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| **Report to:** | Humber and North Yorkshire Integrated Care Board |
| **Date of Meeting:** | 13 November 2024 |
| **Subject:** | **Hope of a life still to be lived: A five-year plan for dementia in Humber and North Yorkshire** |
| **Director Sponsor:** | Teresa Fenech  Executive Director of Nursing & Quality  Humber and North Yorkshire ICB  Brent Kilmurray  Chair of the Mental Health, Learning Disabilities and Autism Collaborative, Humber & North Yorkshire Health and Care Partnership  Chief Executive, Tees, Esk and Wear Valleys NHS Foundation Trust  ICB Board member for Mental Health, Learning Disabilities and Autism |
| **Author:** | Gemma Willingham-Storr (Humber and North Yorkshire ICS Dementia Programme Lead) |

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| **Agenda Item No:** | **13** |



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| **STATUS OF THE REPORT:**  Approve  Discuss  Assurance  Information  A Regulatory Requirement |

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| **SUMMARY OF REPORT:**  ‘Hope of a Life Still to be Lived’ is the Humber and North Yorkshire ICS five-year plan for dementia, with an accompanying action plan to be reviewed annually. This plan has been coproduced in partnership with people living with dementia, their families and care partners, VCSE organisations, mental health providers, acute trust providers, primary care services, local authorities, hospices, and Place colleagues, across Humber and North Yorkshire. This is a high level plan that sets out actions to address six priority areas that will ultimately improve patient experience, improvement dementia diagnosis rates, and reduce variation. This aligns with existing local strategies and local Places and systems are aligning their new localised plans to this ICS plan. This plans aligns to the ICB Blueprint and vision for the next five years, and has been supported by the Clinical and Professionals Group on 1st November 2024.  **RECOMMENDATIONS:**  Members are asked to:   1. Approve the five-year plan ready for its launch in November 2024. |

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| **ICB STRATEGIC OBJECTIVE** | |
| Leading for Excellence |  |
| Leading for Prevention |  |
| Leading for Sustainability |  |
| Voice at the Heart |  |

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| **IMPLICATIONS** |

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| Finance | The priorities have all been developed on the premise that dementia does not receive national funding, therefore all interventions and actions will be developed as far as is practically possible within existing resource. |
| Quality | This plan aims at improving the quality of care and support available for people with dementia and their families. |
| HR | N/A |
| Legal / Regulatory | N/A |
| Data Protection / IG | N/A |
| Health inequality / equality | The action plan aims to address health inequalities and inequities. |
| Conflict of Interest Aspects | N/A |
| Sustainability | Futureproofing is a key priority to ensure services and sustainable longer term. |

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| **ASSESSED RISK:** |

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| **MONITORING AND ASSURANCE:**  Monitoring will be through the following routes which are detailed within the action plan:   * Review of progress towards actions every 8 weeks through the Humber and North Yorkshire Dementia Steering Group. * Briefing paper update to the MHLDA Collaborative Executive Strategic Leadership Group every six months. * Tracking though the Dementia Programme risk register and ICB risk register – reviewed bi-monthly and as required. * Monthly monitoring of memory service referrals, waiting list times, and dementia diagnosis rates via the Humber and North Yorkshire Dementia dashboard (on Epiphany). Performance varies significantly across Humber and North Yorkshire and all partners are working to develop a ‘core offer’ which reflects best practice guidance. * Quarterly Assurance Return to NHSE. * Performance updates on a regular basis via the System Oversight and Assurance Group. * Monthly highlight reports to the UEC Programme ‘Additional Workstreams’ group.   Additional routes to monitor quality and lived experience include:   * Continued engagement with local lived experience groups and individuals, including under-represented groups. * Feedback from lived experience/engagement leads. * Intelligence reports – PALS, Greatix/Datix/Healthwatch Reports). * Direct feedback to the Humber and North Yorkshire Dementia Programme inbox. * Six weekly review of feedback from all of the above. |

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| **ENGAGEMENT:**  Throughout the 15 months from July 2023 to September 2024, the Humber and North Yorkshire Dementia five-year plan has been cocreated with significant involvement of people with lived experience. The plan has been developed in partnership with people living with dementia, their families and care partners, VCSE organisations, mental health providers, acute trust providers, primary care services, local authority, hospices, and Place colleagues, across Humber and North Yorkshire.  The title of the plan encompasses the broader vision of ‘Hope of a Life Still to be Lived’ and was named by the late Dr Wendy Mitchell BEM during the earlier stages of the plan development.  Comprehensive engagement has been held to develop the final five-year plan which includes an annual review of the action plan. Engagement methods and sources of information have included:   * Workshops * Humber and North Yorkshire Dementia Steering Group * Listening sessions * Conference * Survey * The Big Chatty Bus * Intelligence reports such as Healthwatch insight reports, Carnall Farrar economic reports. * National policy including the NHS Long Term Plan, NICE Guidance on dementia, NHSE System Readiness for Disease Modifying Treatments. * Communities of Practice * Research * Lived experience groups * Dementia Advisory Board * Humber and North Yorkshire Dementia Dashboard   The dementia programme has an established workstream that is focussed on understanding the current and future needs of our population and is informed by a monthly dementia data dashboard to ensure interventions are fit for local need.  The plan has been written in accordance with the Innovations in Dementia guidance on how to write and produce accessible information for people with dementia and has been reviewed by the Healthwatch Read Right Panel for accessibility.  We are aiming to launch the plan in November 2024 in line with our annual conference and seek approval from the ICB Board to do so. The NHSE regional mental health team are keen to learn from the Humber and North Yorkshire dementia programme and plan development and have asked for support in sharing our learning with the other ICB’s in the region. |

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| **REPORT EXEMPT FROM PUBLIC DISCLOSURE** No  Yes |
| If yes, please detail the specific grounds for exemption. |

**Hope of a Life Still to be Lived –**

**A five-year plan for dementia in Humber and North Yorkshire**

1. **INTRODUCTION**
   1. The dementia programme has an established workstream that is focussed on understanding the current and future needs of our population and is informed by a monthly dementia data dashboard to ensure interventions are fit for local need. Making best use of existing data, local knowledge and significant multi-agency engagement over the last 15 months, a five-year plan has been developed. The six key priorities have been identified as below and have all been developed on the premise that dementia does not receive national funding, therefore all interventions and actions will be developed as far as is practically possible within existing resource. The plan aims to focus on prevention of dementia (40% of dementia’s are preventable) and prevention of further avoidable ill health, improve access and support to people with dementia and their families, and ensure that all changes are sustainable for the future and take into account the needs of our future population.
   2. 
2. **BACKGROUND**

* 1. The Humber and North Yorkshire Dementia 5 year plan is aligned to the below:
* Humber and North Yorkshire ICB strategy and vision for everyone in Humber and North Yorkshire to live longer, healthier lives. For everyone to start well, live well, age well, and die well.
* Humber and North Yorkshire 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.
  1. A high level Strategic Outline Case (SOC) and has been shared with the Board previously which highlights the case for change and the challenges that the plan aims to address. Attached below for reference.



* 1. This plan has been approved by the MHLDA Operational Leadership Group (OLG) and by the MHLDA Collaborative Executive Strategic Leadership Group in October 2024.

#### ASSESSMENT

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* 1. The five year plan aims 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.

The actions aim to improve access, prevention, communication, education, futureproofing, research and innovation. Addressing these key areas will aid in the improvement of the Humber and North Yorkshire dementia diagnosis rates whilst ensuring the system is equipped to manage additional demand.

* 1. Lived experience – people across Humber and North Yorkshire 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.
  2. Access to services is variable and does not always take into account the demographics and population health groups. There is a greater need to understand this is more depth to improve access accordingly.
  3. We have an ageing population and the expected dementia diagnosis rates are expected to rise significantly. Modelling commenced within the dementia programme show the age trajectory across Humber and North Yorkshire over the next 15 years allowing for targeted focus to reflect population need.
  4. 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.
  5. 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 those 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. Humber and North Yorkshire are working with the region to explore alternative models such as virtual wards or delirium follow up clinics.
  6. Alternative models of diagnosing and managing dementia should be explored such as the work done by the frailty team from the Jean Bishop Integrated Care Centre in Hull. This is a centre of excellence for the assessment and management of frail patients who have proven they can reduce the number of these patients who require admission to the local acute NHS trust. The centre also runs a weekly MDT who manage complex dementia patients with distress in dementia and the team often diagnose dementia in these frail patients avoiding referral to the memory clinic.
  7. Economical impact – Carnall Farrar (2024) report the UK cost of dementia currently is £42b annually. This is expected to increase to £90b by 2024.
  8. Prevention: 45% of dementia’s are preventable so the programme will have a focus on the 14 known modifiable risk factors to address this (Annex 1). Additionally, there will be focus on reducing adverse outcomes for people with a dementia diagnosis within inclusion health groups and making use of existing and upcoming population health data.

##### CONCLUSION

This is a five year plan commencing November 2024 with some workstreams already in progress. The benefits of delivering on the action plan include:

* 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).

The action plan will be reviewed annually with further exploration work to refine the core offer and agreed performance outcomes (in addition to existing DDR target), with refined targets being agreed within the first 12 months based on the findings of the initial scoping work to better understand capacity and demand and finance modelling.

1. **RECOMMENDATIONS**
   1. Members are asked to:
2. Approve and endorse this five-year plan for dementia in Humber and North Yorkshire.

**Annex 1**

