

Greater Manchester Dementia and Brain Health Quality Standards

March 2024

Contents

Contents	. 1
Introduction	. 2
Background and context	. 3
Development of the standards	
Intended use	
Greater Manchester Dementia and Brain Health Quality Standards	. 7
Self-assessment tool	

Introduction

Dementia is a priority both nationally and in Greater Manchester. As people live longer and our population ages, more people, families and carers in Greater Manchester will be affected by dementia.

In Greater Manchester we are working to bring the NHS, public services, and the wider community together to deliver integrated, person-centred care and support that enables people to live a good life.

NHS Greater Manchester are proud to have a dementia programme in place to support quality improvement across all areas of the health and social care system. Much of this work aims to address unwarranted variation in access, experience, and outcomes for residents of Greater Manchester.

These quality standards provide a vision for the future as we work together to improve the experience of all those affected by dementia in Greater Manchester.

Alongside the <u>Dementia and Brain Health Delivery Plan 2023 to 2025</u>, the standards offer a framework for all localities and organisations in Greater Manchester to evaluate against and develop action plans. Our Place Leads will be working closely with partners in each locality to ensure these plans are developed and overseen within local structures, as well as at a NHS GM level.

We will continue to work towards making Greater Manchester the best place to live for all those affected by dementia.

For information about how you can become more involved with this vital work, please visit www.dementia-united.org.uk or email gmhscp.dementiaunited@dementia-united.org.uk.

Dr Claire Lake
Deputy Chief Medical Officer, NHS Greater Manchester

Background and context

"One in two of us will be directly affected by dementia in our lifetime, either by caring for someone with the condition, developing it ourselves or both" 1



Cartoon by Tony Husband

Dementia is a life-limiting condition and people living with dementia are likely to access multiple points in the wider health and social care system.

- 1 in 3 people born today will develop dementia in their lifetime²
- In January 2024, there were 30,000 people aged 65 and over estimated to have dementia in Greater Manchester. Of those, 21,897 have been formally diagnosed. You can access a breakdown of the dementia diagnosis rate at <u>GM Dementia</u> <u>Dashboard Draft WIP | Tableau Public</u>
- The number of people living with dementia in the UK is expected to reach 1.5 million by 2050³
- Dementia and Alzheimer's Disease was the leading cause of death in England in 2022 (2023 data not available)⁴
- Up to 40% of cases of dementia are linked to modifiable risk factors⁵

¹ https://www.alzheimersresearchuk.org/wp-content/uploads/2023/08/Tipping-Point-Report.pdf

² UK Dementia Research Institute, 2022

³ Alzheimer's Research UK, 2023

⁴ Office for National Statistics, May 2023

⁵ Alzheimer's Research UK, 2023

Dementia United is the dementia programme for Greater Manchester NHS, part of Greater Manchester Integrated Care Partnership. Dementia has been declared a priority in Greater Manchester and our shared ambition is to make Greater Manchester the best place to live for all those affected by dementia. Our Greater Manchester programme is called 'Dementia United' because partners are united in our longstanding vision to improve the quality and experience of care for everyone affected by dementia, and to deliver this vision across the whole of the region.

Greater Manchester includes ten localities: Bury, Bolton, Manchester, Oldham, Rochdale, Salford, Stockport, Tameside, Trafford, and Wigan.



These GM dementia and brain health quality standards have been developed to promote our vision and ambitions as we work to make Greater Manchester the best place to live for people affected by dementia. This document is designed to be read alongside the 'Dementia and brain health delivery plan 2023-2025'

You can find a three-page printable version of the standards here <u>Greater Manchester</u> <u>Dementia and Brain Health Quality Standards 2024 Short version</u>

System leadership and working is required to deliver on these standards and Dementia United will continue to work closely with dementia leads in localities and organisations, as well as partners from across the Greater Manchester system. More information about Dementia United can be found at www.dementia-united.org.uk.

Development of the standards

The Greater Manchester dementia and brain health quality standards have been developed in partnership with Dementia United stakeholders including people with lived experience of dementia and representatives from each locality of Greater Manchester.



They have been developed with the aim of promoting equity of services, improving quality of experience, and allowing for consistent evaluation across our complex system. This is in line with Greater Manchester's approach to "drive consistent improvement, reduce unwarranted variation and make the best use of our collective resources" 6. They are an overarching set of standards, and it is recognised that additional standards may be available/in development for specific areas of practice.

The current standards build on previous standards developed by Dementia United in 2016 and the dementia care pathway recommendations produced between 2018 and 2023⁷. In the development, National policy and guidance were also considered, and the standards reflect the cross-cutting themes of the Dementia United programme; co-production with people with lived experience of dementia and carers, diversity and inclusion, and partnership working.



Health inequalities are recognised throughout given,

"Greater Manchester's population experiences higher mortality than it should, and people spend a greater proportion of their lives in poor health, especially those with disabilities, those from racially minoritised communities and those facing multiple disadvantage" 8.

⁶ Greater Manchester Integrated Care Partnership Strategy, 2023

⁷ https://dementia-united.org.uk/greater-manchesters-dementia-care-pathway/

⁸ Greater Manchester Integrated Care Partnership Strategy, 2023

Intended use

The dementia and brain health quality standards are designed to drive quality improvement across the system. It is therefore intended that localities and sectors will endorse the standards and use these alongside the Dementia United 'Dementia and brain health delivery plan 2023-2025' and local dementia strategies and action plans, to benchmark their current position and identify actions for improvement. Dementia United will work with partners to support this work.

The standards will next be reviewed in November 2025, with an earlier review completed if requested by the Dementia United Strategic Group.

For further information, please contact us at gmhscp.dementiaunited@nhs.net.

Greater Manchester Dementia and Brain Health Quality Standards

1

There is a dedicated **dementia strategy lead** for the Integrated Care Board, with a dementia strategy and dementia specific steering group in place

2

People affected by dementia are involved with all elements of the dementia programme, both at Integrated Care Board and locality levels.

3

Each locality and sector have a **named dementia lead** to lead on the development and implementation of locality dementia delivery plans, working across the system and including Voluntary Community and Social Enterprise (VCSE) partners.

4

Appropriate training is provided for people living with dementia, carers, staff working in health and social care, and the wider public.

Dementia awareness training is provided for all students and staff across the health and social care system, with additional training provided for staff directly supporting people living with dementia.

5

Population health and prevention programmes include actions to **raise awareness about brain health** and risk reduction. Targeted interventions may be required for those at increased risk of developing dementia.

6

Everyone can **access an assessment** and be considered for a formal diagnosis of dementia. Specific action may be required to support diverse populations to access an assessment and services should be culturally accessible.

7

Dementia pathways are in place in each locality, including post diagnostic support. Post diagnostic support includes access to pharmacological and non-pharmacological interventions and meets the needs of diverse communities, including those with young onset or rarer forms of dementia.

8

Public services and transport systems are accessible for people affected by dementia, and all services for people affected by dementia are physically and culturally accessible.

9

Those affected by dementia, including families and carers, are **equal partners** in decision-making at all stages of the dementia care pathway.

10

Everyone living with dementia has a **named care navigator/ co-ordinator** as part of a service for dementia advice and navigation.

11

Everyone living with dementia has a **dementia care plan** that is completed with the person living with dementia and their carer/people involved in their care. This is reviewed regularly and at least every 12 months.

12

Activities are available for people affected by dementia who wish to access these, including via social prescribing schemes.

A range of social, meaningful, active, and culturally appropriate activities are provided, as well as peer support groups, for people living in their own homes as well as care environments.

13

People living with dementia who experience distress have **access to appropriate services and support**, including non-pharmacological and pharmacological interventions.

14

Anyone at risk of developing delirium, including someone living with dementia, is **assessed for delirium** where there is an acute change in presentation or on admission to hospital. Appropriate information, treatment, and support is available.

15

Opportunities and support to **complete an advance care plan** are regularly offered to people affected by dementia.

16

People living with dementia have **equitable access to acute and community services**, including rehabilitation and palliative and end of life services, as well as public spaces and transport systems.

17

Carers of people living with dementia are offered a carers assessment and carer support, including financial advice and bereavement support.

18

People affected by dementia are **offered regular opportunities to participate in research** and the outcomes of research are used to inform the future development of the dementia programme.

Self-assessment tool

No.	Quality standard	Evidence	Action required
1.	There is a dedicated dementia strategy lead for the Integrated Care Board, with a dementia strategy and dementia specific steering group in place.		
2.	People affected by dementia are involved with all elements of the dementia programme, both at Integrated Care Board and locality levels.		
3.	Each locality and sector have a named dementia lead to lead on the development and implementation of locality dementia delivery plans, working across the system and including Voluntary Community and Social Enterprise (VCSE) partners.		

No.	Quality standard	Evidence	Action required
4.	Appropriate training is provided for people living with dementia, carers, staff working in health and social care, and the wider public. Dementia awareness training is provided for all students and staff across the health and social care system, with additional training provided for staff directly supporting people living with dementia.		
5.	Population health and prevention programmes include actions to raise awareness about brain health and risk reduction. Targeted interventions may be required for those at increased risk of developing dementia.		
6.	Everyone can access an assessment and be considered for a formal diagnosis of dementia. Specific action may be required to support diverse populations to access an assessment and services should be culturally accessible.		

No.	Quality standard	Evidence	Action required
7.	Dementia pathways are in place in each locality, including post diagnostic support. Post diagnostic support includes access to pharmacological and non-pharmacological interventions and meets the needs of diverse communities, including those with young onset or rarer forms of dementia.		
8.	Public services and transport systems are accessible for people affected by dementia, and all services for people affected by dementia are physically and culturally accessible.		
9.	Those affected by dementia, including families and carers, are equal partners in decision-making at all stages of the dementia care pathway.		

No.	Quality standard	Evidence	Action required
10.	Everyone living with dementia has a named care navigator/co-ordinator as part of a service for dementia advice and navigation.		
11.	Everyone living with dementia has a dementia care plan that is completed with the person living with dementia and their carer/people involved in their care. This is reviewed regularly and at least every 12 months.		
12.	Activities are available for people affected by dementia who wish to access these, including via social prescribing schemes. A range of social, meaningful, active, and culturally appropriate activities are provided, as well as peer support groups, for people living in their own homes as well as care environments.		

No.	Quality standard	Evidence	Action required
13.	People living with dementia who experience distress have access to appropriate services and support, including non-pharmacological and pharmacological interventions.		
14.	Anyone at risk of developing delirium, including someone living with dementia, is assessed for delirium where there is an acute change in presentation or on admission to hospital. Appropriate information, treatment, and support is available.		
15.	Opportunities and support to complete an Advance Care Plan are regularly offered to people affected by dementia.		

No.	Quality standard	Evidence	Action required
16.	People living with dementia have equitable access to acute and community services, including rehabilitation and palliative and end of life services, as well as public spaces and transport systems.		
17.	Carers of people living with dementia are offered a carers assessment and carer support, including financial advice and bereavement support.		
18.	People affected by dementia are offered regular opportunities to participate in research and the outcomes of research are used to inform the future development of the dementia programme.		