LEICESTERSHIRE JOINT STRATEGIC NEEDS ASSESSMENT 2018-2021

DEMENTIA

February 2022

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FOREWORD

The purpose of the Joint Strategic Needs Assessment (JSNA) is:

- To improve the health and wellbeing of the local community and reduce inequalities for all ages.
- To determine what actions the local authority, the local National Health Service (NHS) and other partners need to take to meet health and social care needs, and to address the wider determinants that impact on health and wellbeing.
- To provide a source of relevant reference to the Local Authority, Clinical Commissioning Groups (CCGs) and NHS England for the commissioning of any future services.

The Local Authority and CCGs have equal and joint statutory responsibility to prepare a JSNA for Leicestershire, through the Health and Wellbeing Board. The Health and Social Care Act 2012 amended the Local Government and Public Involvement in Health Act 2007 to introduce duties and powers for Health and Wellbeing Boards in relation to JSNAs. The JSNA offers an opportunity for the Local Authority, CCGs and NHS England's plans for commissioning services to be informed by up to date information on the population that use their services. Where commissioning plans are not in line with the JSNA, the Local Authority, CCGs and NHS England must be able to explain why.

The Health and Wellbeing Board has agreed that the JSNA will be published in subject-specific chapters throughout a three-year time period. Chapters will be developed in line with CCG and local authority commissioning cycles. As many of the relationships required for the JSNA in Leicestershire are wide ranging, involving representation from NHS England, CCGs, Leicestershire Partnership Trust, University Hospitals of Leicester, District Councils and the voluntary sector, a Reference Group has been established. This Reference Group supports the JSNA work across the Health and Wellbeing Board. To examine the detail of the chapters, Task and Finish groups have been established to bring together local professionals, where they can share their expert knowledge on the work area being examined.

The outputs of the JSNA will include:

1. Subject-specific chapters providing an assessment of current and future health and social care needs

2. An online infographic summary of each chapter available on the internet

3. An online data dashboard that is updated on a quarterly basis to allow users to self-serve high level data requests

Please note, the majority of indicators presented in this needs assessment are from national sources so are subject to a time lag due to the time required for data collection, data analysis and publication. Where possible, comparisons have been made to national averages and local context has been included. The term significance is used throughout the report and refers to statistical significance. This examines if the result presented is different to the national result, due to something other than chance. Most often, this is calculated using 95% confidence intervals.

EXECUTIVE SUMMARY

This JSNA chapter considers the data, current services and policy and best practice in relation to dementia in Leicestershire.

Unmet needs and 'gaps' are identified, and recommendations developed, in line with the categories of: Prevention, diagnosis, supporting, living well, and dying well.

Dementia is a growing challenge. As the population ages and people live longer, it has become one of the most important health and care issues facing the world. In the whole of the UK, the number of people with dementia is estimated at 850,000.[1]

The QOF prevalence of dementia (all ages) in Leicestershire is 0.8% (2020/21). This recorded prevalence provides an indication of the concentration of people within the local population who have been diagnosed and are now living with the condition.

It is estimated that, in Leicestershire, the population over 65 will increase by 43.2% between 2020 and 2040. Projected estimates indicate that the population over 65, with dementia, is set to increase by 64.5% over the same time period.

Dementia – Unmet Needs/Gaps

The following unmet needs/gaps were identified:

Prevention – There is increasing awareness of the role of prevention in addressing dementia, particularly vascular dementia. More could be done to raise awareness of the links between lifestyle behaviours and dementia.

Diagnosis – Research suggests that timely diagnosis of dementia is important to enable the initiation of appropriate treatment. Government aspirations to ensure that there is a 6 week average wait between referral from GP to initial assessment and starting treatment, have not been met in Leicestershire. In addition, the estimated dementia diagnosis rate in 2021 (up to March), in the 65 plus population, was 61.2%, significantly lower than the benchmarking NHSE goal of 67%. Where care plans were in place, for the last three time periods, significantly fewer dementia patients and their carers had received a review in the last 12 months when compared to the national average.

Supporting – The guidance reinforces the importance of having support services in place for individuals suffering from dementia and their carers. Whilst there are a number of support services in place, there was variation in service availability across County, this included Admiral nursing services which provide support to carers and family members, as well as those directly affected.

Living Well – Gaps identified included: Accommodation for those with complex needs, and quality

of nursing and residential care which has declined to below the national average. The impact of COVID-19 was also highlighted, particularly the effect of lack of social contact and connectivity on those suffering with dementia, and the need to mitigate this and learn lessons.

Dying Well – Having early conversations with those affected by dementia, about future planning, including dying well, was perceived to be a 'gap.' This also flagged up a related need for workforce training including staff in adult social care, primary and secondary care services.

Other – There was recognition of the importance of raising awareness of the level of need where the rate of dementia is higher, such as those with Down's syndrome. Also gaps in strategic leadership, awareness and knowledge in specific groups affected by dementia including: People with learning difficulties, younger people, Veterans, those in prison and BME communities.

Based on above identified unmet needs/gaps, a set of recommendations have been developed in relation to Dementia with the aim of preventing this condition, where possible, and improving help, support, and quality of life for people affected by Dementia in Leicestershire.

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1. Introduction

Dementia is a term that is used to describe a group of progressive neurological disorders, that is conditions affecting the brain.[5] This may include memory loss and difficulties with thinking, problem solving or language.[3] There are many different types of Dementia, the most common subtypes of Dementia are:[2,3]

- **Alzheimer's disease** – is the most common cause of dementia making up two thirds of dementia cases. Alzheimer's disease occurs when the connections between nerve cells in the brain are lost. This is due to proteins that build up and form abnormal structures called 'plaques' and 'tangles'. Eventually the nerve cells die, and brain tissue is lost.
- **Vascular dementia** – is the second most common type of dementia making up 20% of dementia cases. Vascular dementia is caused by reduced blood supply to the brain, due to diseased blood vessels.
- **Dementia with Lewy bodies (DLB)** – is a type of dementia that shares symptoms with both Alzheimer's and Parkinson's disease. DLB accounts for 10 to 15 percent of all cases of dementia. Lewy Bodies are tiny deposits of a protein that appear in the nerve cells of the brain.
- **Frontotemporal dementia (FTD)** – is one of the less common types of dementia making up less than 5% of cases. FTD occurs when the frontal lobes of the brain are damaged. The frontal lobes of the brain deal with behaviour, problem-solving, planning and the control of emotions.

Dementia is a growing challenge. As the population ages and people live for longer, it has become one of the most important health and care issues facing the world. In England it is estimated that around 676,000 people have dementia. In the whole of the UK, the number of people with dementia is estimated at 850,000.[1]

2. Who is at risk?

Minimising those at risk of developing dementia fits within the first part of the well pathway for dementia, preventing well. Whilst demographic factors cannot be changed, risk factors and protective factors can be used to decrease the likelihood of dementia.

2.1. Demographics

2.1.1. Age

Age is the strongest known risk factor for dementia. Whilst it is possible to develop the condition earlier - at least 1 in 20 people with dementia developed it at age under 65 - the chances of developing dementia rise significantly as we get older. Above the age of 65, a person's risk of developing Alzheimer's disease or vascular dementia doubles roughly every 5 years. It is estimated that dementia affects one in 14 people aged over 65 and affects one in six people aged over 80.[3] Table 1 below shows the current population in Leicestershire aged 65 and over and the projected increase until 2040. There is a predicted increase of 43.2% in over 65-year-olds and an 84.7% increase in over 85-year-olds in Leicestershire from 2020 to 2040.

Table 1: Current and projected population for Leicestershire in over 65's and over 85's, 2020-2040

	2020	2025	2030	2035	2040	% Change 2020 to 2040
Total population 65 and over	147,600	162,600	182,100	199,800	211,300	43.2%
Total population 85 and over	19,000	21,400	25,600	32,700	35,100	84.7%

Source: Projecting Older Peoples Populations Information, (POPPI), 2021

2.1.2. Gender

More women are affected by dementia than men. Worldwide, women with dementia outnumber men two to one. In mid-2020 Leicestershire was estimated to have 78,620 females and 68,055 males[4]. Twice as many women over the age of 65 are diagnosed with Alzheimer's than men whereas vascular dementia is diagnosed in slightly more men than women.[5] Women are more likely to develop Alzheimer's disease than men. This is the case even if we allow for the fact that women on average live longer. The reasons for this are still unclear. It has been suggested that Alzheimer's disease in women is linked to a lack of the hormone oestrogen after the menopause. However, controlled trials of hormone replacement therapy (HRT, which replaces female hormones) have not been shown to reduce the risk of developing Alzheimer's. The age at which HRT is started, however, may affect the outcome. HRT (prescribed mainly to help with symptoms of the menopause) is not recommended as a way for women to help reduce their risk of dementia.[3]

2.1.3. BAME

Studies have found that Black, Asian and Minority Ethnic communities are at greater risk of developing dementia. In 2010, a study found a significantly higher prevalence in African Caribbean people compared to the White British group.[6] A study by Adelman et al in 2018 found the prevalence of dementia in African Caribbean people was higher than in White people and onset at almost 8 years younger.[7] It is thought that some of this increased risk of dementia is due to increased risk of diabetes and cardiovascular diseases, including hypertension in Black and South Asian populations as these are risk factors for dementia. For example, a study in 1997 found the prevalence of adult Type 2 diabetes is about three to five times greater in African-Caribbean and South Asian people respectively compared with the White European population.[8] According to the 2011 census 11.1% of the Leicestershire population are from BAME ethnicities, when applied to the mid 2019 population this would equate to around 78,383 people.

2.1.4. LGBTQ

Lesbian, gay, bisexual, and transgender (LGBT) older adults comprise a unique and growing subset of the aging population. The historical context in which they came of age was imbued with victimization and discrimination. These experiences are subjectively stressful and collectively known as minority stress. This stress can lead to LGBT health disparities, including cardiovascular disease and depression, conditions that in turn increase risk for premature cognitive decline.[9]

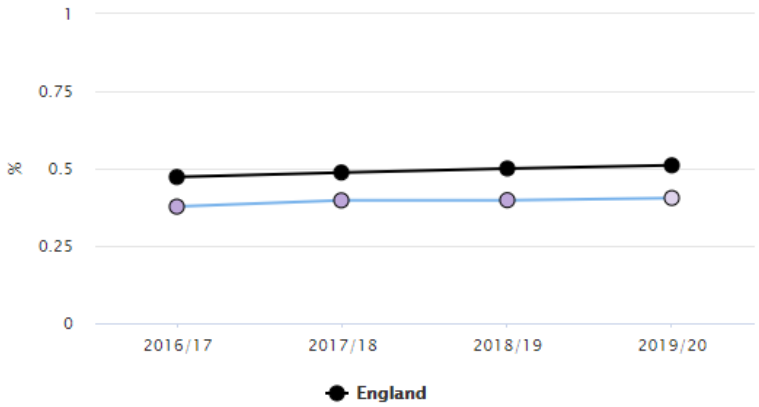
2.1.5. Learning Disability

People with learning disabilities, particularly those with Down's syndrome, are at increased risk of developing dementia. If a person with a learning disability develops dementia, they will face different and additional challenges to people who do not have a learning disability. Dementia generally affects people with learning disabilities in similar ways to people without learning disabilities. However, there are some important differences. People with a learning disability:[3]

- are at greater risk of developing dementia at a younger age - particularly those with Down's syndrome
- often show different symptoms in the early stages of dementia and are more likely to have other physical health conditions which are not always well managed
- are less likely to receive a correct or early diagnosis of dementia and may not be able to understand the diagnosis
- may experience a more rapid progression of dementia, although this can be complicated by difficulty or delay in diagnosis[9]**Error! Bookmark not defined.**

In 2019/20 in Leicestershire, the prevalence of persons with a recorded learning disability is 0.4% and this is significantly lower (better) than the England average of 0.5%. The prevalence of recorded learning disability is in the lowest (best) quintile of England, having before been in the 2nd lowest (best) quintile from 2016/17 to 2018/19 (see Figure 1).

Figure 1: Proportion of persons all ages with a learning disability in Leicestershire, 2016/17-2019/20



Quintiles: Best Worst Not applicable

Source: PHE Fingertips, Learning Disability Profiles

2.1.6. Prisoners

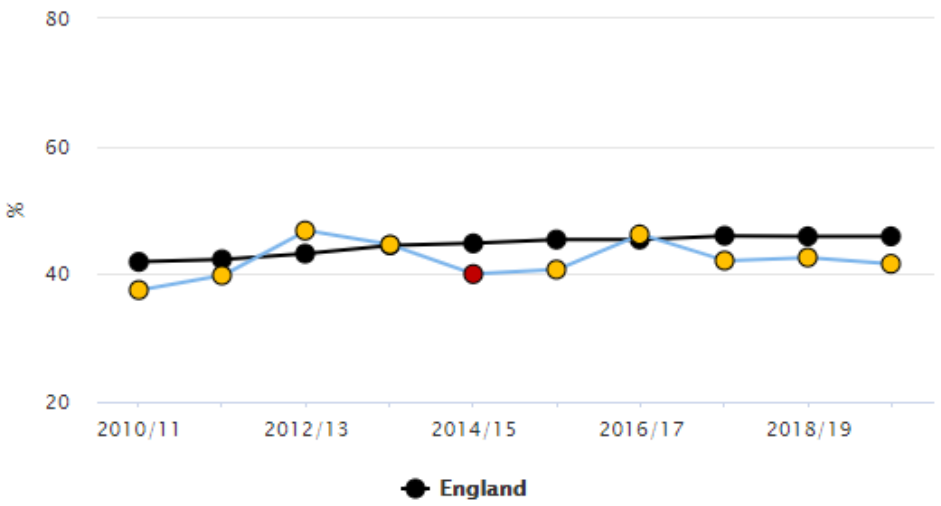
Dementia is a growing problem within prisons. There are currently 680 prisoners within Leicestershire all incarcerated in HMP Gartree. Prisoners over the age of 60 are the fastest growing age group in prisons, with the latest figure standing at 10,000. This number is set to increase unless there are major changes in sentencing trends. There is currently no national plan for older prisoners, but action is needed. There is still limited understanding of the needs of older prisoners in England and Wales and this should be addressed through the DAA's campaign. As the number of older prisoners rises, so too will the prevalence of dementia. People with dementia in prisons will face a number of challenges just by being in this environment, and many of these will be exacerbated by cuts to the prison service.[6]

2.1.7. Social isolation

Many of us will feel lonely occasionally. Being alone every once in a while, can be beneficial. It may provide an opportunity for self-reflection and awareness. However, research suggests that social isolation and loneliness can be harmful.[3] A study by Sutin in 2018 found loneliness is associated with increased risk of dementia. It is one modifiable factor that can be intervened on to reduce dementia risk.[10] A systematic review and meta-analysis of longitudinal cohort studies suggest that aspects of social isolation, including low levels of social activity and poor social networks, are significantly associated with poor cognitive function in later life.[11]

In 2019/20, the proportion of adult social care users who reported they have as much contact as they would like in Leicestershire was 41.6%. This is statistically similar to the England average of 45.9%. Figure 2 below shows that every year since 2010/11 Leicestershire had a rate statistically similar to England, with 2014/15 being the only exception when it was significantly lower (worse) than England.[12]

Figure 2: Proportion of adult social care users (aged 18 and over) who have as much contact as they would like in Leicestershire, 2010/11- 2019/20



Compared with benchmark:
Better Similar Worse Not compared

Source: Public Health England Fingertips, Mental Health and Wellbeing JSNA

2.2. Behavioural Factors

2.2.1. Alcohol misuse

Alcohol consumption in excess has well-documented negative effects on both short and long-term health, one of which is brain damage that can lead to Alzheimer's disease or other forms of dementia.[3] A review by Alzheimer's Disease International found that individuals who drank heavily or engaged in binge drinking - where a person consumes a large quantity of alcohol in a short time period - were more likely to develop Alzheimer's disease or any other form of dementia than those who engaged in moderate alcohol consumption.[13]

Data from the Health Survey for England showed that approximately 14.7% of the population in Leicestershire abstained from drinking alcohol in 2015-2018. This is similar to the national average of 16.2%. This data was based on consumption at the point of answering the questionnaire; therefore, it is possible that some individuals, who abstained from alcohol at the point of answering, might have drunk at risky levels in the past and hence remain at risk of developing alcohol-related

conditions.

For the same time period, the survey also showed that Leicestershire had a similar proportion of adults who drink more than 14 units per week to national, with 20.8% doing so compared to 22.8% across England.

2.2.2. Obesity

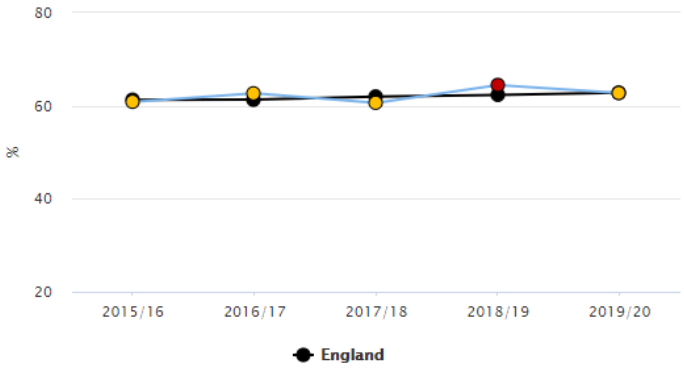
Obesity is already having an impact on people's lives in terms of our quality of life, across the generations. Being overweight increases the risk of numerous health conditions including heart disease, diabetes, depression and anxiety. Severely obese individuals are three times more likely to require social care than those with a normal weight, resulting in increased risk of hospitalisation and associated health and social care costs.[14]

The UK is seeing reduced rises or even a plateauing effect of overweight and obesity among adults and children, but the reasons for this remain unclear. For example, this may be due to a combination of government policies and programmes, and increased health literacy in the population; or indeed overweight and obesity levels may have reached a point of 'saturation equilibrium.'[14]

People who have a high body mass index (BMI) are more likely to develop dementia than those with a normal weight, according to a new UCL-led study.[15]

The 'Active Lives' 2019/20 data for Leicestershire, showed that 62.7% of adults aged 18 or over were classified as overweight or obese; this is not significantly different from the national figure of 62.8%. Over the 5 years that data has been reported from this survey, only 2018/19 was significantly worse than the national average, with the prevalence remaining similar to the national average throughout the previous 3 years as shown in Figure 3.[16]

Figure 3: Proportion of adults aged 18+ classified as overweight or obese in Leicestershire and England, 2015/16- 2019/20



Compared with benchmark:

Better Similar Worse Not compared

Source: Public Health England Fingertips, Physical Activity

Table 2 shows the variation of adult obesity amongst the districts in Leicestershire. In 2019/20, North West Leicestershire (71.3%) and Blaby (67.5%) had a significantly higher (worse) percentage of adults classified as overweight and obese compared to the national average (62.6%). North West Leicestershire has been significantly worse than the national average since 2015/16. Oadby and Wigston had a significantly better (lower) percentage of overweight and obese adults in 2019/20 (56.4%). All other districts had a statistically similar percentage of overweight and obese adults in comparison to the national level. [16]

Table 2: Proportion of adults aged 18+ classified as overweight or obese by Leicestershire districts, 2015/16-2019/20

Area	2015/16	2016/17	2017/18	2018/19	2019/20
Blaby	64.9	54.6	63.3	64.9	67.5
Charnwood	54.2	66.9	55.2	65.5	59.4
Harborough	56.7	56.1	57.7	61.5	62.8
Hinckley & Bosworth	61.5	60.1	64.1	62.3	60.6
Melton	63.9	60.9	64.5	61.9	62.8
North West Leicestershire	69.9	66.4	68.2	69.7	71.3
Oadby & Wigston	59.6	65.1	56.6	63.6	56.4
Leicestershire	60.9	62.7	60.6	64.5	62.7
England	61.3	61.3	62.0	62.3	62.8

Compared with benchmark:
Better Similar Worse Not compared

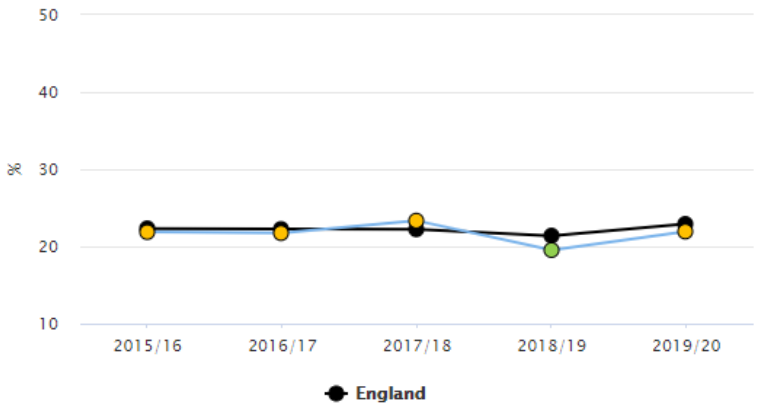
Source: Public Health England Fingertips, Physical Activity

2.2.3. Physical Inactivity

Of all the lifestyle changes that have been studied, taking regular physical exercise appears to be one of the best things that you can do to reduce your risk of getting dementia. Several studies looking at the effect of aerobic exercise (exercise that increases your heart rate) in middle-aged or older adults have reported improvements in thinking and memory, and reduced rates of dementia.[3] A study by Nepal et al (2010) found that a decline in physical inactivity rate by 5% would reduce dementia by 11%.[17] While a study by Najar et al (2019) found that higher cognitive and physical activity in midlife were independently related to reduced risk of dementia disorders in a population sample of women followed over 44 years. Cognitive activity in midlife reduced the risk of Dementia, while physical activity reduced the risk of mixed dementia and dementia with CVD.[18]

In 2019/20 the proportion of adults aged 19 and over who were physically inactive was 21.9%, this is not significantly different from the England figure of 22.9%. See Figure 4 for more details.[16]

Figure 4: Proportion of adults aged 19+ physically inactive in Leicestershire, 2015/16-2019/20



Compared with benchmark:
Better Similar Worse Not compared

Source: Public Health England Fingertips, Physical Activity Profile

Table 3 shows the variation of physically inactive adults amongst the Leicestershire districts. In 2019/20, Oadby and Wigston (27.8%) had a significantly higher (worse) percentage of physically inactive adults compared to the England average (22.9%). Harborough, Melton and North West Leicestershire have a significantly better (lower) percentage of physically inactive adults in 2019/20, in comparison to the England average. All other districts had a statistically similar percentage of physically inactive adults in comparison to the national level.

Table 3: Proportion of adults aged 19+ physically inactive by Leicestershire districts, 2015/16-2019/20

Area	2015/16	2016/17	2017/18	2018/19	2019/20
Blaby	27.5	18.3	20.4	18.8	21.7
Charnwood	18.5	20.2	22.9	17.4	24.3
Harborough	24.6	21.2	19.7	19.0	16.3
Hinckley and Bosworth	20.8	21.2	26.0	19.7	23.5
Melton	22.4	27.7	18.2	19.3	18.8
North West Leicestershire	20.2	23.3	25.3	19.8	19.2
Oadby and Wigston	23.4	26.1	25.4	28.2	27.8
Leicestershire	21.9	21.7	23.3	22.2	21.9
England	22.3	22.2	22.2	21.4	22.9

Compared with benchmark:
Better Similar Worse Not compared

Source: Public Health England Fingertips, Physical Activity Profile

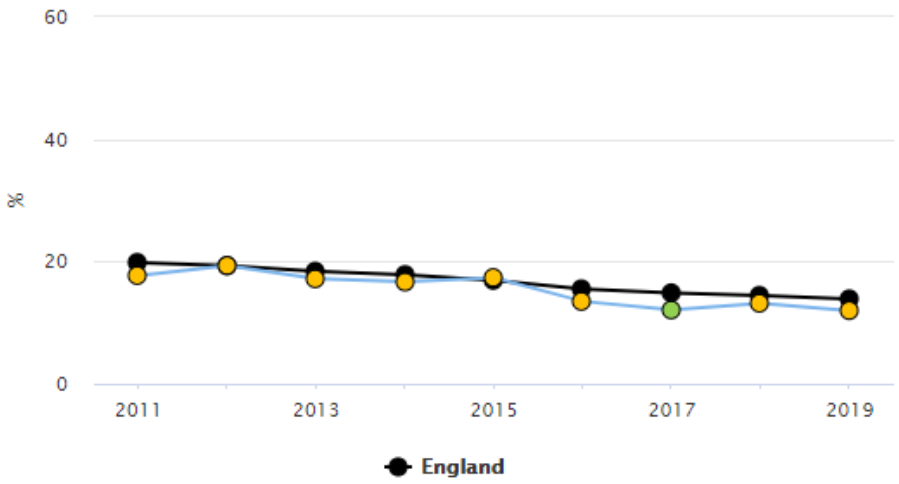
2.2.4. Smoking

There is strong evidence that smoking can increase your risk of developing dementia. Not everyone who smokes will get dementia, but stopping smoking is thought to reduce your risk back down to the level of non-smokers.

Some reasons behind this include 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 (your heart and blood vessels). It is known that smoking increases the risk of vascular problems, including via strokes or smaller bleeds in the brain, which are also risk factors for dementia.[3] A study by Ott et al (1998) found that smoking was associated with a doubling of the risk of dementia and Alzheimer's disease.[19]

The Annual Population Survey (APS) collects the number of persons aged 18 and over who are self-reported smokers. In Leicestershire, in 2019, the prevalence of adults (18+) who were self-reported current smokers was 12.0%. This was statistically similar to the national average of 13.9%. Figure 5 shows the percentage of adults (18+) who were self-reported current smokers in Leicestershire has decreased from 17.7% in 2011, to 12.0% in 2019. In Leicestershire, the smoking prevalence in adults aged 18+ has remained statistically similar to the national rate since 2011, excluding 2017 where the Leicestershire figure was significantly lower (better) than England.

Figure 5: Trend of prevalence in adults (18+) who were self-reported current smokers (APS) in Leicestershire, 2011 - 2019



Compared with benchmark:
Better Similar Worse Not compared

Source: Public Health England Fingertips, Local Tobacco Control Profiles

Table 4 shows the prevalence in adults aged 18+, who were self-reported current smokers across Leicestershire districts in 2019. Compared to the national average (13.9%), Harborough has a

significantly better (lower) percentages of adults (18+) who were self-reported current smokers (8.6%). All other Leicestershire districts are statistically similar to the England figure.[16]

Table 4: Prevalence in adults (18+) who were self-reported current smokers (APS) across Leicestershire districts, in 2019

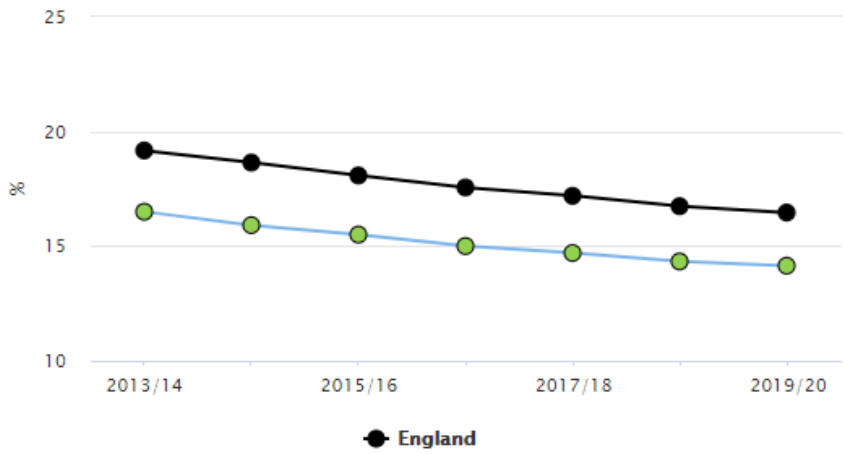
District / Area	England	Leicestershire	Blaby	Charnwood	Harborough	Hinckley and Bosworth	Melton	North West Leicestershire	Oadby and Wigston
Smoking Prevalence (%)	13.9	12.0	10.9	12.0	8.6	10.4	20.9	14.1	10.0

Better | Similar | Worse

Source: Public Health England Fingertips, Local Tobacco Control Profiles, 2019

The Quality and Outcomes Framework (QOF) data provides estimates of patients aged 15 years and over that are registered at GP practices as current smokers. In 2019/20 in Leicestershire, 14.1% of patients aged 15 years and over were estimated smokers, this equates to 85,187 patients. This was significantly better (lower) in comparison to the national percentage of 16.5%. The prevalence for current smokers (aged 15+) has been significantly decreasing (getting better) over the last 5 time periods.

Figure 6: Trend of prevalence in adults (15+) who are current smokers (QOF) in Leicestershire, 2013/14 – 2019/20



Compared with benchmark: Better Similar Worse Not compared

Source: Public Health England Fingertips, Local Tobacco Control Profiles

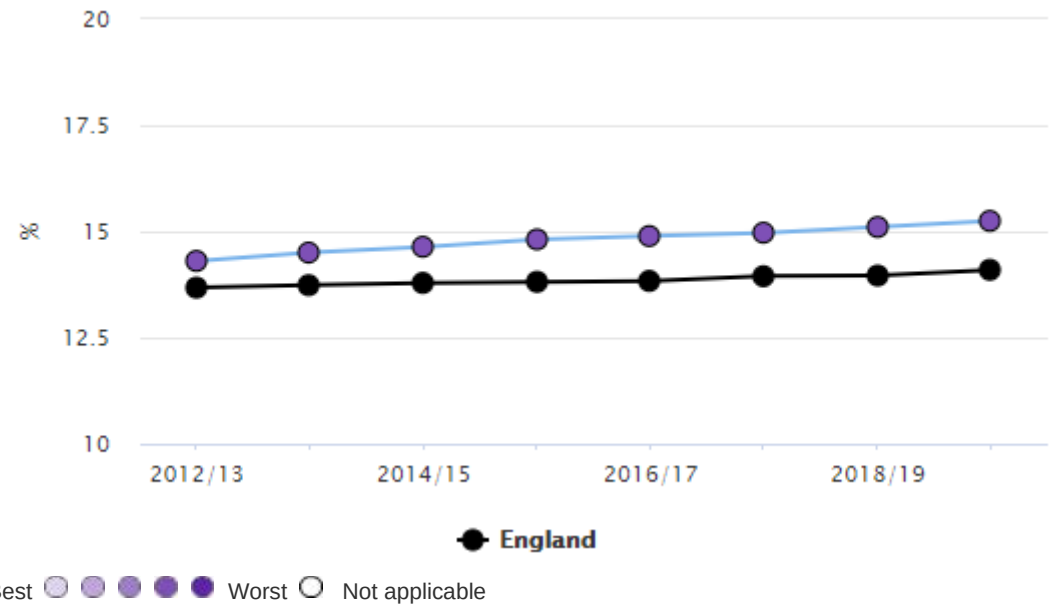
2.3. Risk factors

2.3.1. Hypertension

High blood pressure, or hypertension, rarely has noticeable symptoms. But if untreated, it increases your risk of serious problems such as heart attacks and strokes. If your blood pressure is too high, it puts extra strain on your blood vessels, heart and other organs, such as the brain, kidneys and eyes. Persistent high blood pressure can increase your risk of a number of serious and potentially life-threatening health conditions, such as: heart disease, stroke and vascular dementia.[20] A comprehensive review by Kennelly et al (2009) identified midlife hypertension is a significant risk factor for the later development of both Alzheimer's Disease and vascular dementia.[21]

The latest data from QOF registers for 2019/20 shows that the prevalence of hypertension in persons of all ages in Leicestershire is 15.2%. This is significantly higher (worse) than the England figure of 14.1% (see Figure 7). Since 2012/13, the prevalence of hypertension in persons of all ages in Leicestershire has remained significantly higher (worse) than the England figure and within the 2nd highest (worst) quintile of England. During this time, the prevalence of hypertension for persons of all ages in Leicestershire has consistently increased each year, which could be due to an increase in prevalence and/or an improvement in the diagnosis of hypertension.[12]

Figure 7: Trend of hypertension prevalence all ages in Leicestershire, 2012/13 to 2019/20



Source: Public Health England Fingertips, Physical Activity Profile

2.3.2. Diabetes

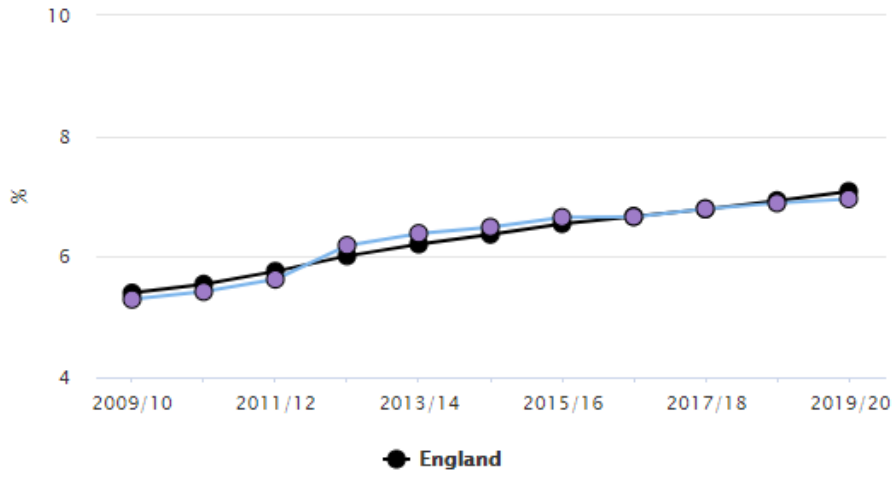
Research has shown that diabetes can increase the risk of developing both Alzheimer's disease and Vascular Dementia. This is thought to be because the mechanisms behind diabetes development

can damage small blood vessels in the brain, which is likely to contribute towards vascular dementia. It is also thought that diabetes-related blood vessel damage could lead to a reduced blood flow to the brain, which may be a factor in Alzheimer's disease development.[1]

Several studies have shown that the presence of Type 2 Diabetes in midlife is associated with increased risk of dementia, Alzheimer's disease, Vascular Dementia and cognitive impairment. Longer duration and greater severity of diabetes may further increase the risk of dementia. A review of relevant studies found that diabetes was associated with a 47% increased risk of any dementia, a 39% increased risk of Alzheimer's disease, and more than 2-fold risk for Vascular Dementia.[22]

In 2019/20, the prevalence of diabetes in persons aged 17 and over in Leicestershire is 7.0%, which is not significantly different to the England average of 7.1% (see Figure 8). Since 2009/10, Leicestershire has remained in the 3rd (middle) quintile of England.[16] Since 2016/17, the prevalence of diabetes in persons aged 17 and over, for both Leicestershire and England, has increased each year, which could be due to an increase in prevalence and/or an improvement in the diagnosis of diabetes.

Figure 8: Trend of diabetes prevalence (QOF) in persons aged 17 and over in Leicestershire, 2009/10-2019/20



Quintiles: Best Worst Not applicable

Source: Public Health England Fingertips, Productive Healthy Ageing Profile

2.3.3. Depression

Depression affects people in different ways and can cause a wide variety of symptoms. They range from lasting feelings of unhappiness and hopelessness, to losing interest in the things you used to enjoy and feeling very tearful. Many people with depression also have symptoms of anxiety. There

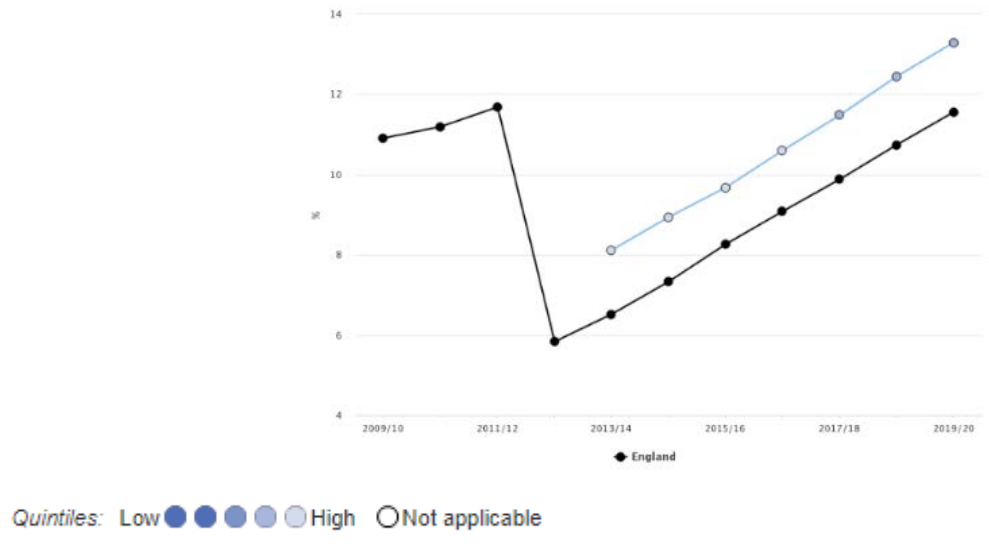
can be physical symptoms too, such as feeling constantly tired, sleeping badly, having no appetite or sex drive, and various aches and pains.[23]

The relationship between depression and dementia is not clear and it is not completely understood. A paper in 1998 found that people who had or have a severe mental illness such as depression or schizophrenia were three times more likely to develop dementia than those who did not, although the reasons for this are not clear.[24]

One 14-year longitudinal study of older men confirmed that a history of depression is associated with an increased risk of incident dementia, a risk that is particularly high among men with clinically significant symptoms of depression at the start of the follow-up period. A study found there was a graded association between the severity of depressive symptoms and the risk of dementia, with the risk being more pronounced for men with severe depression.[25]

Figure 9 shows the most recent year of data (2019/20) for depression recorded prevalence. In 2019/20 in Leicestershire, the prevalence of adults aged 18+ with recorded depression was 13.3%, this is significantly higher (worse) than the England average (11.6%). Since the data for Leicestershire was recorded in 2013/14, Leicestershire has consistently remained significantly higher (worse) than the national figure. Figure 9 shows an increase in both the Leicestershire and national figure; this increase could be explained by an increase in prevalence and/or an improvement in the diagnosis of depression.

Figure 9: Trend of depression prevalence in persons aged 18 and over in Leicestershire, 2009/10-2019/20



Source: Public Health England Fingertips, Mental Health and Wellbeing JSNA Profile

2.3.4. Serum Cholesterol

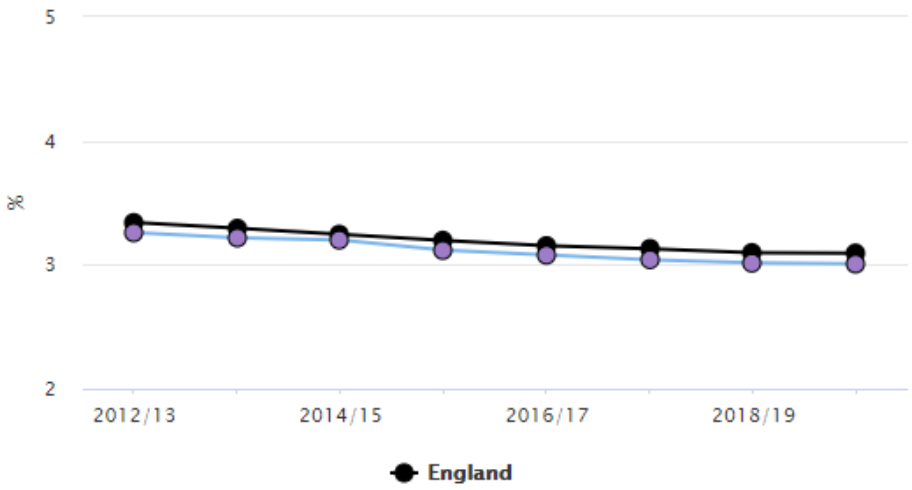
Cholesterol is a fatty substance that is found in our blood and cells and can be transported in the bloodstream. We make cholesterol naturally, and it can also be found in certain foods. Studies investigating the relationship between cholesterol and dementia look at many different ways that they might be linked. Evidence suggests that there is a relationship between having high cholesterol levels in the blood in mid-life and going on to develop dementia.[3] People that have high cholesterol levels in the blood often have other factors associated with dementia risk such as high blood pressure and diabetes, so separating these factors is complex.[3] A study by Solomon et al in 2009 found that midlife serum total cholesterol was associated with an increased risk of Alzheimer's Disease and Vascular Dementia. Even moderately elevated cholesterol increased dementia risk. Dementia risk factors need to be addressed as early as midlife, before underlying disease(s) or symptoms appear.[26]

2.3.5. Coronary Heart Disease

Coronary heart disease (CHD) is the term used to describe when the coronary arteries become narrowed by a build-up of fatty material within their walls.[27] It is the single most common cause of premature death in the UK. Reduced blood flow to the brain may increase the chance of Vascular Dementia. Additionally, guidance provided by National Institute for Health and Care Excellence (NICE) suggests CHD can form blood clots which may damage brain cells and in turn, lead to Vascular Dementia. According to 'The NICE Disability, dementia and frailty in later life – mid-life approaches to prevention publication', Vascular Dementia has been found to have the same risk factors as cardiovascular disease and stroke, indicating that risk of diagnosis can be reduced by similar preventative measures.[16]

In 2019/20 the prevalence of coronary heart disease was 3.0%, which is not significantly different than the England average of 3.1% (see Figure 10). Since 2012/13, Leicestershire has remained in the 3rd (middle) quintile of England. [16]

Figure 10: Trend of Coronary Heart Disease (CHD) prevalence in persons all ages in Leicestershire, 2012/13-2019/20



Quintiles: Best Worst Not applicable

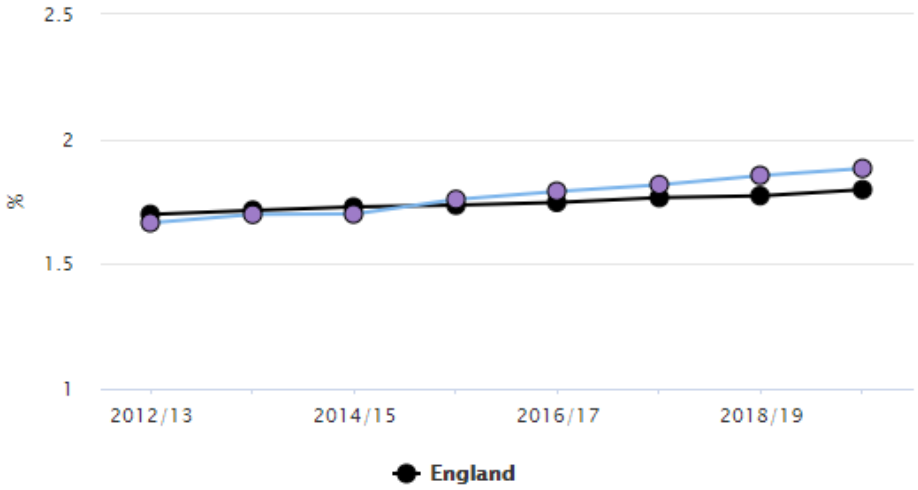
Source: PHE Fingertips, Physical Activity Profile

2.3.6. Stroke

A stroke occurs when the blood supply is cut off to part of the brain.[28] PH England reported strokes to be the third most common cause of death in the developed world, with a quarter of all stroke deaths occurring under the age of 65. Evidence suggests that appropriate diagnosis and management can improve outcomes of stroke patients. Transient ischaemic attacks (TIAs), often referred to as 'mini strokes', cause small but widespread damage to the brain. TIAs and strokes are two known causes for Vascular Dementia. [29]

The latest data from the QOF registers for 2019/20 shows that the prevalence of stroke in persons of all ages in Leicestershire is 1.9%. This is not significantly different to the national value of 1.8% (see Figure 11). Since 2012/13, Leicestershire has remained in the 3rd (middle) quintile of England for stroke prevalence.

Figure 11: Trend of Stroke prevalence in persons all ages in Leicestershire, 2012/13-2019/20



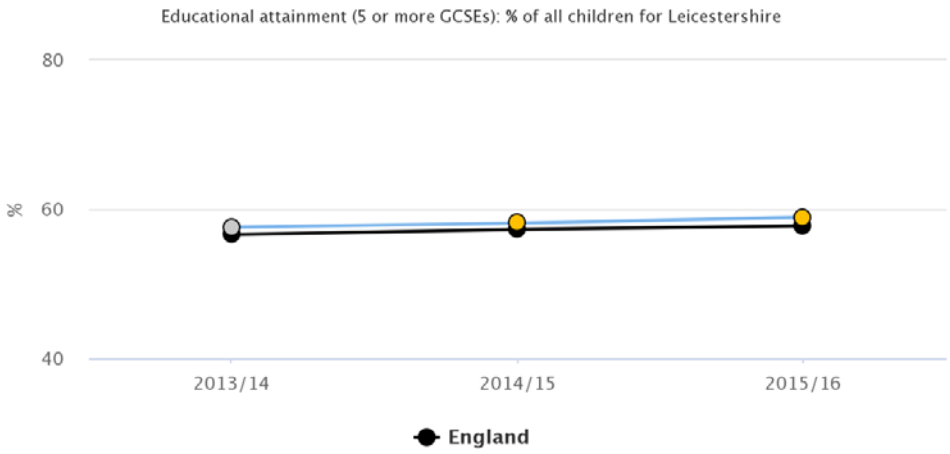
Quintiles: Best Worst Not applicable
Source: PHE Fingertips, Physical Activity Profile

2.3.7. Education Attainment

There has been a lot of research dating back to the late 1980s on the effects of education in early life on developing dementia in later life. Due to this large body of research, it is now accepted that increased educational attainment is associated with lower risk of dementia. However, a systematic review in 2012 found lower education was associated with a greater risk for dementia in many, but not all, studies. The level of education associated with risk for dementia varied by study population and more years of education did not uniformly reduce the risk for dementia.[30]

Figure 12 shows that in 2015/16, the prevalence of educational attainment (5+ GCSEs) in all children within Leicestershire was 58.9%, which was not significantly different to the national figure (57.8%).[31]

Figure 12: Trend of educational attainment (5 or more GCSEs) prevalence in all children in Leicestershire, 2013/14-2015/16



Compared with benchmark: Better Similar Worse Not compared

Source: PHE Fingertips, Wider Determinants of Health Profile

2.3.8. Mild Cognitive Impairment (MCI)

The causes of mild cognitive impairment are not yet completely understood. Mild cognitive impairment (MCI) causes a slight but noticeable and measurable decline in cognitive abilities, including memory and thinking skills. A person with MCI is at an increased risk of developing Alzheimer's or another dementia.[32] A study by Visser et al found the majority of subjects with MCI do not progress to dementia at the long term. Age strongly influences the dementia risk. MCI often represents the predementia stage of a neurodegenerative disorder in elderly subjects but rarely in younger subjects.[33] It is estimated that between 5 and 20 per cent of people aged over 65 have MCI.[3] In 2019 in Leicestershire this equates to between 7,240 and 28,960 estimated to have MCI*. This figure is estimated to increase to between 9,965 and 39,860 by the year 2035.[34]

2.3.9. Hearing impairment

The discovery of the relationship between hearing loss and the onset of dementia is new. It's thought that hearing loss may add stress to an already vulnerable brain regarding the changes that occur. Hearing loss may also increase feelings of social isolation. However, it's also possible that old age could have a role to play in this association.[35]

In 2020 it is estimated 89,334 people over 65 in Leicestershire have some hearing loss with 11,405 of these having severe hearing lost.[34]

* Applying the estimates to the Leicestershire population.

The Lancet Commission on Dementia Prevention, Intervention and Care (LCDPIC) analysis found that hearing loss could be responsible for 9.1% of the risk of developing dementia.[36]

2.4. Protective Factors

2.4.1. Remaining Active

A systematic review by Patterson et al found evidence (from studies named below) that regular physical activity is associated with a reduced risk of dementia. Results from the Canadian Study of Health and Aging (CSHA) found regular physical activity was associated with a reduced risk of Alzheimer's Disease (AD). In the Cardiovascular Health Study from the USA, those expending the highest quartile of energy expenditure had a lower relative risk of All Cause Dementia (ACD). The CSHA also found regular exercise was associated with a reduced relative risk of vascular dementia in women.[37]

2.4.2. Reduce alcohol intake

There has been a lot of research relating to alcohol as a risk factor to dementia, with some research finding a protective effect in moderate alcohol consumption such as by Peters in 2008.[38] Similarly, the Rotterdam study by Ruitenberg et al found light-to-moderate drinking (one to three drinks per day) was significantly associated with a lower risk of any dementia.[39]

2.4.3. Quit smoking

Similarly to alcohol, there is some conflicting evidence in relation to smoking and its relationship with dementia. Some studies have found a protective effect while others have shown a detrimental effect.[40] A study by Ott et al found that smoking was a strong risk factor for Alzheimer's disease in individuals and was associated with a doubling of the risk of dementia and Alzheimer's disease.[19]

2.4.4. Increase exercise

Doing regular physical activity is one of the best ways to reduce your risk of dementia. It's good for your heart, circulation, weight and mental wellbeing.[3] A study by Lee et al found that although physical exercise is widely promoted as a nonpharmacological intervention for dementia prevention, not all types of exercise appear to be useful in reducing risk of dementia in older people. Their findings suggest that daily participation in aerobic and mind-body exercises, but not stretching and toning exercises, might protect community-living older adults from developing dementia.[41]

3. Level of need in Leicestershire

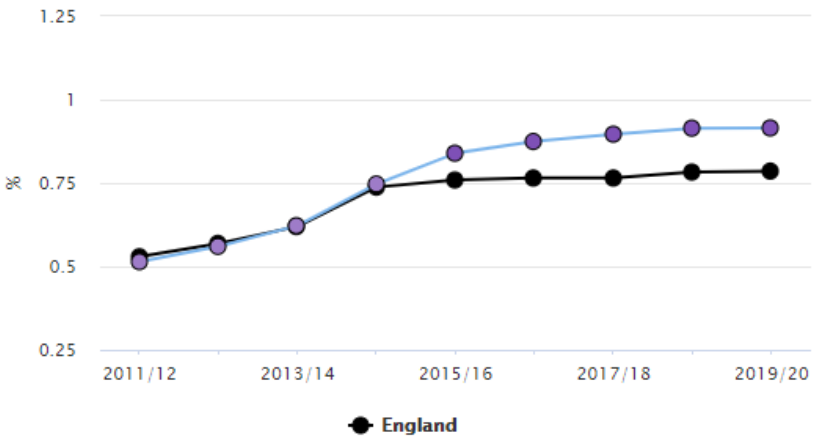
3.1. Current burden of dementia

The recorded dementia prevalence provides an indication of the concentration, within a population, of the number of people who have been diagnosed and who are now living with the condition. This indicator can be used to inform local service planning as to the scale of services required to provide treatment, care and support as needed, so those with dementia can live well with the condition.[42]

3.1.1. Dementia prevalence

In 2019/20, there were 6,579 patients recorded on GP practice disease registers with dementia in Leicestershire. This equates to a prevalence of 0.9% and is significantly higher than the national prevalence of 0.8%. As shown in Figure 13 below, over the last five years the prevalence of recorded dementia in Leicestershire has been significantly increasing. Since 2015/16, the prevalence of recorded dementia in Leicestershire has remained in the 2nd highest quintile in England.

Figure 13: Trends in recorded prevalence of dementia in persons all ages in Leicestershire, 2011/12-2019/20

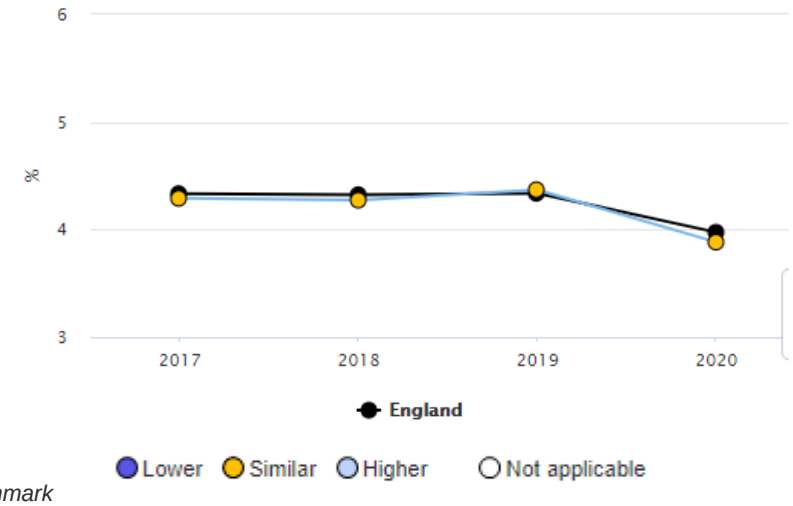


Quintiles: Best Worst Not applicable

Source: PHE Fingertips, Dementia Profile

Figure 14 provides information on the percentage of people with recorded dementia aged over 65. In 2020, 3.9% (5,765) of people aged over 65 years with dementia were recorded on GP practice registers in Leicestershire. This is statistically similar to the England average of 4.0%. The percentage of people aged over 65 years with dementia in Leicestershire has remained statistically similar to the national average since 2017.

Figure 14: Trends in recorded prevalence of dementia in persons aged 65+ in Leicestershire, 2017-2020



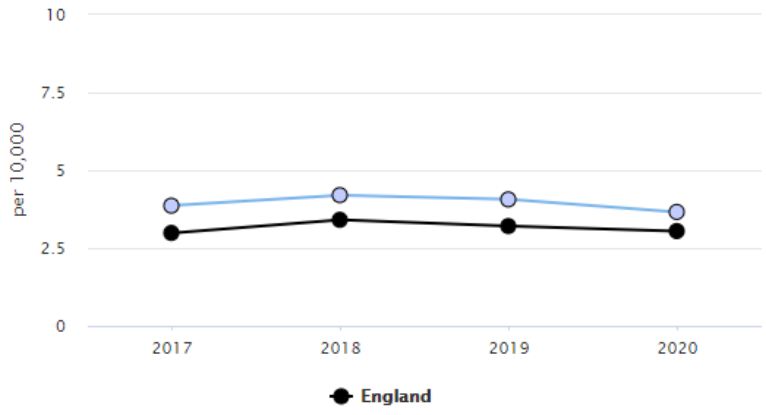
Compared with benchmark

Source: PHE Fingertips, Dementia Profile

Young-onset dementia refers to dementia that is diagnosed before the age of 65 (the age at which people traditionally retire); however, the age cut-off point has no medical or biological significance. This indicator is important as people diagnosed with dementia under the age of 65 have different needs and commitments. They also follow a different clinical pathway and may also need different forms of support compared to those aged 65 and over that are diagnosed with dementia.[43]

Figure 15 below shows the crude recorded dementia prevalence in those aged under 65 years that are recorded on the GP practice registers in Leicestershire. In 2020, there was a total of 210 people aged under 65 years with dementia, recorded on GP practice registers in Leicestershire. This equates to a crude rate of 3.66 (per 10,000 population aged under 65) and is significantly higher in comparison to the England rate of 3.05 (per 10,000 population aged under 65). The crude recorded prevalence for dementia in those aged under 65 years in Leicestershire has remained significantly higher than the England rate since 2017.

Figure 15: Recorded Dementia Prevalence in Under 65s in Leicestershire, 2017-2020

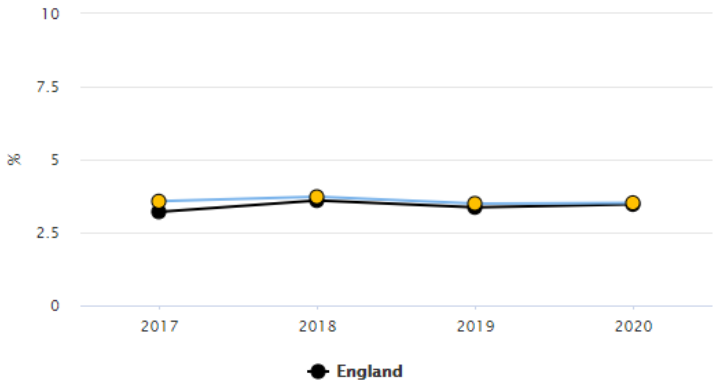


Compared with benchmark: Lower Similar Higher Not compared

Source: PHE Fingertips, Dementia Profile

Figure 16 provides information on the percentage of people with recorded dementia under the age of 65 years, as a proportion of total dementia in all ages, as this could potentially highlight complex epidemiological issues at a localised level. In 2020, 3.5% (210) of people aged under 65 years with dementia were recorded on GP practice registers in Leicestershire. This is statistically similar to the England average of 3.5%. The percentage of people aged under 65 years with dementia in Leicestershire has remained statistically similar to the national average since 2017.

Figure 16: Dementia (under 65 years) as a proportion of total dementia (all ages), Leicestershire, 2017-2020



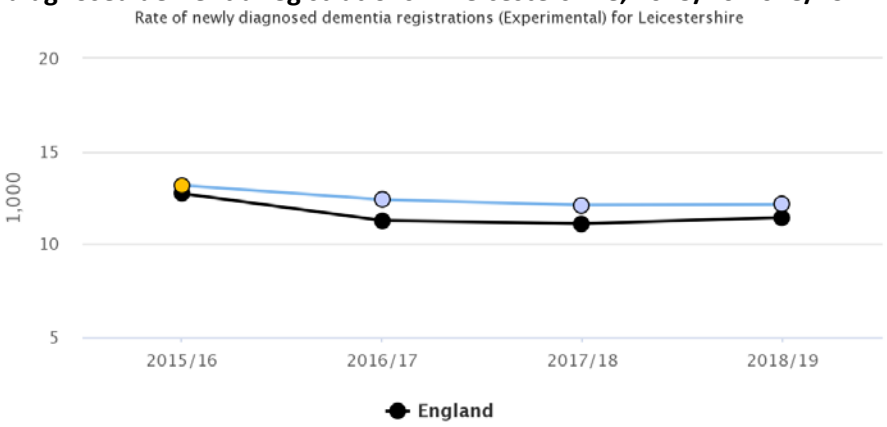
Compared with benchmark: Lower Similar Higher Not compared

Source: PHE Fingertips, Dementia Profile

3.1.2. Newly diagnosed dementia registrations

This indicator is a proxy for an incidence rate and should therefore be considered as experimental. The indicator provides insight into the number of patients who are newly registered for dementia with their GP. Used alongside the prevalence figure; planners and commissioners can determine the burden of dementia and the types of need in their CCG or local authority.[42] Figure 17 shows the rate of newly diagnosed dementia in Leicestershire is 12.1 per 1,000 population aged 65 and over. This is significantly higher than the England rate of 11.4 per 1,000 population aged 65 and over. The rate of newly diagnosed dementia in Leicestershire has remained significantly higher in comparison to the England rate since 2016/17.

Figure 17: Newly diagnosed dementia registrations in Leicestershire, 2015/16-2018/19



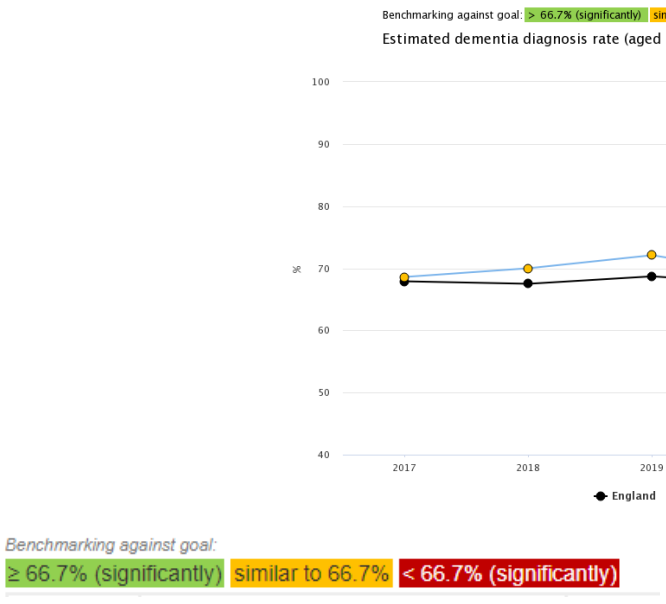
Compared with benchmark: Lower Similar Higher Not compared

Source: PHE Fingertips, Dementia Profile

3.1.3. Dementia diagnosis rate

In 2013 the government set targets to increase the diagnosis of dementia due to the very low diagnosis rates. This feeds in to the diagnosing well step of the well pathway for dementia. The benchmark target is equal or above 66.7% (two thirds) to be diagnosed so the appropriate care and support can be given.[44] In 2021 (up to March), the estimated dementia diagnosis rate for those aged 65 and over in Leicestershire was 61.2%, which is significantly lower than the benchmarking goal (note – statistical significance is determined by the nonoverlapping of confidence intervals with the 66.7% benchmark). The estimated dementia diagnosis rate for those aged 65 and over in England was 61.6%, which is statistically similar to the benchmarking goal (see Figure 18).

Figure 18: Estimated dementia diagnosis rate in Leicestershire, 2017-2021

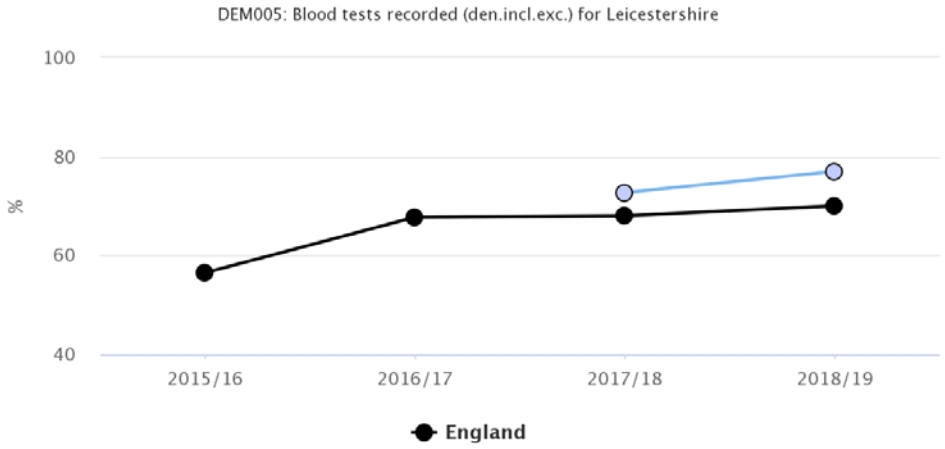


Source: PHE Fingertips, Dementia Profile

3.1.4. Identifying dementia

The Quality and Outcomes Framework (QOF) is a component of the GP contract where achievement is measured against certain indicators. Within the clinical domain there are three dementia indicators which GPs are measured against. The main reason for undertaking investigations in a person with suspected dementia is to exclude a potentially reversible or modifying cause for the dementia and to help exclude other diagnoses (e.g. delirium). Reversible or modifying causes include metabolic and endocrine abnormalities (e.g. vitamin B12 and folate deficiency, hypothyroidism, diabetes and disorders of calcium metabolism).[42] Figure 19 shows the percentage of patients with a new diagnosis of dementia who had a record of FBC, calcium, glucose, renal and liver function, thyroid function tests, serum vitamin B12 and folate levels recorded between 12 months before and 6 months after entering on to the register. In Leicestershire in 2018/19, the percentage was 77.0% and this was significantly higher than the England average of 70.0%. The percentage of patients with a new diagnosis of dementia who had a recorded blood test in Leicestershire has remained significantly higher than the England average since 2017/18.

Figure 19: Blood test to confirm dementia in Leicestershire, 2015/16-2018/19



Compared with benchmark: Lower Similar Higher Not compared

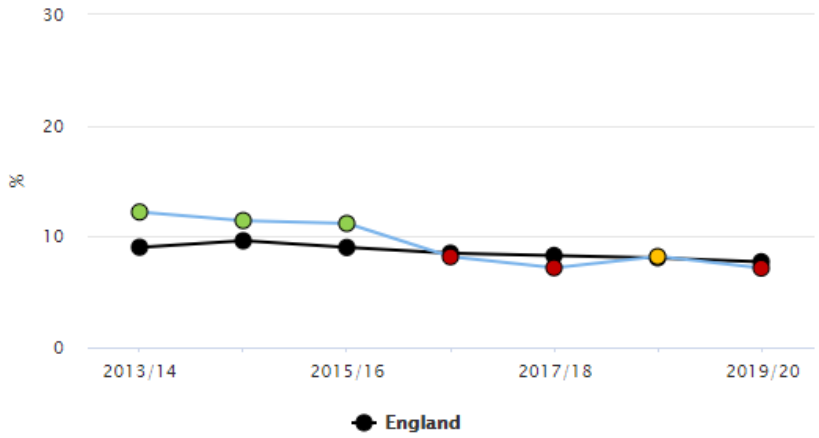
Source: PHE Fingertips, Dementia Profile

The NHS Health Check Programme aims to help prevent heart disease, stroke, diabetes and kidney disease. A high take up of NHS Health Check is important to identify early signs of poor health leading to opportunities for early inventions. The NHS Health Check is also used to promote opportunities in mid-life to reduce the behavioural risk factors for dementia by providing advice on dementia to the relevant age group.[20]

In 2019/20, 7.1% (14,861) of people (aged 40-74) in Leicestershire who were eligible for an NHS Health Check, received a health check. This is statistically lower (worse) than the England average

of 7.7%. Over the last five years, the trend in the proportion of people in Leicestershire who are eligible for receiving an NHS health check is significantly decreasing (see Figure 20).

Figure 20: People receiving an NHS Health Check per year in Leicestershire, 2013/14-2019/20



Compared with benchmark: Better Similar Worse Not compared

Source: PHE Fingertips, Dementia Profile

3.2. Projected levels of dementia

3.2.1. Dementia prevalence and projected estimates

As age is a major unmodifiable risk factor for dementia and the older population is expected to increase, so is the number of people with dementia. Overall, between 2020 and 2040 the number of people aged 65 and over in Leicestershire with dementia is estimated to increase from 10,203 to 16,785, an increase of 64.5%. While in persons aged 85 years and over, the increase will be 86.8% (from 4,387 to 8,193). The highest increase is predicted to come in males aged 85 years and over which will increase by 109.7% from 1,234 to 2,588.

See Table 5 below for more information.

Table 5: Current and projected estimates of dementia in Leicestershire aged over 65 years and over 85 years, 2020-2040

	2020	2025	2030	2035	2040	% change 2020 to 2040
Males 65 and over	3,776	4,376	5,098	5,762	6,352	68.2%
Males 85 and over	1,234	1,455	1,792	2,328	2,588	109.7%
Females 65 and over	6,427	7,224	8,246	9,382	10,433	62.3%
Females 85 and over	3,153	3,437	3,992	4,998	5,605	77.8%
Persons age 65 and over	10,203	11,599	13,344	15,144	16,785	64.5%
Persons age 85 and over	4,387	4,892	5,784	7,326	8,193	86.8%

Source: Projecting Older Peoples Populations Information, (POPPI), 2021

3.2.2. Early onset of Dementia prevalence and projected estimates

Dementia is considered 'young onset' when it affects people under 65 years of age. It is also referred to as 'early onset' or 'working age' dementia.[45] Different types of dementia can affect people differently, and everyone will experience symptoms in their own way.

However, there are some common early symptoms that may appear some time before a diagnosis of dementia. These include:

- Memory loss
- difficulty concentrating
- finding it hard to carry out familiar daily tasks, such as getting confused over the correct change when shopping
- struggling to follow a conversation or find the right word
- being confused about time and place
- mood changes

These symptoms are often mild and may get worse only very gradually. It's often termed "mild cognitive impairment" (MCI) as the symptoms are not severe enough to be diagnosed as dementia.[46]

In Leicestershire the estimated numbers of early onset dementia are relatively low in 2020, however, they are predicted to increase by 12.2% in males aged 60-64 years and by 16.7% in females aged 60-64 years in 2040. Due to small numbers in both males and females aged 30-39 years and

40-49 years, data is withheld. In females aged 50-59 years, the numbers are predicted to increase by 7.7% whilst males are expected to stay the same. See Table 6 for more information.

Table 6: Current and projected estimates of early onset of dementia in Leicestershire, 2020 & 2040

	2020	2040	% CHANGE
Males aged 30-39 predicted to have early onset dementia	N/A	N/A	N/A
Males aged 40-49 predicted to have early onset dementia	N/A	N/A	N/A
Males aged 50-59 predicted to have early onset dementia	62	62	0.0%
Males aged 60-64 predicted to have early onset dementia	43	46	7.0%
Total males aged 30-64 predicted to have early onset dementia	116	122	5.2%
Females aged 30-39 predicted to have early onset dementia	N/A	N/A	N/A
Females aged 40-49 predicted to have early onset dementia	N/A	N/A	N/A
Females aged 50-59 predicted to have early onset dementia	39	42	7.7%
Females aged 60-64 predicted to have early onset dementia	25	28	12.0%
Total females aged 30-64 predicted to have early onset dementia	80	87	8.8%

Source: Projecting Adult Needs and Service Information, PANSI

3.3. Preventing well

Prevention primarily looks at risk factors and protective factors that were in the Who is at risk section of this document.

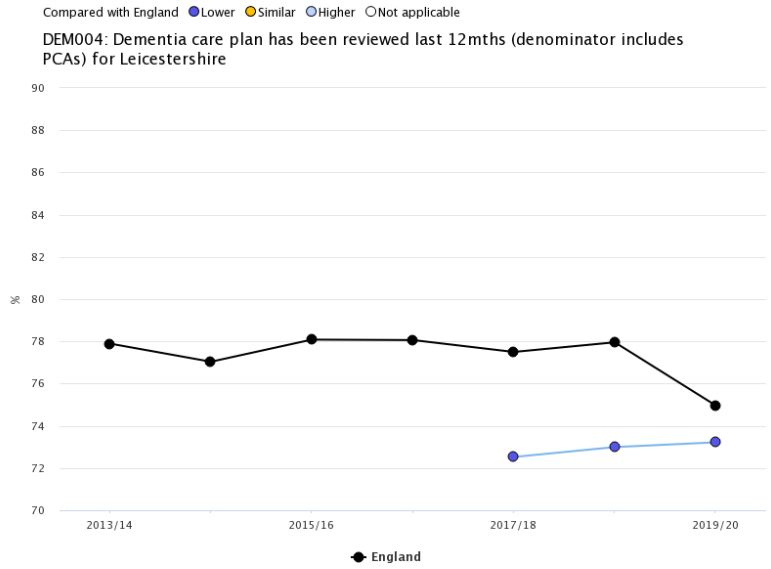
3.4. Living with Dementia

3.4.1. Dementia Care Plan has been reviewed last 12 months

Dementia patients should be reviewed yearly to ensure their physical and mental health needs and those of their carers are being met. It is also an opportunity to monitor if the patient's dementia symptoms and care needs have changed. As such this is a recorded measure on the Quality Outcomes Framework of primary care.

In Leicestershire for the last 3 time periods, significantly fewer dementia patients have received a review in the last 12 months when compared to the national average. However there has been an increase from 73.0% of patients in 2018/19 to 73.2% of dementia patients receiving a review in 2019/20.

Figure 21: Dementia care plan has been reviewed in the last 12 months, 2013/14-2019/20



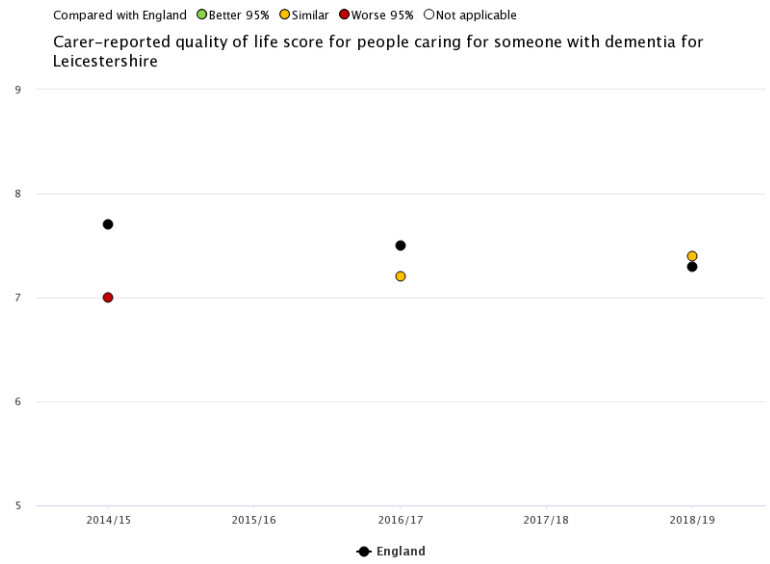
Source: PHE Fingertips, Dementia Profile

3.4.2. Carer reported quality of life score for people caring for someone with dementia

Caring for a person with dementia can significantly impact a carer's mental and physical health. The Adult Social Care Outcomes Framework examines how carers report their own quality of life using a questionnaire, this indicator can give an indication of the level and quality of support available for these carers.

The average score of dementia carers has increased from 7.20 in 2017/18 to 7.40 in 2018/19 this is similar to the national average score of 7.30.

Figure 22: Carer-reported quality of life score for people caring for someone with dementia, 2014/15-2018/19



Source: PHE Fingertips, Dementia Profile

3.5. Supporting those with dementia

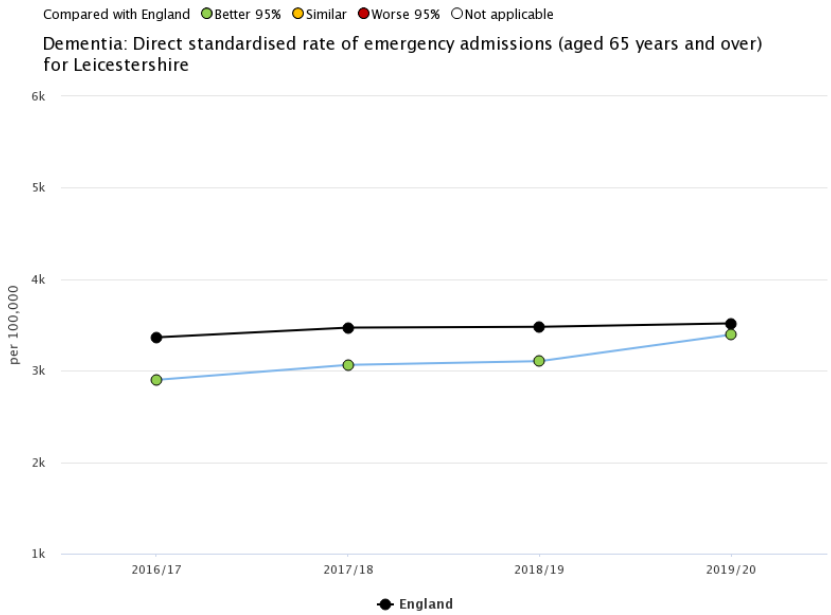
Ensuring people with dementia and their families are supported to live as well as possible with dementia feed into the two stages of the well pathway, supporting well and living well.

3.5.1. Dementia: Direct standardised rate of emergency admissions (aged 65+)

Emergency hospitalisation rates present a proxy for the provision of care for people with dementia. Those areas with higher admission rates may present as needing a change in the support available for dementia patients, as those with less appropriate care are more likely to end up needing medical attention.

In Leicestershire the direct standardised rate of emergency hospital admission has been significantly better than the national average since this indicator has been presented in 2016/17. In 2019/20 the rate is 3,394 per 100,000 which is significantly better than the national rate of 3,517 per 100,000.

Figure 23: Dementia: Direct standardised rate of emergency admissions (aged 65 and over), 2016/17-2019/20



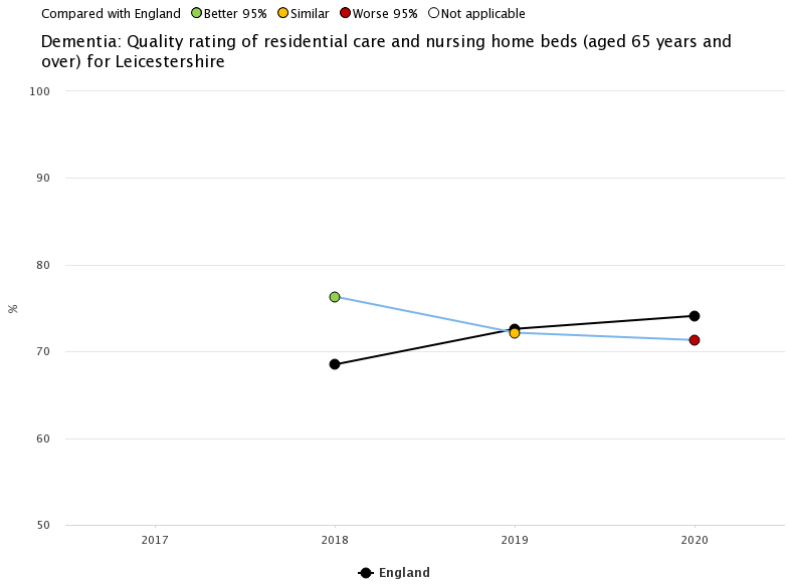
Source: PHE Fingertips, Dementia Profile

3.5.2. Dementia: Quality rating of residential care and nursing home beds (aged 65+)

This indicator looks at care and residential homes assessed by the Care Quality Commission that achieved an overlap rating of good or outstanding. This can then be used to examine dementia care quality.

Over the past 3 time periods Leicestershire has decreased from performing significantly better than the national average in 2018 to significantly worse than the national average in 2020. The percentage of Leicestershire care homes rated good or outstanding has decreased from 72.2% in 2019 to 71.3% in 2020 which is significantly worse than the national average of 74.1%.

Figure 24: Dementia: Direct standardised rate of emergency admissions (aged 65 and over), 2017-2020



Source: PHE Fingertips, Dementia Profile

3.6. Dying with dementia

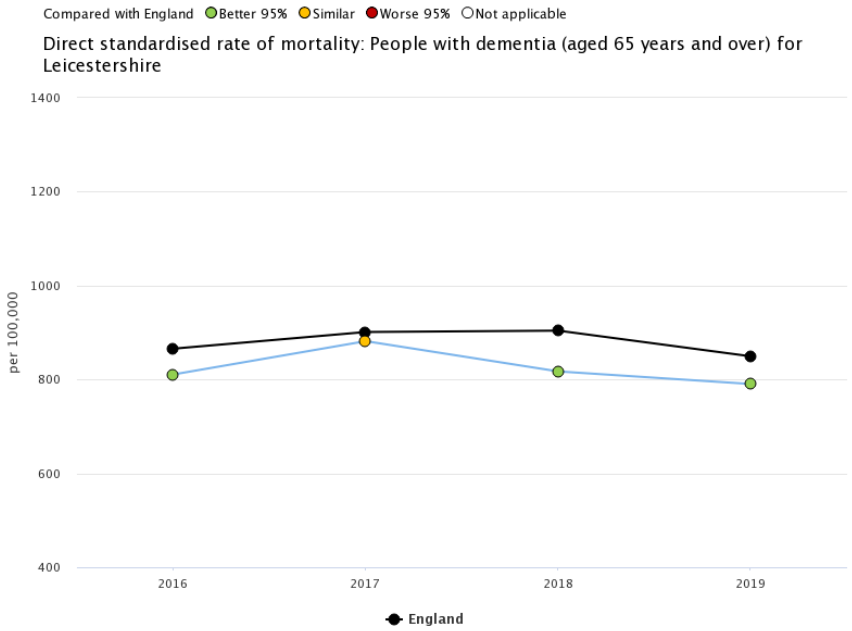
The final step in the well pathway for dementia is dying well. This part of the pathway looks at ensuring people with dementia die in a way that is in line with their needs and respects their wishes.

3.6.1. Direct standardised rate of mortality: People with dementia (aged 65+)

This indicator looks at the rate of people over 65 dying with a diagnosis of dementia and can help identify geographical patterns in dementia deaths.

The standardised rate of death of those with dementia has decreased from 817 per 100,000 population in 2018 to 790 per 100,000 in 2019. This is significantly better than the national rate of 849 per 100,000.

Figure 25: Direct standardised rate of mortality: People with dementia (aged 65 and over), 2016-2019



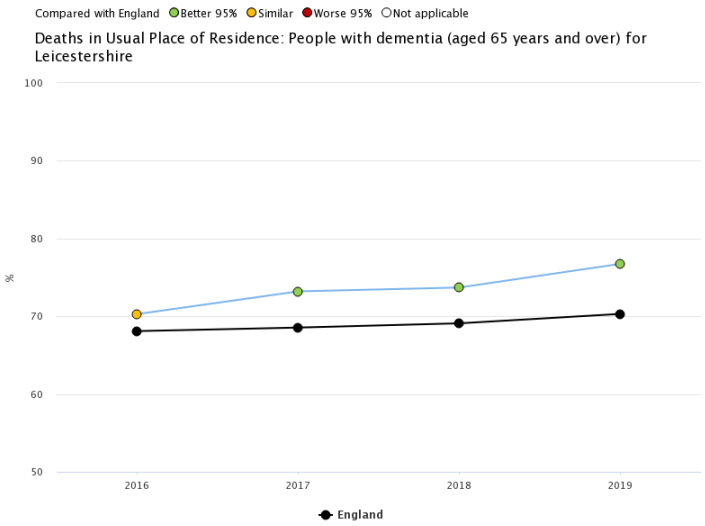
Source: PHE Fingertips, Dementia Profile

3.6.2. Deaths in Usual place of residence

Place of death may give an indication of how well dementia patients and their families are involved in their end-of-life care. Usual place of residence may include family homes, care home or religious establishments.

The percentage of Leicestershire residents with dementia who died in their usual place of residence has increased from 73.7% in 2018 to 76.7% in 2019. This is significantly better than the national average of 70.3%.

Figure 26: Deaths in usual place of residence: People with dementia (aged 65 years and over), 2016-2019



Source: PHE Fingertips, Dementia Profile

4. How does this impact?

4.1. Impact on the diagnosed person

Dementia will affect a person's day to day life, they may lose independence, no longer being able to make decisions for themselves due to issues with capacity. They also may be unable to communicate as they could previously, which in turn can cause distress. Also depending on when they are diagnosed, they may have very different needs, which must be taken into consideration when planning services. Dementia is progressive in nature and so a patient's needs will change over time.

Being diagnosed with Dementia not only affects someone's mental health but also their emotional wellbeing. Dementia diagnosis can cause a range of emotional responses and can cause the person to be treated differently by others. It can also contribute to the person feeling isolated or lonely which in itself has health consequences. Diagnosis can also trigger other mental health conditions in particular anxiety and depression. These additional conditions can negatively affect the patient's health even further than the original dementia.[47] These additional mental and emotional health issues add to the burden placed on the person with dementia but also those caring for them, the wider community they live in and the services they access.

4.2. Impact on family and friends

Dementia doesn't only affect those with the condition but also family or friends who take on caring responsibilities. These carers may experience negative effects including increased mental health issues, physical ill health, social isolation and financial hardship. It is therefore important they are considered as 'second patients' who require support alongside the person with dementia. [48]

It was estimated in 2019 that dementia sufferers and their families in the UK spend around an estimated £8.3 billion pound on paid for care, whilst also contributing around £13.9 billion in unpaid care.[49]

4.3. Impact on health and social care

Up to a quarter of hospital inpatients at one time in the UK may have a diagnosis of dementia, contributing a large amount to the burden on our acute hospitals. In 2014 the NHS spent around £4.9 billion on dementia care. Whilst social care spent around £15.7 billion on care for people with dementia, with £4.5 billion of this coming from local authorities and the remaining cost coming from families paying for state funded care. With these costs expected to rise.[50]

5. Policy and Guidance

This chapter will contain policies and guidelines related to dementia from a national to a local level. Although there are many policies and guidelines that may briefly mention dementia, this will focus on those that specifically highlight dementia needs.

5.1. National Dementia Strategy[50]

This is a best practice guideline complied by the Department of Health with the support of over 50 stakeholders. It provides strategic framework which local services can use to help deliver quality improvements to dementia services and address health inequalities relating to dementia. 17 key objectives were identified by the department. This is also useful for health and social care commissioners regarding planning, developing, and monitoring services.

This strategy however was published in 2009.

5.2. Prime Minister's Challenge on Dementia[51]

Government's aim to improve dementia care and support for people with dementia, their carers, and their families. This is focussed by addressing these groups of people's needs as outlined. The key aspirations include:

- Improving public awareness and understanding of risk factors
- Providing equal access to diagnosis (expectation that the national average for an initial assessment should be 6 weeks following a GP referral)
- GPs to lead the coordination and care for those with dementia
- All patients to have meaningful care post diagnosis
- All NHS staff to receive dementia training targeted for their position
- All hospitals and care homes to become a dementia friendly health and care setting
- Businesses encouraged and supported to be dementia friendly
- National and local government taking a leading role in becoming dementia friendly and local governments being part of a local Dementia Action Alliance

5.3. NICE Guidelines[2]

NICE guidelines for dementia cover assessment and diagnosis, interventions (social and pharmacological), supporting carers and those living with dementia and staff training and education. This is a thorough guideline to be used for healthcare and social care professionals alongside commissioners and providers of dementia healthcare services.

A NICE guideline of importance to note is "Dementia, disability, and frailty in later life – mid-life approaches to delay or prevent onset."

This includes recommendation to develop a positive healthy lifestyle, to help decrease the risk of disability, dementia and frailty.

Advice revolves around:

- Smoking cessation
- Increased physical activity
- Decrease alcohol intake
- Healthy diet
- Maintaining a healthy weight

This is targeted to commissioners and other people within public health and the public.

Nice guidelines are developed by looking for a need for a particular guideline being written. Generally based upon the best available evidence following the appropriate literature searches, with the support of stakeholders. This is done by experts in the field with the support of care providers and service users.

Other supportive NICE guidelines include:

- Dementia Quality Standard
- Donepezil, Galantamine, Rivastigmine and Memantine for the Treatment of Alzheimer's Disease NICE technology appraisal

5.4. NHS England Well Pathway for Dementia[52]

Dementia is a key area of work for NHS England and as a result they are working with many partners including the government to improve dementia related care. NHS England has produced a transformation framework focusing on a variety of areas such as prevention, diagnosis, support and dying with dementia. Other areas focused on, not directly related to patients are research, commissioning, training, integration, and monitoring.

5.5. Joint declaration on post-diagnostic dementia care and support[53]

This is a policy paper published in 2016 by the Department of Health & Social Care. Aware of the individual needs of patients post diagnosis, this declaration was set up to support a flexible and personalised approach. The main ambitions of the declaration centre around the need for a multi-disciplinary approach to holistic care for people diagnosed with dementia alongside their families and carers to provide patient centred care.

5.6. Living Well with Dementia[54]

This is a dementia guide on the NHS website, to be used by everyone including people with dementia

and their carers. This gives general information about dementia, symptoms and diagnosis, living with dementia, care and support and ways for people to help. This also provides useful links and signposting for service users.

5.7. NHS England Dementia: Good Personalised Care and Support Planning[55]

This guidance is written by NHS England to provide information for primary care providers and commissioners. The aim of the guidance is to help improve care planning in dementia by reducing local variation and forming a standardised approach. Despite this being useful for CCGs and commissioners, the main target audience are GPs who provide care plan reviews for patients.

5.8. Royal College of Psychiatry – Dementia care pathway[56]

The Royal College of Psychiatry have a dementia care pathway. This takes information from NICE guidelines, NHS England (NHS Dementia Well Pathway) and Prime Minister's Challenge. This outlines the pathway to help support the delivery of care around people with dementia or mild cognitive impairment (both medically and socially). One of the main aims of this is to standardise timely diagnosis and post diagnostic care (for patients and carers).

The benchmarks for the Dementia Care Pathway are:

1. Achieve and maintain a diagnosis rate of at least two-thirds
2. Increase the number of people being diagnosed with dementia and starting treatment within 6 weeks of referral
3. Improve the quality of post-diagnostic treatment and support for people with dementia and their carers

The following steps of the Dementia Care Pathway include:

- Presentation
- Investigation
- Referral
- Pathway commences -> Memory assessment service
- Assessment made -> Pathway stops
- Review

The pathway also includes valuable considerations for commissioning and service development, to guide local systems.

5.9. Royal College of Psychiatry - Young Onset dementia in mental health services; Recommendations for service provision[57]

This report recognises that a person with young-onset dementia (YOD) and their family will often have complex diagnostic, management and personal needs and it is important that these needs are met in a timely and effective way.

The primary message is that the needs of patients with YOD in the care of mental health trusts are best met by a dedicated specialised service which actively links with the wider clinical and social network of specialties and services, signifying the diverse needs of this patient group. A central component of these specialised services will be staff with the right combination of expertise and training.

5.10. Care Quality Commission (CQC) Inspection Standards[58]

In the UK the CQC are responsible for monitoring, inspecting, and regulating all care providers. This includes care homes, hospitals, and primary care providers. They inspect and regulate services to make sure they meet fundamental standards of quality and safety and publish findings, including performance ratings, to help people choose care.

They set out what good and outstanding care looks like and make sure services meet fundamental standards below which care must never fall. Whilst these standards are not always specific to dementia, the standards they set will greatly affect all areas of care provided for people with dementia.

5.11. Care Quality Commission (CQC) – Cracks in the Pathway[59]

CQC have written a report about the cracks in the pathway of dementia care, particularly looking at people's experiences of dementia care as they move between care homes and hospitals. This was a thematic review in which they found dementia care across the country to be variable in quality and the need for improvement during transition between services. As a result, the CQC made some action to hold services accountable including appointing a specialist adviser for dementia care, training inspectors to understand good dementia care and including a separate section in hospital inspection reports showing how they deal with people living with dementia.

However, this report was dated in 2014 and no update following the actions made can be found.

5.12. Dementia Training Standards Framework[60]

Commissioned and funded by the department of Health and developed in collaboration by Skills for Health and Health Education England in partnership with Skills for Care.

Framework supports implementation and objectives for education, training and workforce development set out in the Prime Minister's Challenge. This aims to help guide a consistent delivery of dementia training and education to people in health and social care, enabling people with dementia to live better lives.

5.13. Department of health Dementia-friendly Health and Social care environments[61]

This guidance has something to say to everybody who is developing a new dementia service, but it is also as relevant to those people who are currently providing care and who may want to look at how they ensure their maintenance and refurbishment programmes deliver the very best environment in which to support people and enable them to have a good quality of life. This is an important document for all health and social care providers, and it should be the foundation for all development and refurbishment decisions.

5.14. King's Fund Environmental Assessment tools[62]

King's Fund in association with University of Worcester developed environmental assessment tools for people with dementia. There are different assessment tools for each care setting: care homes, housing, hospitals, wards and health centres. With the aim of the assessment tool to ensure the environment is dementia friendly. This work was funded by the Department of Health in response to the National Dementia Strategy and Prime Minister's Challenge on Dementia.

5.15. Leicester, Leicestershire, Rutland (LLR) Living Well with Dementia Strategy (2019-2022)[63]

This strategy looks to support those with dementia and carers for those with dementia, using NHS England Well Pathway for Dementia as a framework. It aims to improve experience of people throughout their journey with dementia.

This has been developed with various bodies coming together including local health, social care and voluntary organisations as part of the Dementia Programme Board. This is chaired by the local authority and NHS commissioners. The principles of which are guided by NICE guidelines, the Organisation for Economic Co-operation and Development framework for Dementia and the Dementia I-statements from the National Dementia Declaration.

As it is guided by the NHS England Well Pathway for Dementia, similarly it is divided into:

- Preventing Well
- Diagnosing Well
- Supporting Well
- Living Well
- Dying Well

It has also listed the achievements of the previous LLR strategy of 2011-2014, following on from that it has outlined the plan for 2019-2022. This includes the specifics of the action, the responsible party, guiding principle and timeline. The next strategy is due in 2022.

5.16. Leicestershire dementia friendly guide[64]

This is a practical guide targeted for people living with dementia in Leicester, Leicestershire and

Rutland. This has been compiled by the Joint Chairs of Leicester, Leicestershire and Rutland Dementia Action Alliance. The aim of this guide is to help those living with dementia and their carers by increasing awareness and accessing information nationally and locally. The guide includes information about what is dementia, planning post diagnosis, living with dementia, care & support needs, planning for end of life, legal & financial affairs, local dementia support and useful organisations.

5.17. Leicester Leicestershire Rutland Carers Strategy: (2018-2021):

This strategy is implemented by Leicestershire County Council with a wide range of aims to target. This includes:

- Early identification of carers and recognition of caring roles
- Carers being valued and involved
- Carers are informed
- Carer friendly communities
- A life alongside caring
- Impact of technology products and the living space
- Support of the carers and young carers in particular.

However, in the time of writing this JSNA chapter a new carers strategy is due for review and update for 2022-2025.

5.18. University Hospitals of Leicester NHS Trust Dementia Strategy 2018-2020:

The trust has an aim to provide excellent patient centred care and support and has acknowledged this need in those with dementia. As a result, they have produced this strategy which is reviewed annually. The strategy used themes from the National Audit of Dementia in General Hospitals, Leicester, Leicestershire and Rutland's (LLR) Living Well with Dementia Strategy 2019-2022, Dementia Action Alliance, Dementia Friendly Hospital Charter (2014) and Alzheimer's Society Fix Dementia Care Hospital (January 2016).

The trust has made progress throughout the years in many regards to this including updating the Dementia Care Pathway, increasing the number of Dementia Champions and participating in the National Audit of Dementia Care in General Hospitals in 2016.

The Key strategic priorities of this strategy are:

- Governance
- Comprehensive Assessment of Patients
- Nutrition and Hydration
- Communication for families and carers

- Family and Carer Feedback
- Training for Staff
- Discharge and Transfers from Hospital

5.19. UHL Well Pathway for Dementia:

This is a pathway used by staff in University Hospitals of Leicester for patients with suspected or confirmed diagnosis of dementia. Like the NHS England Well Pathway it focuses on living well with dementia, supporting well with dementia, and dying well with dementia.

Main areas of focus are assessments, managing, supporting, discharging, and dying with dementia. This document also contains guidance on how to manage patients with suspected dementia.

5.20. Local Quality Standards

Adult Social Care commissioners monitor the care services that they contract, including the setting of standards of the services they provide to support people with dementia. The NHS also monitor the quality of care they provide locally.

Although not currently published, in 2018 the Commissioning Team within Adult and Social Care investigated what good dementia care should represent in care homes. The report is based on local and national knowledge and developed 9 key principles suitable for any care setting:

1. Strong leadership and governance with a clear organisational dementia care model
2. Personhood/feeling/relationship-based dementia care and support
3. Person centred care and support plans that address the needs of people with dementia
4. High level of expertise in dementia care across leadership team and workforce
5. High quality dementia friendly environment
6. High quality dementia specific meaningful activities and personal interactions
7. Inclusion of people with dementia within all care home environments
8. Expressions of distress and behaviours that are challenging are supported well
9. Strong partnership working

5.21. Dementia 2015 – Aiming Higher to Transform Lives (Report by the Alzheimer's Society)[65]

This guide has been produced by the Alzheimer's society for the use by a variety of organisations to help improve the quality of life of people with dementia. This is based on their annual survey of people living with dementia, other national policies and guidelines and extracting data from published evidence. It should be noted that the Alzheimer's society are a Charitable organisation whose focus is people diagnosed with dementia and those who care for them. As such their recommendations are aspirational and may not always be possible within a health system.

The guide focuses on:

- Improving diagnosis
- Support following diagnosis
- Support for carers of those with dementia
- Providing dementia friendly healthcare settings (in secondary care and in the community)
- Dementia training in the workforce
- Dementia friendly communities
- Research in dementia

As a result, they based several recommendations with the above outline, with specific targets to help improve the quality of life of people with dementia.

6. Current Services

There are many current services in Leicestershire focused on dementia. This chapter will be structured in the order of prevention, diagnosis, supporting, living, and dying with dementia (as per the NHS Dementia pathway). This chapter will focus on informing of current services available locally, to help highlight gaps in the services.

6.1. Preventing:

Preventative services for dementia locally are non-specific and broad in nature and as a result focus particularly on social determinants and modifiable risk factors. As a result, no specific preventative services regarding dementia were found. However, many services in the county focus on these social determinants and modifiable risk factors on a broader aspect that would minimise the risk of people developing dementia.

6.2. Diagnosis:

The services in this section focus on ensuring timely and accurate diagnosis in dementia.

- Primary care services
  People usually present to their local primary care services (i.e. General Practitioners) with symptoms or concerns about dementia.

- Memory assessment services
  Memory assessment services in Leicestershire are run by Leicestershire Partnership NHS Trust. This is a service where people are referred to for diagnosis of assessment for dementia and treatment where necessary. Referrals are usually made by general practitioners or other healthcare professionals. This service is run for Mental Health Service for Older People (MHSOP) and Young Onset Dementia Assessment Service (YODAS). Healthcare professionals in this service are either psychiatrists or specialist mental health nurses. These assessments can take place in a variety of settings including the person's home, acute hospitals or care facilities. At 23/11/21, the number of patients on the referral to treatment list was approximately 1000, of these 750 were waiting for their first appointment and 250 of these had an appointment booked within the following 4 weeks.

- Neurology and other acute medical specialties
  Acute medical specialities may diagnosis a dementia patient after investigations for related conditions or in addition to other conditions. In particular Lewy Body Dementia and Parkinson's disease may be picked up during neurology investigations.

6.3. Supporting:

The services in this section focus on providing health and social care support for people with

dementia.

- Inpatient services

  This works both with University Hospitals of Leicester (UHL) NHS Trust and Leicestershire Partnership Trust (LPT). UHL often have patients who have dementia as a co-morbidity and as a result have many guidelines and schemes to support these patients. LPT have specialist psychiatric wards, at the Evington Centre based at the Leicester General Hospital. They manage functional psychiatric conditions such as dementia. This particularly helps patients presenting with challenging behaviours.

- Community Mental Health Teams

  They provide a service for supporting people with mental health issues in the community. This can be a bridge to support patients, mitigating the need for admission to inpatient services.

- Local social care providers

  Many local social care providers are available, the full list of which can be found in the Dementia friendly guide

- Day services

  Many local day services are available, a full list of which can be found in the Dementia friendly guide

- Shared Lives

  A service for people to live with a family for a short period of time or provide daytime support eligible for people with a variety of care and support needs including dementia.

  The support the service users receives is based in the home of the carer, who is approved by the Shared Lives Service which is regulated by the Care Quality Commission (CQC).

  These placements can be long term, short term, or day support.

  The cost of the placements varies; however, some service users will be eligible for financial support dependent on their assessment. People will be eligible for a Shared Live placement dependent on care and support assessment completed by a social worker, and dependent on the availability of carers who will be able to meet the needs of the service user.

- Assistive technology and digital services

  There is a variety of assistive technology that can be used to help people with dementia. This can include alarms, telecare, and lifelines (community alarms).

Charnwood, Harborough, Hinckley & Bosworth, Melton and North West Leicestershire operate a lifeline service. Blaby has appointed an assisted technology project manager to look at an offer of assistive technology across the county.

Unfortunately, Oadby & Wigston district council does not operate their own lifeline service but there are other local and national providers covering the area.

Lifelines work by having a pendant that can alert the monitoring centre, and a lifeline alarm unit in the household alongside a secure coded key safe to allow safe access for support to the property where necessary. Some services also provide a fall detector.

Other digital services to help people with dementia can include calendar clocks, memo minders, locating devices and door/bed alarms. Leicestershire County Council website directs service users to where these additional products can be purchased.

- Lightbulb project
  This is a partnership between Leicestershire County Council's Adult Social Care and districts in Leicestershire and provides the assessment and applications for disabled facilities grants. The grants allow work to be done in people's homes to enable independence such as level access showers, grab rails, ramps, stairlifts and rise and fall baths. This helps to reduce the need for residential placements.

  Assessors also carry out "Housing MOT", to ensure the home is safe for the service user and make the necessary referrals providing the most holistic approach and relieving capacity for occupational therapists. The assessors have all had dementia friends training alongside training for the Herbert protocol.

  Recently they have secured funding to hire an officer to specifically deal with service users with dementia. Their role is to provide support and information for newly diagnosed people with low level adaptions at home and potentially a small grant towards this. They will also help to meet service users' specific needs, which is important especially due to the different types of dementia.

  They are also aiming to set up a library of assistive technology service users can try out and swap as needed, e.g. smart plugs.

- Admiral Nurses
  Admiral nurses are specialist dementia nurses who work in a variety of settings. They support patients and families with Dementia and their complex needs, providing one-to-one support, help and guidance. This has been established in partnership with Dementia UK, the service of which is run by donations.

There are two admiral nurses that cover specific parts of Leicestershire. One admiral nurse that covers Rutland and another that covers University Hospitals of Leicester (for the acute setting)

The admiral nurses in Leicestershire only operate in specific parts of the county, including Charnwood, South Blaby and Lutterworth.

The admiral nurse for Charnwood covers Beacon and Watermead Primary Care Network (PCN).

The other admiral nurse covers South Blaby and Lutterworth district.

The referral criteria in Leicestershire for carers focuses on helping carers with identifiable needs such as educational, emotional, coping strategies, conflict resolution around dementia and signposting to additional services.

There was an Admiral Nurse Service at LOROS to support families, staff and carers where the service user is a resident of LOROS. However, at the time of writing this they have retired and not been replaced.

6.4. Living with:

The services in this section focus on helping people with dementia to live a normal life as much as possible and in a safe environment in the community.

- Leicestershire & Rutland Age UK Dementia Support Service

  This is a service commissioned by Leicestershire County Council, the charity provides a service that supports people with Dementia and their families or carers. They provide social, practical and emotional support to help these people throughout their journeys with dementia.

  The variety of support they provide includes:

  -Personalised one to one support
  -Information session post diagnosis
  -Information, advice, and signposting
  -Social groups and activities
  -Informal carer learning sessions
  -Online and digital support

  They can also provide signposting to services: day care services, home care, personal assistants, handyman & gardening, respite, lunch clubs and Age UK business directory

- Age UK Leicestershire and Rutland

AGE UK is a local independent charity that helps to promote the well-being of all older people, by empowering older people with dignity, privacy and independence.
As a local charity it is supported by donations, partnerships, income from charity shops and charitable grants from trusts.

They provide a variety of targeted services for people with dementia across the county.
This includes:

-Community Activities for those Living with Dementia
-Community Resource Centres
-Day Care/Daybreak Care
-Maintenance Cognitive Stimulation Therapy – limited to certain parts of the county.

Age UK also has a drop-in support group for carers of people with dementia. This is based in Loughborough and occasionally the group arrange activities and guest speakers.

- Dementia Friendly Communities in Leicestershire
  Leicester, Leicestershire and Rutland have a Dementia friendly community to support individuals and organisations develop awareness and understanding across communities. This also helps to support those living with dementia, local strategy and future developments. The aim of this programme is to meet the targets of Prime Minister's Challenge on Dementia 2020, to make the daily living of people with dementia easier and more accessible. They work with a variety of local services in the county to provide information and support to help the local community, support people with dementia. It also allows people with dementia to easily access services in the community, such as transport and businesses.

  The Dementia Friendly Communities is a collection of partners who meet quarterly to implement the action plan. They have representation from health, adult social care, care homes, councils, faith groups, residential care, utilities, service users and emergency services.

  In the region this was previously called the Dementia Action Alliance but has rebranded alongside the national programme.

- Dementia friendly guide-Available here
  https://www.carechoices.co.uk/publication/leicestershire-dementia-guide/

- Leicestershire Information and Support Directory
  This is an online directory managed by Leicestershire County Council of local care and health

services. However, the directory is impartial, as a result the County Council does not endorse or recommend any of the organisations in the directory.

- Local Area Co-ordinators (LACs)
  They provide a mixture of services such as signposting and working with local people to help them get the support they require. This helps to reduce demand on health and social care by preventing people from reaching crisis points.

- Herbert Protocol
  This is a national scheme, locally delivered by the Leicestershire Police service. This Protocol was named after George Herbert, a veteran who suffered with dementia and died whilst missing on his way to his childhood home.

  This scheme works by filling in a form containing important information e.g. medication, mobile numbers, recent photograph. This form is then stored and can then be used as a risk reduction tool when a person with dementia goes missing.

- Local authority services
  Local authorities offer more general services to support people such as Community Services, Residents Support, Health and Leisure Services or Cultural Services that may be of use to dementia patients or their carers.

- Primary care services
  Primary Care offers services such as Social Prescribing or Health and Wellbeing Coaches that may support the non-clinical needs of people with dementia.

- Leicestershire Fire and Rescue Service
  They cover home fire safety checks for people living with dementia, mental health or any other users who would benefit. This occurs in small groups or one-on-one basis at a variety of settings and they are also part of the Dementia Friendly Communities. This is based at Loughborough Leisure Centre.

- First Contact Plus Leicestershire
  This is a partnership of services, that provides support and information to local people. The partnership involves GPs, police service, health bodies, voluntary groups, district & borough councils, and social care departments. It is an online tool helping adults find information about a range of services in Leicestershire. Although this is not dementia specific it does have a role in helping people with dementia.

- Leicestershire Libraries

  Local libraries in the county provide a variety of services to help people with dementia. Many of the staff are part of the Dementia Friendly Communities. They offer books suitable for people with dementia and organise activities for people with health and wellbeing issues such as support groups, befriending groups, book group and craft & chat sessions.

- Leicestershire Shared Reading

  This service delivers reading activities to help people with social isolation, including people with dementia.

- Voluntary Action South Leicestershire (VASL) – Your Local Charity
  VASL is an independent charity behind Support for Carers, which is based in Harborough. They run a variety of services to help a variety of people alleviating the burden of carers. Whether full time, or part time, formal or informal.
  Services include:

  -Telephone advice and support line from experienced professionals in confidence
  -Assistance in completing care related assessments
  -Information on carers' support groups
  -Access to website and self-help videos
  -Advice on caring, including financial and legal assistance

- 'Our House' - In 2021, the Team at the Academy for Dementia Research and Education (ADRE) opened 'Our House' on the Lutterworth College Site. At ADRE, support is provided to people in the early stages of dementia and their families and friends who are living in the community in Leicestershire. The aim being to support people to live independently for as long as possible.
- Support for Carers Leicestershire

  This is funded by Leicestershire County Council to provide a variety of services to support people in Leicestershire. As mentioned above VASL is the local charity that provided supplementary finance to Support for Carers to provide enhanced services that they do.

6.5. Dying well:

Many of the services described above also support people with dementia around the time of death, such as social care, housing, supportive living, and residential care homes. Many of these services support a range of service users and those mentioned above include specialist aspects focusing on dementia.

-LOROS

LOROS is a local hospice caring for people in Leicester, Leicestershire, and Rutland. It is a local charity

that raises its own money but also receives financial aid from the NHS. They deliver free care to terminally ill patients, their family and carers. LOROS provide training for dementia care for the end of life.

7. Unmet needs/Gaps

The evidence of local needs, both current and emerging indicates the following:

- Since 2015/16, the prevalence of recorded dementia in all ages in Leicestershire has remained in the 2nd highest quintile in England, reflecting a higher-than-average level of need for dementia services in the County. The crude recorded prevalence for dementia in those aged under 65 years in Leicestershire has remained significantly higher than the England rate since 2017.
- As age is a major unmodifiable risk factor for dementia, so is the number of people with dementia. Overall, between 2020 and 2040 the numbers of people aged 65 and over in Leicestershire with dementia is estimated to increase to 16,785; an increase of 64.5%. While in persons aged 85 years and over, the increase will be 86.8% (from 4,387 to 8,193). The highest increase is predicted to come in males aged 85 years and over which will increase by 109.7% from 1,234 to 2,588. This will generate a need to plan to increase the capacity of dementia services to meet this level of need in the future.

7.1. Preventing:

There is increasing evidence of the important role of prevention in addressing dementia.
Whilst there are a broad range of services available in Leicestershire that would contribute towards preventing dementia, gaps include:

Lack of provision of information on how to reduce the risks of developing dementia by making it clear the links between adopting healthy behaviours and dementia including:

- Raising awareness of the links between benefits of physical activity and dementia and other lifestyle behaviours including smoking, alcohol consumption, and healthy eating.

NHS health check uptake in Leicestershire is lower than the national average.
NHS health check uptake in LLR has been lower than the national average in recent years and varies between Leicester, Leicestershire and Rutland. Between the periods 2017/18 to 2021/22, the percentage of patients receiving an NHS health check were 35.6%, 24.2% and 22.6% respectively[66]. Not all those eligible for a health check received an invitation.

7.2. Diagnosing

Research evidence suggests that robust and timely diagnosis for dementia is important as this can enable the initiation of appropriate treatment as well as allowing individuals to plan their lives. In particular, it is important that people with suspected dementia are referred to a specialist diagnostic service (Dementia Quality standard Q5184) if reversible causes of cognitive decline have been

investigated, to enable dementia sub-types to be identified. Timely, accurate diagnosis and a care plan and review should be in place within the first year (NHSE dementia well pathway).

Whilst diagnostic services are in place in Leicestershire there appear to be some gaps as follows:

- The government aspiration is that the national average wait for an initial assessment (and starting treatment) should be 6 weeks following a GP referral - locally this gap hasn't been met and worsened during the COVID pandemic. Pre-pandemic, these targets were not being met, delays with brain imaging (provided by UHL) cited as a significant factor. Services were paused during the initial phase of the pandemic and have now resumed. LPT memory services are currently commissioned to deliver on an 18-week Referral to Treatment (RTT) pathway.

- In 2021 (up to March), the estimated dementia diagnosis rate for those aged 65 and over in Leicestershire was 61.2%, which is significantly lower than the benchmarking goal NHSE target of 67%. This was improving pre-COVID. Variations exist across the CCG (LLR) and county. GPs have been encouraged to diagnose in care homes using the DiaDem tool or gain advice via advice and guidance, this needs to be evaluated and promoted to increase dementia diagnosis rates.

- During the COVID period contact with family members has declined, as well as reduced face to face contact between patients and primary care professionals resulting in a decline in referrals for individuals with memory issues.

- Access to Scanning (as part of NICE recommended diagnostic testing) was an issue pre-COVID and has worsened during COVID. Scanning was avoided to some extent during the COVID period to prevent people needing to attend UHL and risk infection (COVID). Use of Scanning, in line with current guidance is increasing again. CT is routinely used, rather than MRI, which is the gold standard, as use of MRI would further add to waiting lists.

- Memory clinics, which provide diagnostic services were 'paused' nationally during the COVID pandemic which also had an impact.

- The Memory assessment service does not meet 'gold standard' (NICE guidelines or expected requirements) e.g. provides doctor and nurse clinical services but lacks occupational therapy and wider services.

- NICE guidance is currently reviewing the use of drugs e.g. Aducanumab (guidance due to be published May 2022) for mild cognitive impairment and dementia, however due to the potential requirement for lumbar puncture this would further add to waiting times.

- Care plans/reviews - In Leicestershire, for the last 3 time periods, significantly fewer dementia patients and their carers had received a review, in the last 12 months, when compared to the national average. This process has been affected by COVID.

7.3. Supporting

The guidance (see evidence section) reinforces the importance of supporting services in place for individuals suffering from dementia (and their carers).

Whilst there are a number of support services in place, there are some gaps in provision and potential unmet need as follows:

- Variations in access to service, for example Admiral Nurses, which provide support to carers and family members as well as those affected directly by dementia, are available in some parts of the county and not in others. It may be that there are gaps in providing this type of service across the county that could be considered.

- Post diagnostic support currently provided by Age UK offers NICE recommended interventions such as Maintenance Cognitive Stimulation Treatment only in certain areas of the county. This needs to be provided across all areas of the county.

- Accommodation: There is a need for more accommodation for those with complex needs related to dementia including 'behaviours that challenge'. The Evington centre is in place, but services are costly. A business case has been submitted to help to address this through the building of a new care home in North West Leicestershire anticipated in 2024. Continuing healthcare funding/support may help to address this issue of complex needs accommodation and care.

- Support for carers – Carers feel under strain and can find the system difficult to navigate to gain support. For example, it can be challenging for carers to meet thresholds for social care support, particularly for those who don't have a strong voice – it may be that an advocate is needed in some cases to enable dementia patients and their carers to help access support to have their needs met

- There are many community-based services that are self-funded by donations or charity work. As a result, there appear to be variations in service provision across different parts of the county. This may reflect inequalities across the county.

- There is a need to assess the impact of COVID-19 on those with dementia and their families and the provision of care and support when people have been affected. In particular, there is need to effectively meet the requirements of those with dementia e.g. COVID guidance not being developed to meet the needs of people with cognitive impairment in a sensitive

and appropriate manner. Recognition of impact on staffing on enabling people with cognitive impairment to be tested for COVID, respond to guidance etc.

7.4. Living Well

- Awareness raising and training of the workforce with respect to dementia is an area identified as a gap, particularly in social care.

- Within Adult Social Care services, there are 'dementia care' gaps including where to accommodate people with complex needs.

- Care Quality Commission concerns have been raised in residential care, in nursing and care homes (over 65s) - Over the past 3 time periods, Leicestershire has deteriorated from performing significantly better than the national average in 2018, to significantly worse than the national average in 2020. A Pilot study (quality improvement scheme) started to improve care of people with dementia, there is a care home sub-group that deals with this.

- COVID impact – lack of social contact and connectivity is recognised as important for people with dementia. 'Dementia Friendly Communities' have been supported in some parts of the county.

- Dementia care plans for patients and their carers are not being put into place or reviewed regularly (referred to above).

- The Quality of nursing and residential beds in Leicestershire has declined to below the national average.

7.5. Dying Well

- Gap identified in workforce training (included adult social care) in respect to dementia.

- Education around Dementia is required for staff involved in palliative care, but also other staff in primary and secondary care. Needs may be different at 'end of life' in patients with dementia, and communication may be more challenging. Encouraging early discussions around advanced care plans may help with this. Having early conversations about future planning including 'dying well' is perceived to be a gap. However, discussions around care plans should routinely be covered in 12-month reviews.

Legal considerations:

- There are concerns that important considerations for those affected by dementia such as Lasting Power of Attorney 'should be put into place earlier than tends to be the case'. Also changes due to come into place regarding Deprivation of Liberty safeguards – mental capacity act – will require systems change, although this is broader than just dementia.

Needs of Specific Groups:

- The rate of dementia is much higher in individuals with learning disabilities such as Down's Syndrome. This can generate additional needs in terms of communication, plus life expectancy is shorter so these events occur earlier than we might expect in the general population. There may be a need to raise awareness of this higher level of need.

- There are gaps in strategic leadership, awareness and knowledge in specific groups affected by dementia including: younger people, those in prison, Veterans and BME communities.

8. Recommendations

8.1. Prevention:

People accessing behaviour change interventions and programmes in mid-life are advised that the risk of developing dementia can be reduced by making lifestyle changes:

- Integrate dementia prevention messages into other disease prevention strategies focussed on behaviour health improvement.

- Integrate dementia prevention messages into health behaviour programmes related to smoking, alcohol, physical activity and healthy eating.

- Improve NHS health check uptake to help ensure that key dementia related messages are aimed at those in mid-life.

8.2. Diagnosis:

- Call to action: improve dementia diagnosis rate to meet NHSE target (67%) – explore opportunities to address variations in diagnosis rates across the county building on GP training and other measures underway pre-COVID to support primary care in improving diagnosis rates.

- Encourage GPs to diagnose in care homes using the DiaDem tool or gain advice via advice and guidance, this needs to be evaluated and promoted to increase dementia diagnosis rates.

- Consider opportunity to ask dementia screening questions in settings other than GP consultations e.g. nurse led clinics with patients at increased risk (diabetes and hypertension clinics).

- Ongoing capacity and demand work underway by LPT needs to be completed and shared with commissioners on the basis that a 6 week referral to treatment is considered for commissioning. Alongside this there would be a need for the pathway around brain imaging and treatment to be reviewed to determine if the pathway can be reconfigured to enable the 6 week target to be met.

- Consider addressing shortfalls in Memory assessment services to meet NICE standards, recognising challenges in workforce recruitment.

8.3. Support services:

- Variations in access to dementia related support services across county should be addressed.

- Explore opportunities to ensure a consistent level of funding for dementia related support services is available across the county e.g. where reliance on voluntary sector provision.

8.4. Carers:

- Explore further challenges and issues for families, carers, and other informal carers. Consider use of advocates to support carers (or individuals affected) to secure access to support/funding.

8.5. COVID impact:

- Work with care providers to develop guidance/support specific to the needs of those with dementia. This should include areas such as IPC /safeguarding. Consider ensuring that staff e.g. IPC/safeguarding have training/awareness of the needs of this specific group.

- Implement Dementia Training provision for key workers including adult social care – link with Dementia Training Standards Framework. Develop joint approach across LLR and statutory organisations in relation to dementia learning and development.

- Seek to address maintenance of social contact for people with dementia through situations like COVID.

8.6. Living well

- Explore opportunities to improve frequency of care plan reviews in line with guidance (annually).

- Re-instigate quality improvement scheme exploring a joint approach to quality within care settings, in relation to supporting people with dementia.

- Consideration of accommodation provision for those with dementia including those with complex needs – support existing business case.

- Support further development of 'dementia friendly communities' in Leicestershire and explore links with evolving neighbourhood developments around 'mentally friendly communities' in the County.

8.7. Dying Well:

- Loros have developed tools to support palliative care with dementia – there is a gold standard tool – consider adoption.

- Support adoption of advanced care plans including palliative (health).

- Support adoption of early conversations about future planning including dying well.

- Continue to raise awareness of impact of benefits of putting plans in place at an early stage through post diagnostic service.

- Deprivation of Social Liberties: Implement the guidance when published (April 2022).

8.8. Other Considerations:

- People with learning difficulties: There is a need to consider additional dementia awareness and training to make sure that specific needs related to dementia can be addressed.

- Raise awareness of dementia in younger people, Veterans, those in prisons and BME communities.

GLOSSARY OF TERMS

ACD	All cause Dementia
APS	Annual population survey
BAME	Black, Asian and Minority ethnicity
BMI	Body Mass index
CCG	Clinical Commissioning Group
CHD	Coronary heart disease
CQC	Care Quality Commission
CT	Computed Tomography
DLB	Dementia with Lewy bodies
FTD	Frontotemporal dementia
GP	General Practitioner
HRT	Hormone replacement therapy
KPI	Key Performance Indicator
JSNA	Joint Strategic Needs Assessment
LGBTQ	Lesbian, Gay, Bisexual, Transexual and Queer
LLR	Leicester, Leicestershire and Rutland
LOROS	Leicester Organisation for the relief of suffering
LPT	Leicestershire Partnership Trust
MCI	Mild cognitive impairment
MRI	Magnetic resonance imaging
MSOA	Middle Super Output Area
NHS	National Health Service
NHSE	National Health Service England
NICE	National Institute for Health and Care Excellence
PHE	Public Health England
POPPI	Projecting older people population information
QOF	Quality outcomes framework
RTT	Rapid Transformational Therapy
TIA	Transient Ischaemic attack

UHL	University Hospitals of Leicestershire
VASL	Voluntary Action South Leicestershire
WHO	World Health Organization

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