Humber and North Yorkshire
Health and Care Partnership

High level Strategic Outline Case (SOC)

No options will have been developed at this stage and this document intends to aid planning where there has been a need identified to develop a Strategic Outline Case (SOC).

Please complete and return this form by 12 noon on Monday 16 September.

Please complete for each 'Big Ticket' item.

Please return this form to: Anja.Hazebroek@NHS.net

Case for Change
What is the service proposal at a high level?
To reduce variation in access to dementia prevention, assessment, diagnosis and post-diagnostic support across Humber and North Yorkshire. There is currently significant variation in all aspects of dementia care with 40% of those estimated to have a diagnosis, not currently accessing a diagnosis. Of the 60% who do have a diagnosis, their experiences and outcomes vary significantly.   This change sets out a five year strategy to improve access, prevention, communication, education, futureproofing, research and innovation. Addressing these key areas will aid in the improvement of the HNY dementia diagnosis rates whilst ensuring the system is equipped to manage additional demand.   Strategic alignment: • 'Hope of a Life Still to be Lived' – HNY Dementia 5- year strategy (launch due Nov 2024). • Humber and North Yorkshire ICB strategy and vision for everyone in HNY to live longer, healthier lives. For everyone to start well, live well, age well, and die well. • HNY ICB Innovation, Research and Improvement System (IRIS). • NICE Guideline [NG97] Dementia: assessment, management and support for people living with dementia and their carers. • NHS Long Term Plan – 24/25 planning. • Major Conditions Strategy. • National Inpatient Quality Transformation Programme • NHSE Dementia programme and preparation for new Alzhiemer's disease modifying treatments. • Carnall Farrar (2024) report – The economic impact of dementia.
From a public/patient point of view – "what does it mean for me?" (How will things be different and what are the main benefits I will feel/receive?)
The HNY dementia programme has been fully coproduced with people living with dementia and their families across HNY, alongside health, care and VCSE partners from a range of organisations.   From the last 15 months of engagement the following benefits have been identified from this five year programme of work:

- Better prevention of some dementias through a dedicated campaign focussing on the 14 known modifiable risk factors.
- Better access to timely and good quality dementia diagnosis, including accurate subtyping to ensure the correct support is available to all.
- Greater awareness of how to access the support that is available across HNY so people affected by dementia do not feel alone and unable to cope.
- Better support for care partners so they feel able to cope better, for longer and so they are able to prioritise their own health needs too.
- Hope following diagnosis is key to better outcomes.
- People are kept informed throughout the entire pathway and are in control of their own care.
- People understand dementia better so are not told 'you have dementia, there's nothing else we can do'.
- Better access to non-pharmacological interventions and pharmacological interventions (DMTs, Acetylcholinesterase inhibitors) to improve quality of life after diagnosis.

What is the rationale for the change/developing proposal? (For example, is it about finance, safety, sustainability, staffing difficulties, lack of suitable estate, improved patient experience, efficiency etc). Is there any data or evidence to support?

- Lived experience – people across HNY are having difficulties in accessing timely diagnosis both at primary care and secondary care level. In some areas people are waiting up to 60 months for a dementia diagnosis.
- Engagement over the last 14 has highlighted poor experiences and outcomes for people with dementia and their families (report of findings in progress).
- Access to services is variable and does not always take into account the demographics and population health groups.
- We have an ageing population and the expected dementia diagnosis rates are expected to rise significantly.
- There are 29 disease modifying treatments on the horizon for use by 2030 – access to these is subject to accurate and timely diagnosis. We have a System Readiness workstream with NHSE aiming to address this as currently the system is not equipped to support the roll out. The first tablet form DMT is expected to be decided on by February 2025.
- Capacity within the memory services currently exceeds demand across all services with no access to additional resource to address this.
- Access to neuroimaging remains a challenge and requires further exploration including consideration of CDC's.
- The impact of delayed diagnosis and lack of support is not only detrimental to the person but has a significant impact on the wider system. E.g. increased hospital admissions (acute and MH), carer breakdown (economic cost increases), greater risk of poor physical health (NHSE 2024 report suggests 25% of acute hospital beds are occupied by people with dementia, 43% of these due to conditions that are treatable in the community such as UTI's and chest infections). Locally processes do not facilitate timely follow up for this admitted with a delirium who cannot be assessed for dementia until the delirium has cleared. They are referred to the GP for follow up but follow-ups are not carried out. HNY are working with the region to explore alternative models such as virtual wards or delirium follow up clinics.
- Mild cognitive impairment remains a challenge – linked to the above point regarding lack of follow up after diagnosis. Finding from current primary Care QI

project highlight a significant gap in MCI follow up – partly impacted by lack of national policy/guidance on these. HNY are part of a regional NHSE group to address this.

- Economical impact – Carnall Farrar (2024) report the UK cost of dementia currently is £42b annually. This is expected to increase to £90b by 2024.

[PDF icon]

the-annual-costs-of
-dementia CF report

What is the potential kind of change anticipated (for example, consolidation of service, change of provider, change of location, withdrawal of existing service, closure of beds)?

- Redesign of Memory Assessment Services and pathway – developing a core consistent offer across HNY with reduced unwarranted variation, and a renewed focus on varying groups (young onset dementia, LD and dementia, dementia and minority ethnic groups).
- Workforce upskilling – increasing access to diagnostic training in primary care and secondary care. Upskilling in community and care settings to reduce crisis and carer breakdown, and better manage physical health without the need for acute admission.
- Current QI project in progress addressing coding issues, MCI follow-up gaps, diagnosis in non-MAS services and follow-up. The findings are supporting the development of a toolkit and bespoke work with relevant organisation based on individual need.
- Communications campaign focussing on prevention – working with the ICB Comms team and programme partners in collaboration with lived experience member across HNY.
- Developing accessible web content via the Let's Get Better website to ensure people know where and how to access the right support.

Resources

What is the current workforce? What do we anticipate the future impact on the workforce to be (For example, will there be a change in the workforce profile, will there need to be a change from what we have now)?

- Demand is currently exceeding capacity and requires further analysis of future impact. This has commenced with some modelling around predicted age over the next 15 years and predicated dementia prevalence.
- The HNY dementia programme has a dedicated detailed dementia diagnosis dashboard which highlights target areas and informs planning. This continues to evolve and captures DDR from GP practice level to ICS level, MCI rates in 40+ and 65+ year olds, young onset dementia rates, mortality rates, primary care referral rates (in progress), and from September 2024 will include monthly MAS demand data.

What is the current financial resource attached to this activity? What do we anticipate the future impact on the financial position to be?

Dementia is not included within the MHIS and has not had dedicated funding.

Through 24/25 planning, SDF has been allocated from the MH spend which will address some of the capacity and demand issues, reduce long waits, and therefore improve patient experience and outcomes. Without access to this funding, the services will continue to struggle to address waiting times and waiting lists will continue to rise.

Greater investment in dementia is required to reduce the overall economic burden on the system and improve patient and care partner outcomes.

What is the current estate attached to this activity? What do we anticipate the future estate requirement to be?

We currently have 10 memory assessment services across HNY, some embedded within the CMHT. None have dedicated neuroimaging resources and access to this is variable across HNY.

If appropriate, how will this proposal be digitally enabled?

- Current dementia diagnosis dashboard.
- Use of the Lets Get Better website.
- Use of the NCRS Reasonable Adjustments Flag to improve access and outcomes.
- Digital solutions on the horizon for dementia screening and earlier identification.

Who are the clinical leads and how does this align with existing clinical networks/structures?

- Dr Stella Morris and Dr Stephen Wright – MHLDA Collaborative Clinical Leads.
- Dr Hari Symes – ER Place Clinical lead for Older adults and dementia.
- Dr Charlotte Deasy – NHSE NEY Regional Mental Health Dementia Clinical Lead.
- Various clinical leads from partner organisations support the HNY dementia programme.

Impact and Benefits

What will the benefits be (high level list)?

- Improved patient and family outcomes.
- Reduced inequalities.
- Reduced crisis and carer breakdown.
- Reduced economic impact on the whole system.
- Improved dementia diagnosis rates.
- Earlier intervention meaning better quality of life for longer after diagnosis.
- Reduced out of area placements.
- Reduced hospital admissions (MH and acute).
- Prevention of dementia longer term (potentially 45% of dementias can be prevented by addressing 14 modifiable risk factors).

Lancet Dementia
Report 2024.pdf
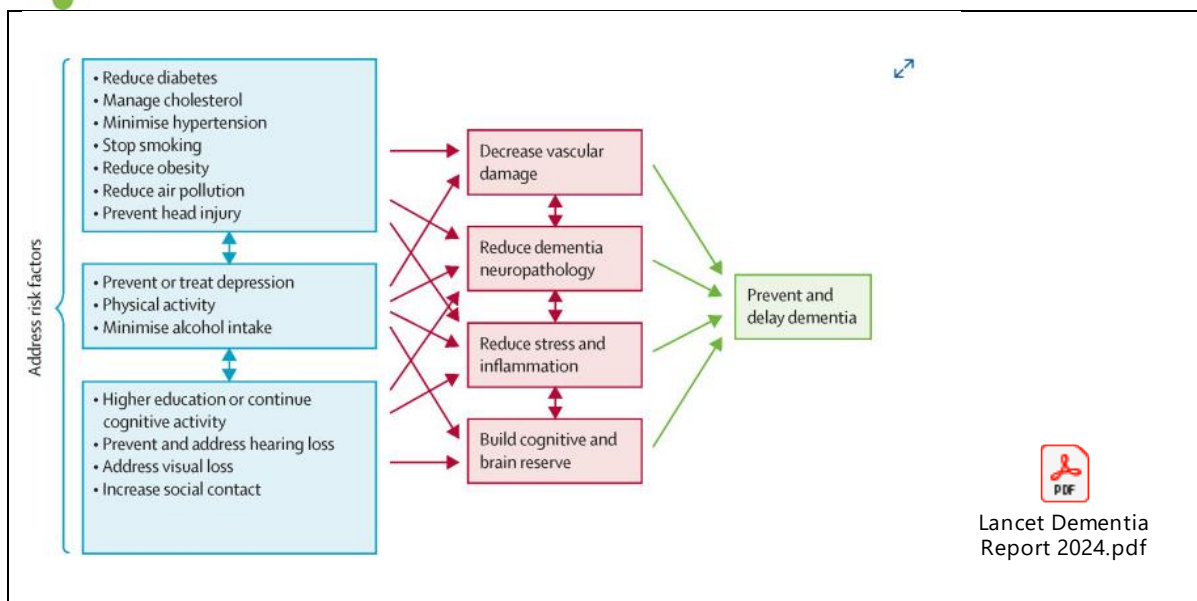
Please supply some detail around the timeframe associated with this proposal?
This is a five year plan commencing Nov 2024 with some workstreams already in progress.

Who is this LIKELY to impact (for example, families expecting/planning a child, cancer patients, families/carers in an EOL situation, patients with enduring mental health difficulties)?
• People with dementia of all ages. • Families and care partners of people living with dementia of all ages.

Is this likely to impact people with a protected characteristic or people living in areas of social deprivation? Are there any particular groups of people we will need to be especially mindful of including in the engagement?
• People from LGBTQIA+ communities are less likely to have family support, and more likely to be poorly represented in services. Older people are more likely to live alone and experience health inequalities and poorer health outcomes, including higher levels of modifiable risk factors. • People from ethnically diverse Groups face higher levels of stigma surrounding dementia which may impact on help-seeking. Higher rates of cardiovascular disease and hypertension in South Asian and Afro-Caribbean communities means they face a higher risk of dementia and co-morbid long term health conditions. There is also a lack of culturally appropriate diagnosis and care. • People with advanced/severe dementia face many care inequalities and have much less control over their lives. They are more likely to require a hospital admission and admissions are likely to be longer. They have less access to meaningful care and interventions and less opportunity to communicate. • People who live alone experience higher levels of loneliness and face significant challenges in accessing care and support, especially if they don't have family nearby. • People with a learning disability, (particularly people with Down's Syndrome) are more likely to develop dementia than the general population and at a younger

age). Access to assessment and diagnosis takes longer and teams aren't always suitably skilled in supporting the needs of both diagnoses.

- People with a hearing impairment are at greater risk of dementia due to reduced cognitive stimulation. They also face inequalities in access to cultural-linguistic care and accessible information.
- People with young onset dementia face a different set of challenges such as navigating health and care support and managing employment and parental responsibilities. Poor recognition can lead to delayed diagnosis which can lead to poorer outcomes.

All of these group are being represented and inequalities addressed through the HNY dementia programme with links being made to improve inclusion with under-represented groups.

Is this going to have a direct impact in one Place or in several Places? If this is HNY wide please specify.

- All of HNY.