DEMENTIA IN LEICESTER ADULTS:

JOINT STRATEGIC NEEDS ASSESSMENT

A Joint Strategic Needs Assessment (JSNA) is a statutory process by which local authorities and commissioning groups assess the current and future health, care and wellbeing needs of the local community to inform decision making.

The JSNA:

Is concerned with wider social factors that have an impact on people's health and wellbeing such as poverty and employment.

Looks at the health of the population with a focus on behaviours which affect health, such as smoking, diet and exercise.

Provides a view of health and care needs in the local community

Identifies health inequalities

Indicates current service provision

Identifies gaps in health and care services, documenting unmet needs

Last updated 7-Nov-23

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1. INTRODUCTION

Dementia is a general term to describe reduced ability to reason, remember, or make decisions which interferes with a person's everyday life. While such things are more common as people get older, dementia symptoms are not a normal part of aging and instead dementia is the result of accumulated damage to the brain.

There are different subtypes of dementia, and these can impact both how the condition presents and evolves over time, however Alzheimer's disease is the most common. A visual summary of the different types is provided below (Figure 1). The subtypes have different causes and often result in different symptoms. Although dementia mainly affects older people, young onset dementia (in people aged under 65 years) accounts for 10% of dementia cases in England.[1]

1.1.1 WIDER IMPACT ON HEALTH AND WELLBEING OF DEMENTIA

Dementia can result in reduced independence and inability to self-care, for example personal hygiene, eating and drinking. This can lead to weight loss and increased risk of infection. People living with dementia often experience mental wellbeing challenges, such as reduced motivation, isolation, depression, and anxiety.

The changes that can occur in behaviour and personality in people living with dementia can be highly distressing, especially when there is a mismatch of understanding between how those surrounded by people living with dementia should respond to instances of the most socially inappropriate actions (e.g. rude remarks or hypersexuality) that the individual living with dementia has little or no control over.

Dementia has had a broad impact on loved ones, with family or close friends often being their primary carer. Loved ones and those who act as their carers face significant changes to their personal wellbeing and relationship, resulting in social isolation, impacting their physical and mental health alongside substantial financial costs.

1.1.2 NATIONAL PICTURE

Dementia is a growing challenge and over half of the population know someone living with dementia. While over 450,000 people in England are living with a recorded diagnosis of dementia, many people are unaware they have the condition, with an estimated 250,000 individuals undiagnosed in England.[1]

After the age of 65, the likelihood of developing dementia roughly doubles every five years.[2] However, for some, dementia can develop earlier, presenting different issues for the person affected, their carer and their family.

England has an ageing population with more than 1 in every 5 of us are over the age of 60, and the number of older adults with dementia is predicted to rise in the future from over 700,000 to 1 million by 2030 and over 1.3 million by 2040.[3] Dementia has a greater prevalence

in women, accounting for 60% of UK cases, which is possibly due women having longer life expectancies than men, and this increasing their risk of dementia in older age.

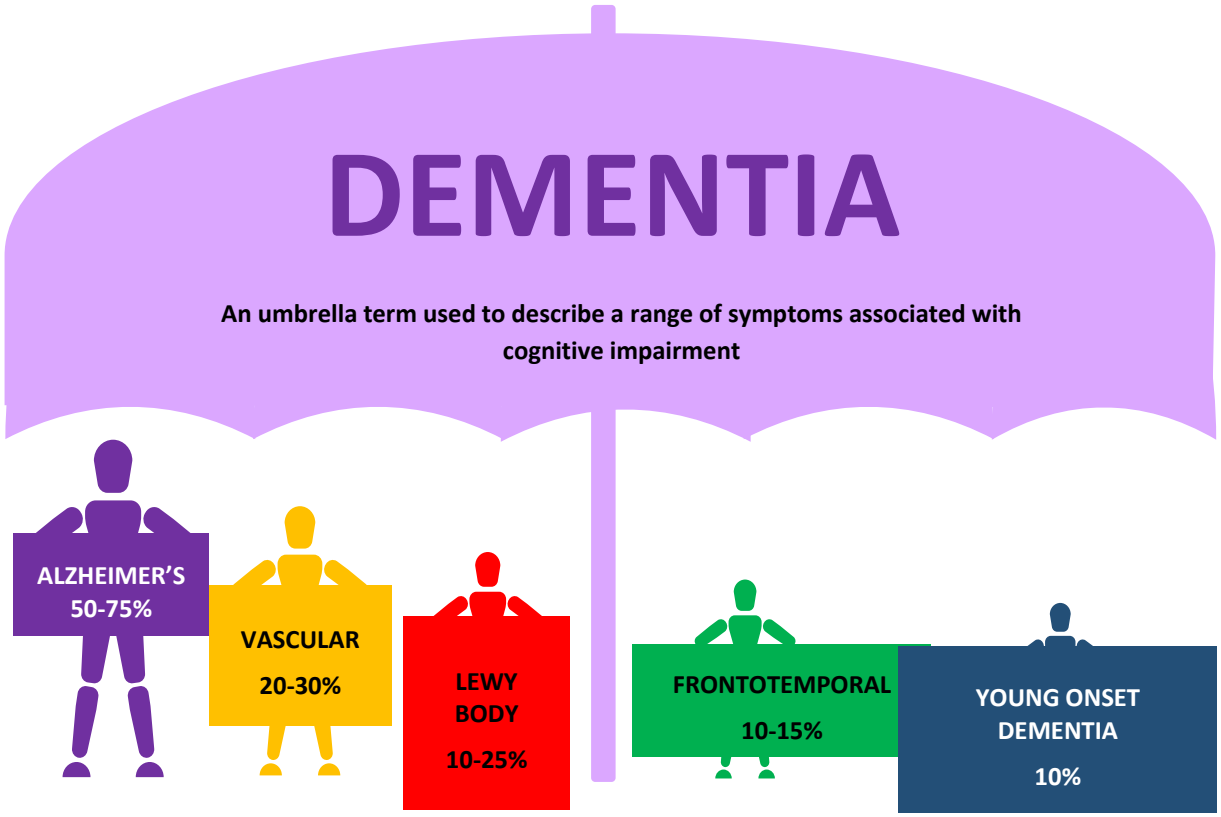
There are around 540,000 carers of people with dementia in England. It is estimated that 1 in 3 people will care for a person with dementia in their lifetime. Half of them are employed and it's thought that some 66,000 people have already cut their working hours to care for a family member, whilst 50,000 people have left work altogether.[4]

The economic cost associated with dementia is expected to triple by 2040 from £23 billion to nearly £70 billion.[1] This is more than the cost of cancer, heart disease and stroke. A large proportion (over 70%) of these economic costs are faced by households, reflecting the way in which dementia has a significant financial impact for loved ones of people living with dementia.

Some ethnic minority communities also have greater rates of dementia. With a rapid increase in the proportion of older ethnic minority adults expected over the next 50 years there is also expected to be an increase in the number of ethnic minority individuals with dementia; doubling from 25,000 in 2011 to 50,000 by 2026 and rising further to over 172,000 by 2051.[4] The increased risk in ethnic minority communities is thought to be related to an increased burden of cardiovascular disease, hypertension and diabetes.

Figure 1: Subtypes of Dementia

Type	Alzheimer's		Vascular Dementia	
Symptoms	Confusion/Disorientation Difficulty making decisions Hallucinations Low mood	Anxiety Problems with speech Personality changes Memory loss	Stepwise progression. Slowness of thought Difficulty understanding	Difficulty concentrating Changes to mood/behaviour Disorientation/confusion Balance problems Memory problems



Type	Lewy Body Dementia		Frontotemporal Dementia		Young onset Dementia
Symptoms	Issues with mental abilities: thinking, understanding, visual perception and memory Hallucinations and Confusion Difficulty swallowing	Fainting and unsteadiness Disturbed sleep Depression Slow movement alongside other parkinsonism symptoms	Personality changes Hypersexuality Language and speech problems	Becoming distracted Memory loss	Problems with walking, co-ordination or balance Less likely to have memory problems initially

2. WHO'S AT RISK AND WHY?

2.1 NATIONAL PROFILE

As of August 2022, 450,542 individuals in England have a recorded diagnosis of dementia (Table 1). With older age being the biggest risk factor for dementia, of those with a recorded diagnosis, 97% are aged 65 or over (Table 2).[1]

Table 1. Recorded dementia by age-band and gender, England, August 2022

	Prevalence (%)			Counts		
Age Group (Years)	Male	Female	Total	Male	Female	Total
0 to 29	0.02%	0.01%	0.02%	37	34	71
30 to 34	0.03%	0.01%	0.02%	45	27	72
35 to 39	0.04%	0.02%	0.03%	60	56	116
40 to 44	0.08%	0.04%	0.05%	143	104	247
45 to 49	0.14%	0.07%	0.10%	244	200	444
50 to 54	0.45%	0.23%	0.31%	764	643	1,407
55 to 59	1.15%	0.70%	0.87%	1,936	1,983	3,919
60 to 64	2.69%	1.41%	1.89%	4,527	3,986	8,513
65 to 69	5.04%	2.76%	3.61%	8,481	7,799	16,280
70 to 74	10.15%	6.68%	7.98%	17,092	18,849	35,941
75 to 79	19.17%	14.90%	16.49%	32,278	42,038	74,316
80 to 84	24.07%	22.00%	22.78%	40,528	62,085	102,613
85 to 89	22.91%	25.75%	24.69%	38,568	72,652	111,220
90+	14.05%	25.42%	21.17%	23,647	71,736	95,383
Total	**100.0%**	**100.0%**	**100.00%**	**168,350**	**282,192**	**450,542**

Source: NHS England

Table 2. Recorded dementia by broad age-group, England, August 2022

Broad-age group (Years)	Prevalence			Counts		
	Males	Females	Total	Males	Females	Total
<65	4.6%	2.5%	3.3%	7,756	7,033	14,789
65+	95.4%	97.5%	96.7%	160,594	275,159	435,753
Total	**100.0%**	**100.0%**	**100.0%**	**168,350**	**282,192**	**450,542**

Source: NHS England

The figures in Tables 1 and 2 are based on those who have sought a formal diagnosis with a GP in England and are likely subject to under-reporting. This is because this figure may exclude those with dementia but who are not registered to a GP, health illiterate and/or experiencing

language barriers, or those with limited access to a GP. Given that older age is the largest risk factor for dementia, those aged under 65 and experiencing symptoms may also be under-represented and underdiagnosed.

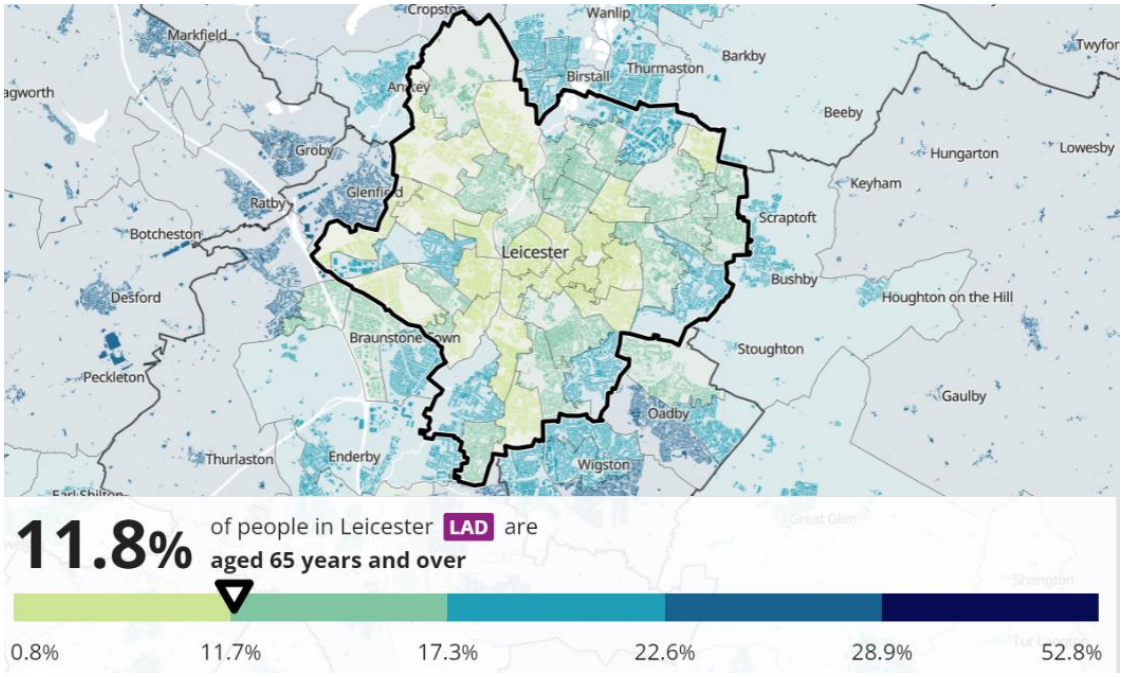
Taking this into consideration, the true prevalence of dementia is thought to be much higher. Estimates vary between sources, but all suggest there is a large gap between recorded diagnoses and estimated dementia cases. NHS England reports around 702,000 individuals aged 65+ *estimated* to be living in England with dementia as of August 2022. This would mean that a large proportion (around 35%) of dementia cases among those aged 65+ are undiagnosed/not recorded, and therefore lack the adequate care, support and treatment to manage their disease.

2.2 NON-MODIFIABLE RISK FACTORS

2.2.1 AGE

The most significant risk factor for dementia is ageing. As dementia is caused by accumulative damage to the brain, most often from existing health conditions, it means that dementia can take a long time to manifest. Older people are more likely to have high blood pressure, blocked blood vessels, a weaker immune system and take longer to recover from injuries. The risk of developing dementia roughly doubles every five years above the age of 65. It is estimated that 2 in every 100 people between the ages of 65 and 69 have dementia compared to around 33 in every 100 people aged over 90.[2]

Figure 2: Proportion of people in Leicester aged 65 years and over.[5]



Source: Census 2021

Although older people are at a higher risk of developing dementia, younger people can still develop dementia, known as young-onset or early onset dementia (in people under 65 years). Dementia in younger people often has different symptoms, even when it's caused by the same diseases as in older people. 1 in 13 of people in England living with dementia (including those not diagnosed) are under the age of 65.[1] In many cases, people with young-onset dementia have similar conditions that increase the likelihood of developing dementia in older adults (such as high blood pressure). However, some causes, such as frontotemporal dementia (FTD), atypical Alzheimer's disease and familial Alzheimer's disease are more common in younger people.[6]

Those with a genetic predisposition (dementia within the family) and those with learning disabilities are at increased risk of young-onset dementia. Those who have regularly misused alcohol, over several years, are also at greater risk of developing young onset dementia/ alcohol related 'dementia' due to the damage caused the brain from prolonged alcohol use.[7]

2.2.2 SEX

More females than males live with dementia, with twice as many females with Alzheimer's disease, the most common form of dementia, than their male counterparts. Risk is not too dissimilar between males and females until over 65+. The increased prevalence in females is mostly related to longer life expectancy among women. However, gender is undoubtedly an important factor in understanding dementia risk; males and females are subject to different experiences over the course of their lifetime, whether this is biological or to do with more traditional gender roles such as education, occupation, and lifestyle. More research is being done to understand the role of gender in dementia risk, and to also understand the risks to those of gender fluid status such as transgenders and those of intersex.[8]

2.2.3 ETHNICITY

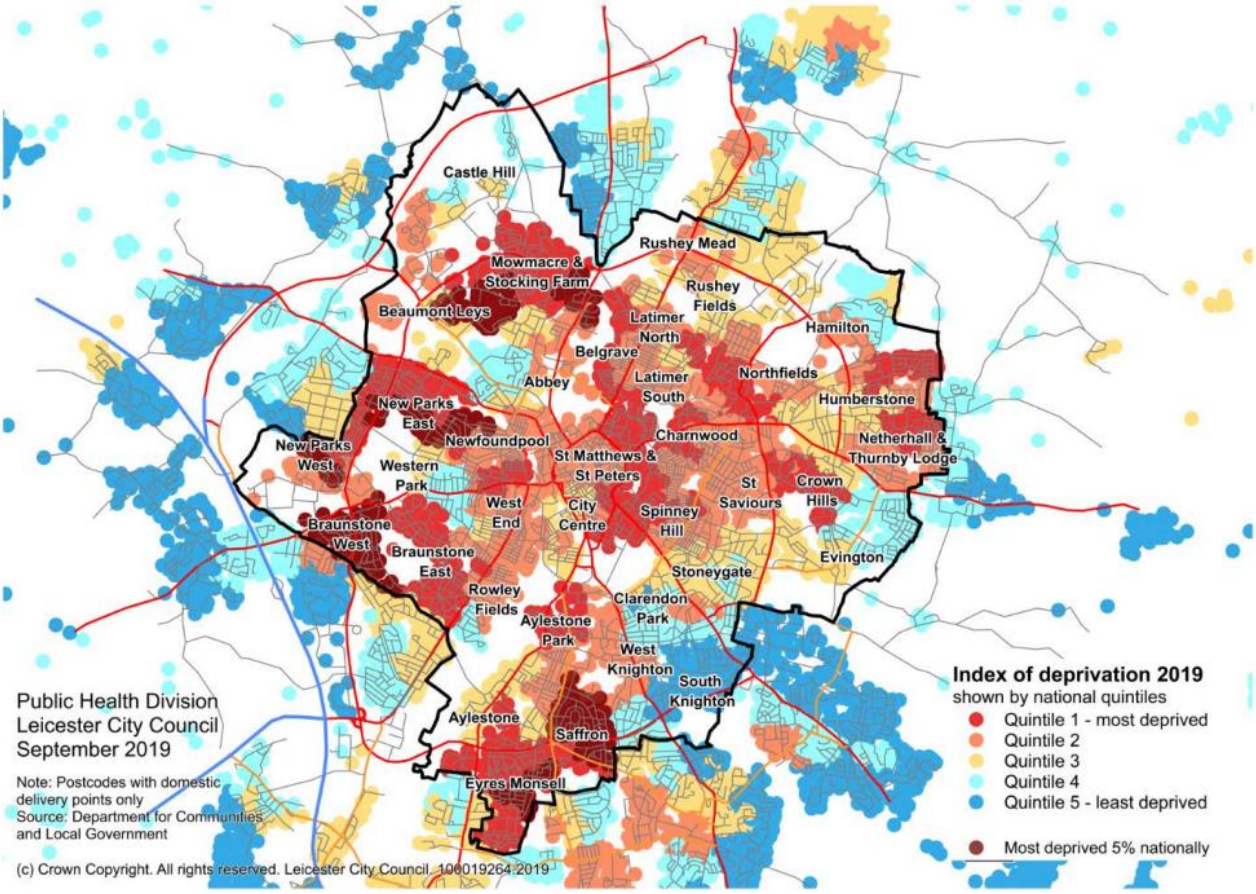
Leicester is a city with high levels of diversity; and non-White backgrounds form approximately 60% of the population.[9] Estimates of incidence and prevalence of dementia assume rates of dementia are the same for all ethnic groups. However, there is possibly increased risk for people from minority ethnic communities.[10] Rates of dementia appear to be higher in people from Black/Black British, and lower in Asian/Asian British, ethnic backgrounds. However, both groups show diagnosis at younger ages of diagnosis, lower survival times, and younger ages at death. This is thought to be related to higher rates of high blood pressure, obesity and diabetes in both groups. These findings all suggest that dementia is more severe in Black/Black British or Asian/Asian British people.

The number of people living with dementia in Black, Asian and minority ethnic groups is projected to rise 7 times by 2051, while the number of white Indigenous UK people living with dementia is projected to double over the same period.[11]

2.2.4 SOCIO-ECONOMIC DEPRIVATION

More than 1 in 5 deaths from dementia are thought to be related to socio-economic deprivation.[12] This trend appears to increase over time. Factors that could explain the higher rates of dementia in more deprived areas include stress, healthcare access, education, diet and higher rates of risk factors for cardiovascular disease. In Leicester, rates of socio-economic deprivation are higher than the national average. Over 1 in 3 (35%) reside in the most deprived 20% of areas nationally.[13]

Figure 3. Deprivation across the city, 2019



Source: Index of Multiple Deprivation 2019[13]

2.3 MODIFIABLE RISK FACTORS

It is thought that modifiable risk factors (see Table 3 for local summary data) related to lifestyle cause up to approximately 40% of dementia cases, with most cases of dementia not having a hereditary component.[14]

Table 3. Summary table of local prevalence of modifiable risk factors in Leicester[15]

Modifiable Risk Factor	Leicester Prevalence
Smoking	20%
Physically Active	58%
Excess weight in adults	50%
Alcohol intake over national limit	9%

Source: Adults Health and Wellbeing Survey (2018)

2.3.1 TOBACCO SMOKING

Systematic reviews have demonstrated that smoking could increase the risk of dementia by between 30% and 50%, increase the risk of an earlier death from dementia compared to non-smokers, and that smoking cessation reduces risk of dementia at all ages.[14]

The World Health Organisation explains many of the reasons behind the link between smoking and dementia, including the fact that the two most common forms of dementia - Alzheimer's disease and vascular dementia - have both been linked to problems with the vascular system (heart and blood vessels). It is known that smoking increases the risk of vascular problems, including strokes or smaller bleeds in the brain, which are also risk factors for dementia. In addition, toxins in cigarette smoke cause inflammation and stress to cells, which have both been linked to the development of Alzheimer's disease.

There are challenges in exploring the role of smoking as a risk factor for developing dementia. One reason for this is that people who smoke are more likely to have other behaviours which may contribute to risk, for example drinking alcohol, which is also a risk factor for dementia. Smoking can also lead to earlier mortality which means that many who smoke may not reach older ages where dementia is most likely to develop.[16]

2.3.2 OVERWEIGHT AND OBESITY

Obesity has been shown to be associated with 60% higher rates of dementia in people between 45 and 65 years of age. Each increase in BMI unit level before diagnosis have also been associated with a 30% higher rate of dementia.[14]

The relationship between excess weight and dementia remains unclear but is thought to be related to the impact of excess weight on the vascular system. Being overweight or obese may result in narrowing of blood vessels within the brain that could obstruct blood flow which can damage the brain, which over time this could result in symptoms of dementia.

Adding to this, those with excess weight are also more likely to have a lower quality diet. One systematic review found that a healthy dietary pattern was associated with lower risk of dementia, irrespective of other factors such as gender.[17]

2.3.3 ALCOHOL

Alcohol-related 'dementia' is a type of alcohol-related brain damage which occurs after long-term, excessive alcohol consumption. The brain becomes damaged in many ways, either directly or indirectly. There may be shrinkage to the brain, and/or reduced blood supply to the brain which damages brain cells, or damage to nerves from alcohol or head injuries associated with alcohol use (e.g., falls or fights). At least 1 in 10 younger people with dementia may have alcohol-related brain damage.[18]

If a person has alcohol-related 'dementia' they will struggle with day-to-day tasks. This is because of the damage to their brain, caused by regularly drinking too much alcohol over many years. The person may experience memory loss and difficulty thinking things through. They may have problems with more complex tasks, such as managing their finances. The symptoms may cause problems with daily life. For example, the person may no longer be able to cook a meal.[19]

High levels of alcohol consumption (over 21 units per week) are associated with a 20% increase in rates of dementia. And it is estimated that at least 1 in 10 younger people with dementia may have alcohol-related brain damage.[14]

3. THE LEVEL OF NEED IN THE POPULATION

3.1 INCIDENCE AND PREVALENCE

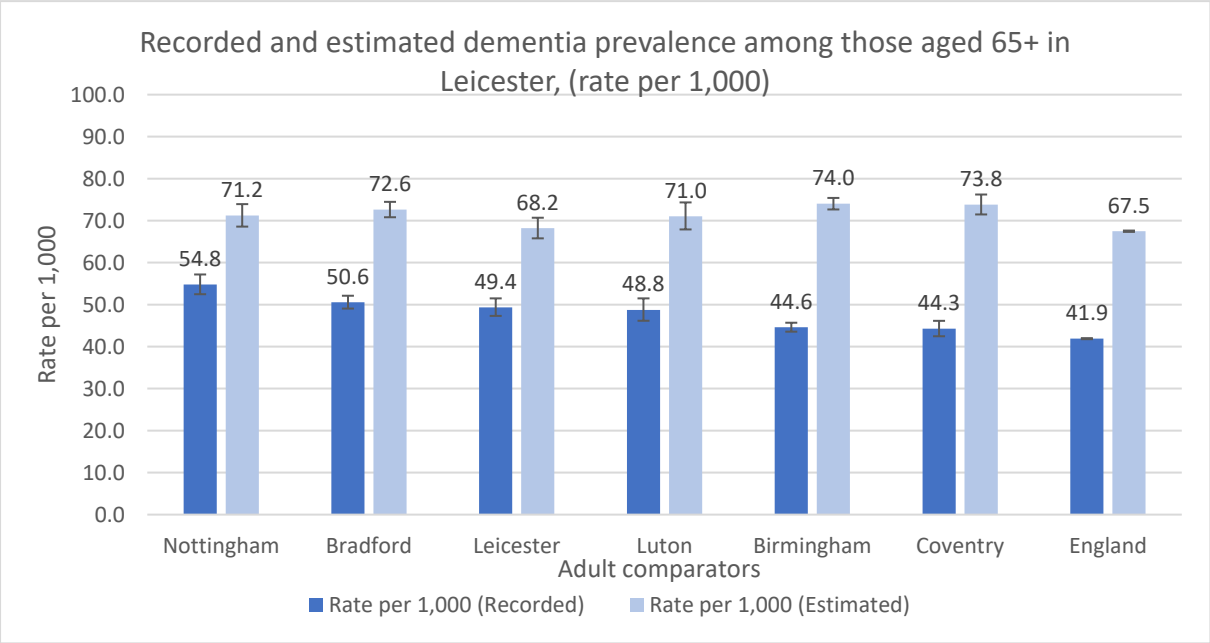
3.1.1 LOCAL PROFILE

The latest figures from NHS England reveal that 2,147 individuals aged 65+ in Leicester have a *recorded* diagnosis of dementia with a GP practice. When calculated as a rate, taking the local 65+ population size into consideration, this would suggest that around 50 people per 1,000 of the 65+ population have a recorded diagnosis of dementia with a GP.

However, the true number of people living with dementia in Leicester is *estimated* to be around 2,966. This considers both those with a recorded diagnosis and those without a diagnosis.[4] When calculating the *estimated* dementia prevalence rate this would suggest that around 70 people per 1,000 of the 65+ population have dementia in Leicester. This highlights the large number of dementia cases that remain undetected in the community.

When compared to Leicester's five adult comparators, Leicester has the third highest recorded dementia prevalence rate. On the other hand, Leicester has the se lowest estimated prevalence of dementia, which is likely related to the young age-structure of Leicester's population, as dementia mostly affects the older population (Figure 4).[1]

Figure 4. Recorded and estimated dementia prevalence among those aged 65+, rate per 1,000, August 2022

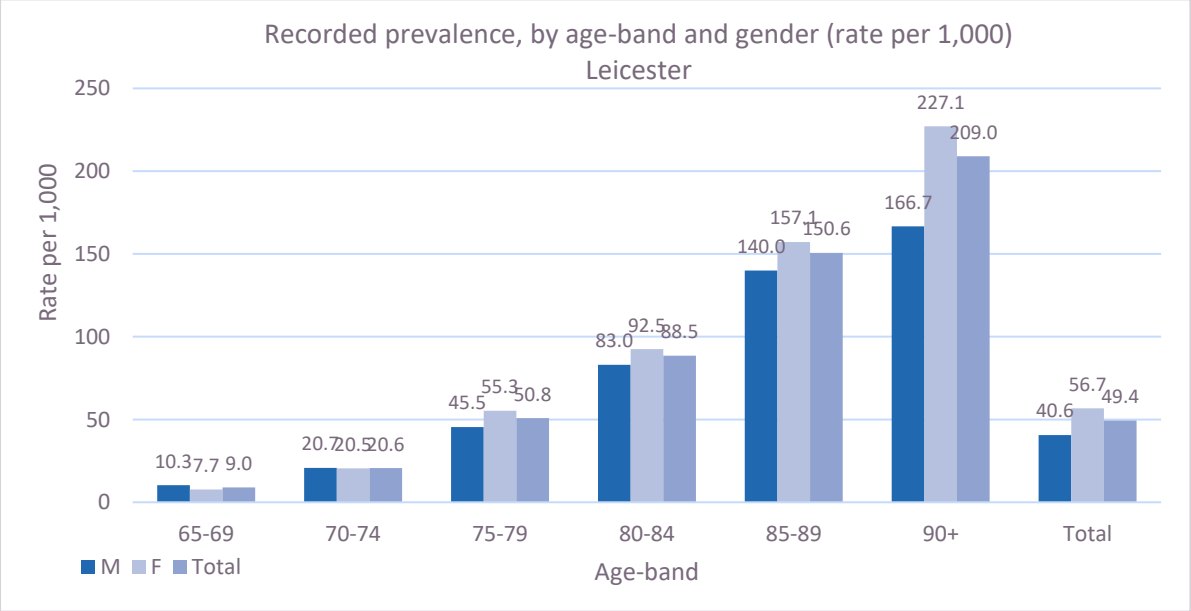


**Rate calculated using 2021 Census UTLA population estimates*

Source: NHS England

There is a slightly higher prevalence of dementia among females than males aged 65+. This is likely related to life expectancy, as a higher proportion of females live to an older age than males (Figure 5).[1]

Figure 5. Recorded prevalence: dementia diagnoses for Leicester by age-band and sex (rate per 1,000), August 2022



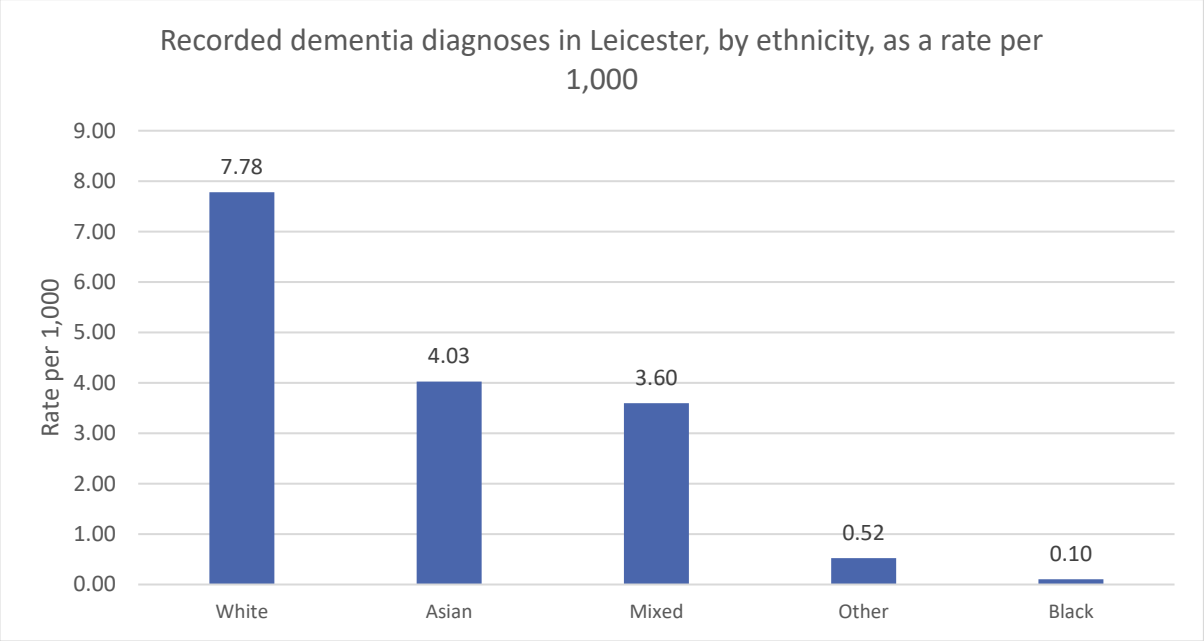
**Rate calculated using 2021 Census UTLA population estimates*

***Data not available for those <65 years*

Source: NHS England

When looking at recorded dementia diagnoses by ethnicity (all ages), those who are of White ethnicity make up around 6 in 10 (63%) of all cases in Leicester, and Asian make up around a third (34%) (see Figure 6 for rate of dementia diagnoses in Leicester by ethnicity). But it is important to note that this may not be a true reflection of dementia prevalence as these estimates are based on residents who have sought a diagnosis with a GP.[1]

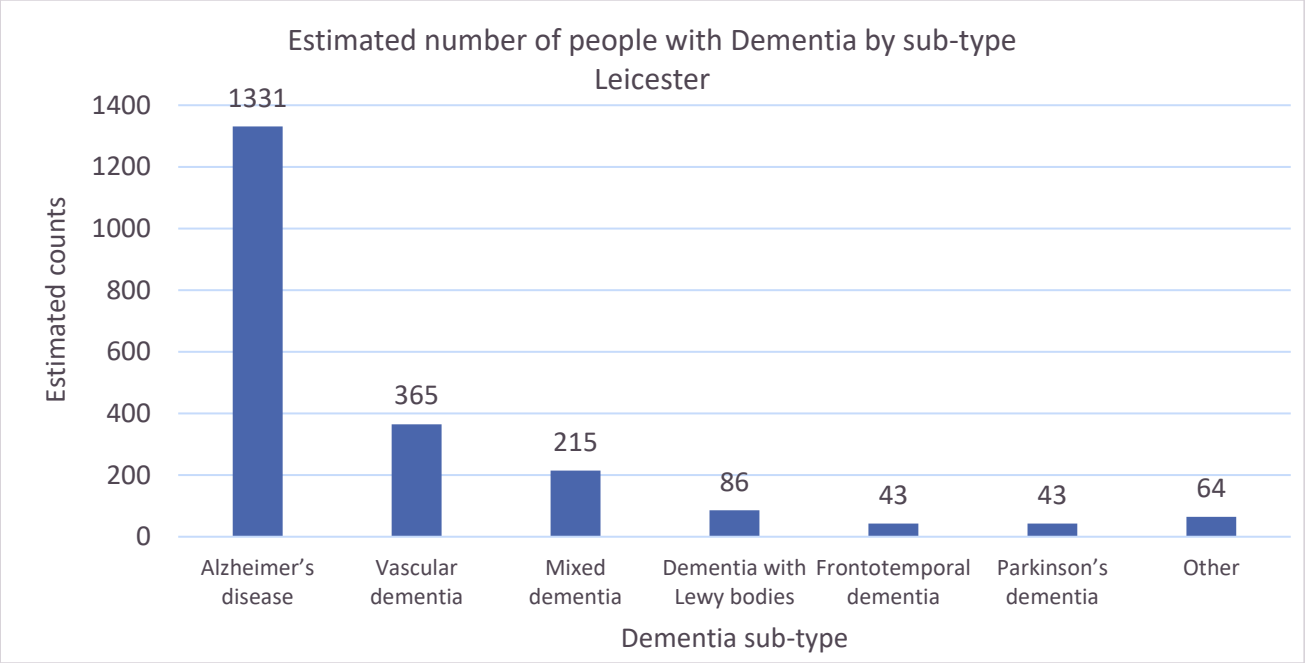
Figure 6. Recorded dementia diagnosis by ethnicity, rate per 1,000, August 2022



Source: NHS England; Census 2021 (population estimates by ethnicity)

Prevalence of different dementia subtypes varies according to gender and age. Figure 7 estimates the proportions of dementia subtypes in people aged 65+ in Leicester based on the recorded dementia figure of 2,147 for Leicester. Based on this figure, Alzheimer's and vascular dementia make up nearly 8 in 10 cases of dementia.[19]

Figure 7. Estimated number of dementia cases, by sub-type, based on recorded dementia diagnoses, 2022



Note: National findings applied to NHS England August 2022 recorded dementia estimates (65+) for Leicester

Source: Based on Alzheimer's Society, Dementia UK, 2014

When applying the national incidence rate to the local population, new cases of dementia increase with older age, as we would expect, with the greatest incidence rate among those aged 80+ years (Table 4).[20]

Table 4. Incidence of dementia (per year) as a rate per 1,000 in those aged 65+ in England and Wales, and estimated numbers for Leicester, 2022

	Incidence per 1,000 (per year)		Leicester estimates (counts)		
Age band	Female	Male	F	M	Total
65-69	4.6	5	33	35	67
70-74	6.4	8.7	37	48	85
75-79	16.1	16.7	64	55	120
80-84	39.6	24.8	127	57	184
85+	55.3	38	194	72	266
Total			**454**	**267**	**721**

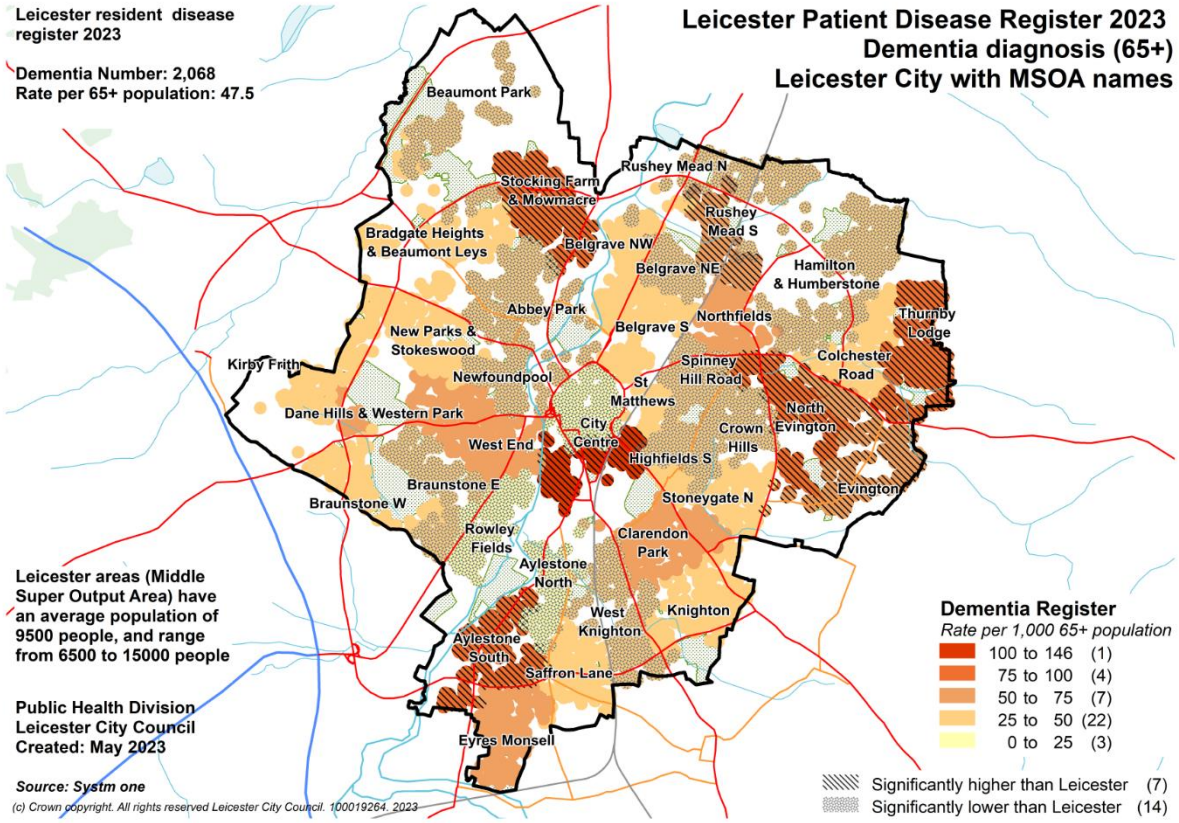
Note: National estimates applied to Leicester's population as per Census 2021

Source: Based on Cognitive Function and Ageing Studies (CFAS) Collaboration, 2016 applied to Leicester population 2021[20]

3.1.2 DIAGNOSIS RATE

As of 2023, there were 2,068 people aged 65+ registered to have dementia in Leicester, as a rate this is 47.5 per 1,000. Rates were generally highest in south of the city centre and east of the city, with significantly higher rates in Aylestone South, North Evington, Thurnby Lodge, Stocking Farm & Mowmacre (Figure 8).

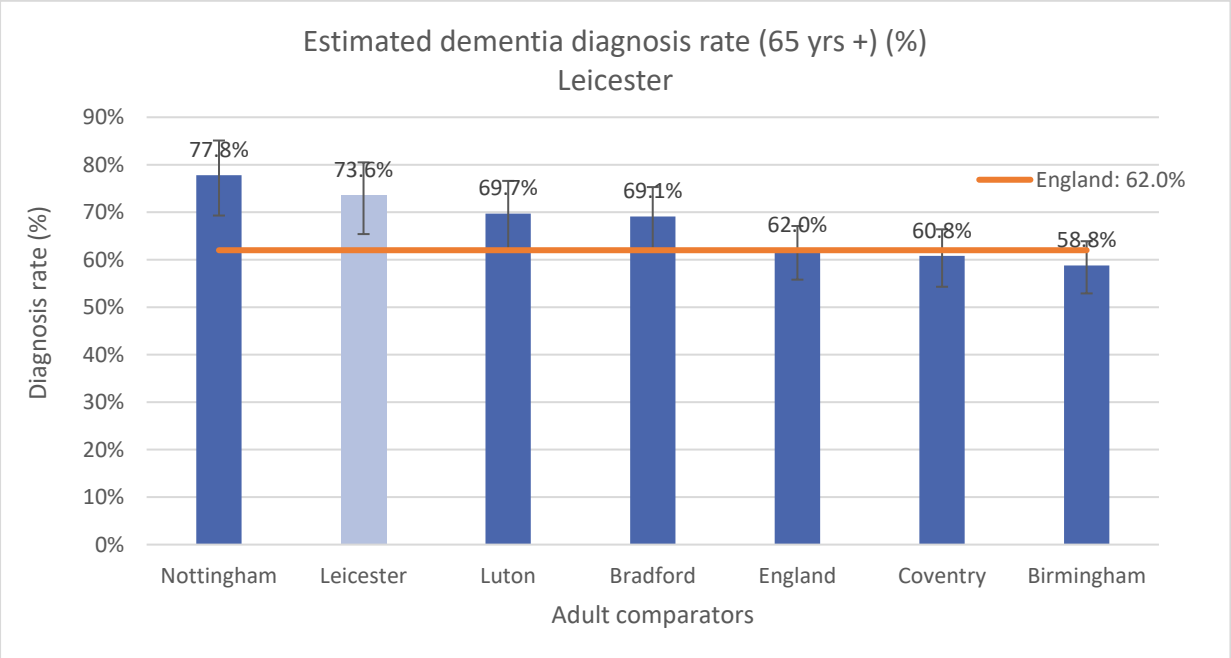
Figure 8. Percentage with a dementia diagnoses (65+), by MSOA, 2023



Source: Systm One

The diagnosis rate refers to the proportion of recorded diagnoses that are made, out of the total (estimated) number of people with dementia. As of 2022, the estimated dementia diagnosis rate for those aged 65+ in Leicester is around 74%, and the second highest when compared to comparators (Figure 9). This indicates that around three-quarters of those with dementia in Leicester have a recorded diagnosis, out of all estimated cases. The diagnosis rate for Leicester is higher than the national average.[21]

Figure 9. Estimated diagnosis rate among those aged 65+, 2022

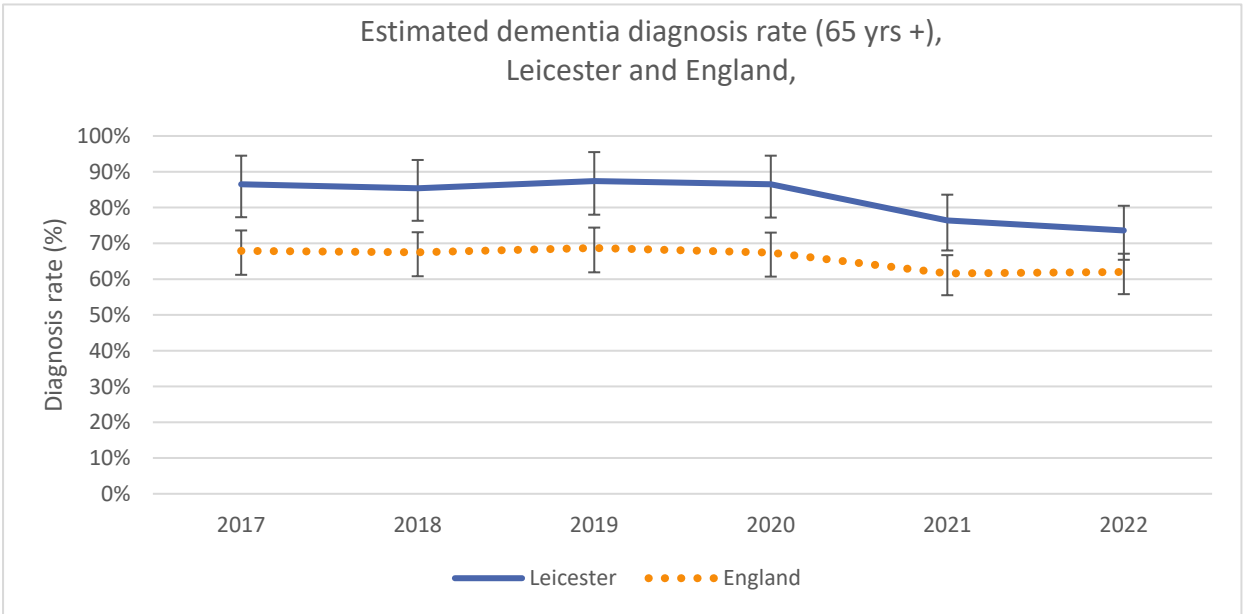


Note: Based on 2022 data (month unspecified); figures may not align exactly with August 2022 figures.

Source: NHS England

Figure 10 shows how the diagnosis rate began to fall during the pandemic (from 2020 onwards), likely due to fewer people visiting a GP during this time. This is true for both England overall, and Leicester. As restrictions have increasingly been eased, we would expect the diagnosis rate to return to pre-pandemic levels from 2023.

Figure 10. Estimated diagnosis rate, trend data, 2017-2022



Note: Based on 2022 data (month unspecified); figures may not align exactly with August 2022 figures.

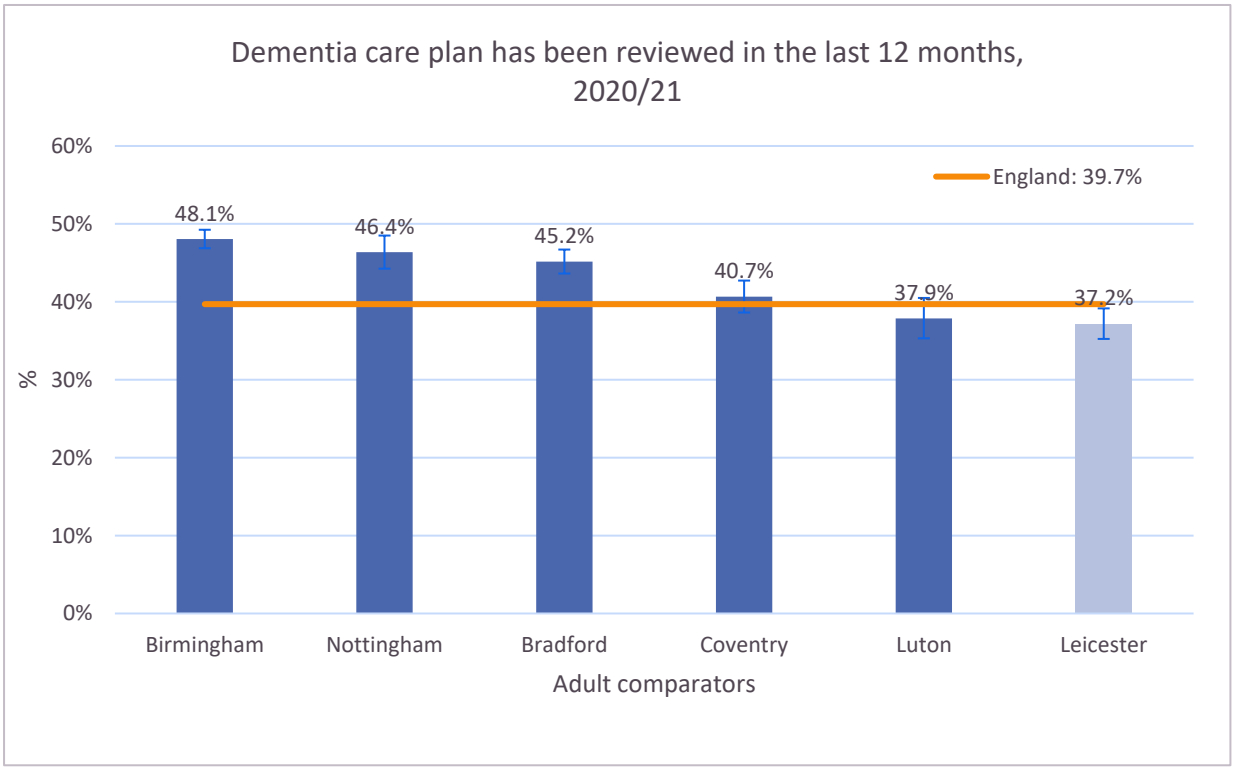
Source: Office for Health Improvement and Disparities, 2022

3.2 SUPPORT FOR PATIENTS

3.2.1 CARE PLAN

In 2020/21, just over a third (37%) of patients with a recorded dementia diagnosis had a face-to-face review with their GP in the last 12 months to discuss support needs of the patient and if applicable, of the care- giver. It is an important measure in place to help improve the quality of life for the patient and/or carer. When compared to comparators, Leicester had the lowest provision of review care plans and was below the national average, although this wasn't statistically significant (Figure 11).[22]

Figure 11. Dementia care plan has been reviewed in the last 12 months, 2020/21

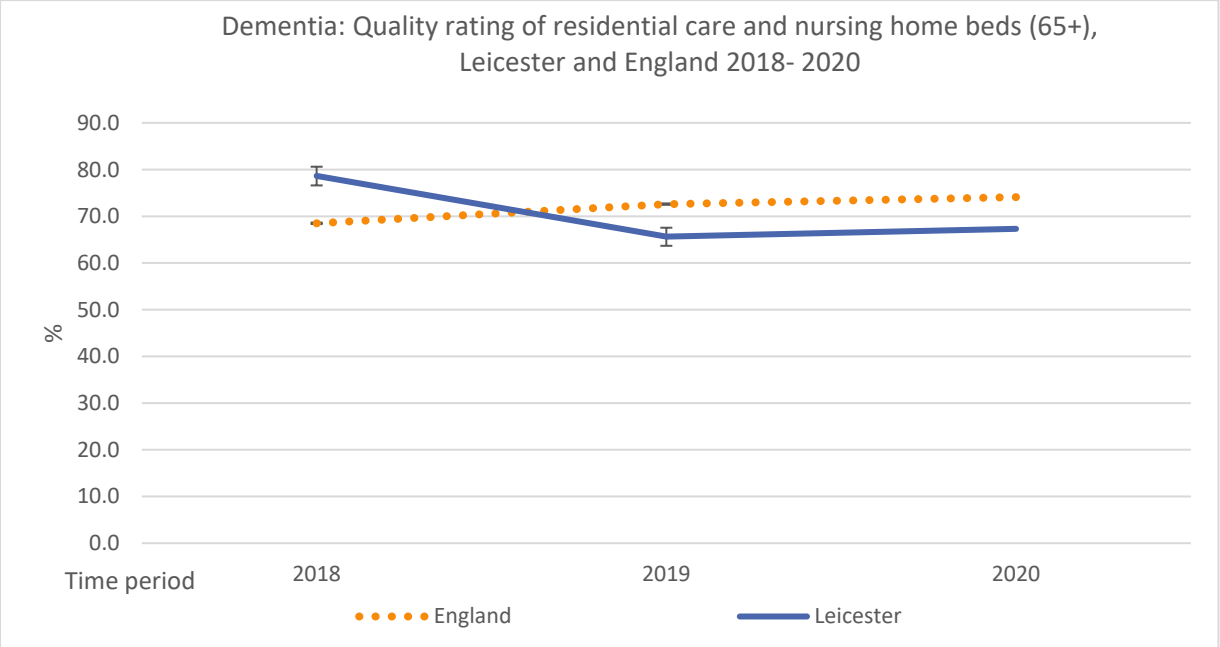


Source: Office for Health Improvement and Disparities, 2022

3.2.2 QUALITY OF CARE

The proportion of dementia patients in Leicester who have access to safe and high quality long-term care services- high quality residential care homes and nursing home beds - was around 67% in 2020 which is significantly below the national average. While locally we have seen declines since 2018, the quality has improved nationally (Figure 12).[23]

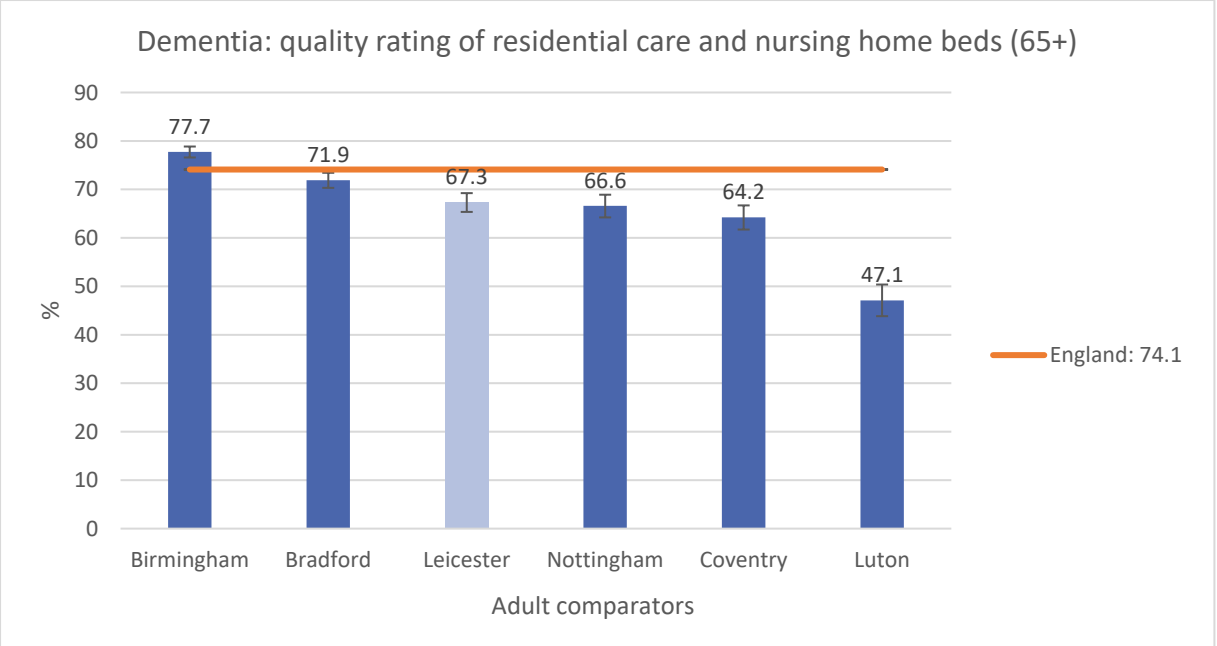
Figure 12. Quality rating of residential care and nursing home beds (aged 65+), Leicester and England, 2018- 2020



Source: Office for Health Improvement and Disparities, 2022

However, when compared to comparators, Leicester has the third highest quality of residential care and nursing home beds (Figure 13).

Figure 13. Quality rating of residential care and nursing home beds (65+) Leicester, 2020



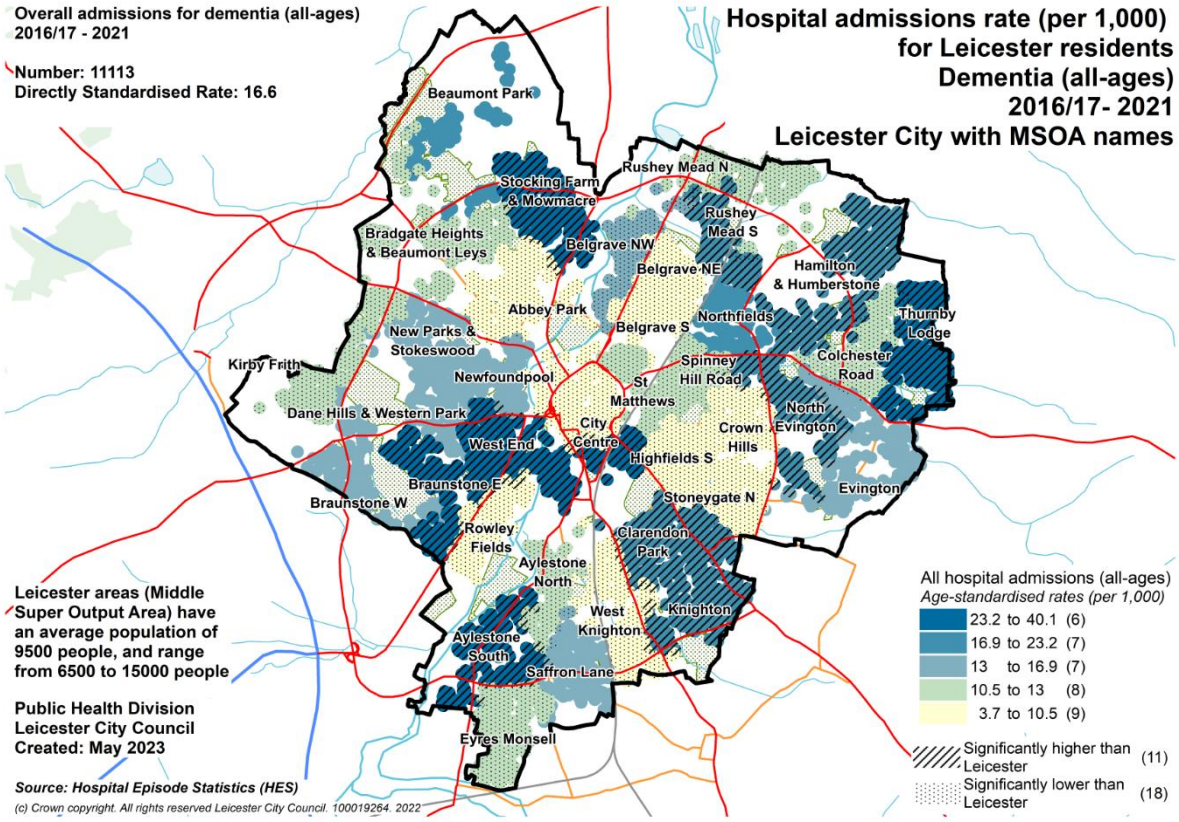
Source: Office for Health Improvement and Disparities, 2022

3.3 HOSPITAL ADMISSIONS

Between the time period 2016/17 and 2021, there were 11,113 hospital admissions for dementia (all-ages) in Leicester. As an age-standardised rate*, this is 16.6 per 1,000. Stocking Farm & Mowmacre, Thurnby Lodge, West End, Braunstone East and Aylestone South all had significantly higher rates of hospital admissions for dementia (Figure 14).

* *Age-standardisation is a method used to adjust for differences in age structures of populations so that they can be compared against other areas*

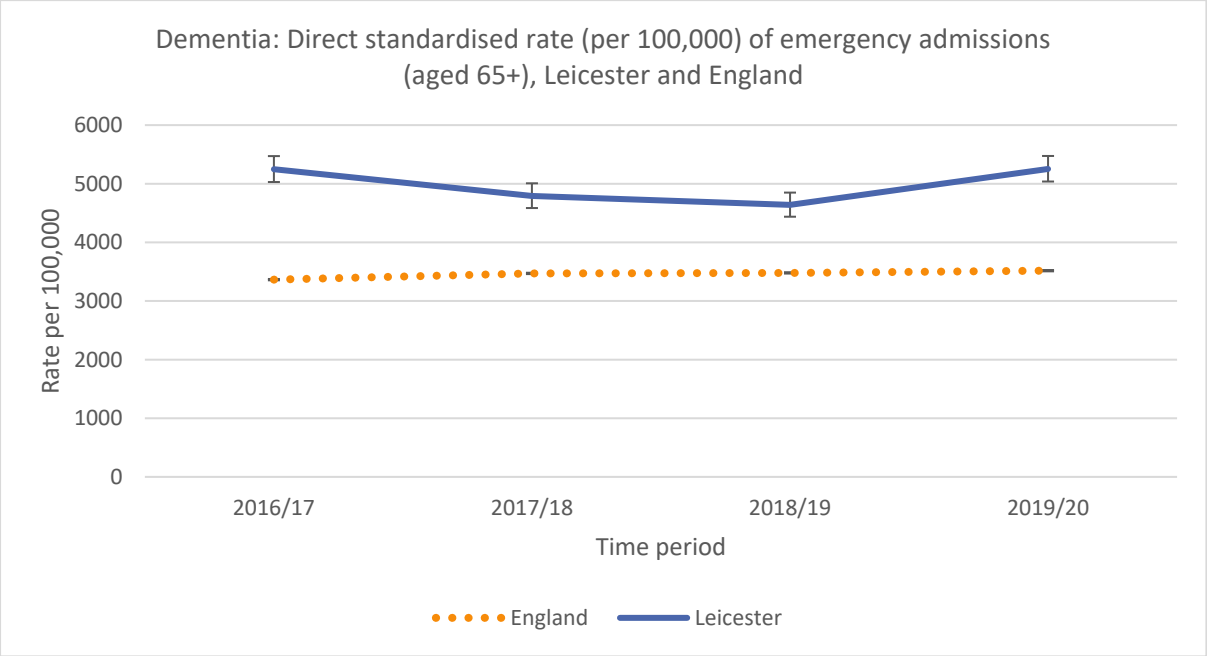
Figure 14. Directly standardised rate of hospital admissions (all-ages), by MSOA, 2016/17-2021



Source: Hospital Episode Statistics (HES)

Leicester has a significantly higher rate of emergency inpatient hospital admissions among those aged 65+ with dementia or Alzheimer's in the diagnosis code compared to the national average, with 5,253 admissions per 100,000 in 2019/20. The rate has remained relatively unchanged since 2016/17 (Figure 15).[24]

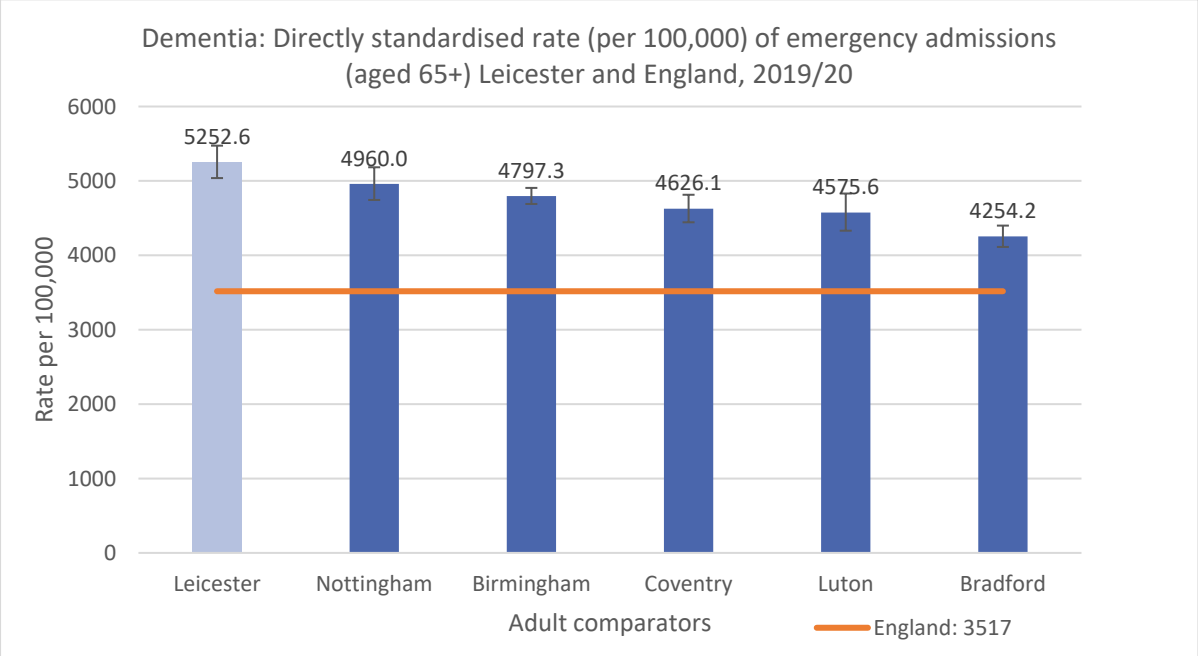
Figure 15. Dementia: Directly standardised rate of emergency admissions (65+), rate per 100,000, Leicester and England, 2016/17-2019/20



Source: Office for Health Improvement and Disparities, *fingertips.phe.org.uk*

Compared to its adult comparators, Leicester also has the highest directly standardised rate of emergency admissions per 100,000 (Figure 16).

Figure 16. Dementia: Directly standardised rate of emergency hospital admissions (65+), Leicester and England, 2019/20

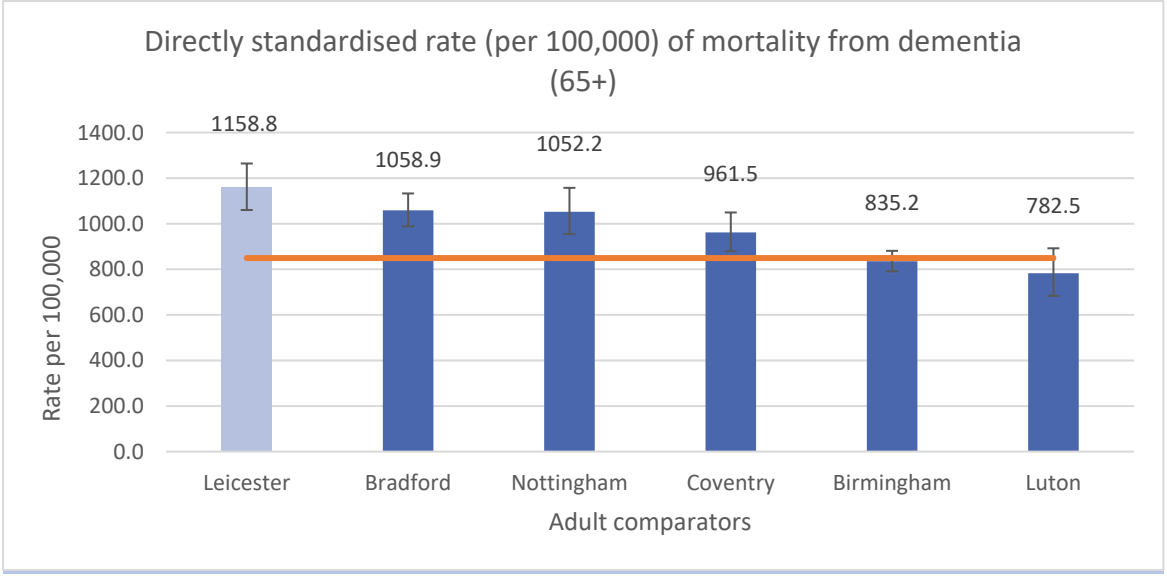


Source: Office for Health Improvement and Disparities, *fingertips.phe.org.uk*

3.4 MORTALITY

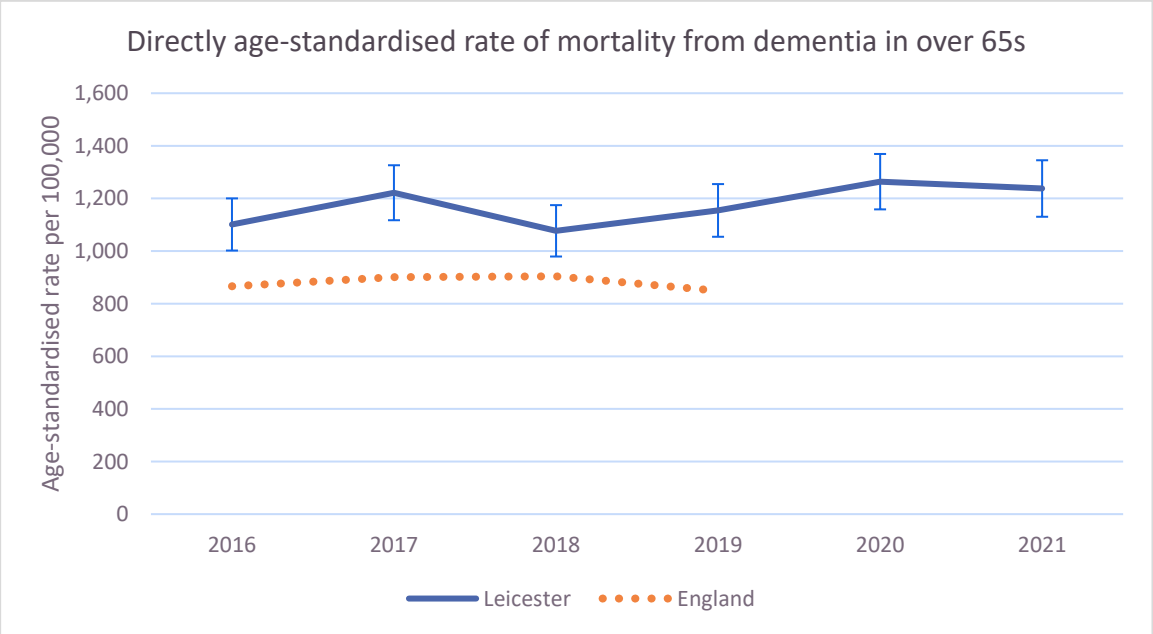
In 2019, Leicester had the highest mortality rate among those aged 65+ per 100,000 for dementia among comparators and was significantly higher than the national rate (Figure 17).[25] Interestingly, the mortality rate doesn't appear to be related to estimated diagnosis rate (Figure 10), with comparators which have a lower diagnosis rate not showing higher mortality rates.

Figure 17. Directly standardised rate of mortality from dementia (65+), 2019



Source: Office for Health Improvement and Disparities, *fingertips.phe.org.uk*

Figure 18. Directly standardised rate of mortality from dementia (65+), 2016-2019



Source: Office for Health Improvement and Disparities, *fingertips.phe.org.uk, ONS mortality data*

The rate of mortality among those aged 65+ with dementia has been significantly higher than the national rate for many years. While the national rate has been consistent, there has been some fluctuation in the mortality rate in Leicester (Figure 18)
Mortality data for dementia is currently only published to 2019. Local data shows that there was a higher rate of deaths where dementia was mentioned on the death certificate during 2020 and 2021. This represents 558 and 513 deaths involving dementia in 2020 and 2021 respectively.

4. CURRENT SERVICES IN RELATION TO NEED

Service design is guided by the National Dementia Strategy Living Well with Dementia, which sets out a vision for health and social care in which people living with dementia and their carers will have improved access to support.[26] The Prime Minister Challenge on Dementia in 2015 included ambitions reforms to be achieved by 2020.[27] Our dementia services are guided by principles developed by NHS England in their 'Well Pathway for Dementia'[28] and has responded to these ambitions. Key guiding principles for service design include:

- Preventing well
- Diagnosing well
- Supporting well
- Living well
- Dying well

While nearly 75% of those predicted to have dementia in Leicester are thought to have a diagnosis and this is above the national target for 66% of people living with dementia to have a diagnosis, this rate has fallen from 2020 when rates of predicted diagnoses was over 85%. Between 2020 and 2021 there was a fall in national (England) estimated diagnosis rates, but this fall was much smaller – from 67% to 62%. Leicester was disproportionately impacted during the pandemic as a city of 'enduring transmission' with restrictions locally being more extensive and more prolonged than other areas of the country. This alongside Leicester's diverse population that is equally challenged by high levels of deprivation could explain why there were more acute changes in diagnoses rates alongside the digital transformation of primary care.

We commission a Dementia Support Service on behalf of partners to provide post diagnostic support to people living with dementia and respite for their carers. The support is provided to adults aged 18+ who reside in Leicester City and Leicestershire. The key aim of this outcome-based service is to support people with a diagnosis of dementia to live well, maintain their independence, promote a strengths-based approach and support people to be self-managing and plan well for the future. The service is person-centred, culturally appropriate and inclusive. The service has a dedicated team of staff, volunteers and a co-production group including people affected by dementia, who have all contributed to shaping and developing

its various elements. This includes specific post diagnosis information and advice sessions, 1-2-1 carer learning sessions and/or group support. Many social groups developed have been launched with the view of offering a wide variety of activities to support people to live well with their dementia, including walking, music, gardening and woodwork groups as well as cognitive stimulation therapy.

Several services in Leicester exist for people living with dementia and their carers. This includes:

- Memory assessment
- Secondary care at University Hospitals Leicester and Leicestershire Partnership Trust
- Primary and Community health and social care services
- Local nursing and residential care.

Commissioning of services have had a longstanding focus on the patient journey, from diagnosing people earlier with dementia to end of life care. Current services are under significant pressure, reflecting a combination of pre-pandemic service pressures worsening during and after the pandemic.

5. PROJECTED SERVICES USE AND OUTCOMES IN 3-5 YEARS AND 5-10 YEARS

5.1 YOUNG-ONSET DEMENTIA

The table below shows that the projected number of males and females with early onset dementia is forecast to not change between 2020 and 2040.

Table 5: Projecting Adults Needs and Service Information System, 2020 [29]

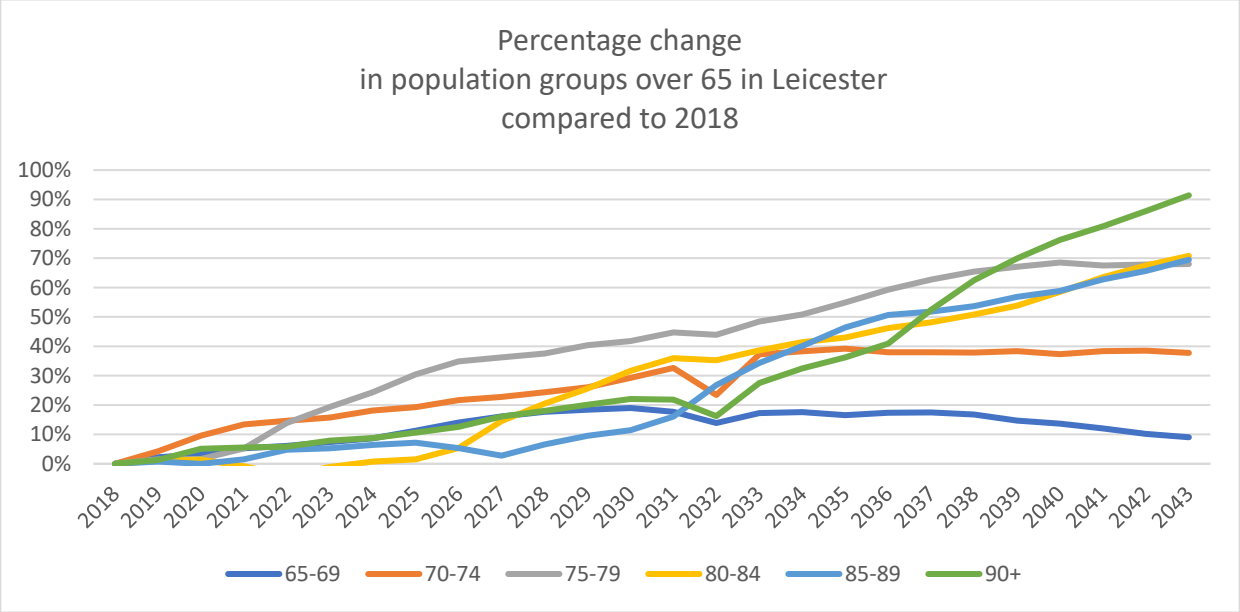
	2020	2025	2030	2035	2040
Males aged 30-39	2	2	2	2	2
Males aged 40-49	4	4	4	4	5
Males aged 50-59	23	22	22	22	22
Males aged 60-64	16	17	17	17	17
Total males aged 30-64	**45**	**45**	**44**	**44**	**45**
Females aged 30-39	2	2	2	2	2
Females aged 40-49	5	5	5	5	5
Females aged 50-59	14	14	14	14	14
Females aged 60-64	10	10	10	10	9
Total females aged 30-64	**31**	**31**	**30**	**30**	**30**
Total all aged 30-64	**76**	**76**	**74**	**74**	**75**

Source: Projecting Older People Population Information System, www.poppi.org.uk, 2020 [30]

5.2 DEMENTIA IN OVER 65S

The number of people aged over 65 in Leicester is estimated to increase from 42,300 in 2016 to 60,900 in 2043. This is a 44% increase. The largest population rises are projected to be from the 75-79 age group and the 80-84 age group that will increase by 4,900 and 4,000 respectively. Figure 19 below shows the percentage changes in population since 2019. The numbers of people over 90 are expected to increase by 90% by 2043.

Figure 19: Projection of population over 65 in Leicester, 2018 – 2043[30]



Source: Projecting Older People Population Information System, www.poppi.org.uk, 2020 [30]

Increasing age is one of the key risk factors for developing dementia. The rise in Leicester's older population will increase rates of dementia locally. The total number of people over 65 with dementia is forecast to rise from 3,000 in 2020 to 6,700 by 2040.

Table 6: Projected number of people living with dementia, among those aged 65+, 2020 - 2040

Age band	2020	2025	2030	2035	2040
65-69	226	245	261	256	249
70-74	338	369	399	430	424
75-79	444	569	616	677	735
80-84	645	654	842	906	1007
85-89	676	711	742	974	1044
90+	731	766	849	943	1214
All 65+	**3060**	**3313**	**3708**	**4185**	**4673**

Source: Projecting Older People Population Information System, www.poppi.org.uk, 2020 [30]

Population projections – people living alone and in care homes within Leicester.

Those who live alone are at higher risk of developing dementia. In people with dementia who live alone co-ordinated care is required to improve their quality of life, avoiding earlier need for nursing, residential care, or hospitalisation. Around 14,000 people over 65 live alone in Leicester, with an expected increase to around 20,000 by 2040, an increase of 41%. There are nearly two times as many females over the age of 65 as males who are living alone in Leicester care homes. These projections illustrate that the need for improved care within institutional settings, alongside improved quality of life will grow in importance over time.[30]

Table 7: People aged 65 and over living alone in Leicester, 2020 to 2040[30]

Age and Gender	2020	2025	2030	2035	2040
Males aged 65-74	2440	2640	2840	2920	2860
Males aged 75 and over	2291	2726	3132	3596	4031
Females aged 65-74	3654	3973	4263	4350	4263
Females aged 75 and over	5650	6200	6950	7750	8600
Total aged 65-74	**6094**	**6613**	**7103**	**7270**	**7123**
Total aged 75 and over	**7941**	**8926**	**10082**	**11346**	**12631**

Source: Projecting Older People Population Information System, www.poppi.org.uk, 2020 [30]

The need for excellent care and provision in institutional settings for people living with dementia will only rise over time. Additionally, drug monitoring and quality of life for people living with dementia in these settings will also become more important in the future.

6. UNMET NEEDS AND SERVICE GAPS

6.1 PERCEIVED NEEDS – PROFESSIONAL & STAKEHOLDER

Dementia Programme board partners were invited to discuss perceived unmet needs and service gaps for people living with dementia in Leicester. Stakeholders welcomed the leadership and strategic oversight of the Dementia Programme Board and expressed the opinion that future initiatives should build on current progress in dementia care. The following is a summary of the stakeholder feedback.

Referrals into pathway

There was some discussion of the appropriateness of referrals for memory assessment for the young onset memory assessment clinic from primary and secondary care. There's an increasing trend towards Memory Assessment being the first point of contact within secondary care. An in-depth review of the existing pathway was suggested to see what new changes or approaches could be used to make the pathway work better.

Diagnosis

Memory assessment service currently focuses on diagnosis, management, and discharge of patients with people with dementia. There was an appreciation that the current diagnostic services provided in the city are facing challenges of high demand and long waiting lists, with vacancies for memory assessment posts exacerbating this issue.

As to the problems gaining diagnosis, there are issues around waiting times and cultural appropriateness of diagnostic tools.

The current dementia pathway involves clinicians completing a referral to the memory assessment service. This includes information on referral criteria. The initial outcome is that the person is placed on a waiting list for specialist assessment. This means that the waiting list comprises people who don't need memory assessment and people with undiagnosed dementia waiting longer for diagnosis and care. These issues are complicated by the requirement for radiological confirmation of diagnosis, which adds to a person's waiting time.

National guidelines support diagnostic tools for dementia that require English as a first language and are not specific for young onset dementia, and use of the GP-COG tool alone would miss up to half of people with dementia in Leicester.

Post diagnosis

Post diagnostic support is complicated by the impact on an individual's life and everyone's experience is unique.

There's concern that existing support services are not accessible to people with dementia and young onset dementia. Access to services can depend on whether professionals are aware of available support and barriers in communication between service providers, users and other professionals.

Clinicians express concern and distress from an inability to support people with dementia and their close or loved ones. The smallest challenges can have a big impact. This includes issues such as ways of making it easier to care for people with dementia, such as flexible working, respite care, appointments at quieter moments, home adjustments.

Support

A gap in awareness of post diagnosis support services offered by Age UK and memory assessment stakeholders involved in this engagement exercise was noted.

6.2 FELT NEEDS – MEMORY CAFÉ ENGAGEMENT

A number of semi-structured 1:1 interviews at memory cafés ran by AgeUK was performed, directly asking questions to people living with dementia and their carers attending. Approximately 20 service users were present across the three cafés with a range of interviewing registrars involved in discussions. An additional focus group from members running memory cafés was performed to capture their perceived needs to reflect the breadth of experiences across cafes. The findings below integrate both perspectives into core themes.

Finding Support

- A key theme expressed by carers and people with dementia was the feeling of need to take initiative as an individual to seek support services more broadly, with limited sharing of support services from clinicians.
- Memory clinic referrals were often the predominant source of information about Age UK services.
- Multiple users reported requiring to 'learn the system' or specifically know what they needed to ask for in terms of support which can feel like an uphill struggle specifically noted for City council.
- Some reported that it feels like you need to fight for services.

Support on offer

- Some carers mentioned the long waits to receive diagnosis.
- It was noted that a large amount of information being provided from multiple providers can be overwhelming for carers.
- Speaking and meeting other carers is especially helpful to discuss and share learning and experiences.
- It can be the smaller challenges in everyday life that are difficult rather than more larger problems; and as they build up it can be more challenging.
- Support needs are unique to the individual and that can be hard to cater for.
- A broader level of support (and respite) was requested by carers and expressed by service providers.

    Many described feeling "burnt out".

    Respite can be hard to arrange or costly, with transport issues.

    Lack of YOD specific offer

- Many expressed a desire for more memory cafes, in more locations, at a range of times and particularly voiced concerns about transport. Many expressed that transport solutions to be provided to those that don't drive or for areas that have poor public transport links.

- Some mentioned a benefit of healthcare professional attendance at some cafes to support discussions that would otherwise result in requests for dedicated appointments (e.g. behaviour changes)
- Young onset dementia support services are limited – with a predominance targeted to people with dementia over 65- this can limit engagement where otherwise able to use services.
- Experience reflects that when dementia is diagnosed, no post diagnostic support is provided.
- Cognitive behavioural therapy groups ran for carers have been positively received where provided. Peer group would likely also be positively received.

7. RECOMMENDATIONS FOR CONSIDERATION BY COMMISSIONERS

Commissioners are recommended to consider the recommendations below:

Diagnosis

- Improve knowledge and uptake of wider support services available for people living with dementia in Leicester.
- Foster shared learning between memory assessment and primary care, exploring localised diagnostic pathways.
- Ensure memory assessment services serve to provide support in diagnosing dementia where there is significant complexity and uncertainty including atypical and young onset dementia.
- Improved diagnostic tools utilised within Primary Care so clinicians can confidently diagnose clear cut cases of dementia and refer only cases where they are uncertain for memory assessment.
- Improve awareness of people living with dementia and their carers of centralised offers available for carers such as carers entitlements and respite services.
- Explore introducing specialised dementia GPs to provide more localised support with dementia diagnosis.
- Improved understanding within our local population of risks factors for developing dementia.

Post- diagnosis

- Develop streams of shared learning and communication between memory assessment services and broader primary care providers.
- Tailor local support considering cultural and gender-specific needs.
- Improve clinical awareness of wider support services available for people living with dementia in Leicester.
- Educate on home adjustments for dementia-related independence.

- Improve outreach to under-represented communities for dementia support.
- Promote dementia-friendly communications locally.
- Expand local community activities for people with cognitive impairment awaiting memory assessment review, such as drop-in sessions ran at neighbourhood centres, with primary care being aware of these services to signpost patients after their initial review and referral.
- Expand awareness of local support networks, e.g. Age UK.
- Improve understanding and provide early support for people living with dementia and their carers to consider applying for lasting power of attorneys to enable trusted loved ones to make decisions on behalf of people living with dementia if they lose mental capacity.
- Increase availability of home adjustments and monitoring tools.
- Improve access to nursing and residential care for people living with dementia.
- Implement comprehensive training for dementia support at all levels.

8. KEY CONTACTS

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