

Technical Report



Contents

Introduction	4
Population of East Lothian	5
Current Population Estimates	5
Population Projections	6
Population by age and sex	8
Life expectancy	9
Mortality	10
Deprivation	12
Ethnicity	13
Dementia.....	14
Dementia in Scotland.....	14
Types of Dementia	15
Life Expectancy with dementia	15
Preventing and delaying Dementia.....	16
Use of hospital services for those with Dementia	17
Ethnicity and Dementia.....	17
Prevalence of Dementia in East Lothian	18
Projected Prevalence of Dementia in East Lothian.....	19
Actual Diagnosis Rates in East Lothian	20
Age at Diagnosis.....	21
Trends in Mild Cognitive Impairment	22
East Lothian Post Diagnostic Support register.....	22
Provision of Post Diagnostic Support.....	23
Dementia in East Lothian by Geography.....	24
Ethnicity of those diagnosed with dementia in East Lothian.....	25
Diagnosis and Support for People with a Learning Disability	25
Substance Misuse and Dementia.....	26
Homelessness and dementia	26
Justice Services.....	27
Levels of dementia in care homes	27
Deaths from Alzheimer’s and Dementia in East Lothian	28
Carers of people with dementia	29
Sensory Impairment.....	31
Prevalence of Sensory Impairment.....	31
Sensory loss and dementia	31
Sensory impairment and impact on health	32

Factors that hinder treatment and management of sensory impairment	32
Engagement	33
The Dementia Diagnosis and the First Year of Support	34
Finding Information	34
Access and Transport	35
Health and Social Care	36
Community Understanding and Education.....	37
Activities and Connections.....	38
Health and Wellbeing	39
APPENDIX A – Alzheimer’s and Dementia Prevalence.....	41
APPENDIX B – Timetable of Consultation and Engagement Events	42
Engagement events for the IJB Strategic Plan and Planning for an Ageing Population:.....	42
Engagement events hosted by Outside the Box.....	42
Engagement with East Lothian Care Home Managers	43

Introduction

This report examines a range of data including national and local data, as well as policy and research to provide a comprehensive picture and evidence base about the East Lothian population and, specifically, those living with dementia to inform the development of the East Lothian Dementia Strategy and future commissioning plans.

The report:

- Describes the current and projected population changes for East Lothian including the projected change in age profile
- Examines data on mortality, leading causes of death, life expectancy and areas of deprivation
- Describes the current and projected increase in prevalence of dementia in East Lothian and the increased impact on women and those within the BME community
- Examines new research on potentially modifiable risk factors in preventing/delaying dementia
- Reviews numbers of people in East Lothian with a formal diagnosis, the provision of Post Diagnostic Support, and current geographical location of East Lothian residents with a diagnosis to support future service provision.
- Identifies the impact that sensory impairment has on the older population and particularly those with dementia.
- Outlines feedback from the engagement completed to support the development of the dementia strategy and to meet the future needs of people living with dementia in East Lothian.

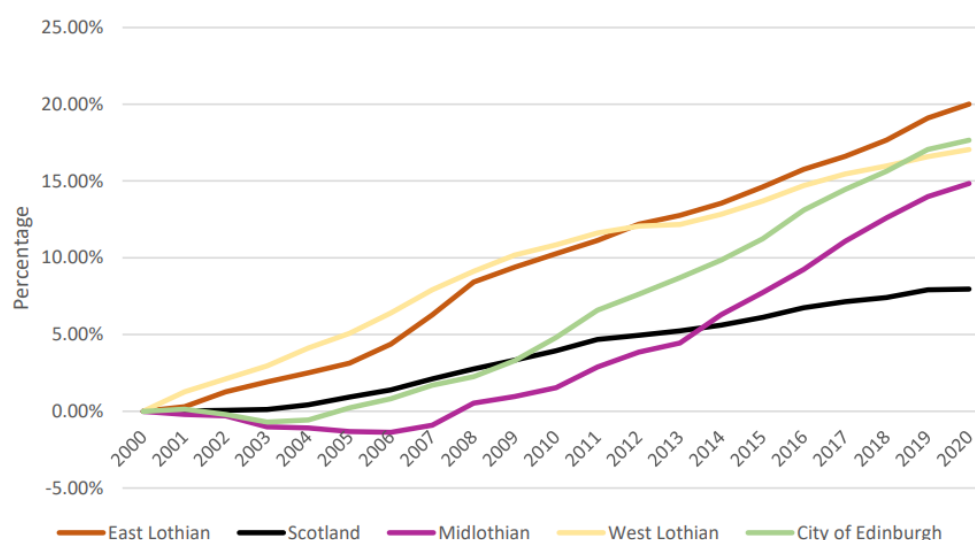
Population of East Lothian

KEY POINTS

- 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 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.
- 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)
- 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

Current Population Estimates

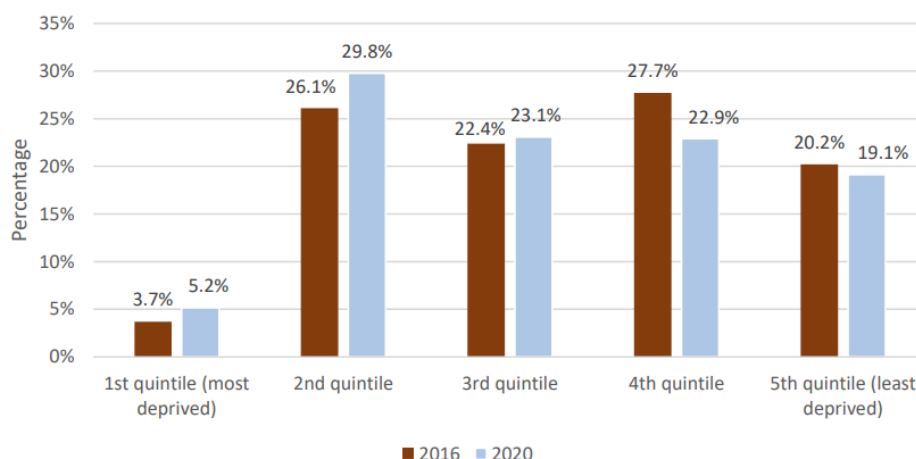
Figure 1. Percentage change of Lothian Partnerships and the Scotland populations



Source: National Records of Scotland, [Yearly Percentage Change in Population](#) (Accessed: Jan. 2022)

East Lothian has maintained a higher population increase than Scotland since 2000 and experienced the largest percentage change of Lothian partnerships, with an overall increase of 20% in 20 years.

Figure 2. East Lothian population by SIMD quintile, 2016 & 2020 comparison

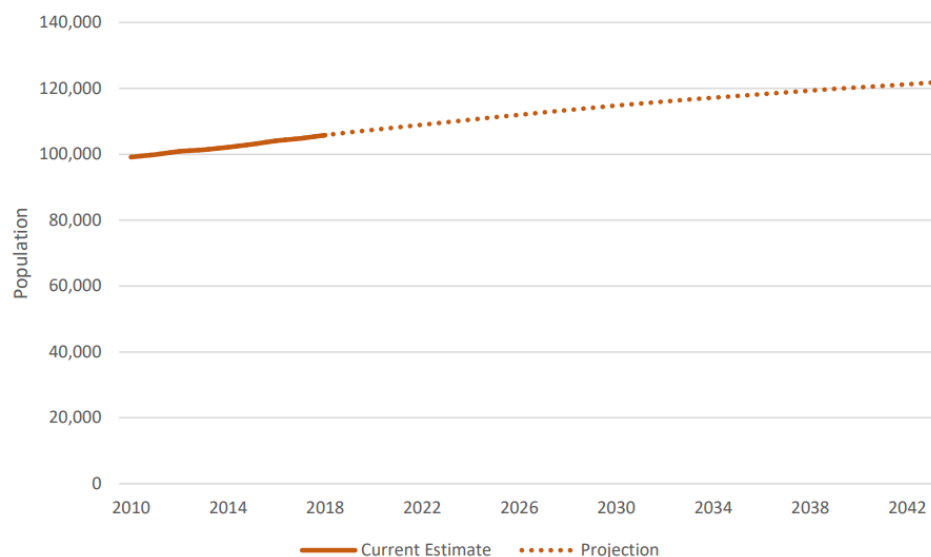


Source: East Lothian by Numbers (Accessed: Jan. 2022)

The Scottish Index of Multiple Deprivation is a measure of deprivation within Scotland across a range of factors. Figure 2 compares the SIMD quintiles (Scottish Index of Multiple Deprivation) breakdown of East Lothian in 2016 and 2020. Quintiles one (most deprived) to three show an increase in percentage since 2016 but the fourth and fifth quintiles have decreased.

Population Projections

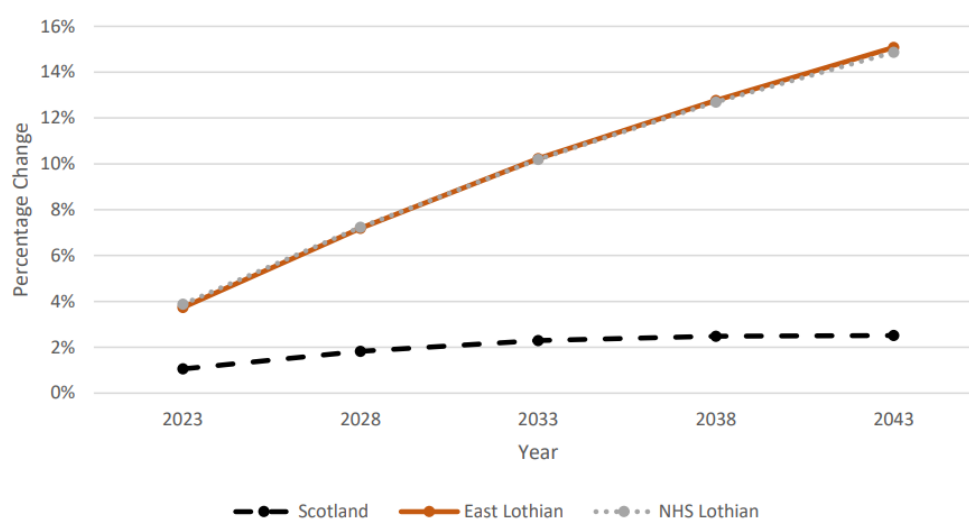
Figure 3. Projected total population for East Lothian (2018-based) 2018 to 2043



Source: National Records of Scotland. [Population Projections](#) (Accessed: Jan. 2022)

Figure 3 shows the population projections for East Lothian up to 2043, based on 2018 population estimates. Between 2018 and 2043 the population of East Lothian is predicted to increase by 12.8%, reaching a peak of 121,743 by 2043.

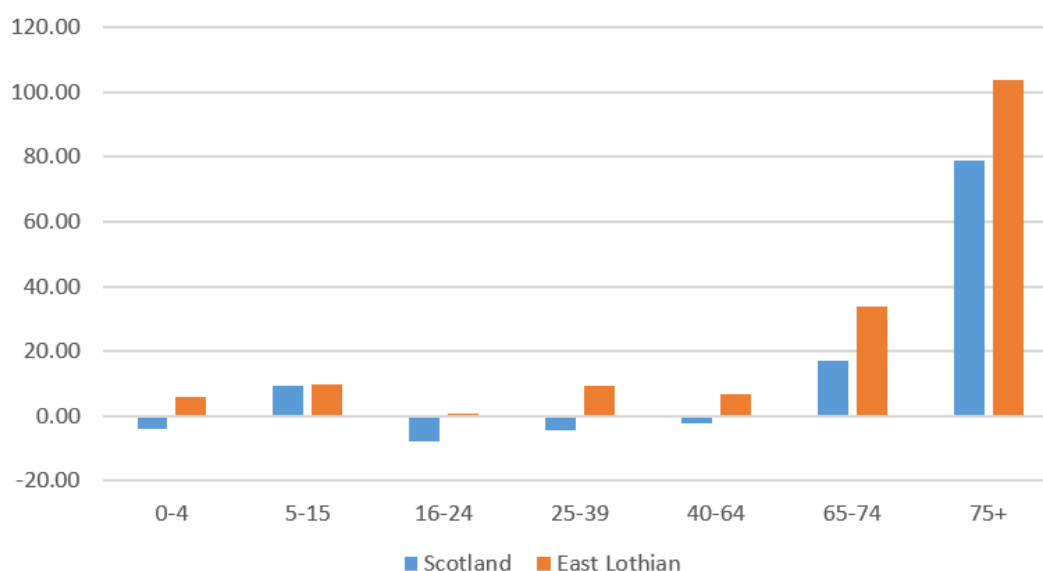
Figure 4. Projected percentage change in population from 2018 within East Lothian, Lothian and Scotland



Source: National Records of Scotland. [Population Projections](#) (Accessed: Jan. 2022)

Figure 4 displays the projected percentage change between 2018 and 2043 within East Lothian, Lothian (comprising the areas covered by Edinburgh HSCP, West Lothian HSCP, Midlothian HSCP and East Lothian HSCP) and Scotland populations. Based on these projections, Lothian and East Lothian will see a faster population growth than Scotland. The cumulative changes for East Lothian and Lothian are predicted to differ by 0.2 percentage points by 2043.

Figure 5. Percentage change in population in East Lothian and Scotland by Age, 2016 to 2041

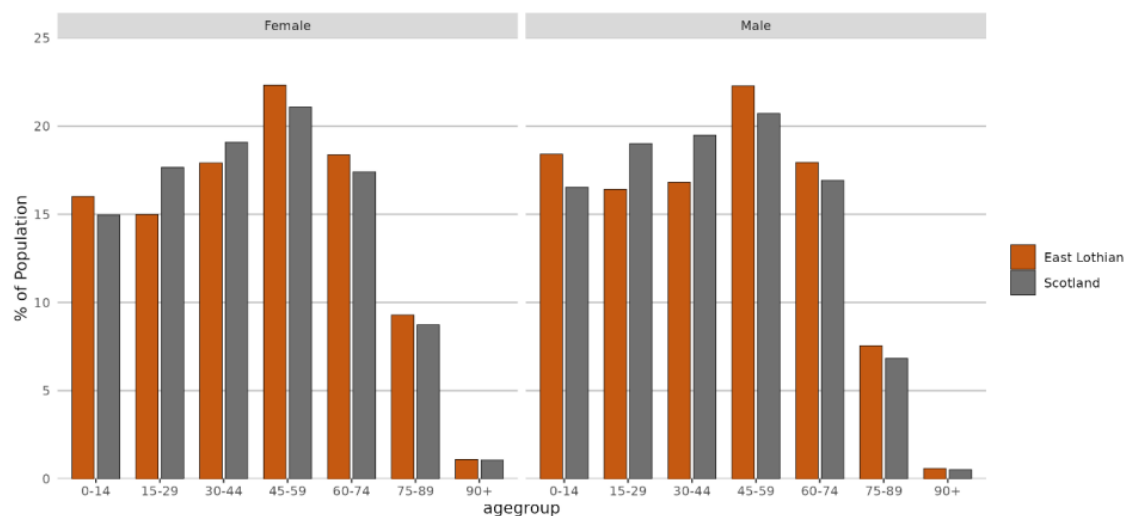


Source: National Records of Scotland. [Population Projections 2016-based](#) (Accessed: Jan. 2022)

Figure 5 shows that East Lothian's older population will grow significantly by 2041. The 65-74 age group will grow by around 33.8% while the population over the age of 75 will grow by 103.8%, effectively doubling. The growth in those population age groups is significantly more than in Scotland as a whole.

Population by age and sex

Figure 6. Estimated percentage of population within East Lothian and Scotland by sex and age group in 2020

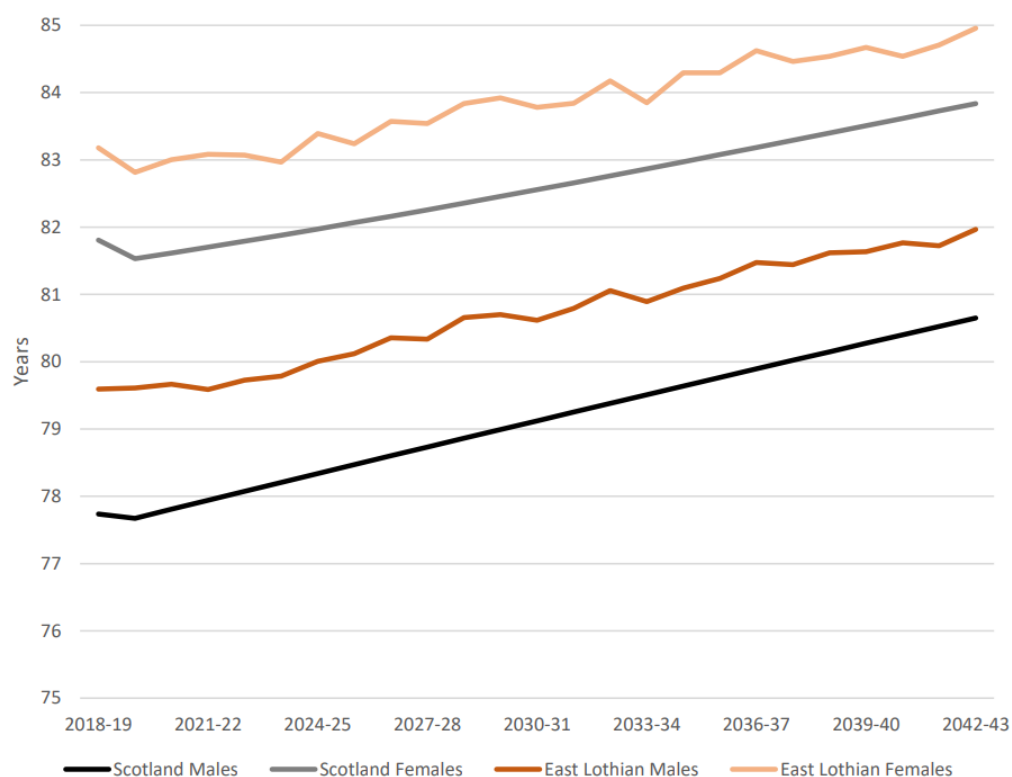


Source: National Records of Scotland. [Population Estimates](#) (Accessed: Mar. 2022)

The age profiles separated in Figure 6 show variance in population percentages between geography and sex. The female population in both East Lothian and Scotland has a higher percentage within the middle-aged population, whereas, the male populations has a higher percentage of younger age groups resulting in a more evenly distributed population from ages 0 to 74. The female population percentage is higher than males for both geographies. This partially results from the life expectancy of females being higher than males. The age group 45 to 59 is the largest for both sexes and consists of more than 20% of the population for East Lothian and Scotland.

Life expectancy

Figure 7. Projected life expectancy at birth, principal projection, 2018/19 to 2042/43



Source: National Records of Scotland. [Life Expectancy](#) (Accessed: Jan. 2022)

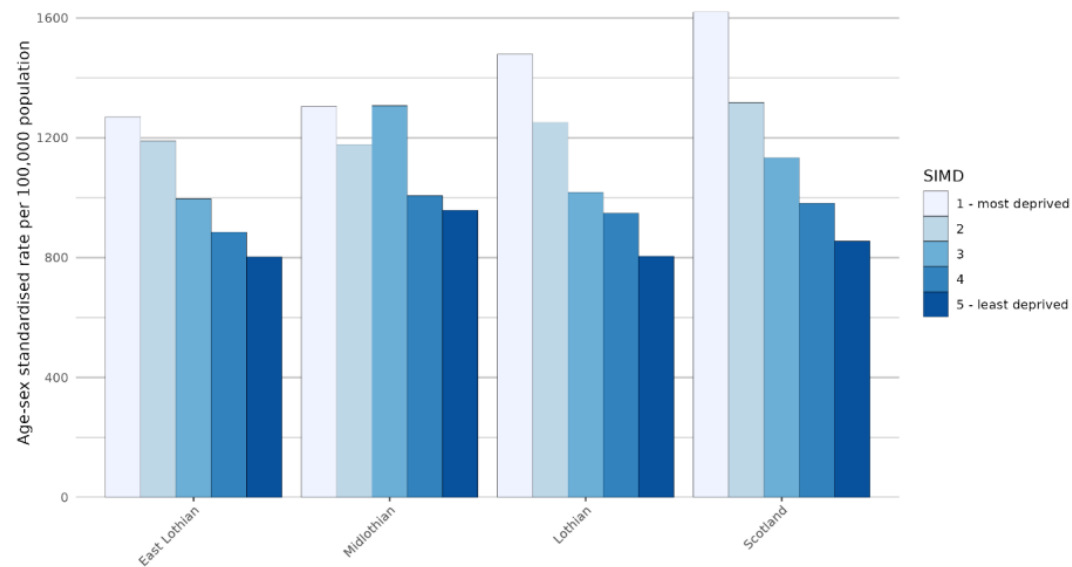
The life expectancy of individuals in the East Lothian and Scottish population is predicted to increase for both sexes up to the latest projected year (2042-43). East Lothian shows more yearly variation than Scotland, likely due to smaller population sizes. Within East Lothian, the life expectancy of males and females is predicted to increase by 2.4 and 1.8 years, respectively by 2042/43. A trend shared by Scotland. Comparing geographies, it is predicted there will be less difference between Scotland and East Lothian life expectancies by 2042-43. There is a predicted decrease of 0.2 (1.4 to 1.2) for females and 0.5 (1.9 to 1.4) for males.

Similar to the outcomes seen in Scotland, East Lothian has a higher life expectancy among females than males

Among females there is a statistically significant difference in average life expectancy between residents of East Lothian (82.9 years) and Scotland (81.0 years). This is also true when looking at the male population, with East Lothian (79.3 years) having a higher average life expectancy than Scotland (76.8 years) again (based on 2018-20 estimates).

Mortality

Figure 8. Mortality rates by geography and SIMD

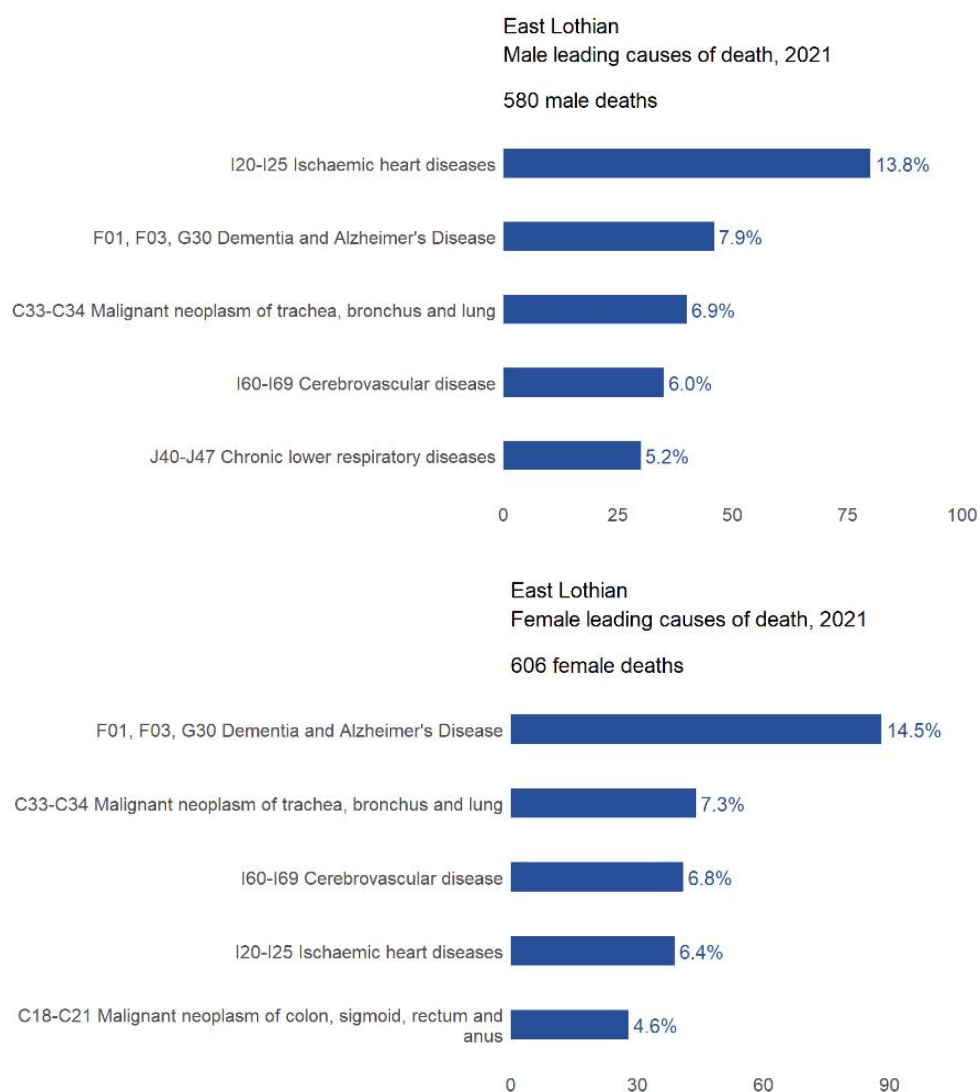


Source: [ScotPHO Profiles](#), (Accessed: Jan. 2022)

Figure 8 separates geographic mortality rates by SIMD. It suggests that mortality in East Lothian, Lothian and Scotland is directly related to deprivation. There is a higher rate of mortality within more deprived data zones for each area.

It also highlights that the mortality rates between the most (SIMD 1) and least (SIMD 5) deprived categories in East Lothian have less difference than Lothian and Scotland categories. A smaller difference in deprivation categories suggests that East Lothian has a more equitable distribution of mortality than the other geographies shown.

Figure 9. Leading cause of death by gender in East Lothian, 2021



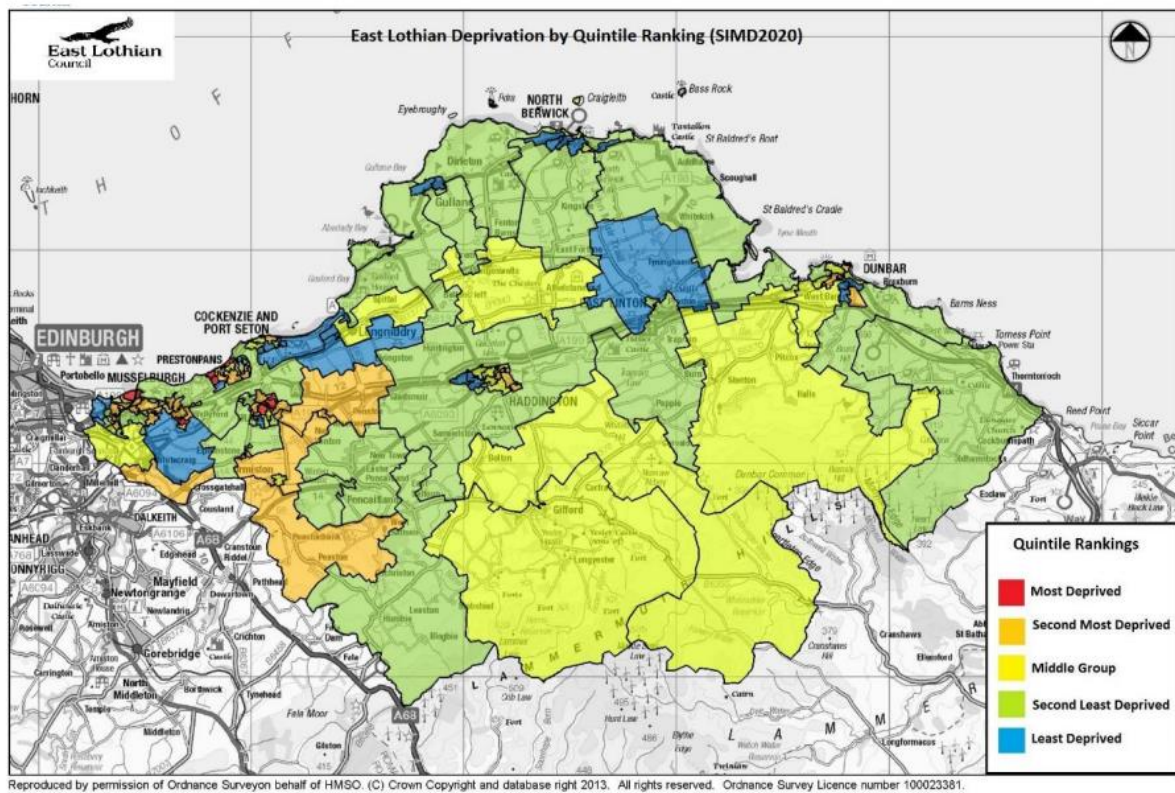
Source: National Records of Scotland, [East Lothian Profile](#), (Accessed: Jan. 2022)

In East Lothian, the leading cause of death for males in 2021 was Ischaemic heart disease (13.8% of all male deaths), followed by Dementia and Alzheimer's (7.9%). In comparison, in Scotland overall, percentage of deaths in males from Dementia and Alzheimer's was lower at 6.2%.

In East Lothian, the leading cause of death for females in 2021 was Dementia and Alzheimer's (14.5% of all female deaths), followed by Lung cancer (7.3%). In comparison, in Scotland overall, percentage of deaths in females from Dementia and Alzheimer's was again lower at 12.8% and remained the leading cause of death in women.

Deprivation

Figure 10. East Lothian deprivation by SIMD quintile



Source: East Lothian by Numbers (Accessed: Feb. 2022)

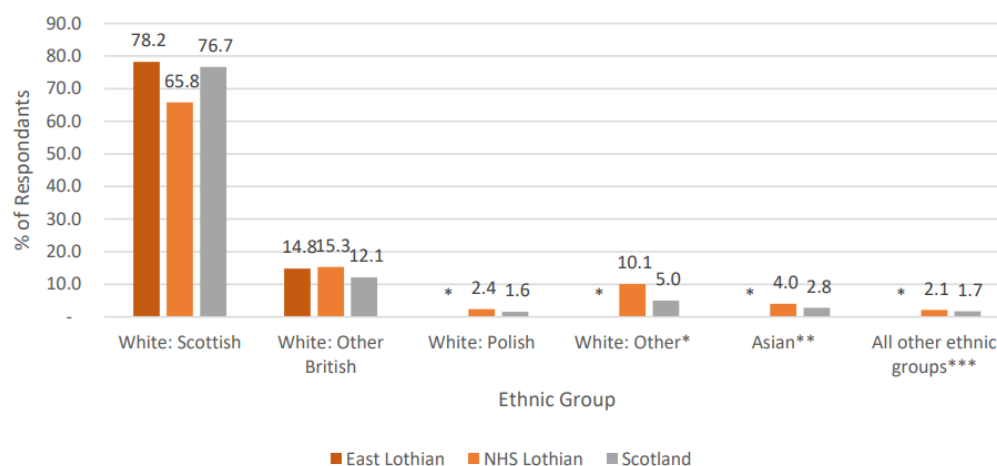
One of the key measurements for deprivation in Scotland is SIMD (Scottish Index of Multiple Deprivation). The index distinguishes the level of deprivation using indicators of income, employment, education, health, access to services, crime, and housing.

East Lothian consists of 6 wards and 132 data zones, of which 8 are in the 20% most deprived of Scotland.

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.

Ethnicity

Figure 11. Percentage of population by response when questioned on their ethnic group



Source: [Scottish Survey Core Questions](#), 2018 (Accessed: Jan. 2022)

'White: Other' includes 'White: Irish', 'White: Gypsy/Traveller' and 'White: Other White Ethnic Group'

** 'Asian' includes the categories Asian, Asian Scottish or Asian British

*** 'All other ethnic groups' includes categories within the 'Mixed or Multiple Ethnic Group', 'African', 'Caribbean or Black', and 'Other Ethnic Group' sections.

The SSCQ survey use of the term Ethnic Group is primarily sourced from the Equality Act (2010). Within this act Ethnic Group is the self or community defined presentation of race. The survey questions focus on the sub-categories of colour, ethnicity, nationality and citizenship which, taken together, delineate Ethnic Group.

Within Figure 11 the largest categories for all geographical areas (East Lothian, Lothian, and Scotland) are White: Scottish and White: Other British.

Note that due to the lower number of responses within East Lothian, the percentage of respondents defining their ethnic group can only be published in the "White: Scottish" and "White: Other British" categories. An asterisk (*) represents a population who were too small to be published publically.

The 2011 Census data however, shows that at the time East Lothian had an increasing range of ethnic minorities residing in the county with the Asian population being the largest ethnic minority group in our area (in 2011 1% of the population). The Polish population had also increased substantially in recent years (0.8% in 2011)¹

¹ [Scotland's Census: East Lothian Overview](#)

Dementia

KEY POINTS

- There are estimated to be 93,000 people with dementia in Scotland, and of those 3200 are estimated to be under the age of 65
- Due to a significant increase in the over 65 population across the UK, rates of dementia are expected to double by 2050, while among the BME population dementia rates are predicted to rise seven-fold by 2051.
- Alzheimer's Disease accounts for the highest proportion of those diagnosed (50-75%) with Vascular Dementia accounting for around 20% of cases.
- Life expectancy following diagnosis varies based on the type of dementia diagnosed but on average life expectancy following diagnosis ranges from 5-10 years.
- Actual incidence of dementia has fallen in many countries with improvements in education, nutrition and health care. New research shows that around 40% of cases of dementia may be preventable or able to be delayed due to changes in modifiable risk factors.
- Around 25% of hospital beds are thought to be occupied by people with dementia although only 1% are estimated to require management within a specialist dementia hospital setting at any one time.
- In 2022, East Lothian has an estimated 2104 people with dementia, projected to rise to 3531 by 2040 (68% increase) while rates of dementia among those under the age of 65 are estimated to remain fairly static.
- Prevalence rates of dementia in East Lothian are higher among women than men in line with national trends. This trend is also confirmed when looking at rates of those with a diagnosis in East Lothian.
- Age has a more pronounced impact on women than men with women having a higher susceptibility to dementia above the age group of 75.
- By 2040, rates of dementia in East Lothian males are projected to peak at the age of 80-84, while East Lothian women will see increasing prevalence for all age groups over the age of 80.
- Of those with a diagnosis, 20% are from the Musselburgh, Wallyford and Whitecraig area and there are higher numbers of people diagnosed generally to the West of the county. Only 5% of those diagnosed live in rural areas.

Dementia in Scotland

In 2017 there were an estimated 93,000 people with dementia in Scotland. Around 65% of these are estimated to be female and 35% are estimated to be male.² Using NRS population data for 2017, this equates to around 1.71% of the Scottish population as a whole.³

Dementia can affect those as young as 30, although this is extremely rare. Most younger people with dementia are middle aged: in their early 50's and early 60's. The term 'young onset dementia' or 'early onset dementia' refers to people diagnosed with dementia under the age of 65. In Scotland in 2017, there were an estimated 3,200 people under the age of 65 with a diagnosis of dementia. This equates to 0.05% of the Scottish population as a whole.

In 2006-2008 Alzheimer Scotland led the European Collaboration on Dementia with the aim to develop and disseminate evidence-based mental health promotion and Alzheimer's disease

² [Alzheimer Scotland: Estimated number of people with dementia in Scotland, 2017](#)

³ [National Records of Scotland: Population projections 2016](#)

prevention strategies across Europe. The project also formulated estimates for prevalence which continue to be used as a basis for dementia projections today.

In 2019, Alzheimer Scotland updated their prevalence estimates based on the most up to date studies. The studies show that within the UK there will be an increase in population for the period 2018 and 2050 with a significant increase in the numbers of people aged over 65, and in particular, the over 85 age range which more than doubles between 2018 and 2050. As a result, the overall number of people with dementia in the UK as a whole are expected to double from 1,031,396 to 1,977,399 in 2050. As a percentage of the overall UK population, people with dementia will represent 2.67% in 2050 compared to 1.56% in 2018⁴.

Types of Dementia

Although there are many subtypes of dementia the most common ones are Alzheimer's disease, vascular dementia, lewy body dementia, frontotemporal dementia and mixed dementia.

Information on the proportions of those with different forms of dementia varies so these should be taken as estimates:

- **Alzheimer's disease** – 50-75 %. This often co-exists with vascular dementia
- **Vascular Dementia** – up to 20%
- **Dementia with Lewy Bodies** – 10-15%
- **Frontotemporal dementia** – 2%

Life Expectancy with dementia

Reliable estimates on life expectancy of people with dementia and Alzheimer's are lacking. Studies recognise that dementia progresses differently for everyone. However it appears that the later in life that a person is diagnosed, the shorter the life expectancy appears to be, conversely if a person is diagnosed earlier then life expectancy can be much longer. There have been cases of people with Alzheimer's Disease at age 65 who have lived for up to 18 years following diagnosis⁵. There also appears to be variances in life expectancy based on the type of dementia that is diagnosed.

Alzheimer Scotland reports the following life expectancy based on dementia type:

- **Alzheimer's:** Around 8-10 years
- **Vascular Dementia:** Around 5 years as a person with Vascular dementia is more likely to die of an increased risk of stroke or heart attack
- **Dementia with Lewy Bodies:** Around 6 years
- **Frontotemporal Dementia:** Around 6-8 years

⁴ [Alzheimer Europe: Dementia in Europe Yearbook, 2019](#)

⁵ [Life Expectancy With and Without Dementia: A Population-Based Study of Dementia Burden and Preventive Potential | American Journal of Epidemiology | Oxford Academic \(oup.com\)](#)

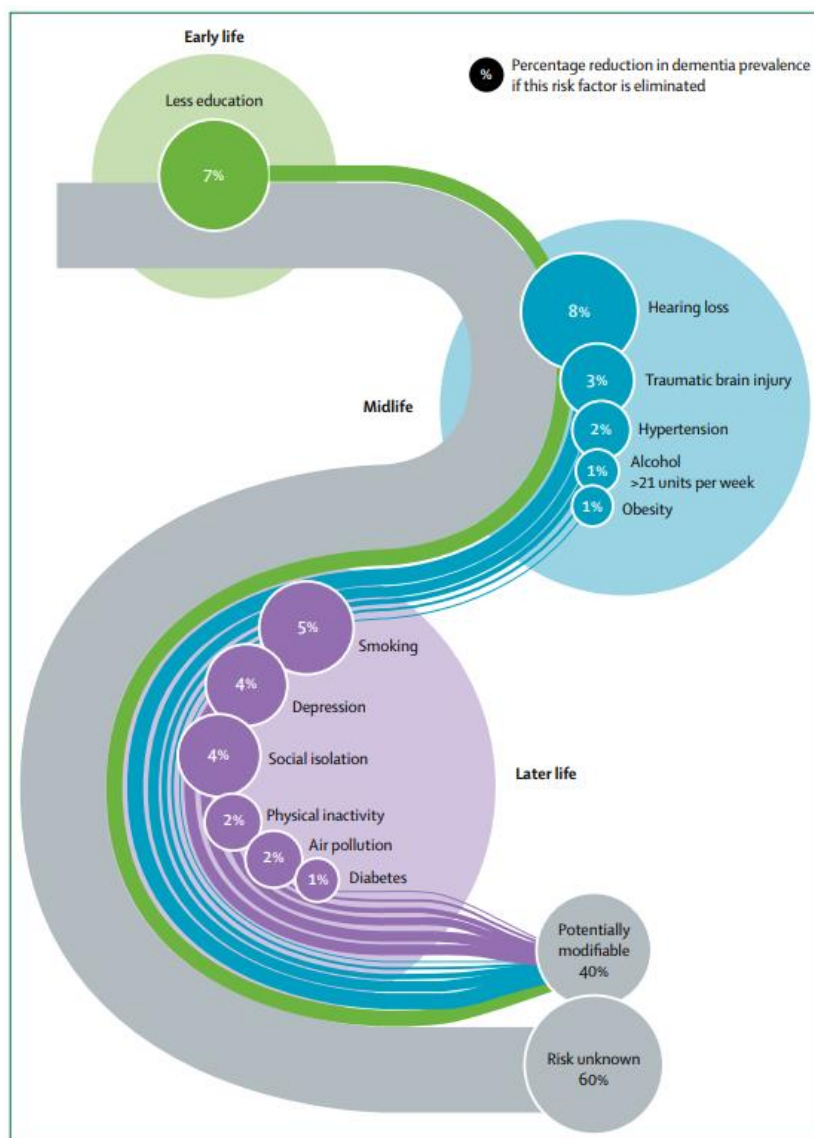
Preventing and delaying Dementia

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 countries, most likely because of improvements in education, nutrition, health care and lifestyle changes.

Growing evidence shows that there are a number of modifiable risk factors that account for up to 40% of worldwide cases of dementia which theoretically if addressed, could be prevented or delayed⁶. These include:

- Minimise diabetes
- Treat hypertension
- Prevent head Injury
- Stop smoking
- Reduce air pollution
- Reduce mid-life obesity
- Maintain frequent exercise
- Reduce occurrence of depression
- Avoid excessive alcohol
- Treat hearing impairment
- Maintain frequent social contact
- Attain high level of education

Figure 12. Population attributable fraction of potentially modifiable risk factors for dementia



Source: [Lancet 2020: Dementia prevention, intervention and care](#)

⁶ [Dementia prevention, intervention, and care: 2020 report of the Lancet Commission - PMC \(nih.gov\)](#)

In addition to addressing life-style risk factors, social and psychological factors have much to contribute in delaying the progression of dementia. The World Health Organisation states that physical ill-health in older years can be directly impacted by people's physical and social environments and the life-style decisions that arise from that. Improving access to supportive and therapeutic environments such as those offering peer and community supports, cognitive stimulation through participation in social and mental activities as well as support to maintain or build social connection can help people with dementia to remain independent for longer and delay the need to access more specialist resources.

Such environments are also of value to carers, offering peer support and respite as well as connections of their own. Challenging the stigma associated with a diagnosis is also important in helping to provide a supportive environment, as stigma brings with it excess harm and disability notably through impacts such as reduced confidence, low self-esteem and negative impacts on family and social relationships.

Use of hospital services for those with Dementia

It is estimated that approximately 25% of beds in hospitals are occupied by people living with dementia. People with dementia often experience longer hospital stays as well as delays in leaving hospital and reduced independent living as a result.

Alzheimer Scotland estimate that only 1% of people with a diagnosis of dementia will need to be managed within a specialist dementia hospital setting at any one time. This will most likely be due to severe psychological symptoms or a co-morbid mental health condition. The majority of people with dementia can be cared for within a community setting.⁷

Ethnicity and Dementia

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.

Most recent estimates are that 25,000 people with dementia in the UK are from the black and ethnic minority group.⁸ This figure is expected to grow to 171,000 by 2051, a more than seven-fold increase in comparison to the expected doubling in dementia rates for the rest of the population. The increase within the BME groups may be explained by the fact that those migrating to the UK in the 1950's to 1970's are now reaching their 70's and 80's.

Incidence of dementia may also differ from the majority of the population for other reasons such as culturally different dietary and exercise patterns and socio-economic factors such as less formal education, lower income and worse occupational conditions which are often over-represented within BME groups.⁹

The estimated prevalence rates for dementia in the BME community are similar to the general population with the exception of early onset dementia and vascular dementia which have been found to be more prevalent. However, people from the BME community with dementia are less likely to present to services and tend to make contact at a later stage in the illness.

Barriers to seeking help may be:

⁷ [Transforming Specialist Dementia Hospital Care | Alzheimer Scotland \(alzscot.org\)](https://www.alzscot.org/)

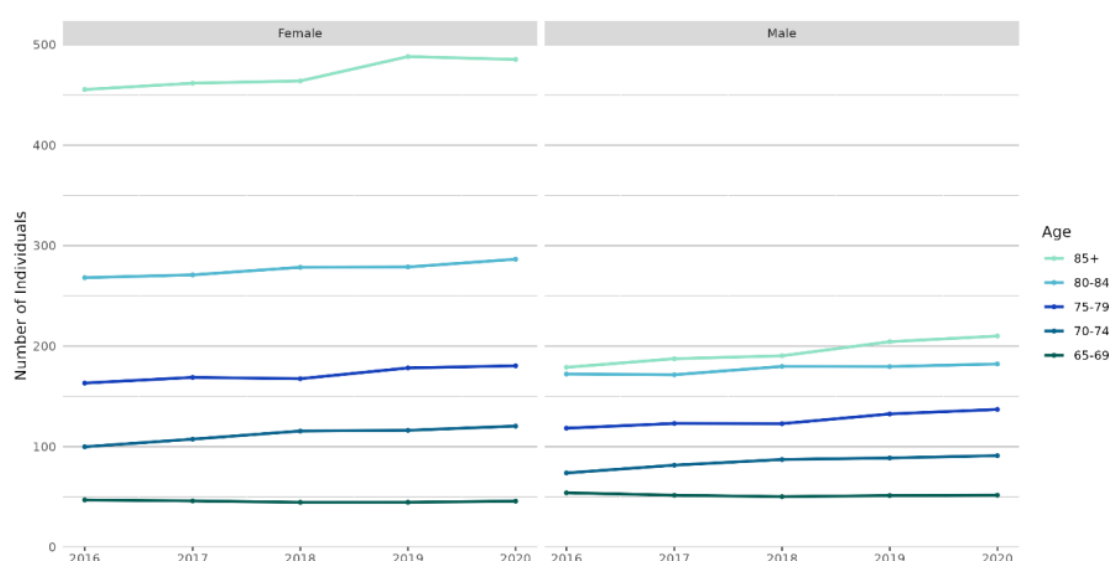
⁸ [Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/)

⁹ [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](#)

- **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 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.

Prevalence of Dementia in East Lothian

Figure 13. Estimated prevalence of dementia in East Lothian by age, based on 2017 EuroCoDe and Harvey study figures.



Source: [Alzheimer's Scotland](#) (Accessed: Mar. 2022)

The prevalence of Dementia within the East Lothian population in Figure 13 was determined by applying 2017 EuroCoDe (European Collaboration on Dementia) and Harvey Study figures to East Lothian population figures (See Appendix A below for further details). The figures are crude estimations and do not account for local variance.

Similar to the national picture, the figure demonstrates higher rates of dementia among women in East Lothian compared to men. This disparity by sex in Dementia prevalence is also seen internationally.

Figure 13 also shows that as an individual's age increases their likelihood of contracting Dementia increases. Age appears to have a more pronounced impact on females than males. In males, there is a consistent and small difference between age groups, whereas the female population shows larger susceptibility to Dementia above the age group 75-79.

The same EuroCoDe and Harvey Study estimates were used across all years, therefore, the yearly increase seen in figure 44 for both male and female populations is due to population increases.

Figure 14. Estimated prevalence of dementia in East Lothian in 2022, based on 2017 EuroCoDe and Harvey study figures.

	Age	Men	Women
Under 65	30-59	14	15
	60-64	7	36
		21	51
Over 65	65-69	56	48
	70-74	86	120
	75-79	157	199
	80-84	198	299
	85-89	150	316
	Avg 90+	102	301
		749	1283

Source: National Records of Scotland, [Population Projections](#) (Accessed: Oct. 2022)

Using the East Lothian population data by age and sex for 2022, we can use the EuroCoDe and Harvey prevalence rates to estimate the current number of people in East Lothian living with dementia. In total 2104 people are estimated to currently have dementia in East Lothian. The figures above show the split by gender and age group.

Note that the NRS population data does not provide further break down of projections for the age groups over the age of 90 and therefore an average of the EuroCoDe prevalence rates for the categories of 90-94, 95-99 and 100+ has been used for these age groups.

Projected Prevalence of Dementia in East Lothian

Again, using the EuroCoDe and Harvey Study prevalence figures and applying them to NRS population projections for East Lothian we can estimate the prevalence of dementia in East Lothian by 2040.

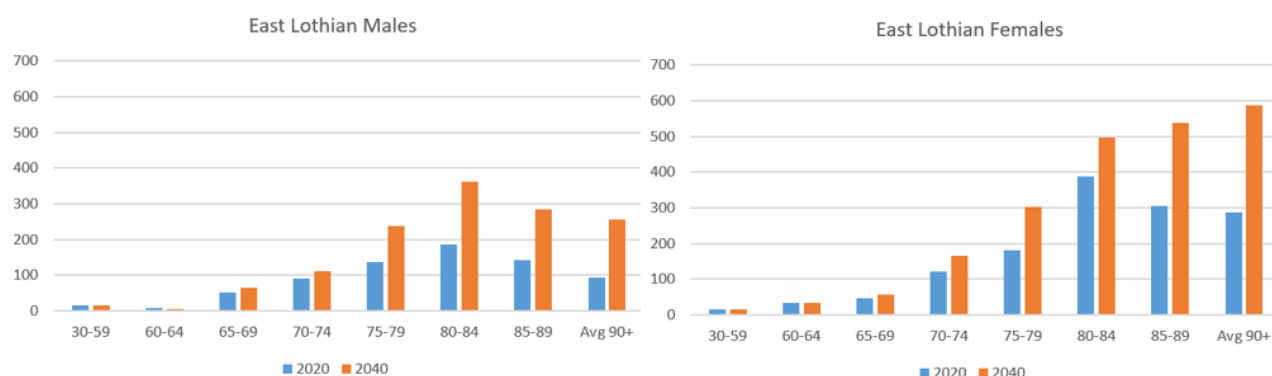
Figure 15. Projected prevalence of dementia in East Lothian in 2040, based on 2017 EuroCoDe and Harvey study figures.

	Age	Men	Women
Under 65	30-59	14	16
	60-64	6	33
		20	49
Over 65	65-69	64	56
	70-74	112	164
	75-79	238	302
	80-84	361	497
	85-89	285	538
	Avg 90+	257	588
		1317	2145

Source: National Records of Scotland, [Population Projections](#) (Accessed: Oct. 2022)

By 2040 there will be approximately 3531 people with dementia in East Lothian, this represents an increase of nearly 68% since 2022 (see Figure 14). In contrast to the population over the age of 65, numbers of those with early onset dementia are projected to remain fairly static: 69 of these will be under the age of 65 in 2040 compared to 71 in 2022.

Figure 16. Projected prevalence of Dementia in East Lothian by age and gender from 2020 to 2040, based on 2017 EuroCoDe and Harvey study figures.



Source: National Records of Scotland, [Population Projections 2016](#) (Accessed: Oct. 2022)

Figure 16 shows that in line with the national picture there will continue to be more women than men with dementia in East Lothian in almost all age groups other than the age groups of 65-69.

In contrast to Figure 13 where between 2016 and 2020 there was a consistent but small difference between the age groups for East Lothian males, Figure 16 shows that by 2040 there will be a larger susceptibility to dementia for men between the ages of 80-84.

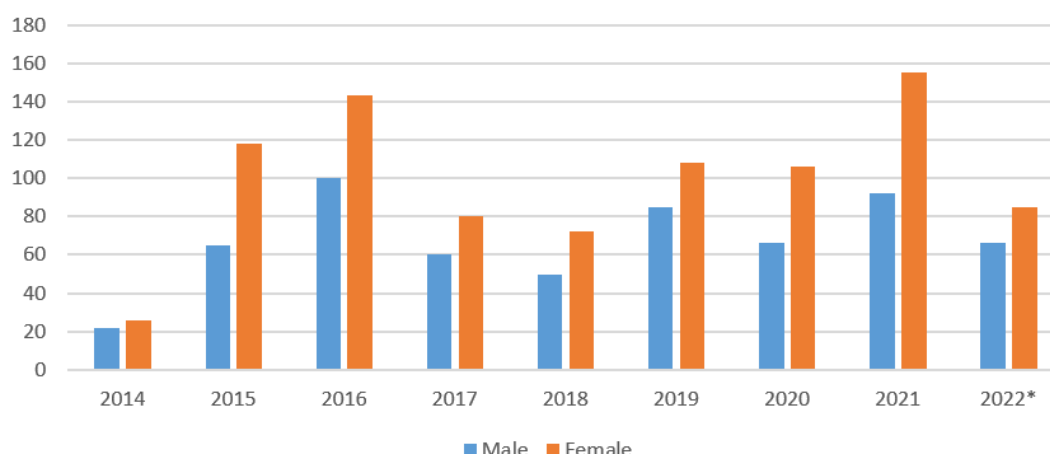
For East Lothian females in 2020, prevalence rates peaked at ages 80-84 and declined in the age range 85 and above. However, by 2040 due to population growth, change in population profile, and longer life expectancy, prevalence of dementia will continue to rise in the age groups of 85 and above in contrast to the male population where dementia rates fall in the over 85 category. Note that NRS population projections show that by 2040 there are estimated to be double the number of women in East Lothian over the age of 90 than men.

Actual Diagnosis Rates in East Lothian

In Scotland, when a person is diagnosed with dementia, a HEAT (Health Improvement, Efficiency, Access and Treatment Targets) Questionnaire is completed and remains open until such time as Post Diagnostic Support has been completed or declined. The data from the HEAT Questionnaires for East Lothian is collated by the NHS Lothian Mental Health Analytics Team and has provided the basis for rates of actual diagnosis in East Lothian.

The Mental Health Analytics Team is part of the wider Lothian Analytics team and provides data relating to mental health services in Lothian including information on demand, capacity modelling and submission to national data sets. These statistics first began to be collected in January 2014 and have been collated until October 2022.

Figure 17. Number of people diagnosed with Dementia in East Lothian by gender, Jan 2014 – Oct 2022



*Data until October 2022

Source: NHS Lothian Mental Health Analytics [Accessed Oct 2022]

The total number of East Lothian residents diagnosed with dementia between January 2014 and October 2022 is 1499. Data begins to be more consistently collected from 2015 onwards. Using data for the full years from 2015 to 2021, the average number of people diagnosed per year is 185.

In line with national trends, Figure 17 also shows higher numbers of women were diagnosed with dementia in East Lothian for each year since data collection began. There were 893 women compared to 606 men diagnosed with dementia between 2014 and 2022 or 59.6% women compared to 40.4% men.

Age at Diagnosis

Figure 18. Number of people diagnosed with Dementia in East Lothian by age, Jan 2014 – Oct 2022

	Age at Diagnosis (Grouped)						Total
	45-54 yrs	55-64 yrs	65-74 yrs	75-84 yrs	85-94yrs	95 + yrs	
No of people Diagnosed by Age Group	4	36	257	738	445	19	1,499
% of People	0.3%	2.4%	17.1%	49.2%	29.7%	1.3%	

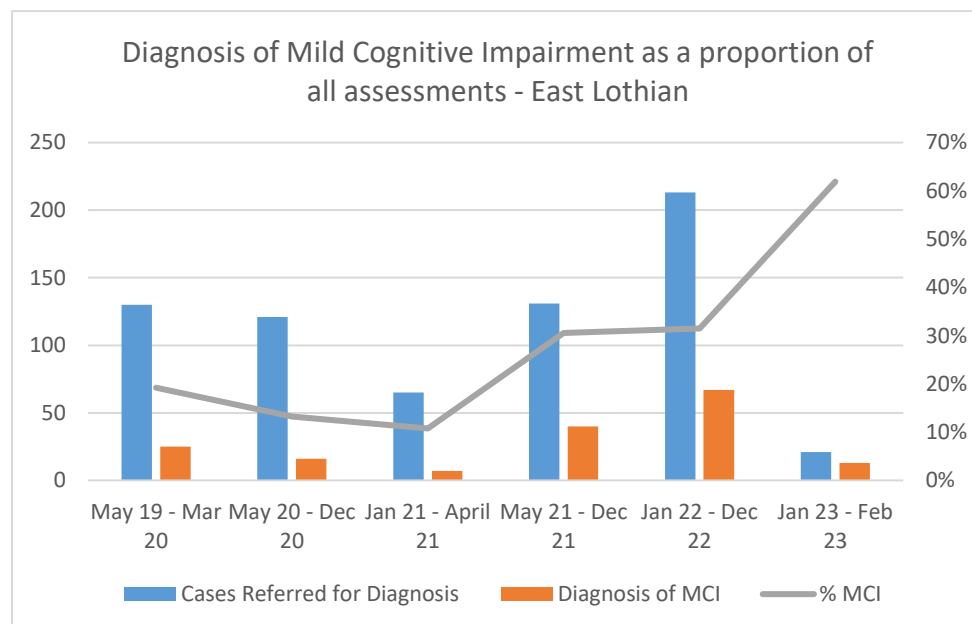
*Data until October 2022

Source: NHS Lothian Mental Health Analytics [Accessed Oct 2022]

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.

Trends in Mild Cognitive Impairment

Figure 19. Rates of those diagnosed with Mild Cognitive Impairment as a percentage of total cases.

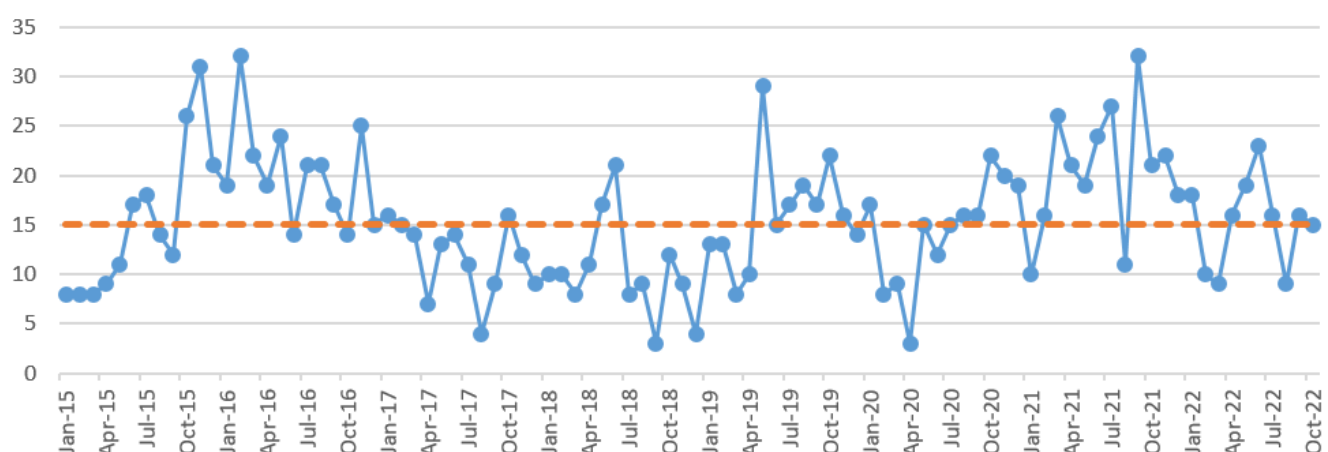


A diagnosis of dementia is made when people reach a certain threshold in the assessment process taking account of medical history, physical examination, testing and assessment of changes in thinking, day-to-day function and behaviour. Below that threshold, people may be diagnosed instead with Mild Cognitive Impairment (MCI) and a certain percentage of those with MCI may then go on to develop dementia.

Data provided by the Consultant at the Memory Clinic shows an increasing trend in the proportion of those diagnosed with MCI rather than dementia. One possibility is that this could demonstrate that GP's are referring people for diagnosis earlier. These statistics do not include people who were re-referred later to be re-assessed where their condition has declined.

East Lothian Post Diagnostic Support register

Figure 20. Number of East Lothian residents added to the Post Diagnostic Support register by month, 2014 – 2022



The data from the Mental Health Analytics team also provides us with the number of people added to the Post Diagnostic Support register by month following diagnosis since data collection began in 2014. Taken over the time period Jan 2014 to October 2022, an average of 15 new diagnoses were made each month.

Provision of Post Diagnostic Support

Figure 21. Post Diagnostic Support Data for East Lothian relating to the LDP Standard

	2018-19*	2019-20	2020-21	2021-22	2022-23**
No referred for PDS	128	188	195	241	160
% of PDS completed for 12 months, or were exempt	35.9%	95.2%	83.3%	75.3%	Incomplete

*Note that 2018-19 there were reporting issues identified

** % data for 2022/23 not yet available as the year is not complete

Source: Public Health Scotland

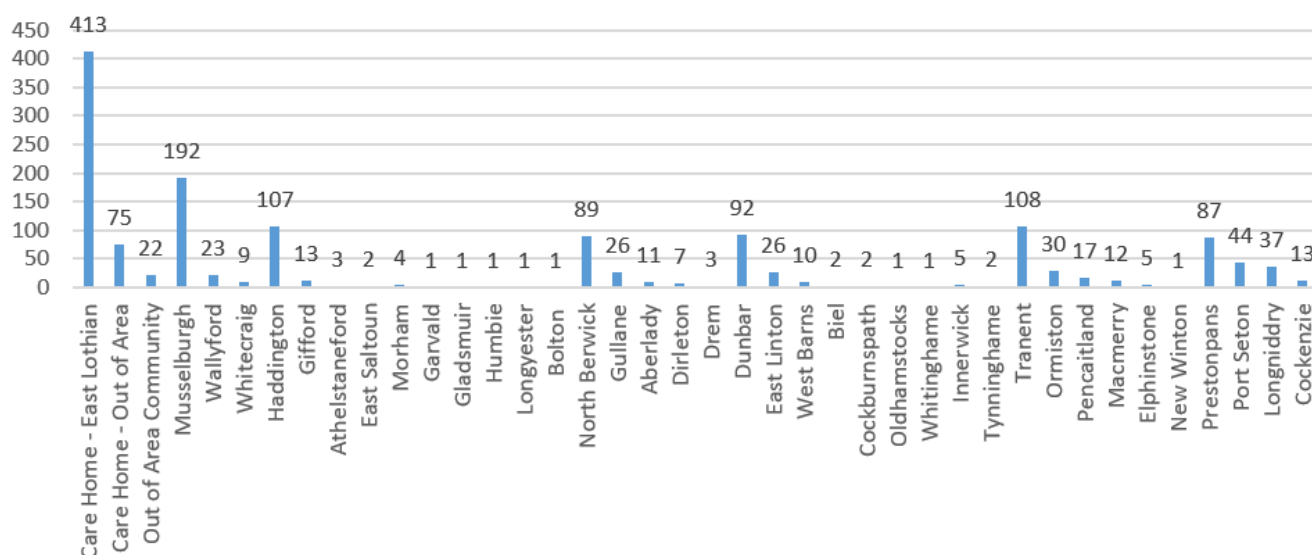
The Scottish Government have set a Local Delivery Standard that all people who are newly diagnosed with dementia receive a minimum of one year Post Diagnostic Support co-ordinated by a named link worker. Data to monitor performance against this standard is collated by Public Health Scotland and shows the percentage of people referred 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%.

East Lothian's performance against this standard has been variable. Note that there were reporting issues for the data in 2018/19. The variation in the remaining years 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.

Dementia in East Lothian by Geography

The Heat Questionnaire also provides us with data on the current geographical location for East Lothian residents diagnosed since 2014. However, note that as the data is taken live from TRAK, the NHS electronic patient management system, some resident's locations will have changed since their original diagnosis.

Figure 22. Number of East Lothian residents added to the Post Diagnostic Support register by month, 2014 – 2022



Source: NHS Lothian Mental Health Analytics [Accessed Oct 2022]

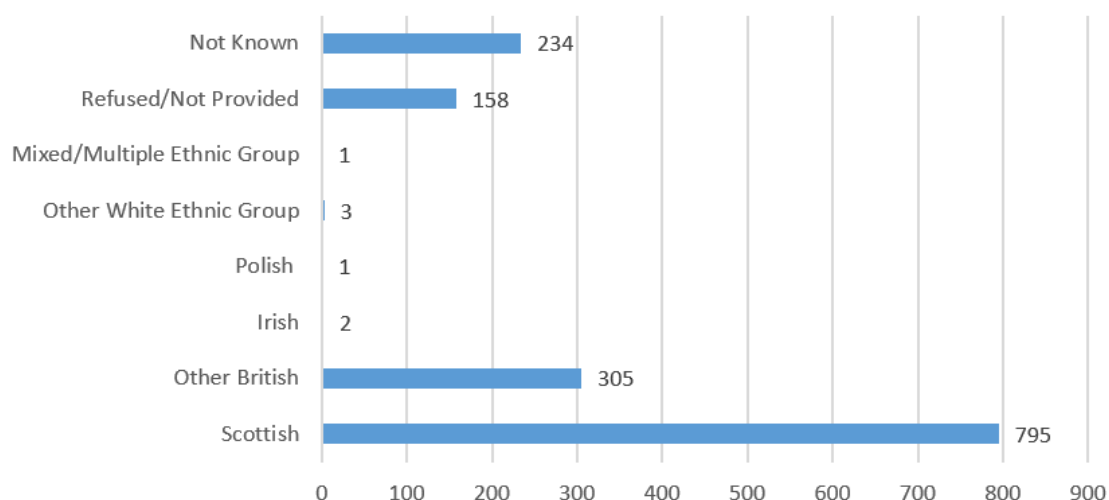
Of the 1499 residents diagnosed since 2014, 488 now reside in a care home either in East Lothian or out of area. A further 22 residents have since left East Lothian but continue to live in the community and the remaining 989 residents (or 65%) diagnosed with dementia continue to live within a community setting within the county. This is in line with the national picture where 61% of people with a diagnosis of dementia live in the community.

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. 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).

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.

Ethnicity of those diagnosed with dementia in East Lothian

Figure 23. Number of people diagnosed with dementia in East Lothian by ethnic group.



Source: NHS Lothian Mental Health Analytics [Accessed Oct 2022]

Unfortunately, the HEAT questionnaire data does not provide sufficient information on the ethnicity of those diagnosed with dementia in East Lothian. The majority of people diagnosed are in the categories Scottish and Other British. However, a significant proportion of people responding (26%) did not have their ethnicity recorded either because it was refused, was not provided, or was not known. Only 5 people had their ethnicity recorded as either Polish, Other White Ethnic Group or Mixed/Multiple Ethnic Group.

Diagnosis and Support for People with a Learning Disability

There is an increased prevalence of dementia in those with a learning disability, particularly among people with Down Syndrome. Psychologists within the Community Learning Disability Team (CLDT) proactively complete baseline assessments for people with Down Syndrome after the age of 35 and review these annually to monitor for changes. At present there are 10 people with a Learning Disability with a diagnosis of dementia. The majority of these have Down Syndrome and are in their 50's and 60's. Only one person with a diagnosis is their 40's.

There are over 700 adults with a learning disability living in East Lothian.

There is a broad range of support available both pre and post-diagnosis from the wider Learning Disability service which takes a multi-disciplinary approach. The Learning Disability Service includes Social Work, Community Learning Disability Team and Community Resources and can provide support with:

- monitoring physical and mental health
- working with family to determine how the client is managing at home and to upskill family and next of kin to offer specific support required
- Support to assess functional ability
- Continence care
- Support with dysphasia/difficulties eating and drinking
- Dietetics and assessment of nutrition
- Mental health and memory support
- Medication reviews and prescribing

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. Support also tends to evolve with the person and therefore there can be less of a shift required once a dementia diagnosis is in place and more of a gradual adding on of support as the condition changes.

A further benefit of the Learning Disability service is that reviews are completed 6 monthly once a diagnosis is in place to determine how the client is managing, and family/guardian or support provider can self-refer into the service at any time should a function or behavioural change occur, or if additional support is required. As a result, support offered is person-centred and based on what the individual requires.

Substance Misuse and Dementia

Alcohol related brain damage (ARBD) is caused through excessive and prolonged use of alcohol and can result in symptoms of dementia. Although there is the potential for the damage to be partially reversed through reducing or ceasing alcohol consumption, for a portion of people with ARBD, the damage can be permanent.

There is currently a wide variation in incidence and prevalence estimates of those with alcohol-related cognitive impairment. These have been complicated by differing patterns of alcohol use as well as other associated lifestyle risk factors among alcohol abusers including head injury, other psychiatric or substance abuse co-morbidities and a higher rate of vascular risk factors. One study indicated high rates of dementia in alcohol abusers (ranging from 10% to 24%) while other prevalence studies showed high rates of alcohol abuse among people with dementia (9% to 22%).¹⁰

Alcohol related dementia typically has a younger age of onset than other forms of dementia and those affected are more likely to be male. Social isolation is also common among those who abuse alcohol with a high proportion of ARBD patients being unmarried or lacking the support of family or friends. Also of note is an increase in reported rates of alcohol abuse among older people and women.

East Lothian currently uses the ARBD clinic in Milestone, Edinburgh to provide support, rehabilitation and treatment to those with alcohol related brain damage. The service uses a person centred and assets based approach to identify needs and to develop a plan to support people to return home. Within East Lothian the most common age range for people to experience issues with alcohol abuse is among those aged 40-70.

Mid and East Lothian Drug and Alcohol Partnership (MELDAP) have highlighted that alcohol use amongst this age group is more likely to be attributed to other factors such as depression and social isolation. Older age groups also are more likely to be prescribed medication for other health issues and there are often contraindications when mixing these with alcohol.

Homelessness and dementia

The East Lothian Homelessness Team advise that only a very small portion of those presenting as homeless in East Lothian are over the age of 65. The context of homelessness in the county is very different from the presentation in larger cities such as Glasgow or Edinburgh. In East Lothian there are very few rough sleepers and therefore the older homeless population in East Lothian do not face

¹⁰ [Ridley et al 2013: Alcohol-related dementia: an update of the evidence](#)

the same challenges of ill-health as a result. The homeless team also advised that they currently do not have anyone on their caseload with a diagnosis of dementia.

More commonly in East Lothian, the majority of the contact will be from people who approach the Homeless Prevention Team. Cases referred to the Homelessness Team are also commonly older people who have lived in owner occupied accommodation who are unable to be discharged home from hospital due to the current state of their property. Earlier referral by the hospital discharge team to homelessness team would assist in speeding up discharge and enable the team to make earlier contact with environmental health to undertake relevant property inspections. Improved links with hospitals and GP's will also be required when a new Housing Bill is introduced in 2023 which will include wide-reaching prevention duties in a bid to end homelessness in Scotland.

Justice Services

A prison environment can present significant challenges for people experiencing a cognitive impairment. Issues around cognition may be partly hidden by the rigid schedules frequently in place in prison that can hide some of the difficulties that people with cognitive impairment may experience. This can include undertaking activities of daily living like dressing, eating and drinking at appropriate times. It is possible that many older people in prison experiencing cognitive impairment will not get a formal diagnosis of dementia.

In line with the general population, the prison population is also ageing and there are growing numbers of people in prison with ill-health. As part of the strategy further work is needed to liaise with the Scottish Prison Service NHS to understand how appropriate levels of care are delivered within a prison setting for the ageing prison population and to better understand the particular issues for those with cognitive impairment.

Justice Services in East Lothian note an increase in men currently aged between 60 - 80 who are serving historical prison sentences, with around 50-60 people in East Lothian serving custodial sentences at any one time. However, Justice Services advise the numbers of offenders returning to the community with formal diagnosis of dementia are very low.

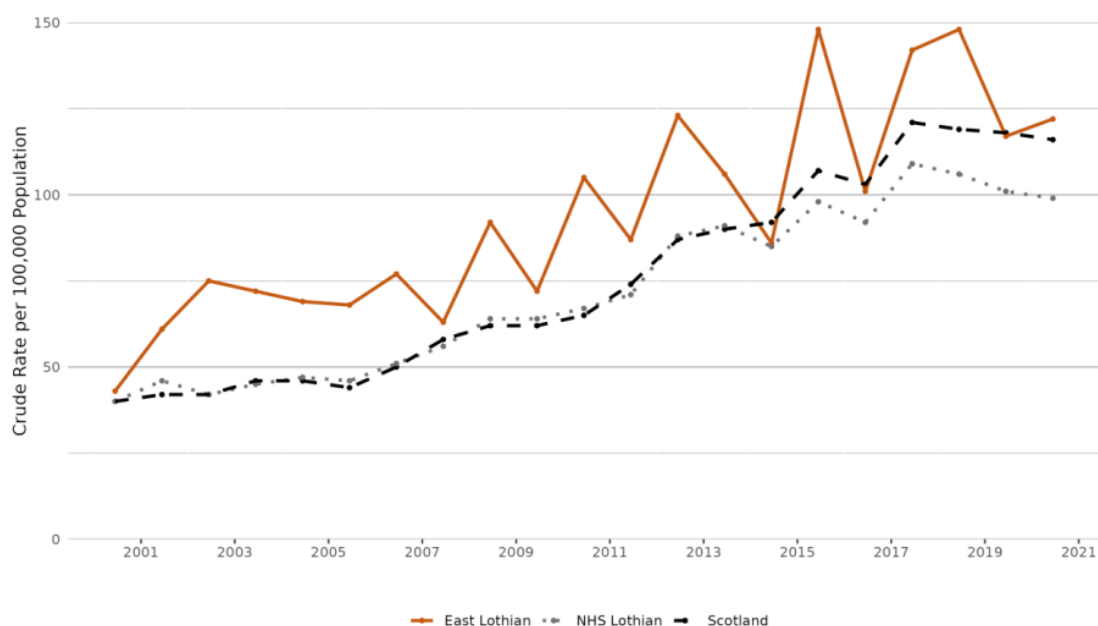
Levels of dementia in care homes

Numbers of residents with a formal diagnosis of dementia in care homes varies across East Lothian. Although residential homes do not provide nursing care, there are higher numbers of people with a diagnosis of dementia in residential homes than in our nursing homes. The percentage of people with dementia in East Lothian residential homes is around 81%, while in nursing homes, the average is around 69%.

Feedback from managers is that nursing homes tend to include residents with a wider range of frailty and other complex health conditions that require nursing care accounting for a lower number of people with a diagnosis of dementia. Nursing homes are also likely to have residents with more advanced levels of dementia. However many homes in East Lothian operate a "Home for Life" approach to maintain residents within the care home despite increasing needs. Managers in residential homes do also support residents with more advanced levels of dementia.

Deaths from Alzheimer's and Dementia in East Lothian

Figure 24. Rates of Alzheimer's Disease and other Dementia deaths in East Lothian



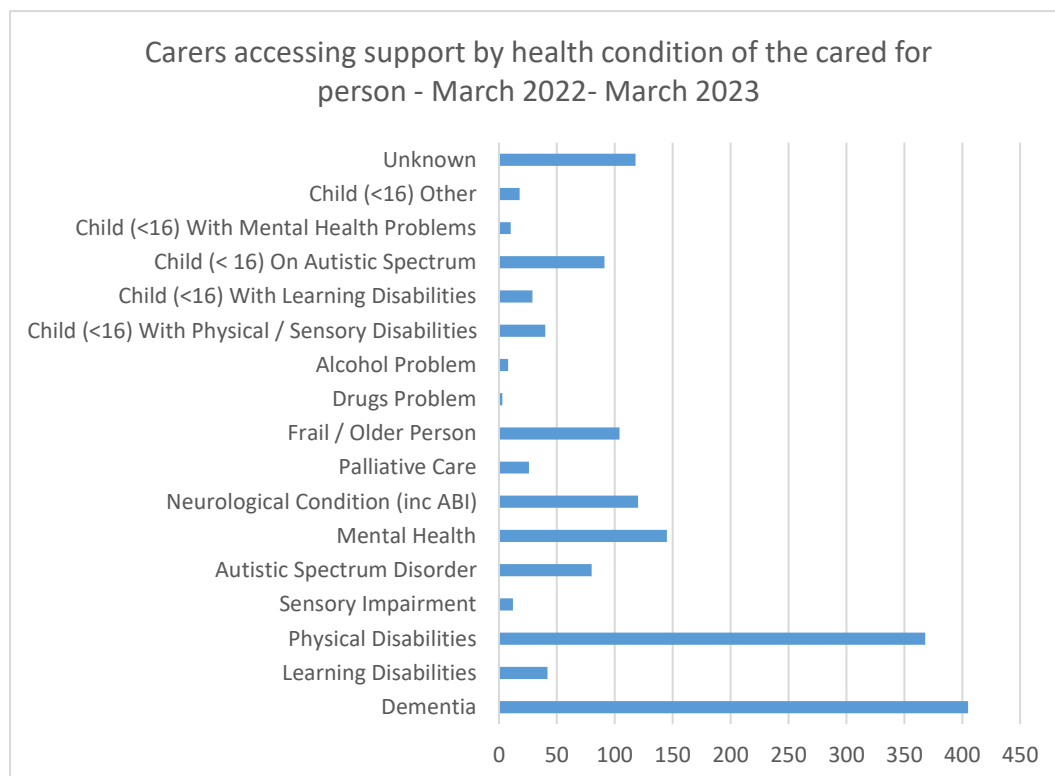
Source: [National Records of Scotland](#) [Accessed Mar 2022]

The number of Alzheimer's and other dementia deaths has increased within East Lothian (183.7% since 2000) Lothian (147.5% since 2000) and Scotland (190% since 2000). Figure 22 shows that the geographies of interest follow a similar upward trend with East Lothian showing more variance between years, likely due to a smaller population size.

East Lothian has a consistently higher rate of death due to Alzheimer's and other Dementias than Lothian and Scotland.

Carers of people with dementia

Figure 25. Carers accessing support from Carers of East Lothian by health condition



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. While it is positive that those supporting caring for someone with dementia are the largest group, we must acknowledge that this number still falls significantly below the estimated total number of people with a diagnosis of dementia (2104 in 2022). There therefore remains a significant portion of carers or someone with dementia not accessing support from a carers organisation.

Figure 26. Age range of carers of people with dementia accessing support from Carers of East Lothian

Age of Carer	Number of Carers
18 To 24	2
25 To 34	5
35 To 49	31
50 To 64	149
65 To 74	61
75 To 84	97
85 and above	28
Unknown	32

Of those who accessed support while caring for someone with dementia, the largest group of carers were aged between 50 to 64. These carers are more likely to be in employment and have family or other responsibilities. Those in employment are more likely to have to reduce their hours or give up working altogether.

We also know based on the work done through the East Lothian Carers Strategy, that it is people over the age of 65 who provide the greatest number of hours of care and who may also have health conditions of their own.

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.¹¹

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.

Carers of someone with dementia also experience issues that are unique from other caring groups. Feedback from our local carers centre is that while carers of someone with dementia often experience similar issues as other groups, they do so at a much higher intensity given the complexity of the illness. There can be increased concerns around accessing a break from caring. Although breaks are still greatly needed, carers may find that on their return that the person with dementia's condition has worsened due to the change in their normal day-to-day routines. This then increases the stress of caring.

We are aware of the challenges of care home staff and other care at home providers in supporting people with complex dementia and have put in specialist training and advice to support these staff groups. However, for those carers caring for someone with dementia in the community, there is no such support in managing stress and distress behaviour.

Carers of those with dementia are also unique in that they frequently experience anticipatory grief, where cognitive function in the person with dementia declines in advance of their physical decline and it can feel to the carer or family like the person is slipping away. There is therefore the need to support carers in managing the emotional toll of this on their own mental health, and where peer support and counselling can be valuable in helping carers to cope.

We are also aware that more people are dying of advanced dementia rather than other diseases such as heart attack and strokes and as a result carers are now having to manage more advanced dementia in the community for longer.

Feedback from professionals is that deterioration in dementia also does not happen in a straight line but can happen very suddenly. Those within a care home setting will be able to receive increased nursing support from care home staff, but those in the community may reach crisis point quicker and may require more urgent support to support them maintain them at home. Again, the impact of this on carers must be considered. The importance of having a single point of contact at such stages would assist with this as well as the offer of longer term post diagnostic support in the form of the 8 pillar model from Alzheimer Scotland.

¹¹ [Impact on carers - Dementia Statistics Hub](#)

Sensory Impairment

KEY POINTS

- 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 is greater on care home residents who are also likely to be living with dementia
- 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.

Prevalence of Sensory Impairment

Data from studies suggests that sensory impairment is more prevalent as people age:

- In Scotland there are estimated to be around 850,000 people with a hearing loss, with over 70% of those over the age of 70.¹²
- Around 1 in 10 people over the age of 65 are estimated to have a vision impairment.¹³
- Up to 90% of those with dementia in long term care are thought to have a hearing or vision impairment.¹⁴
- The majority of people with dual sensory loss (also known as deafblind) are older people who have developed hearing and sight loss later in life. Studies show that around 21% of adults over the age of 80 may experience dual sensory loss¹⁵
- Due to the projected growth in the population of those over the age of 65, those with a hearing impairment are expected to increase by 50% in the next 20 years, and those with a vision impairment are expected to double by 2031.

Sensory loss and dementia

There is also growing evidence of an association between sensory impairment and dementia. Studies now show that hearing impairment may be a risk factor for cognitive decline and brain atrophy, as well as one which may also be modifiable.^{16 17} Around 8% of cases of dementia are now attributed to hearing loss in mid-life. Hearing aid use is the largest factor protecting from cognitive decline.

¹² [See Hear: Scottish Government](#)

¹³ [Court et al 2014: Vision impairment is associated with physical and mental comorbidities in older adults](#)

¹⁴ [Dawes et al 2020: Hearing and vision health for people with dementia in residential long term care](#)

¹⁵ [Heine et al 2015: Dual sensory loss in older adults](#)

¹⁶ [Dawes 2019: Hearing Interventions to Prevent Dementia](#)

¹⁷ [Livingston et al 2017: Dementia Prevention, Intervention and Care](#)

Conversely undiagnosed sensory impairment can also lead to incorrect diagnosis of more advanced cognitive difficulties. People presenting with moderate impairment who then have their hearing and vision difficulties correctly assessed and treated, may then have a lower level of impairment diagnosed.

Sensory impairment and impact on health

Sensory impairment can have a significant impact on people's health as well as their everyday life. In addition to people experiencing difficulties in their ability to communicate, to build and maintain social connections, their mobility, navigating the environment, as well as their ability to access information and learning, people with sensory loss are also shown to have an increased risk of developing other health conditions such as stroke, hypertension and heart disease as well as depression and diabetes.^{18 19}

Care home residents with sensory impairments are, in particular, at increased risk of isolation and reduced social participation which in turn can affect their mental health and quality of life. Care home residents have less control over their environment and therefore activities that were previously enjoyed such as listening to music, watching television or general socialisation and participation may be hindered.

Neuropsychiatric symptoms (NPS) such as depression, agitation, apathy and distressed behaviour are also commonly associated with those with dementia. These are often frequently associated with poorer health outcomes including institutionalisation, prolonged hospitalisation and higher morbidity and mortality. Hearing loss in care home residents with dementia has been shown to increase both the number and severity of Neuropsychiatric symptoms.²⁰

Factors that hinder treatment and management of sensory impairment

It is also common for people to delay seeking help with vision or hearing loss due to a belief that it is a normal part of aging and as a result there can be delays of up to 10 years in people addressing hearing loss. In addition, studies have also identified that between 30 and 45% of adults who report hearing problems to their GP are not referred to NHS hearing services.²¹

As a result of hearing loss being underreported and untreated among older adults, only 1 in 7 people with a hearing impairment use a hearing aid for hearing loss while up to 30% of those who do own a hearing aid do not use them or use them infrequently.^{22 23}

Residents with dementia in care homes can experience additional barriers to managing hearing and vision impairment including:

- Lack of training for care home staff who are therefore not able to identify sensory loss
- Hearing aids or glasses not being used as intended
- Loss of dexterity resulting in residents being unable to effectively handle and manage their own hearing aids
- Lack of screening for impacted wax which can cause pain and present as hearing loss
- Poor links between care home and hearing and vision services resulting in infrequent optometric and audiological assessments for residents

¹⁸ [Andrusjak et al 2020: Identifying and managing hearing and vision loss in older people in care homes](#)

¹⁹ [Court et al 2014: Vision impairment is associated with physical and mental co-morbidities in older adults](#)

²⁰ [Kim et al 2021: Association of hearing loss with Neuropsychiatric Symptoms in older adults with cognitive impairment](#)

²¹ [NICE: Hearing loss in adults: assessment and management](#)

²² [Kim et al 2021: Association of hearing loss with Neuropsychiatric Symptoms in older adults with cognitive impairment](#)

²³ [Dawes 2019: Hearing Interventions to Prevent Dementia](#)

- Reliance on family members accurately reporting hearing or vision impairments for pre-admission assessments due to cognitive decline in residents. Family members frequently do not identify these as issues
- Cognitive decline impacting on performance during hearing and vision assessments

Engagement

Over the course of 2022 numerous engagement events were held as part of the work of developing the East Lothian IJB Strategic Plan and the Planning for an Ageing Population project. Events took place between April and September and in total we spoke to over 1500 people. Around 660 people attended sessions or fed into questionnaires where dementia was mentioned. Feedback was gathered from Day Centre attendees and staff, Community forums, Health and Wellbeing subgroups, locality engagement, carers, veterans and a range of Health and Social Care Partnership staff as well as from online consultation questionnaires accessible to the public.

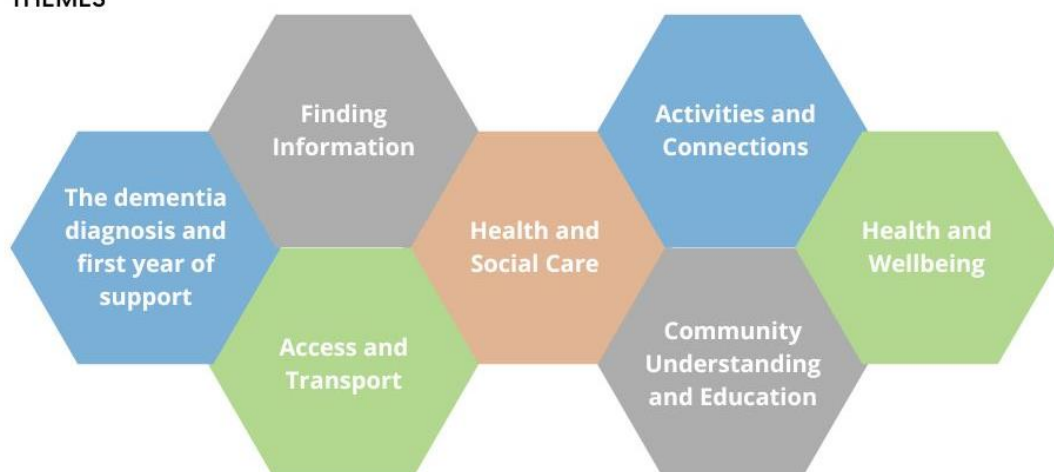
East Lothian Health and Social Care Partnership also commissioned a separate piece of community engagement specifically for people living with dementia and their unpaid carers. Events took place between July and October 2022 using a storytelling approach. The work was led by Outside the Box in partnership with Alzheimer Scotland, Harlawhill Day Centre, The Fraser Centre, Dementia-Friendly East Lothian and RVS. In total 5 group sessions using a storytelling approach were held at different venues across east Lothian including in Dunbar, Tranent, Musselburgh and Prestonpans. Sessions were also hosted with staff, volunteers and carers. During the course of the consultation, Outside the Box spoke with 117 people.

Separate 1:1 engagement was also completed with care home managers across East Lothian to further understand the experience of care home staff in supporting people with dementia at the more advanced stages of the illness.

The Life Changes Trust also held an event in May 2018 for carers of people with dementia offering carers a chance to think about how carers can care for themselves as well as their loved ones. Information and feedback from the event offers valuable insights to help inform improvements of services from a carers perspective. 26 carers attended this event.

Feedback from all these events have been combined into 7 main themes which are categorised below. A full timetable of events are listed in Appendix B.

THEMES



The Dementia Diagnosis and the First Year of Support

People with dementia and their carers told us that it can be difficult to identify themselves or their family member as having dementia as it's not always recognisable. There can be a tendency to put everything down to age-related forgetfulness which can delay visiting their GP. Early identification is key for families and people with dementia to ensure access to services and support.

It was felt that more could be done around early intervention and prevention as new research shows that promoting good health care, wellbeing and socialisation can help prevent up to 1/3 of dementia cases. People of all ages could be involved in this work to have a positive impact on future generations.

When asked about their experience around diagnosis people with dementia and their carers highlighted concerns that they were having to wait significant lengths of time to receive a diagnosis, citing difficulty in getting primary care appointments. Many family carers reported experiencing a 'gap' between receiving a diagnosis and getting further information and support.

Although people were aware that they are entitled to a 'year of support' there was little clarity around what that year of support should actually look like and a sense they were not informed as to what that entitlement meant in practice. People with dementia also cited being placed on a waiting list for support, in some cases taking them past 'the window' for receiving it as their dementia had advanced to the stage where other support was needed. Carers also told us that there was a lot of support available during the post-diagnostic period but it was difficult to navigate. A transition strategy is also needed for when the 1 year support ends.

A lack of support for carers and those living with dementia was also noted as well as a sense of frustration that practice is not getting any better, and in some cases is getting worse. Carers felt they are being forced to refuse to take loved ones home to push services into action for the support needed at home. Carers and family members also felt that they should be better informed as to what they need to consider such as equipment, prompts, personal care and power of attorney.

Concerns were voiced around the fact there is no clear single point of contact as well as pressures on the Community Mental Health Team, and suggested workers be dotted across the different localities. There is also the issue of workers changing regularly, having to get to know people from scratch, or different workers dealing with the same patient.

Reviews of the person living with dementia were always focused around their clinical state rather than their mental health. Others felt the dementia test itself was unreliable, producing a diagnosis for some and not others.

Finding Information

A common theme across all consultation events was the general lack of knowledge around where to get information about dementia, support and opportunities to take part in local activities. Carers felt that there was a lot of information out there but it remains a challenge to access this at the right time. Finding out about suitable activities or groups is a 'postcode lottery' and depends on who you speak to. Many people with dementia and their carers found information or groups by chance or through informal chats with others. Being part of one group (such as the D-café or Open Arms Carers) led to signposting and finding out useful information. People with a sensory impairment or those living alone found it even more challenging with written information not always provided in an accessible format.

Several people cited the difficulties in completing forms for benefits and reductions including the Council Tax form and Blue Badge form, particularly if these are online for those who are not 'tech

savvy'. Managing the requirements of the person with dementia can often mean carers don't have the time to complete the forms required.

A key issue that was consistently raised was that more could be done to work collaboratively across the community to effectively raise awareness of how to receive support and sign-posting. There was recognition that this involves effort and resources which can stretch the capacity of local community organisations and groups. Despite this, these community support plays a pivotal role in delivering local opportunities for people living with dementia.

Many people spoke highly of the following services:

- Alzheimer Scotland D-café which runs in three different locations and offers ongoing support and information between times.
- Carers of East Lothian offering support for carers regarding benefit and welfare advice from the Tranent Library.
- Open Arms Carers group – offering peer support across a complex landscape of what it means to be a carer for loved ones living with dementia
- The Fraser Centre – community base offering dementia friendly space, including trained staff, dementia-friendly films and hosting the D-café.
- The Volunteer Centre East Lothian – a good source of information including providing a community directory which highlights 10 different groups and organisations for those with dementia
- Dementia Friendly East Lothian – active in spreading a positive message about dementia in the community.
- Radio Saltire – good means for promoting opportunities
- RVS – offer a good library of signposting to different organisations

While people with dementia and their carers felt volunteers played an integral role in keeping these community activities going, there is a gap in volunteering as many people are unsure as to how to go about it. More could be done to promote information in different formats, without the assumption that everyone has access to a digital device. Library staff also spoke of how they would like to do more dementia training to support enquiries to their service and often receive frequent requests for information for people living with dementia.

Access and Transport

Many spoke of the challenges in accessing transport, particularly when attending medical appointments in Edinburgh. East Lothian is a large rural area dotted with small towns but with relatively poor transport links depending on where you live. While Dunbar and some other towns are well connected because of the train, buses can be irregular or not turn up. Without access to a car, attending appointments can be difficult and force people to rely on family or friends to get there. There was also a preference to use public transport to relieve the stress of driving.

RVS provides a community transport system which matches volunteers with their own cars to service users who need to attend appointments. The service is especially useful for those living in rural areas and people using the service often have a dementia diagnosis or memory loss. Issues can arise when there are no family members or friends to inform drivers about details of appointments if the person needs assistance. At times volunteers also don't have time to stay for the duration of the appointment and people with dementia using the service can get lost in hospital depending on whether there are any hospital-based volunteers available.

One person expressed concern that there was no transport to the new Musselburgh Meeting Centre for people living in rural and outlying areas.

Health and Social Care

There was a general consensus that improved communication between health and social care departments and organisations would help. Workers are allocated to cases until the person's need is met and then cases are closed until another need is raised. This led to inconsistency in terms of information not being passed on. Although there was recognition that social workers are overstretched, the current system results in people feeling like people with dementia and their carers are being "passed around".

Relationships are key to joined-up care for the person with dementia and to carer wellbeing and relationships needs time. This can mean time to build trust with a paid carer, to nurture relationships with family and friend, or enough time in appointments with professionals to be able to say what you want to say and be heard.

Many carers reported they were not being supported until they reached crisis point even though they try to raise issues as they arise and of the fight to get support in place. Earlier intervention would help people with dementia build routines that could help them self-manage for longer. Improvements in dementia training for staff are also required with people feeling that some nurses and other health professionals discounted dementia as an illness. Carers compared the system that follows cancer patients as being a preferred model which could be replicated for those with dementia where workers are employed partly by Macmillan and partly by NHS and availability of a one stop shop for people to phone.

Carers of people with dementia spoke of the importance to have permission to think about their own health and wellbeing to make quality of life more sustainable. Many carers often wait too long for mental health support. Better promotion of advocacy services is also needed as not all carers know about it, or what it offers.

There was a sense that dementia is not being dealt with holistically and there is little recognition of the various physical and sensory disabilities and emotional decline related to dementia. Emotional support should also be provided to those living with dementia and their families, particularly those in denial about their diagnosis. Peer support groups were cited as a valuable asset for this and viewed by many as a 'lifeline'

Provision of physical aids was important to the carers we spoke to although there remain significant gaps. We heard of carers having to carry out heavy lifting for self-care at home such as showering with no physical aids in place and having to wait months, in some cases opting to cover the significant cost to have changes made themselves.

Accessing respite is also very challenging with little on offer, making it difficult to attend health appointments and other work and life responsibilities. Carers report opting to pay for this themselves just to get by and arranging support can take significant planning.

Going into hospital can be traumatic for someone living with dementia. People with dementia and their carers felt that more should be done locally at East Lothian Community Hospital to avoid stressful and lengthy visits to Edinburgh acute hospitals. Local appointments for issues such as minor injuries, dental care, audiology or X-rays should be made available to avoid the stress and associated expense of attending these in Edinburgh. It was also felt that hospital staff lack awareness of dementia citing cases where staff did not feed patients as they were unable to answer, or care that was provided that lacked personal dignity.

Almost all care home managers reported that the residents coming into the homes had more complex needs, had more advanced dementia and were frailer than in the past. The vast majority of

residents in care homes now have a diagnosis of dementia. Many homes reported difficulties with staffing and recruitment with appropriate staffing levels key to providing quality support.

Almost all managers spoke very highly of the ELCHASE service which provides support, medication reviews and guidance for managing residents with stress and distress behaviour with some managers reporting they would not have been able to continue to care for some residents without this support. Some felt that medication changes could take time though.

Many managers felt that availability of training for staff was key, and although the homes had general dementia training in place, face-to-face bite size training and sensitisation training to help staff understand the experience of having dementia would make a difference in the provision of quality care. This can be difficult to access and although has been offered by ELCHASE in the past, there is not sufficient capacity in the team to do this widely.

Many homes operate a 'home for life' approach, caring for residents to the end of life and avoiding hospital admission where possible. Palliative and end of life care was reported to be good with District Nurses supporting when needed.

Feedback from managers was that accurate social work assessments at point of admission were important to ensure they could provide appropriate support for the resident and that they fit within their dependency levels. Assessments could be of a better standard.

While managers worked to ensure a range of activities are available, many community and intergenerational activities had stopped over COVID. Homes were at different stages of re-implementing these. Feedback was that continued connection to the community was important and improved resident's mood and outlook. One home in Musselburgh reported continued support from local businesses.

Community Understanding and Education

There was general agreement that a complete shift in culture and attitudes would be one of the most helpful things to support people living with dementia, including greater acceptance and understanding in shops, cafes and the wider community to enable people to be independent for longer. There are many ways people with dementia can continue to lead their lives positively following a diagnosis.

Changes in the language used to describe people with dementia both in professional and wider settings would help reduce barriers and stigma. When applying for benefits or entitlements, the language used in forms is extremely outdated such as "severely mentally impaired or incapacitated" that it puts people with dementia off applying for help. As a result some people with dementia reported preferring to hide their diagnosis than be open about it for fear of the outcome. Extra stigma and discrimination are also faced by some people with dementia and carers, including people who are lesbian, gay, bisexual and transgender.

Stigma could also be challenged by supporting more people with dementia to lead and run things. It is important to recognise that people with dementia can still work, volunteer and give back, and leading an active life can help maintain their dignity and respect. Exploring the Deepness project model would be helpful where people with dementia and unpaid carers are working together to re-write governance and guidance for Meeting Centres. Having people with dementia on key groups is also key to tapping into their lived experience.

There was also the sense that communities want to support people living with dementia and felt the strategy could help link up dementia friendly communities with appropriate resources, time and information to make this happen. Inclusive, accessible communities with good housing, good transport and infrastructure are key to supporting people to live well with dementia. Alzheimer

Scotland provides dementia awareness training in the community and it was felt this could be shared more widely with other groups and young people to support multigenerational awareness raising. Harlawhill staff have a “train the trainer” model – taking training they have received to other staff and people in the community. Training should also be provided by those with lived experience where people as “experts by experience” are at the heart of sharing knowledge. Carers also reported that quality community based services can help reduce unnecessary emergency strips to hospital and admissions.

For carers of people with dementia, awareness and understanding from friends and family of the impact of being a carer is important in supporting them in their role. Carers felt that the more supportive the general community was for all then the more the ‘substantial and critical’ aspects of caring as defined in the Carers Act would be curtailed.

Activities and Connections

Across all the engagement sessions, by far the greatest number of comments were in relation to community activities and connections, recognising that these are key to remaining active, engaged and healthy in older life as well as reducing social isolation.

People with dementia and their carers told us of the impact that a diagnosis had on existing relationships resulting in a change in the dynamics of family and friendships, and even the loss of some existing friendships. For wider families, where adult children lived away from home people, found that the person living closest to the relative with dementia often became the carer, at times resulting in friction within sibling relationships. Becoming a carer of someone with a diagnosis of dementia can mean experiencing loss and grief even before the loved one dies. It is a relationship fraught with guilt, anger and arguments due to the demands and exhaustion. Adequate support would at least make some of that process easier.

While there are groups and activities available locally for people living with dementia, it is often difficult to find out about these groups. Alzheimer Scotland groups which are held regularly in different locations were spoken of very highly. People with dementia told us that they would like these to be held more frequently than once a month. They also organise a regular walking group in Dunbar. Carers of people living with dementia spoke of the importance of access to meaningful activities for themselves in allowing them to take some time where worries and anxieties can be put on the back burner.

The Fraser Centre in Tranent was also cited as being exemplary with a range of dementia-specific events and activities as well as ensuring the centre is generally dementia-aware and inclusive. Many enjoyed both the dementia café hosted there as well as the less formal ‘meetup’ group which provides valuable peer support for carers of people living with dementia. The Fraser Centre also offers dementia friendly films, the friendship group and singing. The centre would like to start advertising and planning more activities but this requires money, staff time and resources.

Day centres were also cited as a valuable resource for people with more advanced in their dementia and mobility problems. Not only do they offer a varied programme of events and an opportunity to develop real relationships between staff and attendees, but they also act as a local resource for signposting to other services, provide much needed respite to carers, and provide advice and support when needed. We were told of the large waiting list for attendance at Harlawhill.

Many were impressed by the development of the new Meeting Centre in Musselburgh but would like to see this approach rolled out more widely and were keen on the idea of it developing into a local support hub to take some pressure off carers.

Some people with dementia reported not being comfortable joining a group and instead would prefer that there was wider acceptance in the community to enable them to be able to be safe when going for a walk or doing other activities they normally enjoyed. Greater focus on building dementia friendly inclusive communities would support this, understanding that continued conversation with local communities about what will work for them are needed as one size does not fit all.

There were also a range of suggestions and comments in relation to other community based activities including:

- The 'Library group' in Dunbar which offers a Dementia Carers' Support Group organising outings and trips as well as offering peer support. People attending reported the peer support as having a very beneficial effect.
- The intergenerational lunch club – more should be done to maximise the use of community buildings and spaces to promote intergenerational activities. Spaces need to be age-friendly. Work should be done with schools and pupil volunteers to promote this. Oral history projects are helpful in preserving memories and could be part of the school curriculum
- Availability of gardening projects as a way of keeping people healthy, engaged and aware of the seasons, time of year as well as a connection to people's previous interests. In Bloom and schools are doing some work on this. There were suggestions of working with housing to develop communal garden spaces as part of planning for new builds, including community parks.
- The Rehab Team felt that more could be done around developing general reminiscence groups. Although these are important people felt that it was key to remember that people with dementia should also be able to continue to develop both their present and future. Local Friendship groups around the county were thought to be very therapeutic for this.
- Developing more volunteering programmes for people living with dementia

Health and Wellbeing

We heard that for people living with dementia and their carers, the effects of dementia could take their toll in many ways. Losing connections, feeling isolated, losing self-confidence and feeling physically exhausted were common. On top of this came feelings of guilt, frustration and overwhelm. Peer support for carers was key in helping carers both emotionally and practically including finding out information, where to go for support and a place to offload. Many carers felt there was a huge amount of knowledge held by carers that could be shared with others in a similar situation, and peer support is a key way that carers can help share information.

Carers reported the difficulties and guilt that came in deciding to move loved ones into a care home. Peer support helps carers to manage these feelings. The pilot course on grief management, run by Carers of East Lothian, had helped carers to deal with grief – even before they lost their partner. Carers also reported the social isolation once their loved one had died and the difficulties in rebuilding their lives. Others had found counselling helpful.

All carers agreed it was difficult to find time for themselves and spoke of the lack of respite resources available with carers not getting the support they need. It can take several months to plan an appropriate respite break. We also heard that during COVID a local day centre provided a sitter service and other day centres were offering outreach services. Although RVS offers a buddy scheme the waiting list for this is long. Carers of East Lothian were also noted for their befriending service. Carers we spoke to wanted to find out more about the range of respite options available, including those for when people's dementia became more advanced.

The mental and emotional wellbeing of people living with dementia varied, mostly dictated by the stage they were at. While some people with dementia were unaware of their deterioration, others expressed frustration, anger at their diagnosis, fear and withdrawing into themselves.

APPENDIX A – Alzheimer’s and Dementia Prevalence

Prevalence Rates of Dementia (%) given by the EuroCoDe and Harvey studies

Age group	EuroCoDe Males (Under 60 Harvey)	EuroCoDe Females (Under 60 Harvey)
30-34	0.0672	0.0672
35-39	0.0672	0.0672
40-44	0.0672	0.0672
45-49	0.0672	0.0672
50-54	0.0672	0.0672
55-59	0.0672	0.0672
60-64	0.2	0.9
65-69	1.8	1.4
70-74	3.2	3.8
75-79	7	7.6
80-84	14.5	16.4
85-89	20.9	28.5
90-94	29.2	44.4
95-99	32.4	48.8
100+	32.4	48.8

Further information can be found via the following link: [Alzheimer Scotland](#)

APPENDIX B – Timetable of Consultation and Engagement Events

Engagement events for the IJB Strategic Plan and Planning for an Ageing Population consultation:

- Health, Social Care, Housing and Place Older People Workshop (19 April 2022 – 11 people)
- Health, Social Care, Housing and Place Dementia Workshop (20 April 2022 – 10 people)
- IJB Strategic Plan questionnaire – 58 people)
- Veterans Lived Experience (5 May 2022 – circa 60 people)
- Health and Social Care, Housing and Place Making – carried out by North Berwick Community Council – self-administered engagement, based on our engagement pack (13- 15 May 2022 – circa 50 people)
- ELHSCP Business Support and Business Admin Teams (16 people)
- Scottish Government Older People’s Strategy Engagement (30 May 2022 – 11 people)
- Planning and Performance Team IJB Strategic Plan Workshop (31 May 2022 – 8 people)
- Adult Wellbeing, Care and Home and Mental Health Staff IJB Strategic Plan Workshop (1 June 2022 – 32 people)
- Re-imagining Health and Social Care Questionnaire (185 online respondents)
- North Berwick Day Centre Engagements (7 and 27 July 2022) (51 participants)
- Lunch with the Bunch (14 July 2022 – 10 participants)
- Harlawhill Day Centre Engagement (19 July 2022) (14 participants)
- Dunbar Day Centre Engagement (20 July 2022) (14 participants)
- John Bellany Day Centre Engagement (21 July 2022) (16 participants)
- Rural Communities Engagement (4 August 2022) – Teams (23 participants)
- Eastern Communities Engagement (11 August 2022) – Teams (27 participants)
- Western Communities Engagement (18 August 2022) – Teams (29 participants)
- Carers Engagement (25 August 2022) – Teams (7 participants)
- Providers Engagement (29 August 2022) – Teams (11 participants)
- Dunbar Health and Wellbeing Sub Group (22 August 2022) (10 participants)
- Musselburgh Engagement (5 September 2022) (5 participants)
- North Berwick Engagement (6 September 2022) (13 participants)

Engagement events hosted by Outside the Box

Total number of people engaged with: 117

Total number of people living with dementia: 50

Total number of unpaid family carers: 40

Total number of staff and volunteers: 17 and 10

Total number of group sessions: 5

- Storytelling Session 1: Dunbar Townhouse (Alzheimer Scotland café) with c. 8 couples
- Storytelling Session 2: Fraser Centre, Tranent (Alzheimer Scotland café) – c. 6 couples
- Storytelling Session 3: (venue?) Musselburgh (Alzheimer Scotland café) – 5 people with dementia, 3 carers, 3 support workers
- Storytelling Session 4: Harlawhill Day Centre, Tranent – around 5 staff plus 4 volunteers (of whom 2 were previous family carers) + c. 12 day centre attendees (people with dementia) - some of these people from homes/sheltered housing, others from family home
- Open Arms Carers – Haddington - c. 10 people, all family carers/previous family carers, daughters, wives of people living with dementia (some widowed now)

- RVS/community transport staff: consulted with c. 4 members of staff around transport service
- Dementia-Friendly East Lothian: 1:1 chat
- Other 1:1 discussions: volunteer and former carer from Harlawhill, Manager and former family carer from Harlawhill

Engagement with East Lothian Care Home Managers

- Florabank Residential Home – 23/08/2022
- Carberry Residential Home – 13/09/2022
- Tyneholm Stables Nursing Home – 21/09/2022
- St Anne's Residential Home – 28/09/2022
- Astley House Nursing Home – 04/10/2022
- Fidra Nursing Home – 12/10/2022
- Tranent Nursing Home – 19/10/2022
- Lammermuir Nursing Home – 25/10/2022
- Crookston Residential Home – 02/11/2022
- The Abbey Residential Home – 08/11/2022
- Muirfield Nursing Home – 22/11/2022
- Harbour House Nursing Home – 30/11/2022
- Drummohr Nursing Home – 02/12/2022
- Belhaven Nursing Home – 31/01/2023
- Haddington Care Home – 08/02/2023