Item No. 8

SUNDERLAND HEALTH AND WELLBEING BOARD 2 OCTOBER 2025

IMPROVING DEMENTIA DIAGNOSTIC RATES AND PATHWAY REFORM

Report of the Director of South Tyneside and Sunderland Delivery Team

1.0 Purpose of the report

The following report provides a position statement on the dementia diagnosis rate in Sunderland, the findings of the pathway review to date and the development of a radical new model for dementia in Sunderland.

The Health and Wellbeing Board is asked to endorse this direction and support the development of a new Dementia Delivery Plan.

2.0 Executive Summary

Sunderland has sustained a dementia diagnosis rate (DDR) of c.67–68% of the total number of people estimated to have dementia, above the national standard of 66.7% and contributing to the North East and Yorkshire region's position as the best performing nationally. However, referrals into memory services fell to 106 in Q1 2025/26, compared with 457 in the whole of 2024/25 (equating to a quarterly average of 114), indicating a risk that the register has plateaued and that some people remain undiagnosed.

Behind the numbers, feedback from people with dementia and their carers reveals systemic shortcomings: delays in assessment, inconsistent support post-diagnosis, carers feeling invisible, and people living alone left without meaningful assistance. While the city is performing strongly against national targets, these metrics alone do not reflect the lived reality of local people.

The case for change is therefore compelling. Dementia prevalence continues to rise, acute pressures are mounting, carers are under strain, and new disease-modifying therapies (DMTs) will demand earlier, more accurate diagnosis. The economic and human cost of inaction is profound.

The new approach will be co-produced with residents and carers, focus on prevention and equity, and ensure readiness for future treatments.

3.0 National and Regional Context

3.1 National Position

Dementia remains one of the leading health and care challenges in England. As of February 2025, the national dementia diagnosis rate (DDR) stood at 65.4% of the total number of people estimated to have dementia, which is below the long-standing NHS England standard of 66.7%.

This means that nationally, more than one in three people estimated to be living with dementia remain undiagnosed, without timely access to support or planning for future care.

Although NHS England has confirmed the removal of the DDR target from 2025/26, the rationale is not to deprioritise dementia but rather to acknowledge that diagnosis is only one part of the pathway. Current policy direction: the system must now pivot towards quality of diagnosis, equity of access, and readiness for innovation, particularly with the expected arrival of DMTs.

National guidance stresses the importance of tackling inequalities in diagnosis and care. Recent NIHR and NHSE reports show that:

- People from minority ethnic backgrounds are less likely to receive a timely diagnosis.
- People living alone experience later diagnosis and poorer outcomes, with limited service models to meet their needs.
- Carers consistently report lack of recognition and inadequate support, despite being the backbone of the dementia care system.

3.2 Regional Position – North East and Yorkshire (NEY)

The NEY region has consistently outperformed national averages, achieving a DDR of 68.1% in February 2025. This makes the region the best performing nationally, reflecting strong collaboration across Integrated Care Boards (ICBs) and a shared emphasis on ageing well.

Within NEY, variation is evident:

- South Yorkshire performs significantly above the standard at 75.6%.
- West Yorkshire also outperforms at 70.1%.
- North East & North Cumbria (NENC), which includes Sunderland, stands at 68.7%, above national standard.
- Humber and North Yorkshire lags behind at 60.3%, well below the standard

This benchmarking demonstrates that while Sunderland contributes to a high-performing regional picture, there is still scope to learn from sub-regions that have achieved exceptional results, particularly in relation to referral practices, public awareness, and memory service configuration.

3.3 Implications for Sunderland

Three key implications arise from this national and regional context:

- **Sunderland cannot stand still.** While current performance (67%) is above the national average and standard, the plateau in referrals (Q1 2025/26) suggests the city risks falling behind if proactive steps are not taken.
- **Equity is now paramount.** Nationally, there is a clear focus on underserved groups – people living alone, carers, and minority communities. Sunderland's dementia register shows that 96% are white. Sunderland's 2021 census identified 94.6% of Sunderland's population as white (dementia register is 71% white nationally). This may demonstrate that minority ethic groups are being underdiagnosed.

- **Future readiness is non-negotiable.** The arrival of DMTs will fundamentally reshape expectations. Unless Sunderland strengthens its diagnostic infrastructure (including neuroimaging capacity and subtyping accuracy), local residents will not be able to benefit from new treatments.

In summary, while Sunderland contributes positively to a high-performing region, the national and regional direction of travel requires a shift in focus from targets to transformation. Diagnostic rates are necessary but insufficient. The imperative now is to ensure timely, accurate, equitable diagnosis and meaningful post-diagnostic support – underpinned by strong prevention and preparation for future innovation.

4.0 Sunderland Position (to June 2025)

4.1 **Diagnostic Rate and Register**

Sunderland's DDR remains stable at c.67–68%, equating to around 2,425–2,526 people on the dementia register against an estimated prevalence of 3,668. This stability indicates consistency in maintaining national standards, but it also reflects a plateauing trend rather than continued growth. Without fresh action, Sunderland risks embedding a diagnostic ceiling that masks undiagnosed need.

At this trajectory, Sunderland is on course for significantly lower annual referral volumes. This suggests either a reduction in detection and help-seeking or constraints in capacity to process referrals. Both explanations point to systemic weaknesses that must be addressed if diagnostic improvements are to be sustained.

4.2 Inequalities in the Local Population

- **People living alone**: In Sunderland, numbers mirror the national picture with around 40% of people with dementia living alone, many without adequate support structures. These individuals are at highest risk of later diagnosis, hospitalisation, and premature admission to long-term care.
- **Ethnic diversity**: Sunderland's dementia register is 96% white compared to Sunderland's population of 94.6% white (and compared to 71% white for the dementia register nationally). This might indicate under-diagnosis in minority communities, with cultural, linguistic, and service access barriers likely at play.
- **Carers**: Local carers continue to report invisibility in care planning, high stress levels, and insufficient respite. This not only impacts carer wellbeing but increases the risk of crisis admissions and long-term care demand.

4.3 **Implications**

While Sunderland is statistically outperforming national averages, the June 2025 data highlights three strategic risks:

- **Plateauing diagnostic performance** driven by falling referrals.
- **Entrenched inequalities** for people living alone, carers, and minority communities.
- **System fragility** in the face of future treatment demands.

5.0 The Case for Change – Why We Must Act

The case for change in Sunderland is compelling and rests on three interlinked domains: the voices of people and carers, the pressures on the health and care system, and the imperative of preparing for future innovation.

5.1 Voices of People and Carers

Engagement with people living in Sunderland, carers' forums, cross referencing with working already completed through the ambassadors and local research highlights a consistent set of themes:

- **Delays and uncertainty**: Families describe the diagnostic process as fragmented and slow. One carer reported, *"It felt like months of waiting, then we were sent home with little explanation."*
- **Carer invisibility**: Carers often feel excluded from conversations, despite carrying the burden of daily care. *"Professionals spoke to my dad, but not to me – yet I am the one making sure he eats, takes his tablets, and is safe."*
- **Living alone with dementia**: People without family support express deep isolation. A local participant noted, *"I was told I had dementia and then went home to an empty flat. No one checked if I had support."*
- **Need for hope and information**: Families want to hear messages of hope, what can be done, what treatments are coming, and how to live well. *"We need more than a diagnosis – we need to know what life with dementia can look like."*

These local lived experience insights of dementia highlight a key issue: national targets often fail to reflect the realities faced locally. A diagnosis without clear information, appropriate support, or carer involvement is inadequate.

5.2 System Pressures

- Dementia already accounts for 25 - 40% of acute hospital beds nationally, with nearly half of admissions linked to conditions that could be prevented or managed in the community
- Carer breakdown is a significant driver of hospital admission and long-term care costs. Local carers report exhaustion and lack of respite.
- The economic cost of dementia is projected to rise from £42bn to £90bn by 2026, outpacing inflation and consuming an increasing share of health and social care budgets.

5.3 Readiness for the Future

- **29 DMTs** are expected by 2030, with the first likely to be approved in the UK in the next 12 - 18 months.
- These treatments will require early and accurate subtyping of dementia, yet current diagnostic infrastructure is insufficient to meet this demand.

6.0 Review of the Current Offer

6.1 Strengths

Sunderland has clear foundations to build upon:

- **Diagnostic performance**: At 67 - 68% of the total number of people estimated to have dementia, Sunderland is above the national DDR standard and contributes positively to regional success. This demonstrates established diagnostic pathways and strong engagement in some GP practices.
- **Community assets**: A range of voluntary and community organisations (including Sunderland Carers Centre and the Alzheimer's Society's Essence Service) provide valuable post-diagnostic support.
- **Ageing Well Ambassadors**: With more than 270 ambassadors, this group provides a strong community voice, challenges stigma, and advocates for dementia-friendly practice.
- **Strategic prioritisation**: Dementia is recognised as a priority within the Healthy City Plan, and governance arrangements.

6.2 Weaknesses

The pathway review (March–August 2025) has identified significant areas for improvement:

- **Variable referral practice**: Wide differences exist across GP practices, with some referring consistently fewer patients. This creates postcode inequity and reflects variation in GP confidence, awareness, and thresholds for referral.
- **Resource usage and diagnostic practice variability**: The challenge is not simply "capacity bottlenecks" but how existing diagnostic resources are used. National guidance (NICE NG97) advises against exhaustive or advanced investigations where dementia subtype is already clinically clear, recommending instead a proportionate and structured approach. In Sunderland, some patients undergo more tests than necessary, while others experience delays in accessing investigations that would meaningfully inform care. This mismatch creates both inefficiency and inequity.
- **Fragmented post-diagnostic support**: Families frequently describe a "cliff edge" after diagnosis, with inconsistent follow-up and unclear routes into support groups, community resources, or social care.
- **Carer invisibility**: Carers report being overlooked during consultations and lacking respite or wellbeing support. This increases the risk of carer burnout, crisis admissions, and premature moves into long-term care.
- **Equity gaps**: Sunderland's dementia register is 96% white compared to Sunderland's population of 94.6%. This might indicate that minority ethnic groups are slightly under-diagnosed. Furthermore, people living alone often receive limited follow-up once diagnosis is made.

6.3 Opportunities and Enablers

- **Research partnerships**: The University of Sunderland is piloting work on dementia awareness, prevention, and the carer experience, providing locally relevant data to inform commissioning.

- **National policy focus on innovation**: The anticipated arrival of disease-modifying therapies provides both urgency and opportunity. Early preparation of pathways and workforce will allow Sunderland residents to access new treatments as soon as they are approved.
- **Healthy City Plan Grant funded engagement research**: A pilot research study through the University of Sunderland is currently exploring local views about the awareness of dementia and associated risk factors, together with the support available, and wanted, for families affected by dementia. These findings should help inform the local Dementia Delivery Plan.

6.4 Summary

While Sunderland has strengths in its diagnostic rate and community assets, the current offer is not sufficiently equitable, efficient, or future-proofed. The system is hampered by variation in referral practice, misaligned use of diagnostic resources, and fragmented post-diagnostic support.

Crucially, carers and people living with dementia repeatedly highlight that the system does not feel joined-up or person-centred. These findings reinforce the need for a radical redesign of the dementia pathway, one that ensures proportionate and structured diagnosis, equitable access across all communities, and meaningful, ongoing support after diagnosis.

7.0 Towards a New Model

7.1 Vision

Through the pathway review and engagement process, Sunderland has developed a proposed new dementia model. This work has been grounded in three things:

- **Learning from our own pathway review and data** (referrals, register size, inequalities).
- **Listening to people with dementia and their carers**, who have been clear about what is and isn't working.
- **Drawing on good practice guidance and national evidence**, including NICE guidance and regional exemplars.

7.2 Principles Underpinning the Model

The proposed model is designed around a set of clear principles:

- **Equity** – ensuring no one is excluded from diagnosis or support due to background, postcode, or living circumstances.
- **Prevention and hope** – making risk reduction visible and showing people that dementia is a condition where they can live well with the right support.
- **Continuity of support** – moving away from the "cliff edge" after diagnosis, towards a joined-up pathway across NHS, social care, and community services.
- **Carer recognition** – treating carers as equal partners in planning and ensuring they receive support to sustain their role.
- **Future readiness** – ensuring Sunderland is prepared for innovation, including disease-modifying therapies.

7.3 Distinctiveness of the Sunderland Approach

The proposed model represents a system-wide redesign, informed directly by people's lived experience and by best practice guidance. It reframes dementia services as proactive, preventative, and person-centred, rather than reactive and target-driven.

8.0 Risks and Mitigations

The development of Sunderland's dementia pathway carries several strategic risks. These are being actively managed and will be monitored through the mental health/ learning disabilities/ neurodiversity (MH/LD/ND) Oversight Group.

Risk 1: Plateauing diagnostic rates due to declining referrals

- *Impact*: Missed diagnoses, unmet need, widening inequity.
- *Mitigation*: Practice-level dashboards to monitor referral variation; targeted GP engagement; learning from high-performing areas.

Risk 2: Inequity in access and outcomes

- *Impact*: Possible under-diagnosis in minority communities and those living alone; carers remaining unsupported.
- *Mitigation*: Targeted outreach, culturally competent pathways, stronger carer support offers and embedding co-production.

Risk 3: System not prepared for disease-modifying therapies (DMTs)

- *Impact*: Residents excluded from access to transformative treatments; reputational and ethical risk.
- *Mitigation*: Workforce and imaging capacity modelling underway; pathway redesign embedding NICE-compliant, proportionate diagnostic practice.

Risk 4: Carer breakdown leading to crisis admissions

- *Impact*: Increased hospital demand, premature entry into long-term care, financial and social cost escalation.
- *Mitigation*: Strengthening carer pathways, including respite and wellbeing support, as part of the model.

9.0 Recommendations

The Health and Wellbeing Board is recommended to:

i. Note Sunderland's current dementia diagnostic position.
ii. Recognise the risks of plateauing performance, inequities, and future system pressures if the pathway is not reformed.
iii. Endorse the direction of travel set out through the pathway review: a radical new dementia model grounded in learning, lived experience, and good practice guidance, to be informed by and address the variation of referral levels across GP practices
iv. Support the continuation of governance processes and co-production activity to refine the Dementia Delivery Plan.
v. Agree that a full Dementia Delivery Plan will be brought back to the Board for consideration and endorsement in early 2026.
vi. Receive future assurance on the delivery of the Dementia Delivery Plan through the Sunderland Place Committee assurance reports.