

IIA Report – East Lothian Dementia Strategy 2023 Interim IIA

Each of the numbered sections below must be completed

This is an interim IIA.

1. Title of proposal

East Lothian Dementia Strategy 2023

2. What will change as a result of this proposal?

The main changes proposed by the strategy following engagement include:

- Improving access to information at all points of the dementia pathway.
- Offering diagnosis away from the community mental health team including from GP practices to reduce waiting times and delays
- Increasing the current offer of 1 year post diagnostic support to support throughout the lifetime of the person's time with dementia.
- Formalising the post diagnostic support offered to those with a Learning Disability who also have a diagnosis of dementia.
- Improving understanding and training among staff in hospital settings in managing and diagnosis dementia
- Supporting care home managers and staff to better manage complex behaviour in residents with dementia through face to face training on stress and distress
- Improve support offered to carers of people with dementia including increasing access to local respite, peer support and training to manage complex behaviour at home.
- Increase awareness among local partners and organisations of the value of supporting Dementia Friendly Communities.
- Increase the offer of local community groups and services for people with dementia including expanding the Musselburgh Meeting Centre model, increasing frequency of Alzheimer Scotland Dementia Café groups as well as the day centre outreach support. We also aim to develop a hybrid/pop up model to ensure access to such services in rural areas
- Develop joint commissioning of services for people with young onset dementia with a neighbouring authority given lower numbers
- Support independence through the earlier access to smart tec and better integration of the East Lothian Rehabilitation service with post diagnostic support.

3. Briefly describe public involvement in this proposal to date and planned.

- The Outside The Box Engagement Team was commissioned to engage on the Dementia Strategy. It engaged with 117 people across five sessions and 1-to-1 Zoom sessions (including people living with dementia)
- Feedback on dementia from the East Lothian IJB Strategic Plan and Planning for an Older Population engagements (including, workshops, focus groups, 1-to-1 interviews and online questionnaires with around 1,500 people and organisations)
- LCT Trust Feedback
- Engagement with 15 care home managers/providers
- Ongoing engagement with Dementia Friendship Groups across East Lothian

4. Is the proposal considered strategic under the Fairer Scotland Duty?

Yes.

5. Date of IIA



3rd May 2023 – 11am to 1pm via Teams

6. Who was present at the IIA? Identify facilitator, lead officer, report writer and any employee representative present and main stakeholder (e.g. Council, NHS)

Name	Job Title	Date of IIA training
Ashley Hardy (Lead Officer)	Strategy Officer, Planning and Performance, ELHSCP	March 2023
Janice McLeod	Chair, Musselburgh Area Partnership Health and Wellbeing Sub-Group	
Julia Mackenzie	Post-Diagnostic Support Lead, Alzheimers Scotland	
Christine Johnston	Manager, Planning and Performance, ELHSCP	
Anne Bissett	Lived experience of being a carer of someone with dementia, organiser of peer support for carers of people with dementia	
Jess Wade	CEO, Carers of East Lothian	

Name	Job Title	Date of IIA training
Kathryn Leslie	Deaf Social Worker, Deaf Action	
Sue Northrop	Dementia Friendly East Lothian	
Jane Ogden-Smith	Equalities and Engagement Officer, ELHSCP	Sept 2009 Dec 2022

7. Evidence available at the time of the IIA

Evidence	Available – detail source	Comments: what does the evidence tell you with regard to different groups who may be affected and to the environmental impacts of your proposal
Data on populations in need	<ul style="list-style-type: none"> • Dementia Strategy  ELHSCP Dementia Strategy DRAFT V8.doc • Dementia Strategy Technical Report  Dementia Strategy - Technical Report v2.doc • Ward Profile/Snapshots • East Lothian Joint Strategic Needs Assessment • National Standards for Dementia Care 	<ul style="list-style-type: none"> • The East Lothian population has grown by 20% since 2000 and at a higher rate than the Scottish population as a whole • Our population has grown at a higher rate in areas of higher deprivation, specifically within the 1st quintile (most deprived) to the 3rd quintile while the population has decreased in areas of lowest deprivation (4th and 5th quintiles). • From 2018 to 2043, East Lothian's population is predicted to increase by a further 12.8% reaching a peak of 121,743, and will grow at faster rate than Scotland as a whole. • East Lothian currently has a higher female than male population, although the largest percentage age group in both categories is currently in the middle aged group (aged 45-59). • While life expectancy is set to increase for both males and females, women in East

Evidence	Available – detail source	Comments: what does the evidence tell you with regard to different groups who may be affected and to the environmental impacts of your proposal
		<p>Lothian continue to have a longer life expectancy than men. By 2043 this projected to increase to 82 years for males and 85 years for females.</p> <ul style="list-style-type: none"> • Similar to Scotland as a whole, East Lothian has higher mortality rates among the most deprived areas of the county. The leading cause of death in women in East Lothian is Dementia and Alzheimer's (14.5% of all female deaths) and it is the second leading cause of death in men after heart disease (7.9% of all male deaths).
Data on service uptake/access	As above	<ul style="list-style-type: none"> • In East Lothian, of those with a formal diagnosis 1459 (or 97.3%) were over the age of 65 and only 40 (2.7%) were under the age of 65. The youngest person diagnosed with dementia in East Lothian is 47 and the oldest person is 101. The age groups with the highest numbers of people diagnosed were ages 75-84 and 85-94 years old. • The Scottish Government have set a Local Delivery Standard that all people who are newly diagnosed with dementia receive a minimum of one year Post Diagnostic Support co-ordinated by a named link worker. Data to monitor performance against this standard is collated by Public Health Scotland and shows the percentage of people referred

Evidence	Available – detail source	Comments: what does the evidence tell you with regard to different groups who may be affected and to the environmental impacts of your proposal
		<p>for post diagnostic support who successfully received this support for a minimum of one year. The national average performance against this standard for 2019/20 was 81.3%.</p> <ul style="list-style-type: none"> • East Lothian’s performance against this standard has been variable. The variation has been attributed to challenges with recruitment due to the short term nature of the contract with the provider. East Lothian HSCP have now awarded a longer term contract to support this and as a result the number of link workers in post have had a positive effect on reducing the post diagnostic support waiting list from 120 people to 70 as of March 2023, with the expectation that this will reduce further to around 20 people once the new link workers reach a full caseload following training.
<p>Data on socio-economic disadvantage e.g. low income, low wealth, material deprivation, area deprivation.</p>		<ul style="list-style-type: none"> • The areas of highest deprivation in East Lothian are largely to the west of the county specifically in areas in Musselburgh, Wallyford, Tranent and Prestonpans. There are also pockets of deprivation in Haddington and Dunbar. • Around 95% of people in East Lothian living in the community live within an urban setting and 5% live in more rural settings.

Evidence	Available – detail source	Comments: what does the evidence tell you with regard to different groups who may be affected and to the environmental impacts of your proposal
		<p>Around 22% of those diagnosed live in the Musselburgh, Wallyford and Whitecraig area. Indeed, there are higher numbers of people diagnosed generally to the West of the county (578 people in Musselburgh, Fa'side and Preston/Seton/Gosford wards) compared to the East (411 in Haddington & Lammermuir, North Berwick Coastal and Dunbar & East Linton wards).</p> <ul style="list-style-type: none"> • Of the 5% living in rural settings, the highest proportion of these residents are within the Haddington and Lammermuir, and Dunbar and East Linton wards. These include the rural towns of Garvald, Gifford, Morham, Humbie, Bolton, Cockburnspath and Innerwick.
Data on equality outcomes		<p>Still awaiting outputs from National Records of Scotland for the 2022 census. They forecast that detailed demographic information by local authority area will not be available until summer 2024.</p> <p>Work has begun in ELHSCP to encourage more equalities monitoring of patients/service-users using our services.</p>
Research/literature evidence	<ul style="list-style-type: none"> • National Records of Scotland, <u>Yearly Percentage Change in Population</u> 	<p>Although rates of dementia are increasing due to the rising number of older people in the population, the actual incidence of dementia has fallen in many</p>

Evidence	Available – detail source	Comments: what does the evidence tell you with regard to different groups who may be affected and to the environmental impacts of your proposal
	<ul style="list-style-type: none"> • <u>ScotPHO Profiles</u>, (Accessed: Jan. 2022) • <u>Scottish Survey Core Questions</u>, 2018 (Accessed: Jan. 2022) • <u>Alzheimer Scotland: Estimated number of people with dementia in Scotland, 2017</u> • <u>Alzheimer Europe: Dementia in Europe Yearbook, 2019</u> • <u>Life Expectancy With and Without Dementia: A Population-Based Study of Dementia Burden and Preventive Potential American Journal of Epidemiology Oxford Academic (oup.com)</u> • <u>Dementia prevention, intervention, and care: 2020 report of the Lancet Commission - PMC (nih.gov)</u> • <u>Transforming Specialist Dementia Hospital Care Alzheimer Scotland (alzscot.org)</u> 	<p>countries, most likely because of improvements in education, nutrition, health care and lifestyle changes.</p> <p>Race <i>BME communities:</i></p> <ul style="list-style-type: none"> • Accurate data on black and minority ethnic (BME) people with dementia either at the UK or Scottish level is not available, making it difficult to conduct a needs assessment. Alzheimer Scotland concluded that further research is required to clarify dementia risk within BME groups. • Barriers for BME people to seeking help may be: <ul style="list-style-type: none"> ▪ Knowledge related: Beliefs about dementia including the belief that dementia is a normal part of the ageing process. ▪ Society-related: Including fear of stigmatisation and the view that dementia is a private problem. Cultural expectations that relatives should care for the older person with dementia ▪ Health-care Related: Reluctance to engage with health services and previous experiences of discrimination. Clinicians may also be reluctant to diagnose dementia in BME

Evidence	Available – detail source	Comments: what does the evidence tell you with regard to different groups who may be affected and to the environmental impacts of your proposal
	<ul style="list-style-type: none"> • <u>Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities (alzheimers.org.uk)</u> • <u>Pham TM, Petersen I, Walters K, Raine R, Manthorpe J, Mukadam N, Cooper C. Trends in dementia diagnosis rates in UK ethnic groups: analysis of UK primary care data. Clin Epidemiol. 2018</u> • NHS Lothian Mental Health Analytics [Accessed Oct 2022] • <u>Impact on carers - Dementia Statistics Hub</u> • <u>See Hear: Scottish Government</u> • <u>Court et al 2014: Vision impairment is associated with physical and mental comorbidities in older adults</u> • <u>Dawes et al 2020: Hearing and vision health for people with dementia in residential long term care</u> 	<p>groups to awareness of cultural bias in standard cognitive tests. Language barriers may also impact diagnosis as well as an understanding of how to access appropriate healthcare.</p> <p>Disability <i>People with sensory impairment</i></p> <ul style="list-style-type: none"> • Prevalence of sensory impairment is more common as people age. Over 70% of those with a hearing loss are over the age of 70, and 90% of those with dementia in long term care are thought to have a hearing or vision impairment • New research shows evidence of a link between sensory impairment and dementia, including that hearing loss is a factor in cognitive decline • Hearing loss is one of the modifiable risk factors thought to be able to prevent or delay dementia and is estimated to account for up to 8% of dementia cases • There is frequent under-reporting and under-treatment of sensory impairment • Sensory impairment has a significant impact on people's health and everyday life and has been attributed to an increased risk of developing health conditions. This impact

Evidence	Available – detail source	Comments: what does the evidence tell you with regard to different groups who may be affected and to the environmental impacts of your proposal
	<ul style="list-style-type: none"> • <u>Heine et al 2015: Dual sensory loss in older adults</u> • <u>Dawes 2019: Hearing Interventions to Prevent Dementia</u> • <u>Livingston et al 2017: Dementia Prevention, Intervention and Care</u> • <u>Andrusjak et al 2020: Identifying and managing hearing and vision loss in older people in care homes</u> • <u>Kim et al 2021: Association of hearing loss with Neuropsychiatric Symptoms in older adults with cognitive impairment</u> • <u>NICE: Hearing loss in adults: assessment and management</u> 	<p>is greater on care home residents who are also likely to be living with dementia</p> <ul style="list-style-type: none"> • Hearing loss in care home residents has been shown to increase the number and severity of Neuropsychiatric symptoms which lead to poorer health outcomes. • There are significant barriers to managing hearing and vision impairment within care homes although research shows that improvements in screening, assessments, environmental adaptations and stronger links with external professionals would improve this. <p><i>People with learning disabilities</i></p> <ul style="list-style-type: none"> • There are over 700 adults with a learning disability living in East Lothian. Many people with a Learning Disability already have substantial support packages in place prior to a dementia diagnosis given the life-long condition of an LD diagnosis. This is a fundamental difference to older people diagnosed with dementia. <p>Age <i>Older people in care/nursing homes</i></p> <ul style="list-style-type: none"> • Although residential homes do not provide nursing care, there are higher numbers of people with a diagnosis of dementia in residential homes than in nursing homes in East Lothian. The percentage of people with

Evidence	Available – detail source	Comments: what does the evidence tell you with regard to different groups who may be affected and to the environmental impacts of your proposal
		<p>dementia in East Lothian residential homes is around 81%, while in nursing homes, the average is around 69%.</p> <ul style="list-style-type: none"> • East Lothian has a consistently higher rate of death due to Alzheimer’s and other Dementias than Lothian and Scotland. <p><i>Young people</i></p> <ul style="list-style-type: none"> • We do not have specific data on young carers supporting people with dementia and this is something that we aim to improve on through the strategy. <p>Sex</p> <p><i>Women</i></p> <ul style="list-style-type: none"> • Statistics for the UK also show that women are 2.3 times more likely to provide care for someone with dementia for over 5 years, and around 60-70% of carers for people with dementia are women. It also shows that 48% of carers of someone will themselves have a longstanding disability or illness. <p>Carers</p> <ul style="list-style-type: none"> • Of the total 1619 carers who accessed support from Carers of East Lothian from March 2022 – March 2023, 405 carers accessed support as a carer of someone with dementia. This number still falls significantly below the estimated total number of people with a diagnosis of dementia (2104 in 2022). A significant number of

Evidence	Available – detail source	Comments: what does the evidence tell you with regard to different groups who may be affected and to the environmental impacts of your proposal
		<p>carers of someone with dementia are not accessing support from a carers' organisation.</p> <p>Geographical areas</p> <ul style="list-style-type: none"> • Around 95% of people in East Lothian living in the community live within an urban setting and 5% live in more rural settings. Around 22% of those diagnosed live in the Musselburgh, Wallyford and Whitecraig area. Higher numbers of people are diagnosed to the West of the county (578 people in Musselburgh, Fa'side and Preston/Seton/Gosford wards) compared to the East (411 in Haddington & Lammermuir, North Berwick Coastal and Dunbar & East Linton wards). • Of the 5% living in rural settings, the highest proportion of these residents are within the Haddington and Lammermuir, and Dunbar and East Linton wards. These include the rural towns of Garvald, Gifford, Morham, Humbie, Bolton, Cockburnspath and Innerwick
Public/patient/client experience information	From engagement and research publications listed above	<ul style="list-style-type: none"> • People with dementia have difficulty in accessing information in order to

Evidence	Available – detail source	Comments: what does the evidence tell you with regard to different groups who may be affected and to the environmental impacts of your proposal
		<p>participate in the decisions that affect them.</p> <ul style="list-style-type: none"> • People with dementia and their carers want timely diagnosis as a gateway to receiving quality post-diagnostic support, medication to delay symptoms, as well as information to understand the condition. • Carers need support at home before they reach crisis point • The overwhelming impact of caring for someone with dementia for full-time carers • Issues around waiting times for people with dementia in A&E, travel for hospital admission • Access to good palliative and end of life care • The stigma of dementia • The need for more dementia inclusive communities and community activities – people want to access a wider range of support in their local community • A desire to having more Meeting Centres and Dementia Cafes • Access to day centres provides respite for carers and stimulation for the person living with dementia • Fear of losing employment after diagnosis and general worries about finances • Access to transport and lack of parking can be problematic for people with dementia and their carers.

Evidence	Available – detail source	Comments: what does the evidence tell you with regard to different groups who may be affected and to the environmental impacts of your proposal
Evidence of inclusive engagement of people who use the service and involvement findings	See engagement section above	There are issues in that we do not have good information about minority ethnic and ethnic minority people in the East Lothian Community. Lack of established forums in East Lothian makes it difficult to secure views and engagement.
Evidence of unmet need	See section on data and access to/uptake of services	See section on data and access to/uptake of services
Good practice guidelines	See section on research	See section on research
Carbon emissions generated/reduced data	This strategy is still in development and formal action plan is still to be produced. Carbon emissions will be explored once actions become clearer.	Not possible to assess at the moment.
Environmental data	As above	As above
Risk from cumulative impacts	None	
Other (please specify)	None	
Additional evidence required	None	-

8. In summary, what impacts were identified and which groups will they affect?

Equality, Health and Wellbeing and Human Rights	Affected populations
<p>Positive The IIA group's response to the draft strategy was very positive, particularly because it took a human rights approach and it was clear that it had been informed by extensive engagement and research.</p>	<p>Disabilities/Older People/Carers Positive impacts would include:</p> <ul style="list-style-type: none"> • An overall commitment to

Equality, Health and Wellbeing and Human Rights	Affected populations
	<p>developing services and support that helped people to stay as independent as possible, and to enjoy activities and connections, and be recognised for their own worth</p> <ul style="list-style-type: none"> • People have more access to community resources and are able to connect to them easily • A commitment to swifter diagnosis • Post-diagnostic support – expanding the period of support from just one-year post diagnosis to support throughout the person’s dementia pathway/for as long as they need it in line with Alzheimers Scotland’s Eight Pillar approach • Introducing a single point of contact for service-users and carers • Introducing a formal post-diagnostic pathway • Improving information to support people – not just at the time of diagnosis but throughout their subsequent journey • Rolling out Stress and Distress,

Equality, Health and Wellbeing and Human Rights	Affected populations
	<p>sensitisation and face-to-face training</p> <ul style="list-style-type: none"> • Ensuring that care planning takes account of carers needs • Enabling access to more peer support, local activities, rolling out the meeting-centre model across the other five local area partnership areas and looking at hybrid/pop-up models for people in rural areas • Reducing stigma and discrimination attached to dementia to improve community connections and access to local activities • Emphasising the contribution that people living with dementia can make as employees and volunteers • Making better use of Allied Health Professionals and improving access to physiotherapy, adaptation and physical aids to help people to remain independent longer.
Negative	<p>Race</p> <ul style="list-style-type: none"> • The lack of evidence about/networks for

Equality, Health and Wellbeing and Human Rights	Affected populations
	<p>people in ethnic minority and minority ethnic groups means that these groups are largely invisible in service planning and delivery.</p> <ul style="list-style-type: none"> • Lack of knowledge about/access to interpretation and translation services acts as a barrier to access to statutory and community services for potential service-users and staff supporting them. • Pressures on accredited interpretation agencies mean that there can be long waits for interpreters for specific languages <p>Sexual orientation</p> <ul style="list-style-type: none"> • Issues for Trans people in care homes and other places – research shows that they are very vulnerable in care settings and at risk – not covered explicitly in the strategy. <p>Disability</p> <p>There were a range of issues for Deaf BSL users and their families that hadn't been explicitly considered in the strategy. These included:</p>

Equality, Health and Wellbeing and Human Rights	Affected populations
	<ul style="list-style-type: none"> • lack of BSL interpreters, interpreters not understanding the Deaf person's signing idiolect in the same way as a long term dedicated worker • issues with filling in physical or online forms due to English being second language • support being accessible to Deaf carers in the same way as to hearing carers with English as a first language (written, in-person and phone support) • Deaf service-users and carers being unable to access supporting community activities due to lack of BSL interpretation. <p><i>People with dementia as a disability group</i></p> <p>Using GPs as additional route to dementia assessment was seen to be problematic for a number of reasons, including:</p> <ul style="list-style-type: none"> • Difficulties for patients getting a GP appointment • Concerns about the need for more training around dementia for GPs

Equality, Health and Wellbeing and Human Rights	Affected populations
	<ul style="list-style-type: none"> • Anecdotal evidence about GPs being reluctant to provide dementia assessments • GP assessment would mean no access to the Memory Clinic and the route into community mental health teams. • There were also concerns around the nature of the assessment itself but it was acknowledged that it was not in the strategy's gift to change that. <p>Vulnerable groups</p> <ul style="list-style-type: none"> • It was suggested that further work should be done before the strategy was finalised around issues affecting people with drug and alcohol problems, homeless people, people that are in touch with justice services. • People on lower incomes, or with lower levels of literacy/English as a second language may find it difficult to access online information (or able to afford the devices/broadband to

Equality, Health and Wellbeing and Human Rights	Affected populations
	access it) (Fairer Scotland Duty).

Environment and Sustainability including climate change emissions and impacts	Affected populations
Positive	n/a
Negative	n/a

Economic	Affected populations
Positive	n/a
Negative	n/a

9. Is any part of this policy/ service to be carried out wholly or partly by contractors and if so how will equality, human rights including children’s rights, environmental and sustainability issues be addressed?

Some services may be carried out by external contractors, but this process would be governed by ELHSCP’s ethical commissioning strategy and East Lothian Council’s ethical procurement processes.

10. Consider how you will communicate information about this policy/ service change to children and young people and those affected by sensory impairment, speech impairment, low level literacy or numeracy, learning difficulties or English as a second language? Please provide a summary of the communications plan.

A communications plan will be developed incorporating a wide range of information methods, including print and posters, online and social media, partner networking, press and community connections. This will include information in community languages on request or in response to identified need.

11. Is the plan, programme, strategy or policy likely to result in significant environmental effects, either positive or negative? If yes, it is likely that a Strategic Environmental Assessment (SEA) will be required and the impacts identified in the IIA should be included in this. See section 2.10 in the Guidance for further information.

No.

12. Additional Information and Evidence Required

- The group agreed to do further research with homeless people, those living with substance use problems and people with experience of the Justice system to further inform the development of the strategy.
- Further engagement is continuing with people living with dementia and their carers in Friendship Groups and other dementia-friendly activities to test the direction of the draft strategy.

13. Specific to this IIA only, what recommended actions have been, or will be, undertaken and by when? (these should be drawn from 7 – 11 above) Please complete:

Specific actions (as a result of the IIA which may include financial implications, mitigating actions and risks of cumulative impacts)	Who will take them forward (name and job title)	Deadline for progressing	Review date
Race – The Equalities and Engagement Officer is working with colleagues across ELHSCP and with ELC Equalities Officers to look at how to improve equalities monitoring for service-users and the establishment of East Lothian Equalities Networks	Equalities and Engagement Officer	Ongoing	April 2024
Gender-reassignment –	Dementia Strategy Officer	Ongoing	June 2024
Disability – the points raised about the experiences of Deaf BSL users will be considered as part of the strategy’s development	Dementia Strategy Officer	Ongoing	June 2024

Specific actions (as a result of the IIA which may include financial implications, mitigating actions and risks of cumulative impacts)	Who will take them forward (name and job title)	Deadline for progressing	Review date
Disability – the points raised about the capacity of GP practices to deliver dementia assessment will be further considered as part of the strategy’s development	Dementia Strategy Officer	Initial Discussion with Clinical Director Ongoing review of actions in strategy	June 2023 June 2024
Vulnerable groups - the points raised about the need for further research with people in vulnerable groups will be further considered as part of the strategy’s development	Dementia Strategy Officer	Initial Discussion with MELDAP, Homeless Team and Justice Services Ongoing review of actions in strategy	June 2023 June 2024
Digital access to information/forms - the points raised about the issues for people on low incomes or with low levels of literacy will be further considered as part of the strategy’s development	Dementia Strategy Officer	Ongoing	June 2024

14. Are there any negative impacts in section 8 for which there are no identified mitigating actions?

- Issues with the format of the dementia assessment itself – too old; too rigid; not geared to people from different cultures; not geared to people with different communication needs; not geared to people with low literacy or low educational attainment, and doesn’t take into account pre-existing conditions like paranoia or schizophrenia.
- Issues around the numbers of community language and BSL interpreters available to interpret at assessments and other appointments (national shortages).

15. How will you monitor how this proposal affects different groups, including people with protected characteristics?

Through ongoing engagement and evaluation.

16. Sign off by Head of Service

Name:



Date:

07/06/23

17. Publication

Completed and signed IIAs should be sent to:

jogden-smith@eastlothian.gov.uk for publication on the ELHSCP [IIA Database](#) on www.eastlothian.gov.uk