier to engage with Jeremy and we began to slow the process of getting his health needs met. He continued to refuse to attend appointments and became very anxious and upset when it was suggested to him.

When his support staff attempted to discuss the COVID vaccine, he refused to engage in any discussion about it. It was noted that he had never had a flu vaccine either. A best interest decision was made for an attempt to be made to administer the first vaccine to Jeremy through the Community Learning Disability Team Vaccinators.

We gathered information about what had been unsuccessful about previous attempts and discussed what reasonable adjustments could be considered prior to attempting to administer. We arrange for him to have a short-sleeved t-shirt on, and we collected a copy of the radio times to take with us – this is something he enjoys each week and we felt it might support engagement.

When we arrived, we prepared the vaccine out of sight of Jeremy. To reduce anxiety further we sat with him for a short while, looking through his Radio Times with him and chatting about the TV shows he enjoys.

When the vaccine was shown to Jeremy, “oh it’s the vaccine” and allowed the vaccine to be administered quickly and efficiently. Jeremy thanked us for administering the vaccine. This was a positive outcome for the patient and by using reasonable adjustments, time and patience, the vaccine was administered with full consent from Jeremy.

When the time came for Jeremy’s second vaccine, we spoke with the staff team. We felt that due to the success of the first vaccine it was possible that Jeremy may consent without the need for a capacity assessment and best interest discussion. We all agreed that, to prevent unnecessary anxiety and distress, we should not inform Jeremy of the planned appointment and see how he was on the day.

As per the first visit, we arrived and prepared the vaccine out of sight of Jeremy. One CTLD vaccinator approached Jeremy – who again was wearing a short sleeved t-shirt and explained why we were there. He willingly accepted the second dose of the vaccine and again thanked us.

When Jeremy was due his COVID booster, the CTLD vaccinators contacted Jeremy’s support team to offer support again.

We were delighted to be informed that, due to the support, education and reasonable adjustments we had provided with he first two vaccines Jeremy was able to attend his GP clinic for his booster. He also received his first flu vaccination, an annual health check was completed for the first time in a number of years. Jeremy is now much more trusting of health professionals and identifying and meeting his health needs and will be a much easier process in the future.

Appendix 5 – Greater Manchester Asian Family Right Day

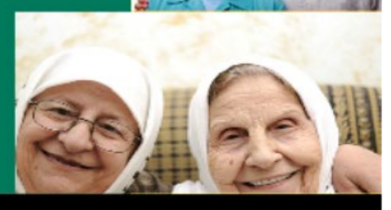
THURSDAY
23RD FEBRUARY 2023
9.30AM - 4PM

Greater Manchester
Asian Family Rights Day

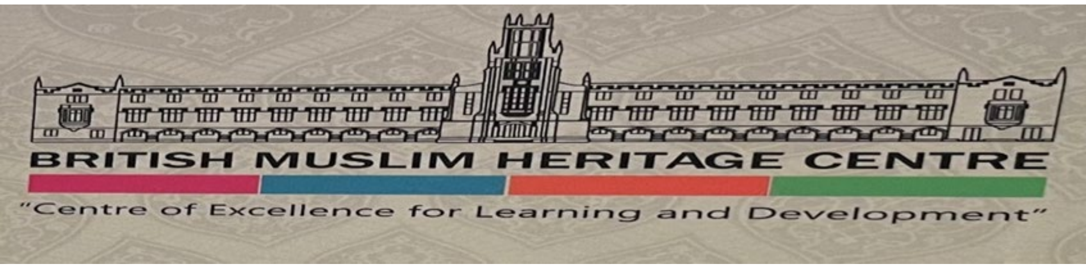
British Muslim Heritage Centre,
Whalley Range,
M16 8BP
Refreshments available
Interpreters available (Urdu, Punjabi, Sariki, Hindi, Pushto, Kashmiri and more)

- Information on Culturally appropriate care
- Know your rights & what is on offer
- Information & Knowledge
- Help Completing forms
- Health Information
- Ask questions

Question and Answer session
1pm - 2pm
with senior leaders from the health and care system for Greater Manchester.
If you have anything to ask please let us know.



Reigster:
Asian Family Rights Day Tickets, Thu 23 Feb 2023 at 09:30 | Eventbrite
Call 07901336912 Email: gmasiancarersnetwork@gmail.com



Appendix 6 – References and links to further information.

Comments

The programme was previously known as the Learning Disabilities Mortality Review (LeDeR) programme, with the new national LeDeR policy introducing a name change to better acknowledge the focus on lives lived and the planned inclusion of autistic people. It is still abbreviated to LeDeR.

Previously the death of a person with a learning disability and autism was eligible for a LeDeR but not autism alone.

The national autism strategy for autistic children, young people, and adults: 2021 to 2026 (July 2021), updates and brings together adult and children's improvement initiatives into one all-age strategy. Regarding health improvements, it includes trialling initiatives from learning disability services, i.e., an autism annual health check, expansion of the STOMP-STAMP programmes to stop the over-medication of autistic people, improving the flagging of health records to ensure reasonable adjustments are known and recorded.

Long term health conditions are acquired conditions that can be controlled with ongoing management but cannot be cured.

Cancer, cardiovascular conditions, dementia, deep vein thrombosis, diabetes, epilepsy, hypertension, kidney problems, mental health conditions, respiratory conditions.

Reference links

NHS Long Term Plan

The National Quality Board's Learning from Deaths framework requires acute, mental health, community and ambulance trusts to improve how they identify, report, investigate and learn from patient death. Framework.

Improvement Standards.

Initially implemented on a non-statutory basis for all patients who die in hospital, the medical examiner system is being widened to include all deaths in the community and will be a statutory requirement to confirm the cause of death for all non-coronial deaths Report.

NHSE Action from learning report 2021.

LeDeR policy (2021).

The Independent Review into Thomas Oliver McGowan's LeDeR Process, published in October 2020, made twenty-one recommendations, including improvements to national and local LeDeR governance and oversight processes (Review).

ONS Average Age at Death by Sex UK.

ONS Ethnic Group.

NHS Race and Health Observatory publication.

LeDeR Annual report 2021.

ONS Deaths Registration Summary Table 2020.

NHS Digital health and care of people with learning disabilities.

Microsoft Power BI.

Know Your Body – Thera Trust.

British Thoracic Society – Aspiration Pneumonia.

NHS England – RightCare.

SUDEP.

The Guardian – How learning disability liaison nurses are transforming patient care.

Bristol – constipation newsletter.