

LeDeR: Learning from Lives and Deaths of People with a Learning Disability and Autism

NHS Greater Manchester Annual Report 2023/2024

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Greater Manchester

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Acknowledgement

- The LeDeR programme in Greater Manchester (GM) would not have been possible without the support and commitment of the many people and organisations across GM who have worked to notify deaths of people with a learning disability and autistic people, provided information and conducted reviews.
- 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 GM. We take time to remember them all.



Executive summary



Greater Manchester

This is the second combined Greater Manchester (GM) LeDeR report and the first year we have moved review information over a calendar year (January-December) as opposed to a business year to be in line with the national LeDeR reports. This will afford a greater opportunity to have insight of comparative data to measure both progress and outcomes. Working on a GM scale is giving a deeper insight into thematic analysis and trends, which is resulting in tangible change in response.

The aim of the report is to share learning from the LeDeR programme to promote change across the health and care system with the aim of reducing health inequalities and preventing premature mortality. For this reason, the data charts in this report have been kept to a minimum and reflecting only essential information, with the main aim being the influence the learning is having on change and service improvements for the population in GM.

The number of notifications to the LeDeR programme has remained consistent over the past three years. The overall median age of death remains at 62 years which is the same as the national average. There is still a disparity of 20 years in comparison to the national average of the general population. There has been an increase by 8% in the number of completed reviews of people with a documented profound or severe learning disability in 2023 (42%). Nationally, severity of learning disability was associated with age of death.

Epilepsy was again the most frequently reported long term health condition present in 41% of the reviews which was an increase on the previous year and at least 22 people had a BMI over 30 (obesity). Respiratory conditions remain the main cause of death at 34% of the total with an equal distribution between aspiration pneumonia and other pneumonias/chest conditions.

Utilising quality improvement initiatives including Appreciative Inquiry and Plan Do Study Act has led to service change across GM because of LeDeR learning. A key priority in 2023 was ensuring people died in a place they chose, and this has seen a reduction in hospital deaths by 9% in comparison to 2022. There is still further work to do if this is to be in line with the general population. Reviewers have judged Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) to be correctly followed 75% of the time which continues to demonstrate a yearly improvement in GM and on the national average of 63%. Annual health checks continue to demonstrate an improvement each year with uptake at 81%, and 98% of people having a health action plan.

Executive summary continued

Screening uptake has been lower nationally in people with a learning disability, and this was strongly reflected in LeDeR learning. Following an initial pilot, the bowel screening project has been expanded across all GM and is resulting in an improvement in the uptake of bowel cancer screening. A Breast Screening Charter and Reasonable Adjustment Cervical Cancer pathway are both being launched in April 2025.

Autism became part of the LeDeR programme in 2022, and this report only reflects 2 completed autism reviews. A key priority was increasing the number of autism notifications, and this has seen an increase in 15 notifications for 2024. GM is also increasing the number of focused reviews in line with the national aspiration of 30-35%.

There remains key priorities for 2025-2026. This includes the development of a GM learning disability dashboard to measure outcomes and monitor prevalence of long-term conditions and preventative uptake such as screening and immunisations.

We will continue to work with our stakeholders, people with lived experience, families and professionals to further strengthen our analysis and interpretation of findings and better service the needs of people with a learning disability and autistic people within GM.

Why this is Important

Leanne- young lady with lived experience

“Our health is important. It's important to make things easier to understand, giving me extra time and getting the support I need. It's hard to wait around at appointments. Reasonable adjustments are important to prevent health inequalities. Going to a cancer screening workshop gave me confidence, once I got more information, I thought I better do this (Cervical screening) . It's important to involve people with lived experience”

Our Learning Disability and Autism Good Health Charter in GM – 2025-2026- our aspirations



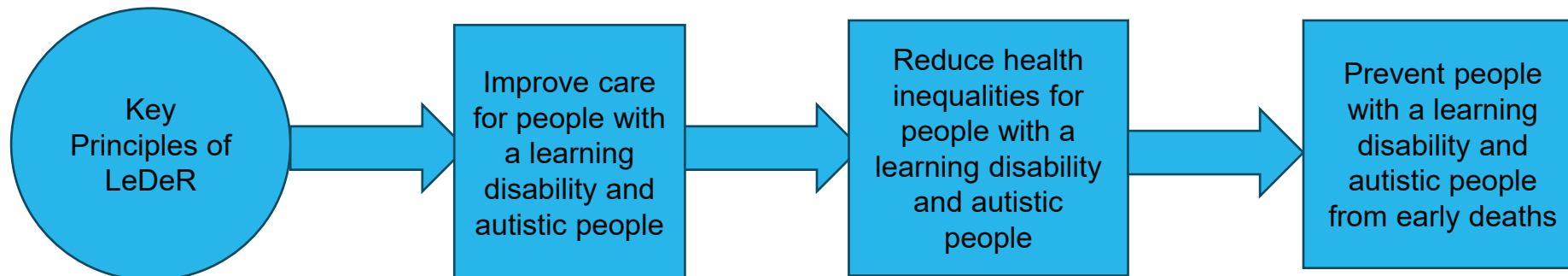
Greater Manchester

- **Annual Health Checks** - All people should receive a comprehensive annual health check, considering potential health concerns specific to their condition, thorough communication with the individual and their support network, and a focus on preventative measures, all delivered in a way that is tailored to their needs. There is no variation in uptake in people from minority ethnic backgrounds or other vulnerable groups.
- **Epilepsy Management** - People with a learning disability should have access to individualised epilepsy treatment plans that consider their specific needs including clear communication, tailored medication management and coordinated care in which they all have the ability to participate in decisions about their own care.
- **Healthy Weight Management**- People with a learning disability and autistic people should have individualised plans based on their needs, with accessible communication and strong support from caregivers and health professionals. Pathways should be tailored and incorporate reasonable adjustments as required.
- **Mental Capacity Act**- Any decisions about care and support will be in line with the Mental capacity Act. People will be supported to make their own decisions and, for those who lack capacity, any decision must be made in their best interest involving them as much as possible and those who know them well.
- **Inequalities for people from minority ethnic communities** - Providing support that is tailored to their individual needs, considering their cultural background, language preference and religious beliefs, while addressing potential barriers. This to ensure the same quality of care is given regardless of their ethnicity.
- **End of life care**- People will have access to personalised care that reflects their individual needs, preference, and communication style, ensuring they are involved in decision making; this includes open conversations about dying and use of accessible methods to understand wishes.
- **Respiratory care** - prioritises accessible information, personalised care plans, proactive preventative measures, thorough assessment of swallowing abilities and appropriate training for healthcare staff. There is a focus on early identification to manage potential respiratory issues.
- **Management of long-term health conditions**- This care is proactive and integrated across all services with appropriate support given and effective medication managed.
- **Screening Pathways**- There will be reasonably adjusted screening pathways implemented for all screening programmes in GM. There will be no variation in uptake of screening for people with a learning disability and autistic people in GM.

Introduction

Scope of LeDeR

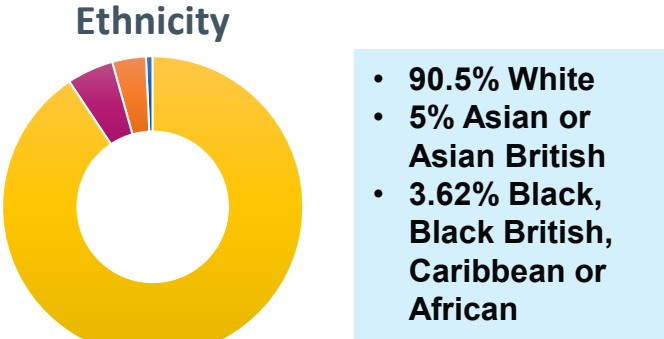
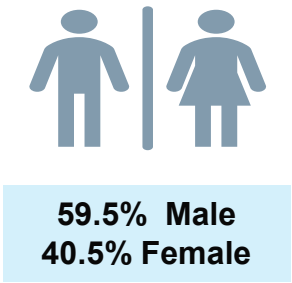
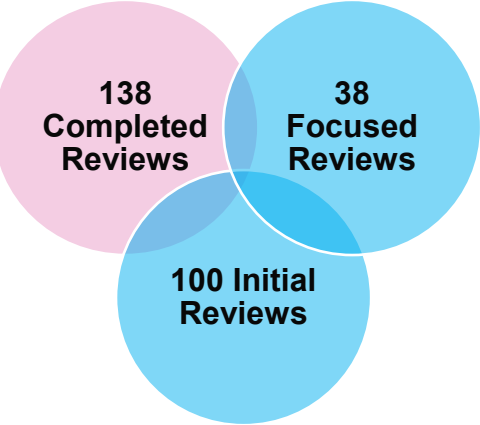
- LeDeR is a service improvement programme for people with a learning disability or autistic people.
- Every adult (18 years and over) with a learning disability or with a clinical diagnosis of autism is eligible for a LeDeR review. The child death review (CDR) process reviews the deaths of all children, and the results are shared with LeDeR.
- Multiple processes – if there has been a Safeguarding Adult Review referral or safeguarding notification, the reviewer links in with the local safeguarding lead or refers to locality/safeguarding leads if concerns are found during course of the review.
- If there has been a patient safety investigation or the person died of suicide - this links in with the patient safety/quality team in each locality.
- A LeDeR review is completed after the coronial process has been completed - even if this means it is placed on hold for a considerable time
- LeDeR reviews are not investigations or part of complaints procedures.



Key findings from the review of lives and deaths, closed reviews - notified deaths 2023



Greater Manchester



Age at Death 62 years old

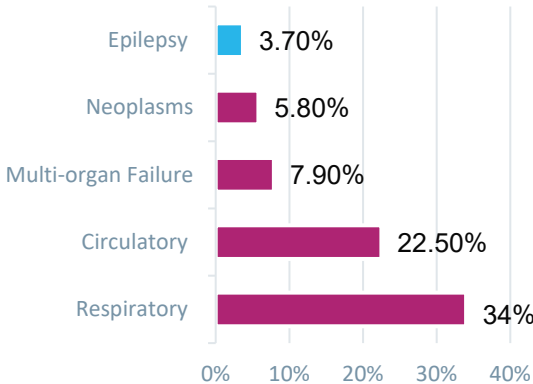
was the median age at death for people with a learning disability in GM. This is the same as 2022.

42% of people reviewed in GM had a severe or profound learning disability. This is an 8% increase from 2022. 24% of completed reviews were for people who has a moderate learning disability and 34% had a mild learning disability

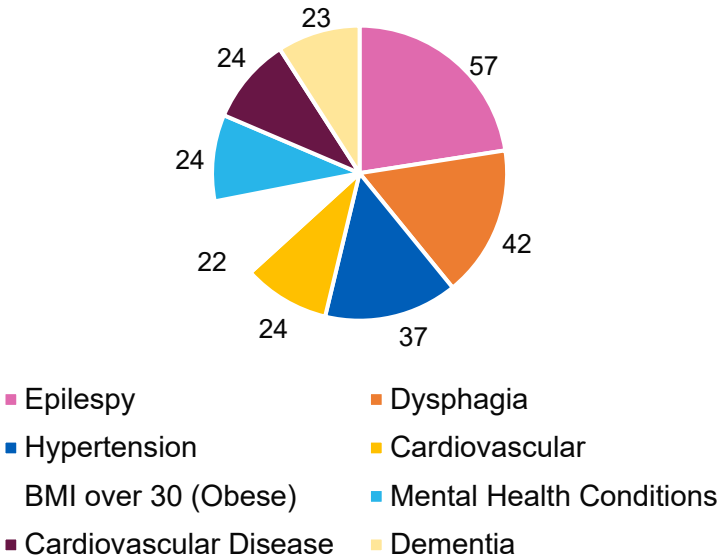
DNACPR

71.7% of people had a DNACPR in place at the time of death. Reviewers judged this was correctly followed 75% of the time. This is slightly higher than 2022 in GM, and higher than the national average in 2022 of **63%**

5 Most Common Causes of Death



8 Most Common Long Term Health Conditions



59% of people died in hospital. This is an improvement from 2022 when 68% of people with a learning disability died in hospital. There have been continued efforts to ensure people die in the place of their choosing

Progress from 2022/2023 LeDeR report

What we said 2022/2023

- Localities to prioritise those people who didn't have an annual health check in 2022 and continue to improve uptake.
- To increase the number of people with a health action plan in 2023/2024

What we have done

- Improvement in annual health check uptake each year with an improvement from 66%-81%
- 98% of people having an annual health action plan

What difference this will make for people

- Annual health checks ensure the early detection of potential health issues allowing for timely intervention. Regular health checks have been shown to identify the early signs of diseases and allow for prompt treatment in addition to uptake of preventative measures such as immunisation and screening.
- LeDeR has shown that those people who have an annual health check and a good quality health action plan have had medication and physical health reviews including vaccination and screening.

- To work with people with lived experience and introduce further bespoke cancer screening reasonable adjustment pathway pilots

- Bowel Screening project expanded across the three screening sites in GM. This has improved the bowel screening uptake
- Breast Screening Charter due for release in 2025
- Cervical screening reasonable adjustment pathway developed and due for launch in 2025

- The screening pathways will ensure that there is appropriate support and reasonable adjustments made for people to attend screening appointments. Screening is important to detect health problems early, before symptoms appear
- There has been an increase in the number of people with learning disabilities returning their bowel screening Faecal Immunochemical Test (FIT) test

Progress from 2022/2023 LeDeR report (2)

What we said 2022/2023

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



What we have done

- Multi-site Calm outreach vaccination services implemented in 2024 providing dedicated appointment-based clinic capacity for residents with additional needs such as learning disability and autism
- Making information about the importance of flu protection more accessible including a new easy read leaflet across GM



What difference this will make for people

- The clinics provided a safe environment where people could take as long as they needed to receive their vaccinations
- Each appointment was tailored to meet individual needs and requirements

- GM will undertake a validation of Learning Disability Registers



- Data validation of learning disability registers to ensure they are accurate to enable targeted intervention. This has led to a 1000 extra increase in people on the learning disability register across GM



- Accurate identification – accurate registers enable more targeted interventions and provision of appropriate reasonable adjustments
- Ensures the correct coding is used so people get the right care and treatment
- Improved efficiency- identifies people incorrectly listed on the learning disability register

Progress from 2022/2023 LeDeR report (3)

What we said 2022/2023

- End of life and palliative care. Nationally more people with a learning disability die in hospital compared to the public. We want more people to have end of life care and to die in a place where they choose
- DNA CPR - To continue to promote and ensure the appropriate use of DNACPR decisions for people with a learning disability and autistic people

- GM Menopause - Patient and Public Engagement Project

What we have done

- The number of people dying in a hospital has reduced significantly in GM (from 69% to 58%) with some excellent examples of end-of-life care in LeDeR reviews
- The hospice educators and community learning disability teams are working together delivering training awareness and developing a standardised training package
- Continued improvement in correctly followed DNA CPR

The project was delivered in three stages:

- Systematic literature review aimed to identify knowledge gaps and improve understanding of existing information
- Workshops – three experience-based, co-designed workshops were developed, delivered and evaluated
- Survey to people with lived experience and wider stakeholders to elicit experience and knowledge

What difference this will make for people

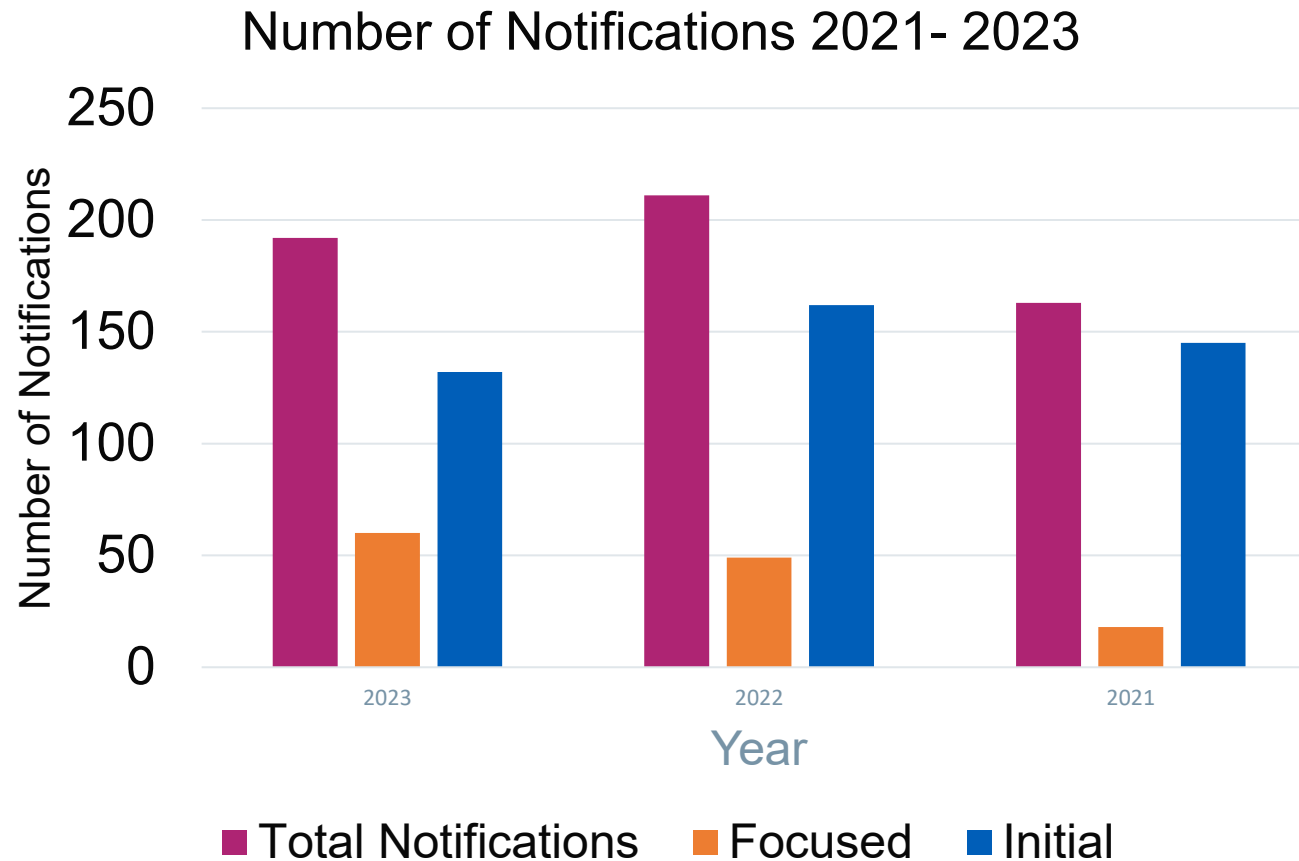
- Good end of life care, particularly when following a Gold Standard Framework provides significant benefit to those nearing their end of lives including improved symptom management. Enhanced quality of life, respect for personal wishes, better communication with families, and a reduced likelihood of hospital admissions, allowing individuals to “live well and die well” in their preferred location.

- [Watch a video about the Menopause Project here](#)
- Recommendations to improve and embed menopause support services across GM have been developed. Previously this has been an area that has not been addressed across GM or nationally leading to poor understanding and potential diagnostic overshadowing. The outcome will have the benefit of raising the profile and supporting women to get the correct support they need.

Review of the Lives and Deaths of People with a Learning Disability and Autism

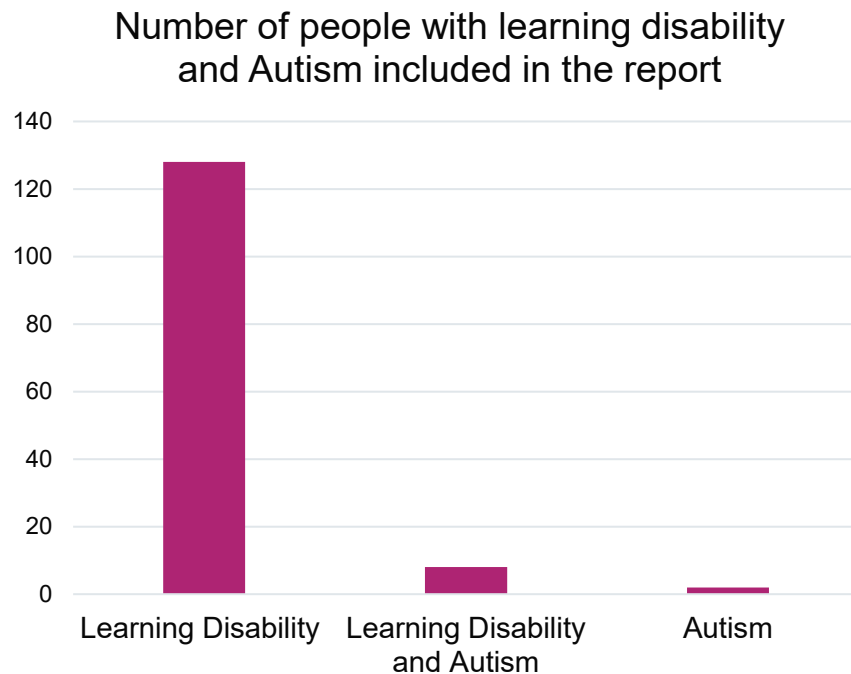
Greater Manchester 2023 notified reviews

GM LeDeR notifications 2021-2023



- GM received 192 notifications in 2023 which is a slight decrease from 211 notifications in 2022 but an increase on 2021.
- There are two types of LeDeR reviews - **Initial and Focused**.
- **Initial reviews** are intended to be an assessment to see if there needs to be progression to a focused review.
- A **focused review** explores in more detail the life and death of a person and any examples of good practice and areas where care could be improved.
- GM is increasing the number of focused reviews each year in line with national recommendation of around 30-35%.

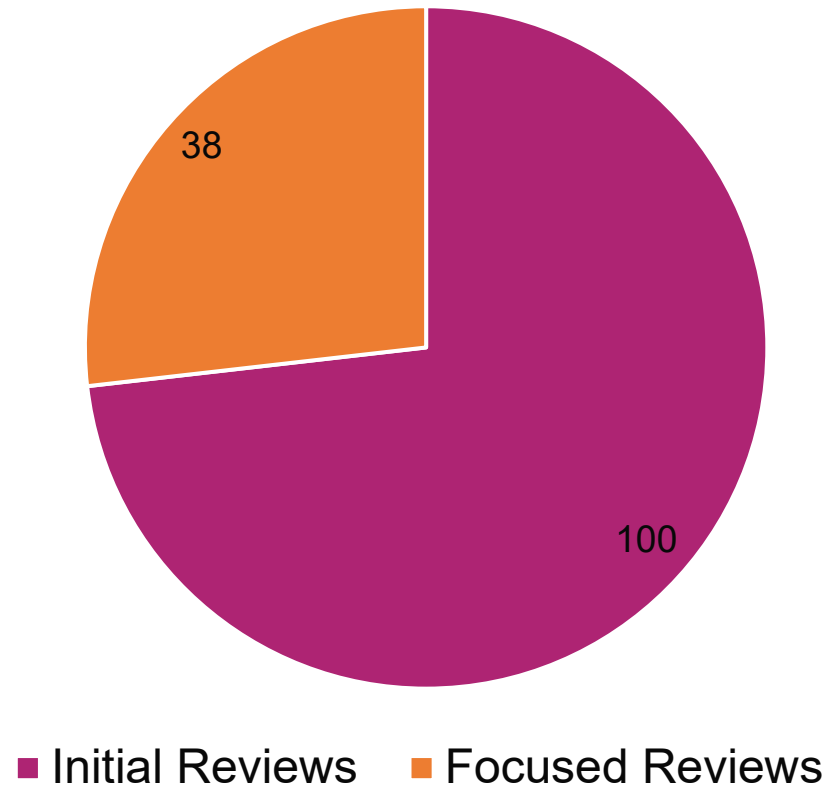
About this report



- This report reflects 138 of the closed 2023 notified LeDeR reviews at the point of data extraction. This is 72% of the total notifications in this year, so there may be some slight additions to the data when these are completed. These reviews were not completed at the point of data extraction.
- The aim of the report is to share learning from the LeDeR programme to promote change across the health and care system with the aim of reducing health inequalities and preventing premature mortality.
- When reading the report, it must be kept in mind that referral to the LeDeR is not mandatory, so this does not have complete record of all eligible deaths of people with learning disability and/or autism. It is a requirement within the NHS contract for eligible deaths to be reported to LeDeR, however there will be a proportion of people that are not known to services and are therefore not notified.
- The numbers in some subcategories are still small; findings and comparisons must be considered indicative rather than conclusive.
- Autism (in the absence of learning disability) became part of the LeDeR programme in 2022. GM completed 2 autism-only reviews in 2023.
- A key priority for GM was to increase the number of autism-only notifications in 2024. **In response** to this, there have been a further 14 autism-only notifications in 2024.

Initial and Focused reviews

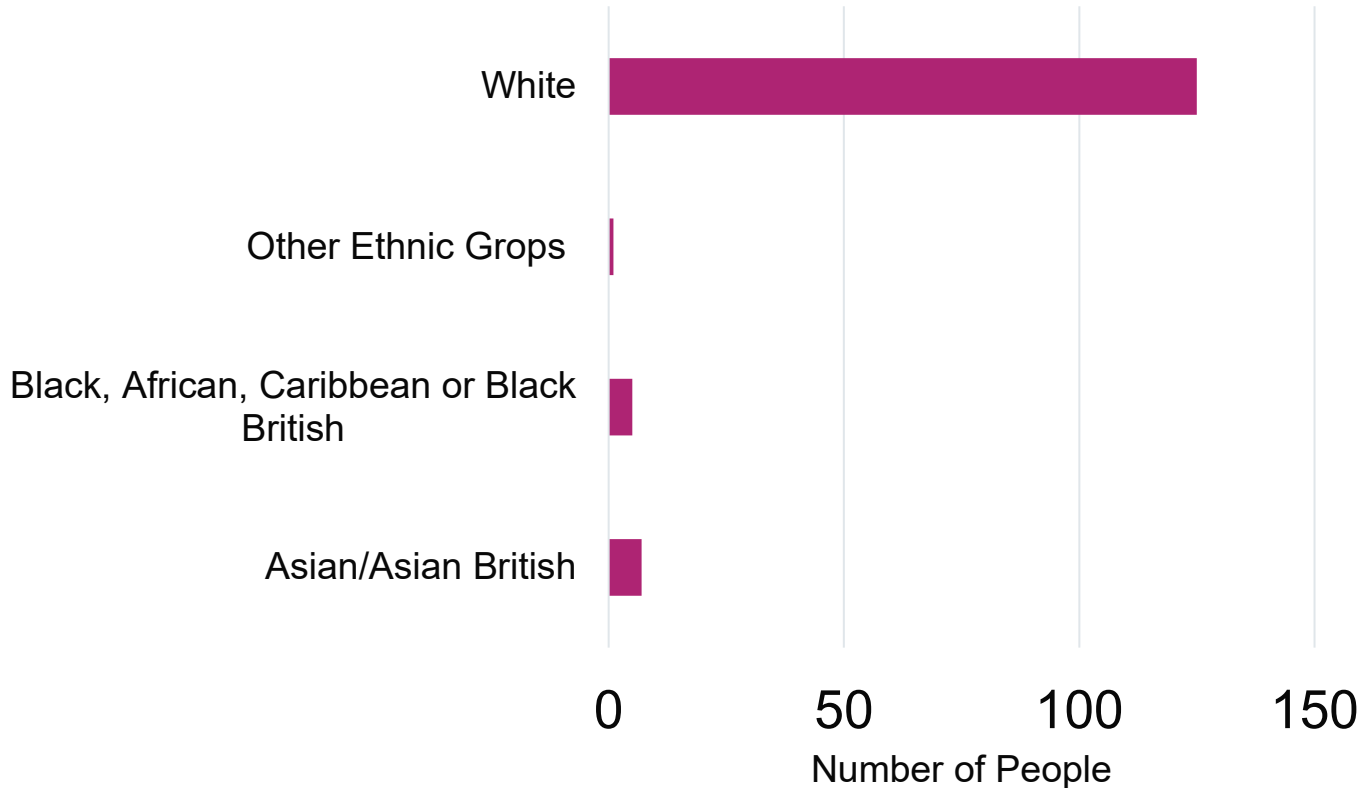
Initial and Focused reviews



- The report includes information from 38 focused reviews and 100 initial reviews.
- In line with national aspirations of 30-35% focused reviews, GM is increasing the number of focused reviews each year and there is an increase in the number of focused reviews reflected in this report.
- A focused review will automatically be carried out where;
 - The person is from a Black, Asian or Minority ethnic group,
 - There is a clinical diagnosis of epilepsy without learning disability
 - The person had been under mental health or criminal justice restrictions at the time of death or 5 years previously.
- GM has implemented local priority areas for which focused reviews will be undertaken. This includes; sudden death in epilepsy (SUDEP), BMI over 30 with two associated long term conditions, causes of death choking, cause of death aspiration pneumonia and concerns noted and cause of death urosepsis. **The outcome** of this is increasing our understanding- both learning and good practice on which we are implementing change and improvements.

Ethnicity

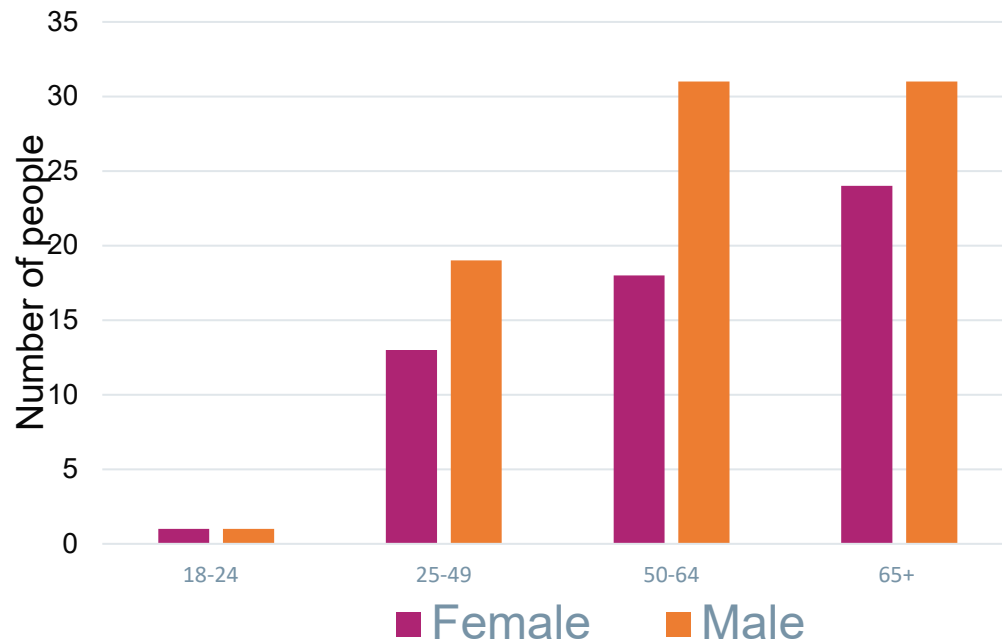
Completed Reviews by Ethnicity



- Most people that were reported to the LeDeR programme in 2023 were white - 125 people (90.6%). This is the same as the 2022 GM LeDeR report. Nationally, 94% of people with a learning disability who died were denoted as white (2022)
- There were 7 people (5%) Asian/Asian British and 5 people (3.62%) Black, African, Caribbean or Black British.
- Whilst the data for ethnicity in GM is too small to draw conclusive summaries, nationally people from ethnic minority groups were more likely to die at a younger ages than those who were white.
- 3 people out of 7 completed reviews from Asian/Asian British did not have an annual health check.

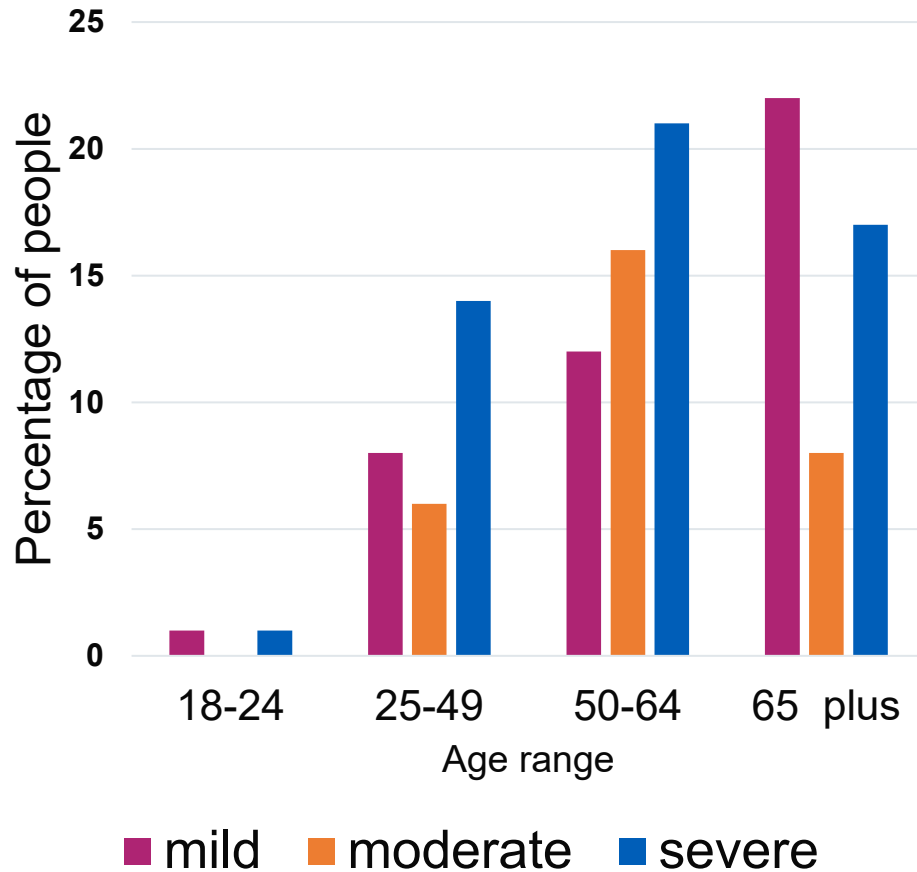
Age and gender

Age range and identified gender of completed reviews



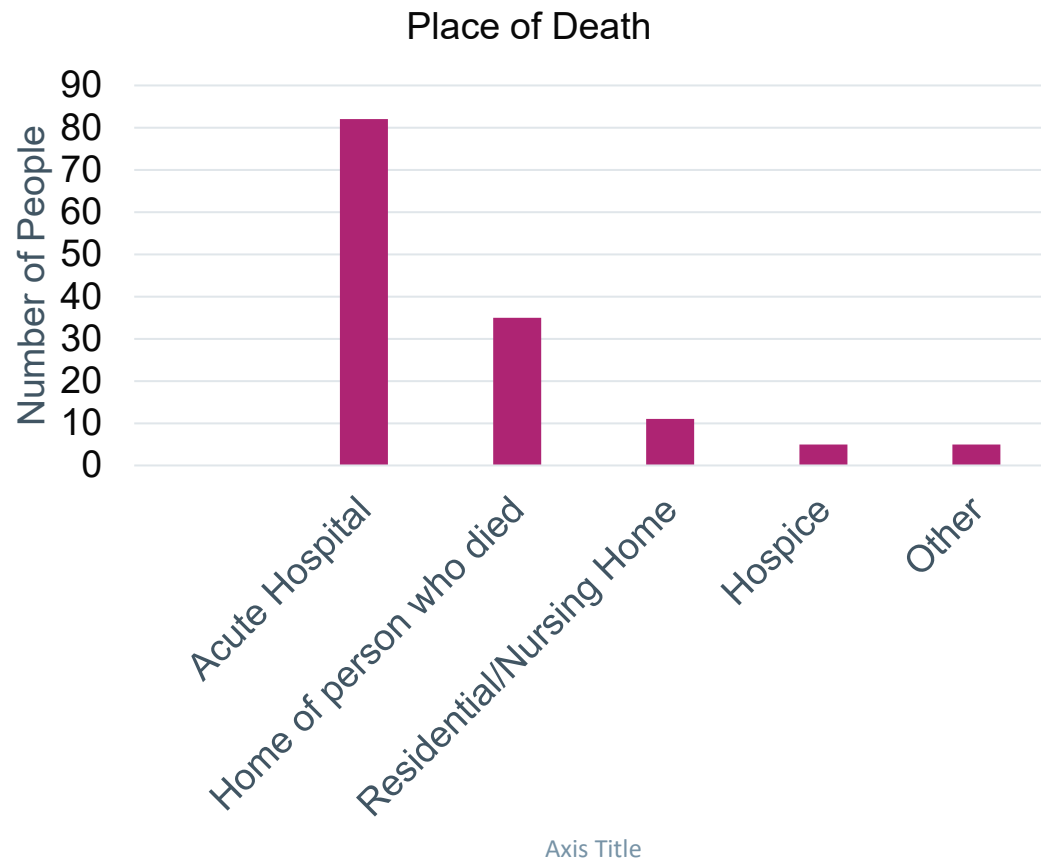
- 40.5% of the completed reviews in 2023 identified as female and 59.5% identified as male. There were slightly more males notified in GM in 2022
- Nationally, 55% of notified deaths to the LeDeR programme were male in 2022.
- 39.8% of the GM deaths were over the age of 65.
- The overall **median age** of death for the completed reviews is **62 years**. This is the same as both the GM and the national average in 2022. Nationally, there is an increase on the median age from 2018 which was 61.8

Level of learning disability



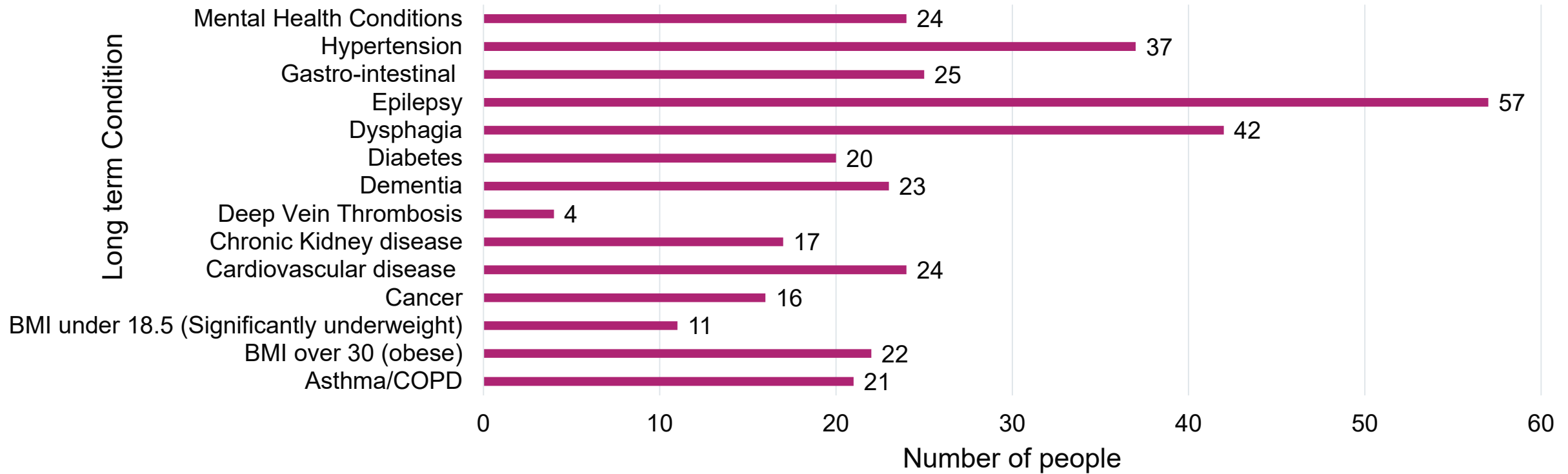
- Information on the severity of learning disability was available for 126 people who had a completed review. This information is important as it allows us to analyse specific health and care to determine targeted learning.
- 42% of people reviewed had a severe or profound learning disability, with 24% having a moderate learning disability and 34% having a mild learning disability. The number of people with a documented severe or profound learning disability with a completed review is higher in 2023 than 2022 by 8%. This will continue to be monitored in 2024/2025.
- More people with a severe or profound learning disability died in the 25-49 age group than people with moderate or mild learning disabilities. Nationally, severity of learning disability was associated with the age of death with the greatest hazard of death amongst those with a profound or severe learning disability.
- Caution must ensue with conclusive correlation of severity of learning disability and age of death; this data relies on this information being correctly coded during the notification/review process and further insight is required.
- Similarly, national learning has stated that people with a mild learning disability are less likely to be in supported settings where carers can monitor their health and safety to reduce the risk of avoidable deaths and support with appointments. Working with our system partners, this will be a focus for GM in 2025.

Place of death



- 59% of people with completed reviews died in hospital in comparison to 45% of the general population in 2021.
- This is a **significant improvement** on 2022 for GM when 68% of people with a learning disability died in hospital.
- The LeDeR reviews have praised the continued efforts made by carers and the wider multidisciplinary team to ensure the person dies at home if it is their wish.
- There has been much work in collaboration with hospices, the wider learning disability teams and localities to improve end of life care, but there is much work to do to improve this further.
- Further exploration of the factors associated with the place of death, such as access to palliative care at home and in the community, is required to ensure optimal end of life care.

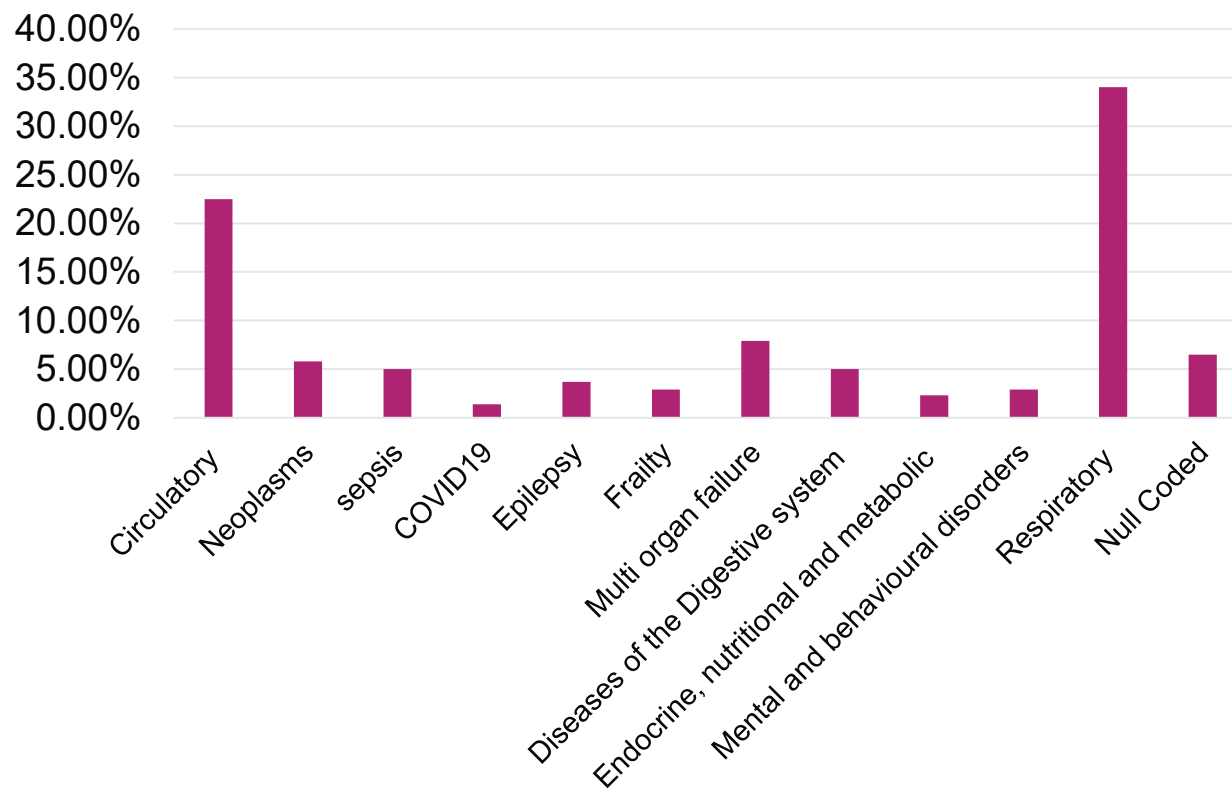
Long term health conditions



Long term health conditions continued

- Data was available on 14 long term health conditions. There are conditions that people had a diagnosis of during their life based on available medical history rather than the cause of death. Most people with a completed review had a least two long term health conditions.
- Overall, epilepsy was the most frequently reported long term condition again in GM, reported in 57 of the reviews (41%). This is an increase from the previous year in which epilepsy was reported in 36% of the reviews.
- Epilepsy was the most frequently reported long term health condition in all age groups except 65 plus where hypertension (high blood pressure) and dysphagia (swallowing difficulties) is the most reported. Nationally in people with a learning disability, epilepsy is the long term condition associated with dying at a younger age.
- There were at least 22 people with a reported BMI over 30 (obesity).
- Dysphagia was the second most frequently reported long term condition in GM which was reported in 42 of the reviews (30.4%).
- Hypertension (high blood pressure) was the most reported long term health condition in people with mild learning disability in GM. BMI over 30 was the second most reported health condition. This is consistent with the information from the 2022 GM LeDeR figures.

Most common causes of death



- Overall, respiratory was the most common cause of reported death in GM for a second year (34%). The most common causes of respiratory deaths are aspiration pneumonia, respiratory diseases and pneumonia.
- Circulatory was the second most reported cause of death in GM (22.5%) with cerebrovascular heart diseases and hypertensive diseases the highest cause.
- Diseases of the circulatory system was the highest reported cause of death for people with a mild learning disability. Respiratory was the most reported cause of death for people with moderate and severe learning disability.
- Nationally, diseases of the circulatory system was the most common underlying cause of death in people with a learning disability.
- In 2022, the most common cause of death in the general population was dementia and Alzheimer's diseases which accounted for 11.1% of all deaths with circulatory (ischaemic heart disease) the next most common cause.

Autism reviews

In Greater Manchester we completed 2 reviews of autistic adults in 2023



Both were men

Age 34 and 54 years respectively

Both were White British

Both had mental health needs

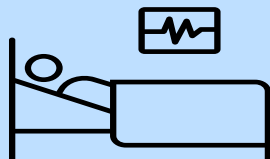
Both had a late diagnosis of Autism

Complex health care needs with limited engagement with services

Death was pneumonia and unascertained

Self-neglect present in both reviews

Both died in acute hospital



Learning from the reviews

- Autism not flagged during hospital admission and no reasonable adjustments put in place
- Limited evidence of collaboration between professionals and no holistic assessment of the person's needs
- Limited evidence of post-diagnostic support

National LeDeR learning informs us there is an increased prevalence of autistic adults experiencing mental health problems across their lifespan with reported difficulties in accessing mental health services on account of their autism diagnosis.

There is an increased prevalence of attempted and actual suicide for autistic adults.

Autistic people are less likely to access routine or long-term condition specific health screening..

Greater Manchester Autism Strategy – our commitments

Greater Manchester

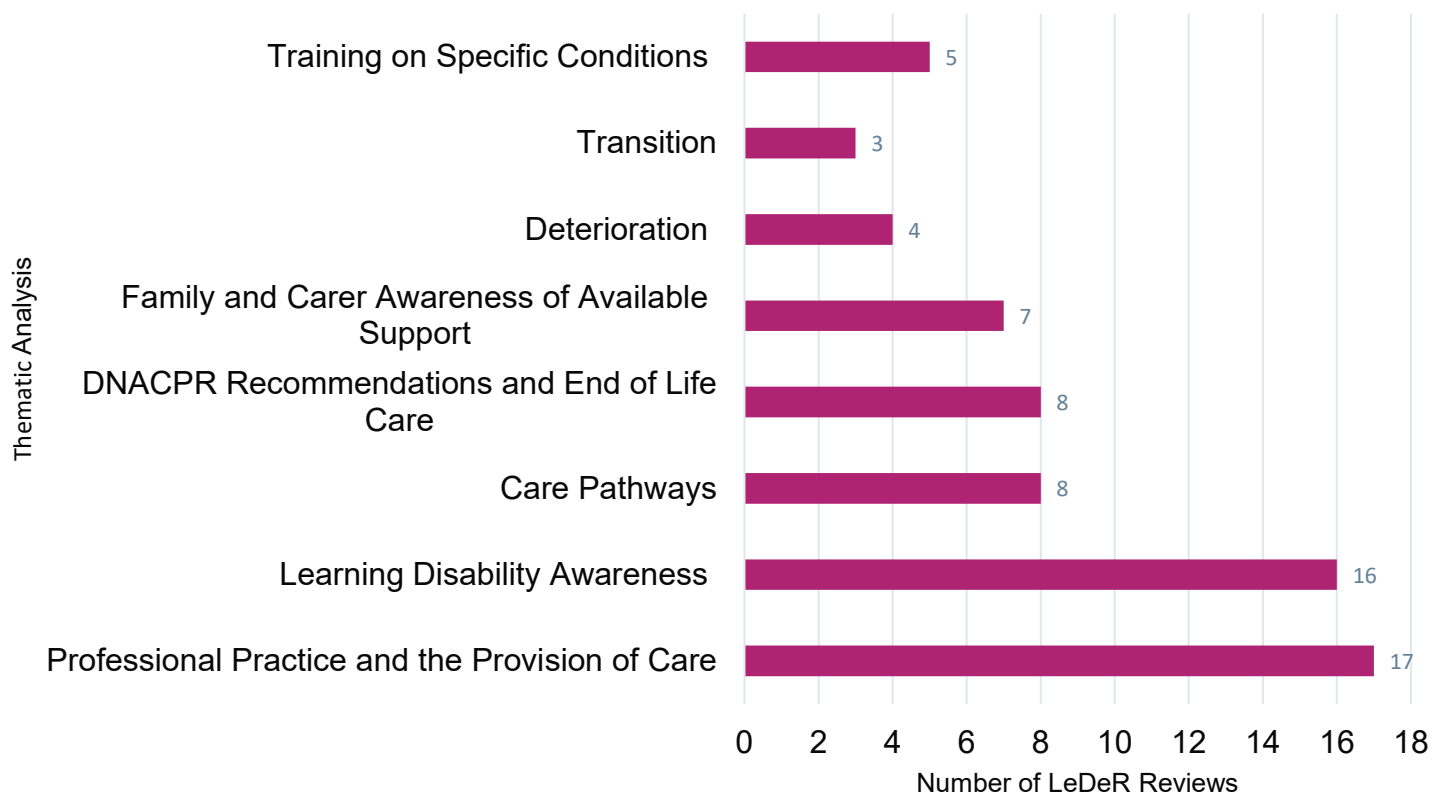
	<p>Understanding and Acceptance</p> <ul style="list-style-type: none"> Autistic people and family members feel that there is widespread acceptance, understanding and celebration of autism from a wide variety of professionals as well as by members of the public 		<p>Health and care inequalities</p> <ul style="list-style-type: none"> Autistic people getting a timely diagnosis and a variety of post diagnostic options are available Autistic people being supported to live a healthy and fulling life and get appropriate and reasonably adjusted mental and physical health support when needed People with intersectional needs are having their needs met in appropriate services that understand their needs
	<p>Education and Transition</p> <ul style="list-style-type: none"> Appropriate, timely, reasonably adjusted educational support and transition support. The support is clear and young people lead on the solutions Autistic people with an EHCP accessing all the support identified in their plan 		<p>Building the Right Support and inpatient</p> <ul style="list-style-type: none"> Less autistic people to be admitted to hospital because the community support is much better If admitted, them autistic people have a reasonably adjusted set of therapies and support offered to ensure they are discharged as quickly as possible Autistic people can access reasonable adjusted support in relation to housing
	<p>Employment</p> <ul style="list-style-type: none"> Autistic people who are able and wish to work to be in fulfilling jobs and careers and more leadership and progression opportunities available 		<p>Criminal justice system</p> <ul style="list-style-type: none"> Autistic people to have a better understanding of the CJS process with appropriate reasonable adjustments in place Autistic people not be exploited or victims of crime CJS services to have a greater understanding of neurodiversity and understand how to apply reasonable adjustments

Tackling health inequalities

- Introduction of GM Post Diagnosis Standards for autistic adults. This will ensure equity of good quality post diagnostic support across GM.
- The standards set out what is required for neurodivergent people who may be on pre-assessment pathways, the information that autistic people receive about autism and the ongoing support they might need.
- An audit of post diagnostic standards for children and adults is being implemented to ensure people get the right support after diagnosis.

Positive practice

Positive Practice Themes



- The thematic analysis of LeDeR reviews includes learning and recommendations and positive practice themes. These have been grouped under key themes.
- There were many examples of positive practice and the provision of care in addition to learning disability awareness. This includes practice across all sectors: primary, secondary, adult social care and the voluntary sector.
- The expertise and positive practice of Learning Disability Nursing was evident when they are involved in care. This includes care coordination, health facilitation, care pathways, training and specialist advice.
- DNA CPR was correctly followed in 75% of reviews with notable excellent examples how this was applied in practice.
- There was some excellent practice around end-of-life care.

Learning themes

Themes	Area of Learning
Professional Practice and Provision of care	<ul style="list-style-type: none">• Quality of annual health checks and health action plans in some cases is poor• Evidence of some people not brought for appointments across all settings (when lack capacity). If not attended for appointment coded as “Did not Attend”. No evidence of follow up in some cases• In some cases, there is still and inconsistent delivery of preventative interventions – immunisation, screening, medication and long-term condition reviews
Care Pathways	<ul style="list-style-type: none">• Length of stay in hospital for some people remains excessive due to complexities with discharge process• Inconsistent involvement of specialist learning disability services both in acute and community settings• Management of long-term conditions inconsistent in some cases - especially weight management, constipation and epilepsy• Reasonable adjustments, including use of hospital passport, not always applied when required in both acute and community settings
Learning Disability Awareness	<ul style="list-style-type: none">• Application of Mental Capacity Act and Best Interest inconsistent
Training on specific conditions	<ul style="list-style-type: none">• Inconsistent management of certain long-term conditions within social care settings
DNA CPR recommendations and End of Life Care	<ul style="list-style-type: none">• Although correct documentation pertaining to DNACPR is improving every year, there are still some instances where the reviewer has felt this was not followed, especially advocacy input• Although LeDeR is seeing more evidence of good of end-of-life care, this is still inconsistent in some cases

Learning into action - Quality Improvement

Improving health and wellbeing in Greater
Manchester

Quality Improvement and Learning into Action

- Collaborative working has helped to address health inequalities whilst transforming the lives of people with a learning disability and autistic people in GM. Our work in the LeDeR programme is fully joined up with our ICB plans to make sure we continue to work together to promote healthy lives and prevent ill health.
- The GM Good Health Group, with representation from each of the 10 localities, oversees the development, delivery and performance of the GM good health priorities.
- GM worked with the University of Salford, utilising **Appreciative Inquiry**, to understand the nature of the LeDeR learning and identified key principles which will help to embed and sustain learning going forward.
- This approach has had the benefit of focusing away from the problems and towards what is working well. In addition, that strong networks and relationships and the use of learning disability focused roles play a significant part in embedding and sustaining learning. GM is committed to working collaboratively with people with lived experience, localities and specialist learning disability services in service improvement and this has been evidenced within learning into action in 2024.

Positive end of life practice

Tina lived in 24 hour supported living tenancy, with access to staff 24 hours a day. Her package of care met her needs well and she was supported to attend all appointments. There was an updated health action plan, care plans, end-of-life plan and risk assessment. This multidisciplinary approach ensured that person centred care was in place. The provider service and other professionals involved at the time demonstrated excellent joined up working to ensure she was fast tracked and discharged home to die in her preferred place (at home) surrounded by her family.

RIP Tina

Peter lived at home with his sister. As his health deteriorated and following numerous hospital admissions, his GP sat down with him and his sister to talk about end-of-life care planning. Peter and his sister's preference was to stay at home and not have any further hospital admissions. Along with his sister, GP and wider health team, they wrote a hospital avoidance plan. As his health further deteriorated Peter was placed on a Gold Standard Framework (a programme that helps GPs and primary care teams provide high quality care for people nearing end-of-life). Peter died at home surrounded by his family

RIP Peter

- GM is continuing to work closely with hospice providers and is currently reviewing palliative and end of life care education needs.
- Education is crucial and we are developing a standardised training resource to support with this.
- GM in conjunction with NHS England (Northwest) will be delivering a conference focused on advanced care planning and end of life support for people with a learning disability. This will further enhance collaborative working and understanding.

Improving respiratory health

Increasing Vaccination uptake

- Respiratory was the leading cause of mortality in GM for the second year, reported in 34% of the total closed reviews.
- Multi-Site Calm outreach services implemented the provision of dedicated appointment-based clinic capacity for residents with additional needs such as learning disability and autism.
- The calm clinics service featured longer appointment slots and clinical spaces suited to caring for individuals less able to tolerate noise and disturbance.
- These clinics will be fully evaluated at the end of the programme.

Dysphagia

- GM is currently scoping Dysphagia pathways considering the new clinical guidance from British Thoracic Society. Working collaboratively with our wider partners, including speech and language therapy, this will inform future pathways across GM.

Get your Flu and COVID vaccinations



It is very important to have your **COVID** and **Flu** vaccinations.



It is safe to have **both vaccinations** at the same time but don't have to if you prefer to have one.



You can have your vaccinations at one of our clinics.



You can book an appointment by calling the Gateway on: **0161 947 0770**



The Gateway can also book you a **free taxi** to and from your appointment.



They can also book you a **BSL interpreter** if you need one.



You will **not be rushed**. You can have a drink and sit down first.



There will be a **quiet space** if you need one.



You can bring a **carer, friend or family member** with you to help.

Epilepsy action in GM

In response to the learning from our LeDeR annual report in 2022, GM is undertaking a comprehensive benchmarking review of epilepsy services. Working with our regional colleagues from NHS England, Midland and Lancashire Commissioning Support Unit and Epilepsy Action, this is a critical to reduce premature avoidable deaths

Working through a comprehensive self-assessment tool has enabled us to collectively review and benchmark how services and support can join together to meet the holistic needs of the population

In 2025 we will bring system partners together to collectively reflect on the outcome of the self-assessment and work together to consider where action and improvement may be needed

Healthy weight and obesity

People with a learning disability are at an increased risk of being overweight or obese compared to the general population, with poorly balanced diets and very low levels of physical activity. This risk, in turn increases the likelihood of a range of health and social problems.

Obesity is a re-occurring theme in LeDeR reviews in Greater Manchester with at least 22 people noted to be obese (BMI over 30) from the completed reviews.

We are gaining an increased understanding of the themes and learning related to this as a key line of enquiry from which we can implement actions. There is significant learning relating to:

- Weight not recorded in Annual Health Check and a missed opportunity to discuss this further
- Weight management pathways not implemented or followed
- No referrals to specialist weight management services
- Numerous associated health conditions including diabetes, hypertension
- Need for (continuous positive airway pressure) CPAP and poor compliance
- Capacity to make decisions relating to balanced eating to manage their weight and health risks not assessed
- Care package did not include weight management support
- Weight management and dietary advice not implemented by providers

Action

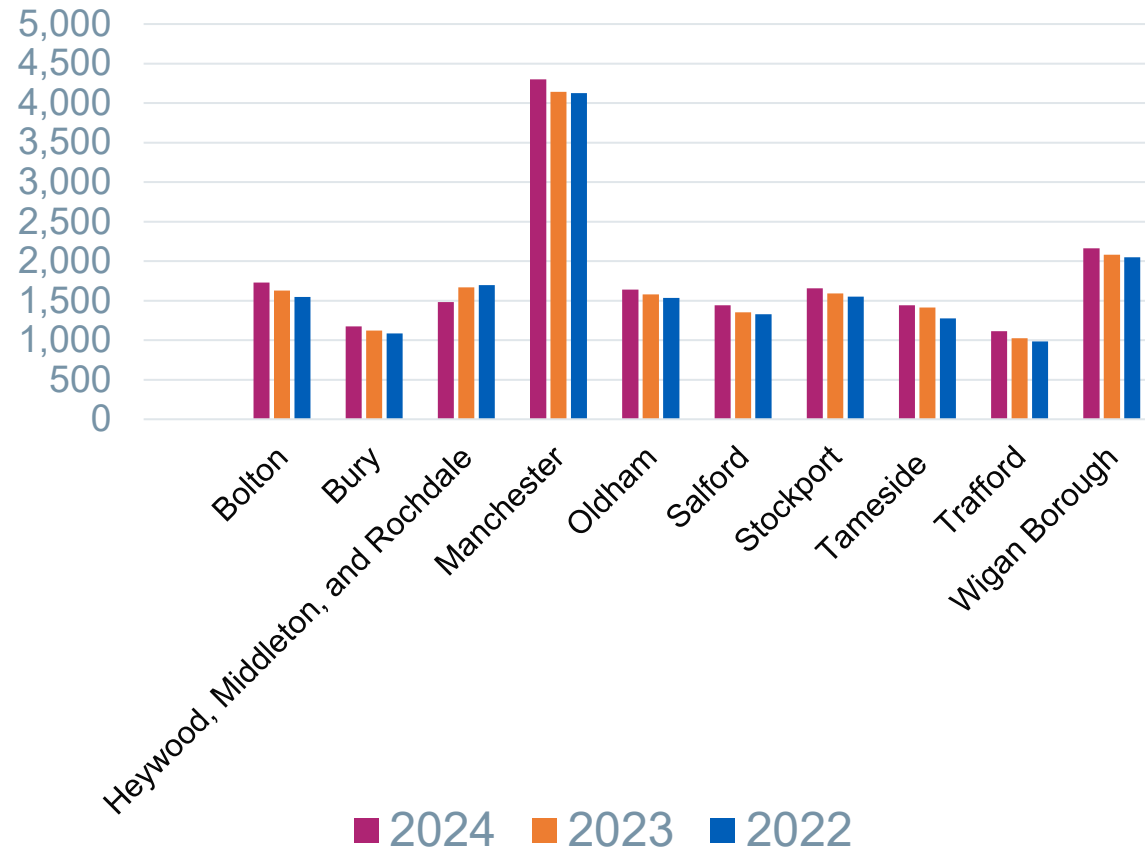


A Weight Management toolkit for all Health Professionals supporting people with learning disabilities and Autism to live well

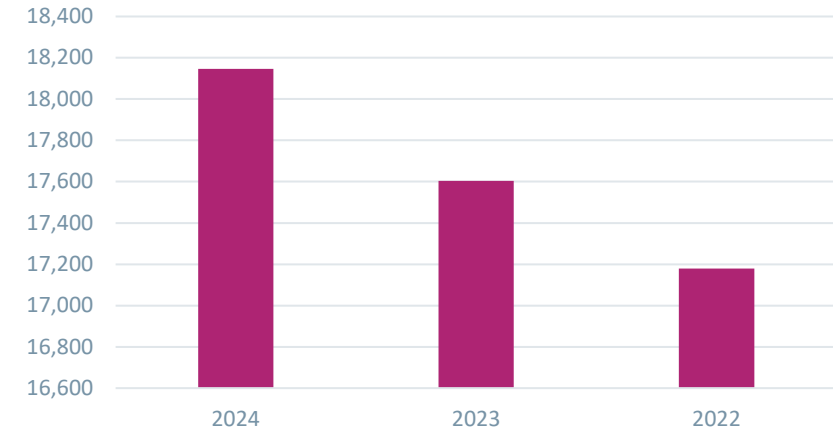
- Launch of Learning Disability and Autism Weight Management Toolkit. This aims to provide an aspirational weight management pathway. This toolkit supports services to adapt, be inclusive and accessible for people with a learning disability and autistic people.
- This includes clear weight management pathways for Tier 1, 2, 3 and 4 and advice and guidance for services to consider.

People with a learning disability on the GP register

Number of people with a learning disability on the GP register by locality 2022-2024

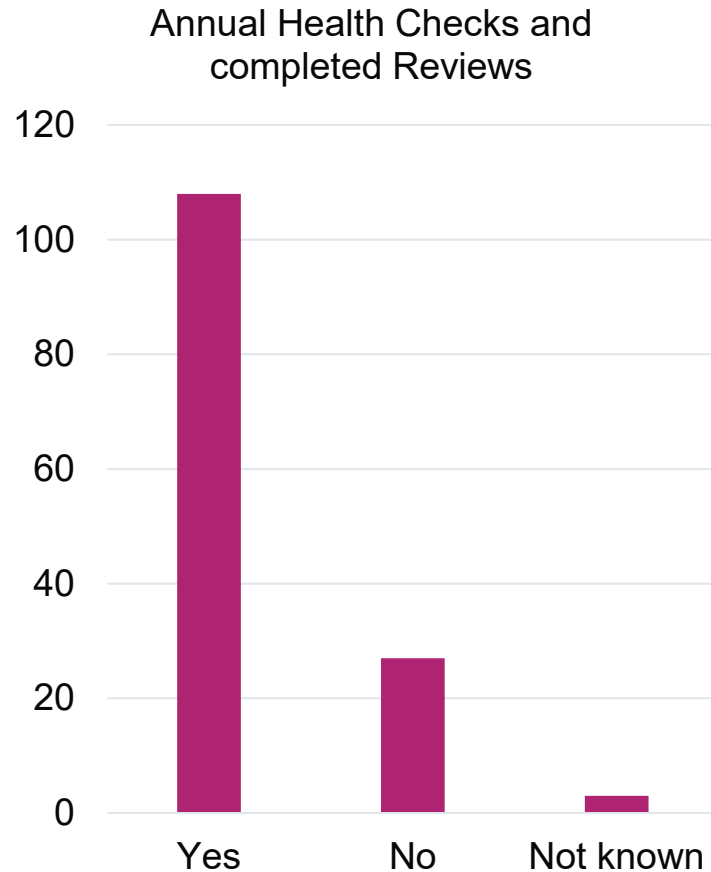


Greater Manchester 2022-2024



- Much data validation work has been ongoing in 2024 to ensure that the learning disability registers held by primary care are accurate.
- This has seen an increase an additional 1000 people on the learning disability registers.
- The register is important because it helps ensure that people with a learning disability receive the support and care they need.
- **The outcome** of this has been a yearly improvement in the number of people having an annual health check. Accurate registers enable targeted interventions.

Annual health checks

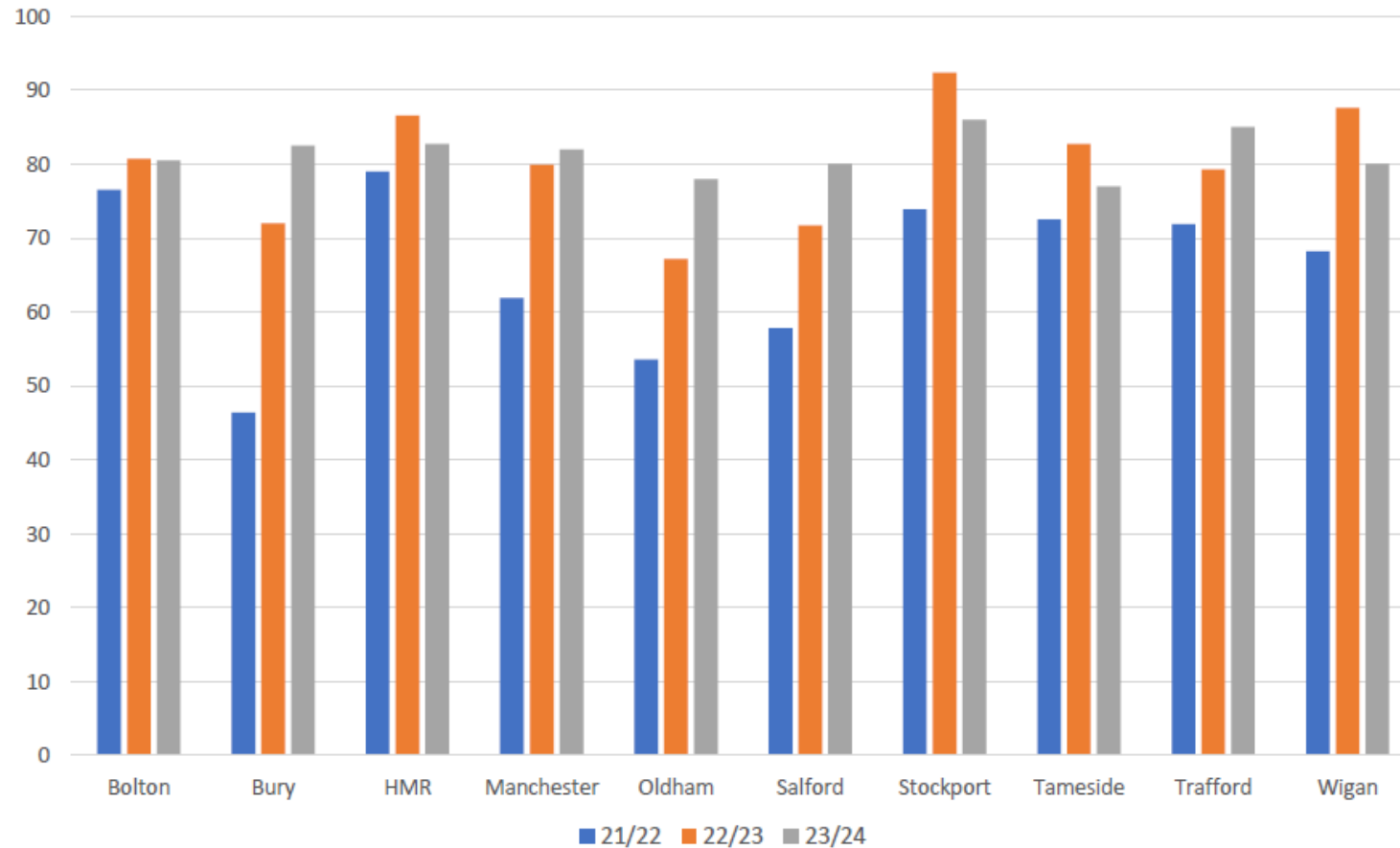


- The question “Did the person have an annual health check” was introduced as a mandatory question in the review in January 2023, therefore it is not possible to provide a comparison to previous years.
- From this data, 108 people (78.2%) had an annual health check compared to 27 people (27%) who did not.
- The lowest uptake of annual health checks is in people with a mild learning disability (68%) with the highest by those with a moderate learning disability. (83%). This is in line with national data that suggests people with a mild learning disability are less likely to live in settings that may provide support to attend appointments.
- It is important that a good quality health action plan is updated following an annual health check. This personalised document outlines specific actions to maintain or improve their health based on the results of annual health check.
- A priority for GM in 2025 is working with primary care to implement self-audits and improving the quality of annual health checks and health action plans.

Annual health checks

What we have done in 2024

- Prioritising those who have not had an annual health check
- Monthly monitoring and targeted communication
- Awareness-raising events
- Employing 5 primary care assistant practitioners across Pennine Care community learning disability teams
- Increased use of Additional Roles Reimbursement Scheme (ARRS)
- Community Learning Disability Teams working with General Practice
- Focused events with young people and raising awareness via Special Educational Needs and Disability (SEND) networks



GM improvement each year

21/22 - 66%
22/23 - 80%
23/24 - 81.4%

98% of people had a Health Action Plan

Importance of annual health checks

- Early detection of disease –such as hypertension (Hypertension) high cholesterol, diabetes and certain cancers in their early stages when treatment is most effective.
- Preventative care - assess risk factors and provide personalised advice.
- Monitoring existing conditions and adjust treatment as necessary.
- Improved quality of life - by addressing concerns early, annual health checks can identify potential issues that may require support.
- **A deep dive of 38 focused reviews** has highlighted that in seven cases, there was either no health action plan with the annual health check or this was cited to be of a limited standard.
- **When there was a comprehensive health action plan with the annual health check, there was documented medication reviews, lifestyle changes including review of long - term health conditions. In addition, there was discussion around screening including the administration of vaccines if required.**

Kevin's Story

Kevin,40, was homeless, misusing substances and highly vulnerable.

Primary care assistant practitioner Akum Ibekwe is from the Oldham community learning disability service, provided by Pennine Care NHS Foundation Trust. She worked with the learning disability champion at an Oldham GP practice to review the learning disability register. This highlighted Kevin hadn't seen his GP or had a health check for four years, due to having no fixed address or phone number.

Akum said: "My first step was to ask if he was happy to collect his weekly money from a local office in cash, rather than having it transferred to a card. This provided a regular opportunity to meet with him, build trust and develop a relationship."

"He began to spend an hour or two with me under a warm roof, where he enjoyed a warm drink and food, and we chatted about support and adjustments he needed. Eventually he agreed for me to arrange for some temporary accommodation. When I next saw him, he was feeling positive as he'd had a warm bath for the first time in months and slept on a nice bed."

"He agreed to have a health check with a nurse from the borough's drug and alcohol service, which meant they could assess his substance misuse issues at the same time as his wider health needs."

"The health check identified Kevin had not received any winter vaccines, had injuries to his back, arms and hands, urinary incontinence, and was severely underweight. There were also concerns about his mental health. The results were shared with his GP, for follow up."

"I'll continue to support Kevin and work with colleagues to make sure he remains healthy and safe."

Bowel cancer screening

- People with learning disabilities have a poorer uptake of bowel cancer screening compared to the general population. This was evident in the LeDeR reviews. The percentage of people with a learning disability who had colorectal cancer screening in 2022/23 nationally was 50% compared to 66% of the general population.
- GM has introduced a learning disability flagging project across the three screening hubs. Pre-notification lists are sent to the Cancer Screening Improvement Leads (CSIL) and referrals are focused on those people who have not previously returned Faecal Immunochemical Test (FIT) kit.
- These referrals are sent to the Community Learning Disability Teams (CLDTs) and subsequently assigned to a Primary Care Assistant Practitioner. This structured approach ensures tailored support, improving participation and access for individuals with learning disabilities.
- The Bowel Screening Flagging Programme is designed to identify people with a learning disability who have not previously participated in the bowel screening programme and offer them tailored support to successfully complete their FIT kit. This initiative includes providing varying levels of assistance, such as educational resources and guidance.
- Evidence indicates that once a person receives educational support and successfully completes their screening, they are likely to do so independently in subsequent years.

Bowel cancer screening

An easy read guide



An easy read about the NHS bowel cancer screening test

Outcomes of bowel screening project (BSP)



Manchester Foundation Trust Programme

230 People identified as part of BSP. Up to now, 126 people have completed their bowel screening kit. 61 out of 117 were first timers to bowel screening- research shows a first-time positive experience with screening is pivotal to continued participation






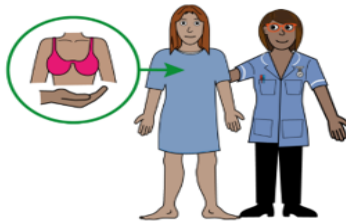
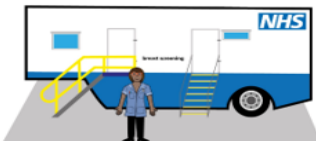

- 2 people had missed 2 invites for bowel screening
- 1 person had missed 3 invites for bowel screening
- 2 people had missed 4 invites for bowel screening
- 2 people had missed 6 invites for bowel screening



Pennine Screening Centre

- 94 people were referred as part of the project for further support. 56 kits have currently been returned
- Uptake has improved by 17% due to the flagging project
- 18 people had not responded up to three time previously

Greater Manchester Breast Screening Charter

<div>Breast Screening Charter</div> <div>For Patients with Learning Disabilities</div> <div>Our Promise to you</div> <div></div>		<div></div> <div>We will phone you before your appointment to see what we can do to help you during your breast screening examination.</div>	
<div>easy read</div> <div></div>	<div>We will send an “Easy Read” invitation for your breast screening appointment.</div> <div>We also have a library of links for further information</div>	<div>friend or carer</div> <div></div>	<div>You can bring a carer or friend with you.</div> <div>We can book two appointments together if your friend or relative is due for breast screening too.</div>
<div>care plan</div> <div></div>	<div>We will send you a reasonable adjustment plan for you or your carer to complete.</div>	<div></div>	<div>All of our staff are women.</div>
<div>breast screening</div> <div></div>	<div>We can show you round before your appointment to help you understand what will happen.</div>	<div></div> <div>We will book a longer appointment for you and will ensure that the appointment time is convenient for you.</div> <div>This is so that the Radiographer can explain what is going to happen.</div>	

- Our breast screening units have worked together with the GM learning disability cancer network to develop the breast screening charter.
- The charter is their pledge to make reasonable adjustments for women to access screening.
- The breast screening charter will be launched in 2025.

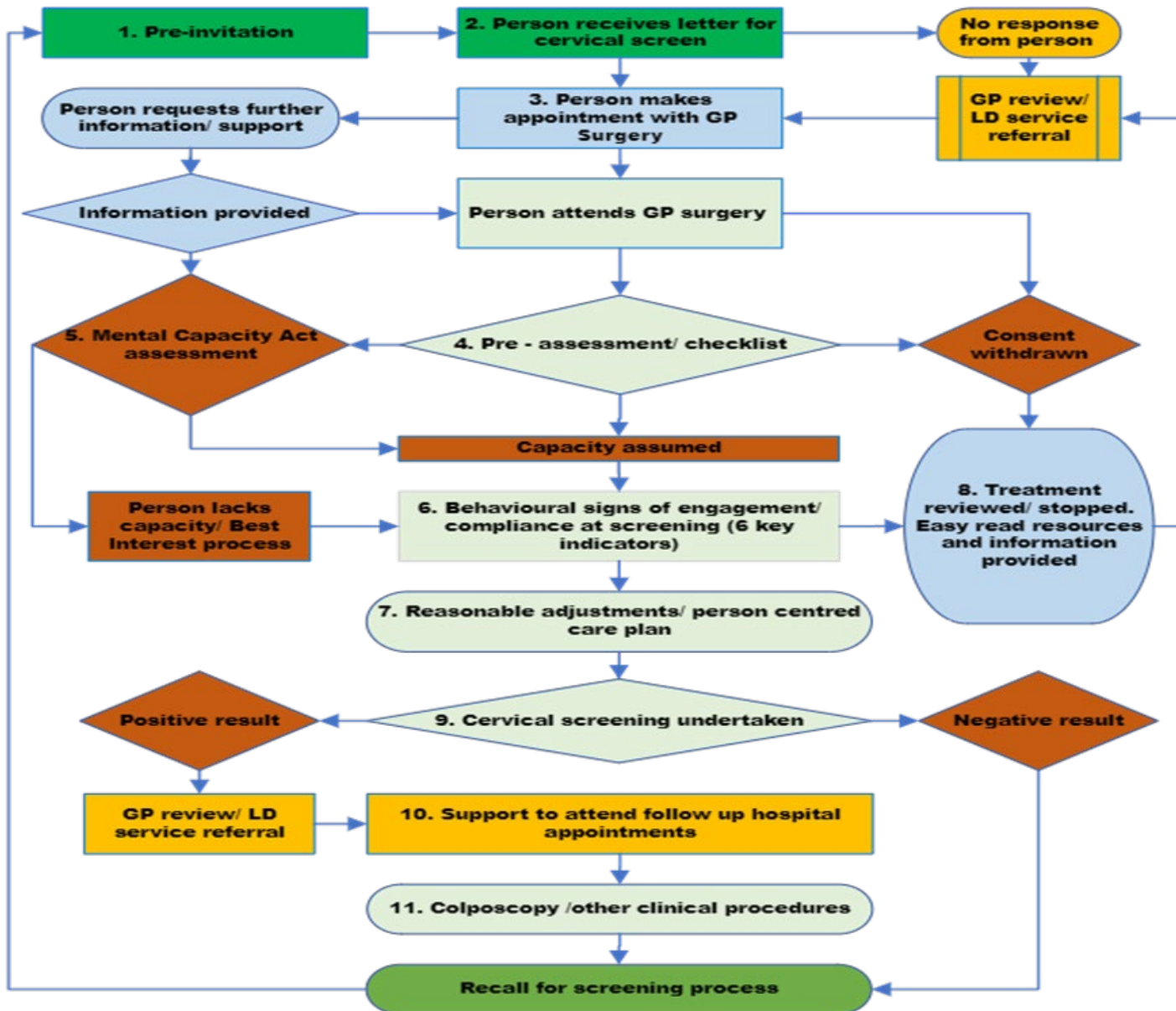
Prevent Breast Cancer



- Prevent Breast Cancer hosted a research conference in September 2024. The conference featured some of the most respected figures in the field, with a focus on prevention.
- A bid of £10,000 was submitted by GM to develop some breast cancer awareness sessions for women with a learning disability
- The bid came 1st in a 'Dragons' Den' style panel at the research conference and GM have been awarded £10,000.
- There will be 10 workshops, one in each locality. The sessions will be co-developed and co-delivered by Pathways Associates, women with lived experience, Answer Cancer, Breast Screening Improvement Leads and the Community Learning Disability teams.
- The outcome of these workshops will measure increase in knowledge and confidence, and uptake in breast screening to inform further research.

Cervical screening reasonably adjusted pathway

- Evidence has shown that cervical screening uptake is lower in people with learning disabilities compared to the rest of the population (NHS Digital). In response to this and the GM LeDeR learning from 2022/2023, GM has worked in partnership with people with lived experience, their advocates, learning disability nurses and the Screening and Immunisation team to develop as reasonably adjusted cervical screening pathway.
- The aim of the pathway is to ensure that professionals have a clearer understanding of the needs of women and people with a cervix who have a learning disability and autistic people.
- There will be a launch of this pathway in 2025, initially as an evaluated pilot, with the aim for this to be fully implemented.



Conclusion and Recommendations

Conclusion

Building on the previous GM report, LeDeR continues to grow in scope and ambition, including the addition of reviews for autistic people where the number of notifications are improving each year. This is a step towards improving information and data collection on the causes of death for autistic people in GM.

This year's report has identified several improvements. The number of notifications to the programme remains constant and GM has increased the number of focused reviews in line with the national ambition. There are higher rates of DNA CPR documentation that have been correctly applied and more people dying in a place they choose. GM continues to increase the number of annual health checks and the number of people with a health action plan year-on-year and this is evident from the LeDeR reviews. There has been service improvements in response to the LeDeR learning including the development of bespoke screening pathways in collaboration with people with lived experience and localities.

The pace of change needs to continue at speed, especially around long-term condition care pathways and management and the continued improvement around preventative health interventions including screening and immunisation. There needs to be an improvement on the availability and quality of data held at a GM level to monitor changes over time and understand the impact of service improvements.

The priorities as cited in the 2022/2023 remain as part of the GM improvement plan with additional priorities to reflect this report. We will continue to work with our stakeholders, with people with lived experience, with families, and professionals to further strengthen our analysis and interpretation of findings and better service the needs of people with a learning disability and autistic people within GM.

Recommendations 2025-2026

Theme	Actions for 25/26	Our commitment and aspirations
Autism-only notifications into the LeDeR programme	<ul style="list-style-type: none"> We will work with our health and social care partners to promote and raise awareness regarding the inclusion of autism-only notifications into the LeDeR programme 	<ul style="list-style-type: none"> Notification to reflect accurate number of deaths in reporting cycle- this will help us learn from deaths to improve services.
Annual Health Checks	<ul style="list-style-type: none"> Support the delivery of the annual health check and health action plans and enable improved access for people from a minority ethnic background and other vulnerable groups. Prioritise those individuals who have not had an annual health check in 22/23 Introduce quality audit cycles to ensure both quality of annual health checks and completeness of health action plans 	<ul style="list-style-type: none"> All people should receive a comprehensive annual health check, considering potential health concerns specific to their condition, thorough communication with the individual and their support network, and a focus on preventative measures, all delivered in a way that is tailored to their needs. There is no variation in uptake in people from minority ethnic backgrounds or other vulnerable groups We will continue to raise awareness of the GP learning Disability register and increase register sizes across GM to reflect accurate numbers.
Cancer Screening Programmes	<ul style="list-style-type: none"> A focus on early intervention and prevention, which recognises the impact of intersectionality, including how people will be supported to access screening and immunisation. Implement “Prevention of Adults not Brought Strategy” To work with people with lived experience and introduce further cancer screening pathway pilots for people with a learning disability and autism. These will be fully evaluated to inform future plans 	<ul style="list-style-type: none"> There will be reasonably adjusted screening pathways implemented for all screening programmes in GM There will be no variation in uptake of screening for people with a learning disability and autistic people in GM.

Recommendations 2025-2026 (2)

Theme	Actions for 25/26	Our commitment and aspiration
Epilepsy	<ul style="list-style-type: none"> 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 In 2025, we will bring system partners together to collectively reflect on the outcome of the self-assessment and work together to consider where action and improvement may be needed 	<ul style="list-style-type: none"> People with a learning disability having access to individualised treatment plans that consider their specific needs including clear communication, tailored medication management and coordinated care in which they have they all have the ability to participate in decisions about their own care.
Healthy Weight	<ul style="list-style-type: none"> Focused reviews will be undertaken on people with a BMI over 30. This to identify a holistic overview of potential contributory factors Complete healthy weight scoping across GM and work collaboratively with partners to ensure mainstream services are accessible for people with a learning disability 	<ul style="list-style-type: none"> People with a learning disability and autistic people should have individualised plans based on their needs, with accessible communication and strong support from caregivers and health professionals. Pathways should be tailored and incorporate reasonable adjustments as required.
Mental Capacity Act and Best Interest	<ul style="list-style-type: none"> Raise the profile of the MCA and BI within primary, 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 	<ul style="list-style-type: none"> Any decisions about care and support will be in line with the Mental capacity Act. People will be supported to make their own decisions and, for those who lack capacity, any decision must be made in their best interest involving them as much as possible and those who know them well.
Learning Disability End of Life and DNA CPR recommendations	<ul style="list-style-type: none"> To continue to work with hospices, Community Learning Disability teams and wider stakeholders to continuously improve end of life care and advanced care planning using a person-centered approach To continue to promote and ensure the appropriate use of DNACPR decisions for people with a learning disability and autistic people 	<ul style="list-style-type: none"> People will have access to personalised care that reflects their individual needs, preference, and communication style, ensuring they are involved in decision making; this includes open conversations about dying and use of accessible methods to understand wishes.

Recommendations 2025-2026 (3)

Theme	Actions for 25/26	Our Commitment and aspirations
Management of long-term conditions	<ul style="list-style-type: none"> Working with our health and social care partners, we will raise awareness regarding the importance of early recognition and correct management Ensure learning disability pathways are included within established workstreams 	<ul style="list-style-type: none"> Each person will receive personalised care to support with long- term health conditions. This care is proactive and integrated across all services with appropriate support given and effective medication management.
Business Intelligence and data	<ul style="list-style-type: none"> To continue to develop the GM Learning Disability and Autism data dashboard so intervention and outcome is based on accurate and timely data 	<ul style="list-style-type: none"> The GM Dashboard needs to be clear and concise, presenting key metrics and allowing the detection to identify trends and patterns while providing features to drill down into specific features.
Inequalities for people from minority ethnic communities	<ul style="list-style-type: none"> To implement the recommendations from the We Deserve Better report. 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 ICB to ensure the quality (completeness, validity and accuracy) of ethnicity coding for people with a learning disability 	<ul style="list-style-type: none"> Providing support that is tailored to their individual needs, considering their cultural background, language preference and religious beliefs, while addressing potential barriers. This to ensure the same quality of care is given regardless of their ethnicity.
Respiratory Health	<ul style="list-style-type: none"> We will work with our partners across the health and care setting to maximise to maximise flu, Pneumonia and COVID vaccination We will work with our partners to scope out Dysphagia pathways considering the new clinical guidance from the British Thoracic Society We will work with our partners to deliver workshops to raise awareness of dysphagia and the risk of aspiration pneumonia 	<ul style="list-style-type: none"> Respiratory care prioritises accessible information, personalised care plans, proactive preventative measures, thorough assessment of swallowing abilities and appropriate training for healthcare staff. There is a focus on early identification to manage potential respiratory issues.