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Greater Manchester LeDeR Annual Report 2022-2023

A synopsis of the main report

Part of Greater Manchester Integrated Care Partnership

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Acknowledgement

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

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Scope of LeDeR

- 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 death of all children, and the results are shared with LeDeR.
- Multiple processes – if there has been a SAR referral or safeguarding notification, the reviewer links in with 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
- We must remember that LeDeR is not an investigation, but a service improvement programme.

Background

- This is the first Greater Manchester (GM) LeDeR report since the inception of the ICB. This allowed for more detailed thematic analysis.
- When reading the report, it must be kept in mind that referral to the LeDeR is not mandatory, so this does not have complete coverage of all deaths of people with learning disability and/or autism.
- The numbers in some subcategories are still small; findings and comparisons must be considered indicative rather than conclusive.
- The purpose of the annual report is to share findings from 164 completed reviews from 1st April 2022- 31st March 2023. There were 81 females and 83 males with one person with autism only.
- GM closed 139 initial reviews and 25 focused reviews. A priority for GM is to increase the number of focused to 35% in line with the national expectations.

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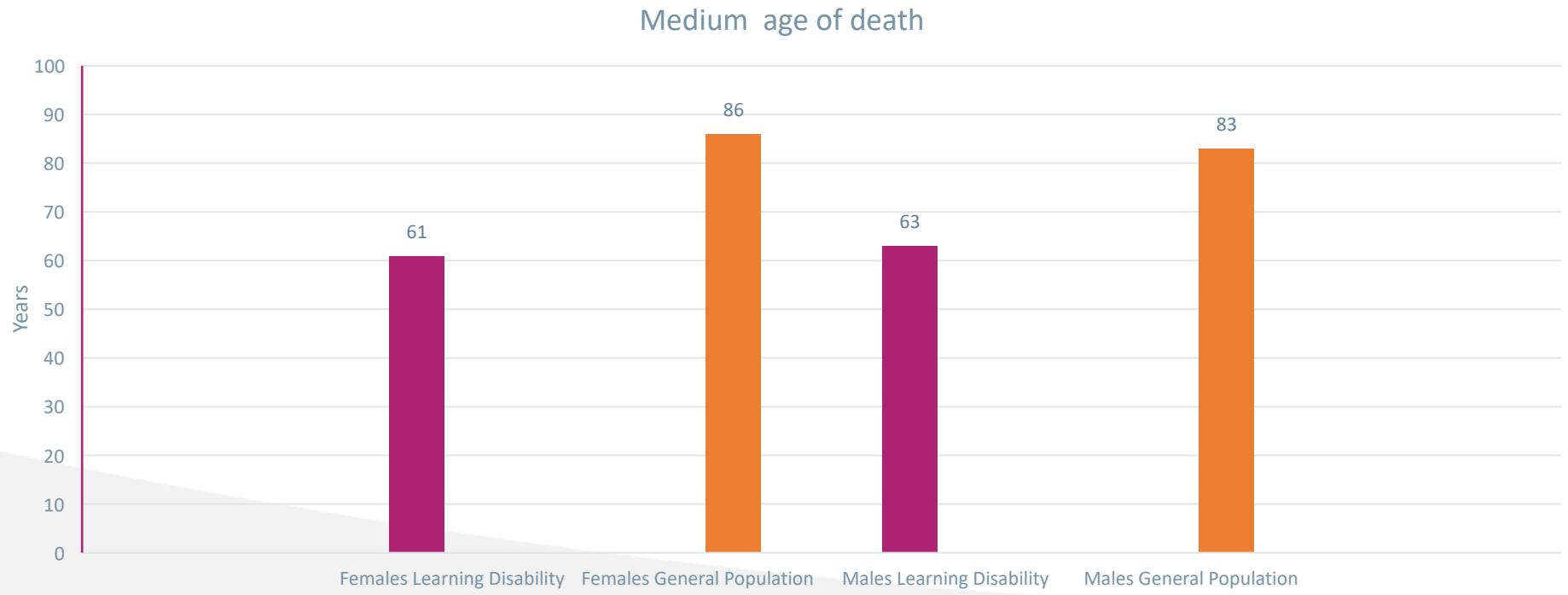
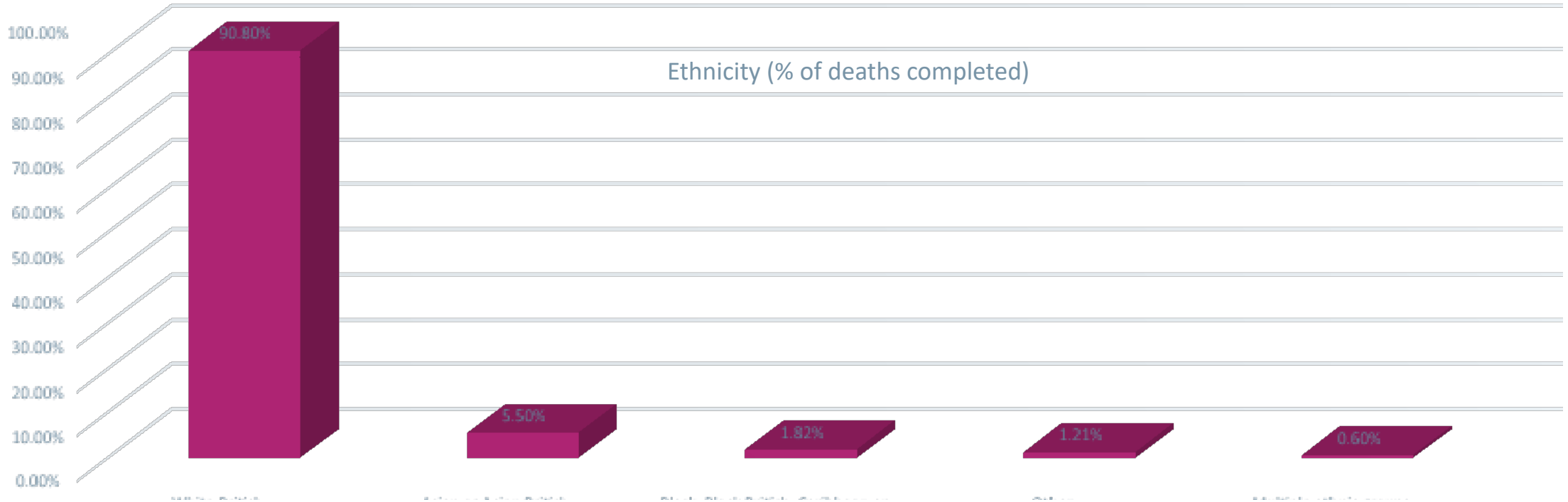
Demographics

Age at death

- The overall median age of death was 62 years. For females, the median age was 61 years and for males this was 63 years. This gives a disparity of 25 years and 20 years respectively in comparison to the general population.



Ethnicity



- Most completed reviews were 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

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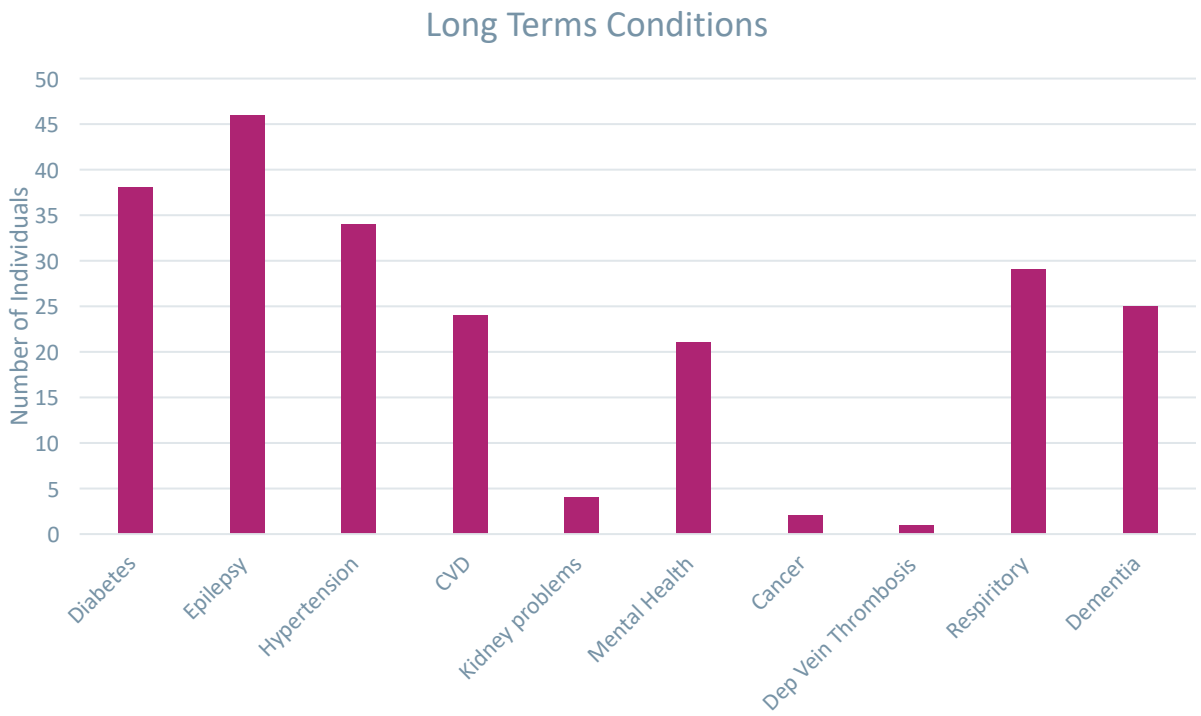
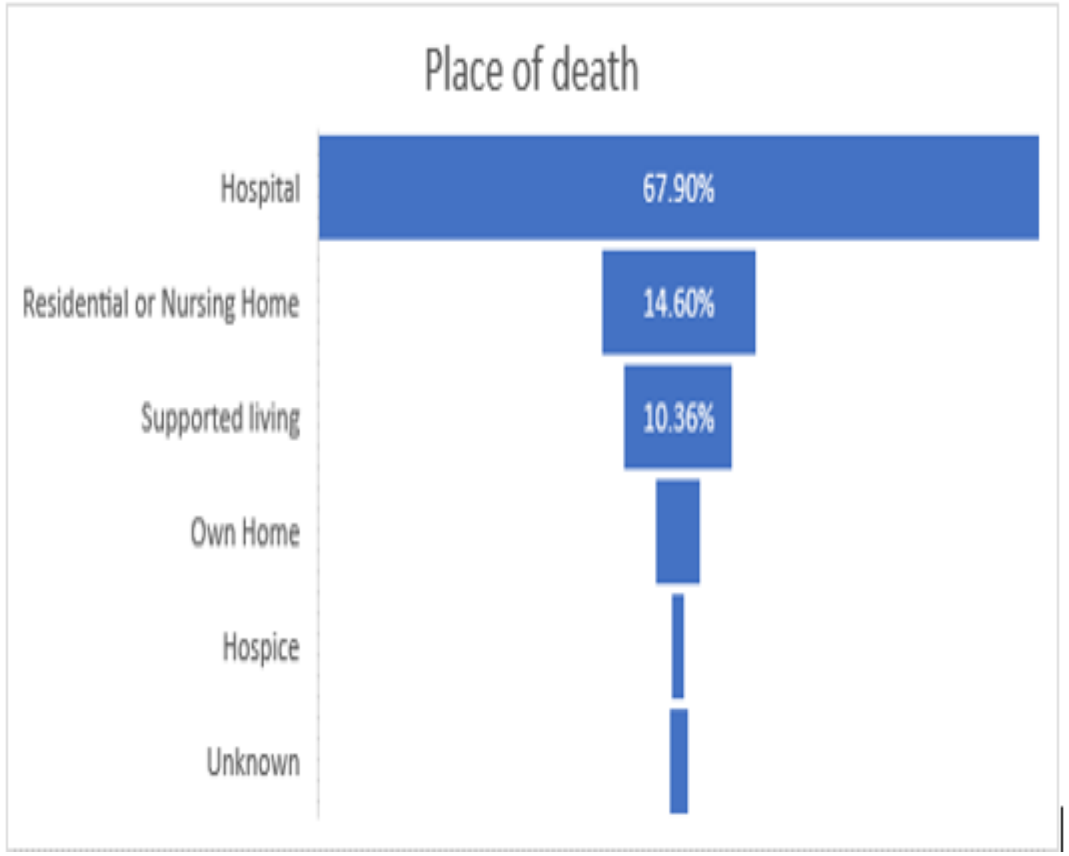
Circumstances of death

Long term health conditions



- Long term health data was available for 125 of the completed reviews For the purpose of the report, 10 conditions were included in this definition of a long term health condition.
- Multi-morbidity is defined as the presence of 2 or more long term health conditions occurring at the same time for which there was at least 29 people with three conditions cited.
- A BMI of over 30 was recorded in 26 reviews; this could be higher as only reflects the information available during the review.

Place of death

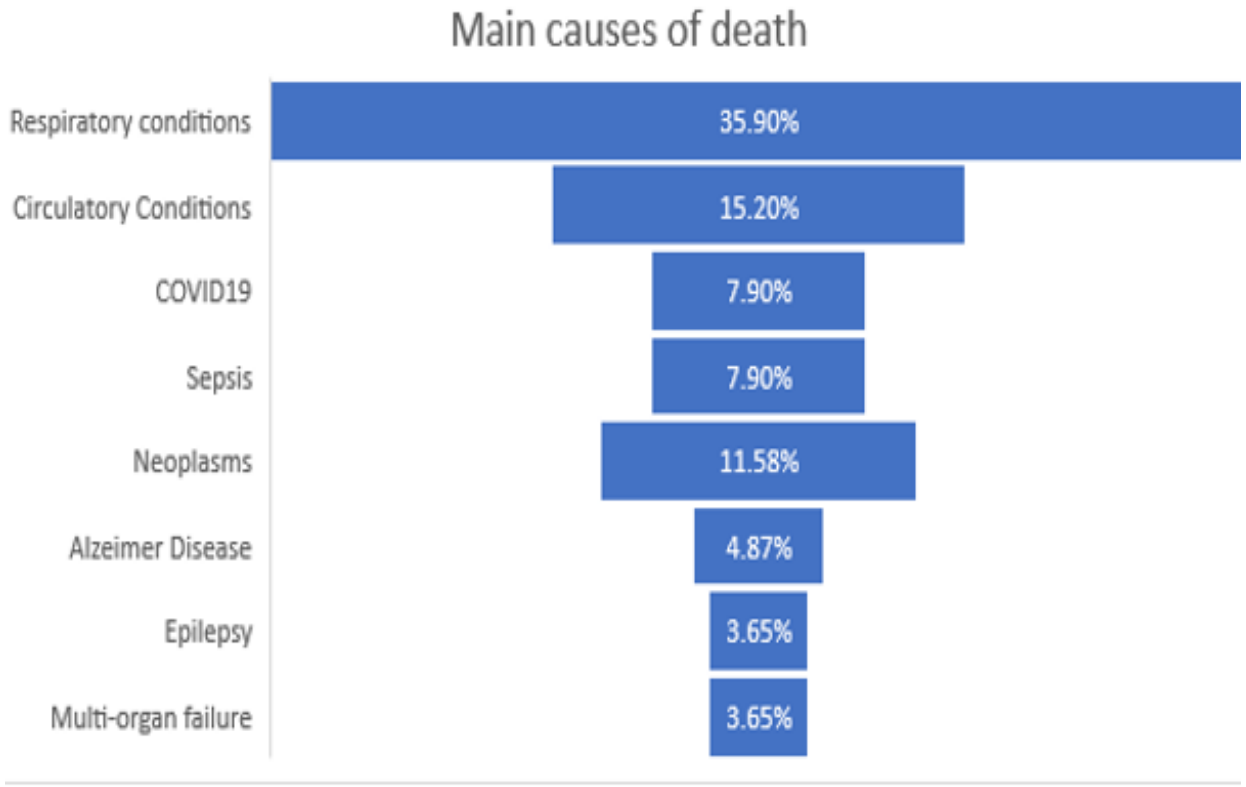


- 67.9% (n=111) of deaths occurred in hospital. This compares to 42% of the population.
- The reasons why a higher proportion die in hospital with a learning disability are multifactorial. This may be due to differences in age characteristics or causes of death or due to factors in living conditions or palliative care and discharge planning.
- This could also reflect a higher proportion of people notified to the programme from hospital rather than the community.

Do not attempt Cardio-Pulmonary Resuscitation (DNA CPR)

- 67.7% (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
- 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.

Main cause of death



- Respiratory conditions accounted for the most causes of death. Of these cases N=59, 38.9% were due to aspiration pneumonia with 49.1% due to pneumonia (organism unspecified).
- Circulatory conditions accounted for the 2nd highest cause at 15.2%. This included conditions such as Myocardial Infarctions (Heart Attack), Cerebral Vascular accidents.
- Neoplasms accounted for 3rd highest cause of death at 11.58%.
- Epilepsy accounted for 3.65% (N=6) of all deaths.

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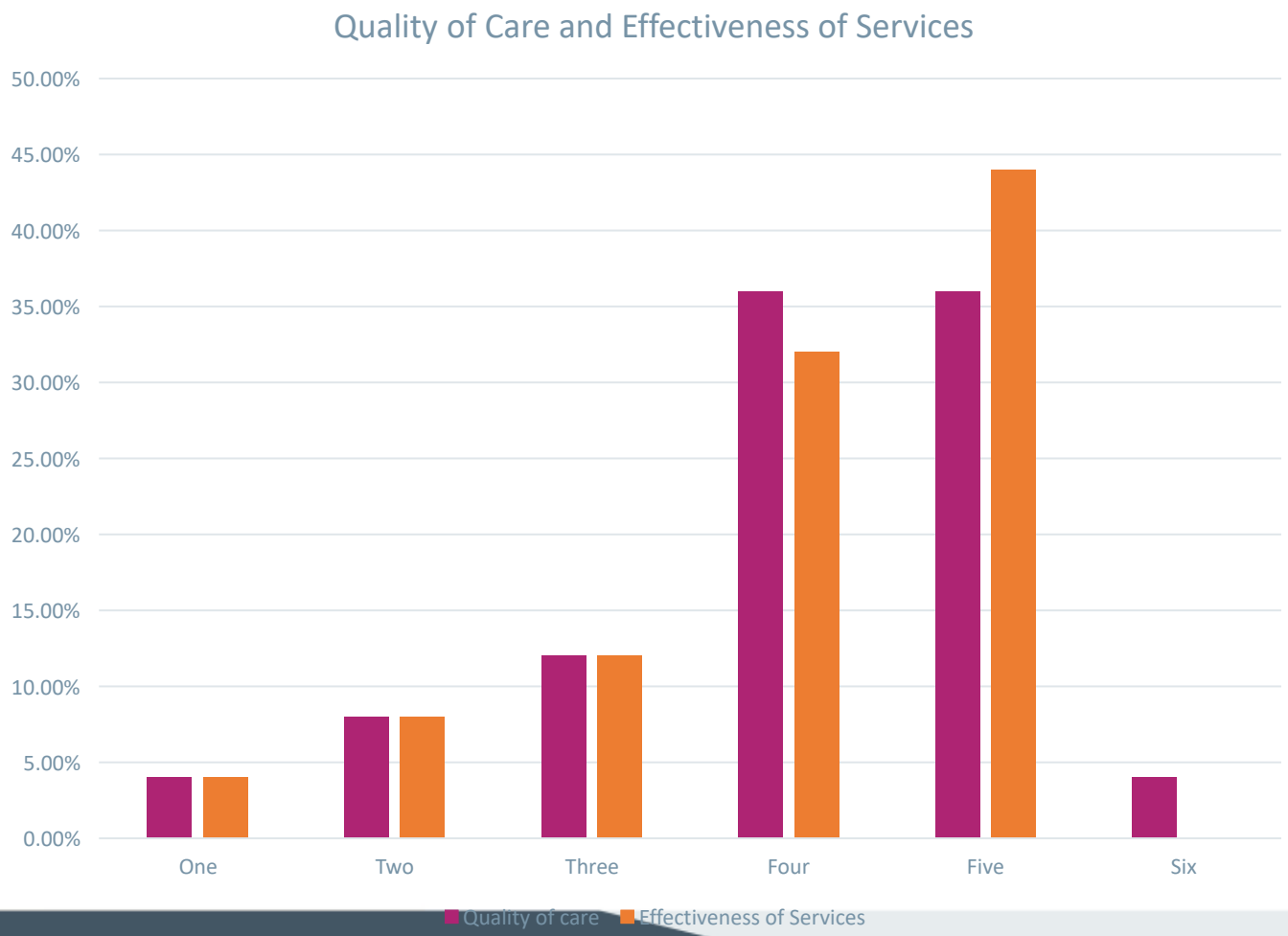
Quality of Care

Quality of care and services

The reviewer is asked to grade overall quality of care and services 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

Quality of care and services



- Most of the care and services fell between rating four and five- satisfactory to good care and availability of services.
- The services scored five and six respectively when there was evidence of good care planning, with no evidence of gaps, with recommended diagnostic and treatment guidelines met. There was good evidence in the application of the Mental Capacity Act and Best Interest and services were proactive to the individuals needs and requirements.

Positive practice

- 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

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

Good practice was identified in 76% of the reviews

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

Thematic analysis

Theme	Area of concern	Care Setting
Professional practice and the provision of care	• Inconsistent delivery and uptake of preventative health care- this includes immunisation and screening • If not attended appointments, coded as “did not attend”- the reviewer could not determine if follow up initiated • Inconsistent use of health action plans following on from annual health check • Incomplete or inadequate annual health checks	Primary and Community Care
Learning Disability awareness	• Application of Mental Capacity Act and Best interest inconsistent	Primary and Community Care Hospital in -patient

Thematic analysis (continued)

Themes	Area of Concern	Care Setting
Care pathways	• Inconsistent use of reasonable adjustments	Hospital in patient care Primary and Community Care
	• Length of stay in hospital felt to be prolonged due to discharge planning and coordination	
	• Inconsistent coordination when a person was under multiple hospital services	Hospital in patient care
	• Inconsistent involvement of specialist learning disability services when an inpatient	Hospital in patient care
	• Inconsistent use of hospital passports	
	• Management of long term conditions were inconsistent, especially weight management and constipation	

Thematic analysis

Themes	Area of Concern	Care Setting
Training on specific conditions	Inconsistent management of certain conditions within social care settings. Most notably is management of constipation, obesity and epilepsy	Social care
DNA CPR recommendations and end of life care	In some case, there was lack of advocacy cited in both general discussions and those decisions involving DNA CPR	Hospital in patient care Primary and Community Care
Transition	Young person's transition to adult services cited as disjointed and complex for the family and person	Hospital in patient care Primary and Community Care

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Learning into action and recommendations for 23/24

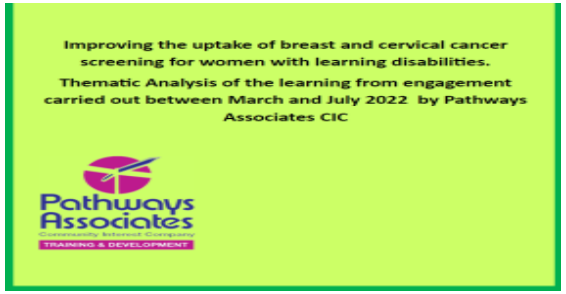
Learning into action- some initiatives in 2022.23

- Annual Health check increase from 66% in 21/22 to 80% in 22/23.
- Implementation of two Primary Care Coordinators with positive outcome in Manchester
- Recruitment of 5 Primary Care Assistant Practitioners to work across 5 localities in 23/24 (Pennine Care Foundation Trust).
- Pilot bowel screening pathway for learning disability with positive outcome –Nursing times award finalist.
- Pathways associates undertaken focus groups in conjunction with people with lived experience to explore key themes to improve uptake of screening programmes.
- Ansar projects created series of accessible resources to support people with a learning disability – national learning disability awards, highly commended .

Nursing Times Awards 2023 FINALIST

The National Learning Disabilities & Autism Awards 2023

HIGHLY COMMENDED



Recommendations 23/24

Theme	Actions for 23/24
Autism only notifications into the LeDeR programme	• 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
Annual Health Checks	• Support the delivery of the annual health check and health action plans and enabling 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
Cancer Screening Programmes	• A focus on early intervention and prevention, which recognises the impact of intersectionality, including how people will be supported to access screening and immunisation. • 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

Recommendations 23/24

Theme	Actions for 23/24
Respiratory Health	• We will work with our partners across the health and care setting to maximise Pneumonia, Flu and COVID19 vaccine uptake for people with a learning disability • We will work with our partners to scope out dysphagia pathways considering the new clinical guidance from British Thoracic Society and utilising RightCare scenarios • We will work with our partners to deliver workshops to raise awareness of dysphagia and the risk of aspiration pneumonia
Epilepsy	• 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

Recommendations 23/24

Theme	Actions for 23/24
Healthy Weight	• 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
Mental Capacity Act and Best Interest	• 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 • 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

Recommendations 23/24

Theme	Actions for 23/24
Constipation	• 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 performance against these standards will be triangulated with outcomes from the LeDeR reviews
Business Intelligence and data	• To continue to develop the GM Learning Disability and Autism data dashboard so intervention and outcome is based on accurate and timely data
Inequalities for people from minority ethnic communities	• 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

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Looking Forward

- 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 health and social care colleagues.
- As the LeDeR dataset grown 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 LeDeR reviews will be further enhanced as we work with key partners around key lines of enquiry that are relevant to our population such as constipation, epilepsy and diabetic care.