Appendix 2

JSNA DEMENTIA

Topic Specific Report

Final Draft

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Public Health

Table of Contents

Executive Summary **2**

Recommendations **6**

Background **6**

Aims and objectives 6

What is Dementia and what is the impact of Dementia? 7

Types of Dementia 7

Dementia Indicators **9**

Prevalence of Dementia 9

Hospital admissions due to Dementia 13

Mortality due to Dementia 18

Other Dementia indicators 24

Risk factors for Dementia 25

Dementia support and services - Wolverhampton **29**

GP Records - Graphnet **29**

CareFirst – Clients with Dementia **32**

Client Demographics 32

Care package distribution 35

NHS Dementia Clusters **37**

Care clusters definitions 37

Patients registered to all clusters 37

Patients within clusters 39

Stakeholder Views **41**

Methodology 41

Survey for people diagnosed with Dementia 41

Survey for people caring for a person with Dementia 49

Survey for professionals working with people with Dementia 56

To be added:

Service Mapping

Executive Summary

Dementia Key Indicators

- **Since 2014-15, the prevalence of Dementia in all ages in Wolverhampton (0.82%) has been significantly higher than the prevalence in England and the West Midlands. Similarly, the prevalence of Dementia in Wolverhampton in the over 65 population (5.04%) is significantly higher than England (4.33%), West Midlands (4.21%) and the Black Country (4.43%).**
- In England, the highest prevalence figures of Dementia are seen in the most deprived deciles, between 4.60% and 4.75% in the three most deprived deciles, compared to 4.16% in the least deprived decile.
- **The number of Wolverhampton residents aged over 65 predicted to have Dementia, is projected to increase by around 47.2% between 2017 (3,194) and 2035 (4,702).** The largest increase is predicted to be in the 90 and over age group, with figures predicted to increase two-fold. However, increase in Wolverhampton is predicted to be smaller compared to the national projections.
- **In Wolverhampton, the directly standardised rate (DSR) of emergency admissions that were for patients with Dementia in the over 65 population increased significantly in a 4-year period from 2,955 per 100,000 (2012-13) to 5,045 per 100,000 (2015-16). Current figures (4,458 per 100,000) in Wolverhampton are significantly higher than national and regional figures.**
- **The proportion of emergency admissions with Dementia which were short stays (defined as a stay of less than 1 day) in Wolverhampton increased significantly from 16.71% in 2012-13 to 30.70% in 2016-17.** Current figures are significantly higher than national and regional figures.
- The most recent data (2016) suggests that the rate of mortality in people with Dementia in Wolverhampton is significantly higher than national and regional figures, though this has not always been in the case in previous years.

GP Records

- **On GP records in Wolverhampton, there are 2,323 patients with a diagnosis of Dementia, of whom 1,441 are female and 882 are males. Over a quarter of these patients are aged between 85-89 years.**

Social Care

- **In Wolverhampton, social services have a record of 1,740 people in Wolverhampton with Dementia. There are 874 social care service users that have a diagnosis of Dementia, 601 service users are female and 273 service users are male. Each service user has an assigned care package.**
- **Of the 874 social care service users with Dementia in Wolverhampton, 306 live in the community either with family or in their own homes and 568 live in residential or nursing homes.**
- The most provided care packages are Domiciliary Care (201) and Residential Care (232). There are also a significant number of packages for Nursing (112) and Day Support (71).

NHS Clusters

- **In Wolverhampton, there are around 1,250 patients registered to a NHS Mental Health cluster that is indicative of a diagnosis of Dementia. Just under half of all patients are in the 80-89 year age group.**
- **Just over half of all patients registered to a cluster that suggest a diagnosis of Dementia fall into cluster 19. Patients in Cluster 19 are characterised by having moderate needs.**

People with Dementia Engagement

- **There were 52 surveys returned from respondents that had been diagnosed with Dementia, of which 1 survey was completed online and 51 surveys were completed on paper.** Of the 52 respondents, 35 reported their gender as female, 13 as male and 4 left the question blank.
- **The majority (60%) of people with Dementia that responded to the survey said they were living well with Dementia.** However, over a fifth (21%) stated they were not living well with Dementia.
- **Around 69% of respondents said they had enough family and friends around them that they could count on for support. But less than half of respondents (44%) said they felt involved enough with decisions about their care and support.**
- **Under a third of respondents (31%) said they had used a Dementia café over the past three years. The most common reasons why the 67% of respondents had not used a Dementia Café included:**
    - **Have never heard of it**
    - **People with Dementia struggle to get out of the house - so cannot attend**
    - **Carers or family members unable to take them due to the opening times.**
- There were a mixture of positive and negative comments about Dementia Café's when respondents were asked what was or was not, useful about them. The positive comments centred around the social aspect of the service; **the negative comments centred around logistic issues and age of attendees.**
- **Around 42% of respondents said they were able to make decisions about how they spend their time on a general day to day basis**, however, 37% said they were not able to make those decisions and 17% said they did not know.

Carers of people with Dementia Engagement

- **The 83 respondents consisted of 51 females, 24 males and 8 who either left their gender blank or said that they preferred not to say.** The 83 respondents cared for 44 Females, 28 Males and 11 people whose gender was not stated, all of whom were living with Dementia.
- 37% of carers were the spouse of the person with Dementia being cared for and 34% were the child. More than half of carers (57%) had been caring for the person with Dementia for more than 3 years.
- **More than a third of carers (37%) said they found getting information of services to support them 'Quite' difficult and a further third (33%) found it 'Neither easy nor difficult, just OK'.** The most selected reasons for finding it difficult to get hold of information were:
    - Not knowing where to get the information needed
    - Not knowing who to ask for the information needed
    - Not being told about something until it's too late
    - It takes too long to actually receive the information you need
- The most commonly used services identified by respondents were Dementia Café's, Carer Support, Memory Clinics, Social Services and Nursing Teams.

- **Although most respondents did not find services difficult to access, a common theme among reasons for finding it difficult to access services was that carers were unable to get the information required to access services from professionals, requiring them to either find the information themselves or get in contact with other support services to obtain the information.**
- **Respondents that found Dementia Café's the most useful support, said they found the social aspects for people with Dementia useful, helped lift spirits, gave them somewhere to go and provided useful information.**
- **When asked about needs that were not met, carers said there was a lack of support for carers when exploring their options for services and care homes, with one respondent suggesting there should be a carers information support programme that is available in other areas.**
- More than two-thirds of carers (69%) said there were no cultural or social issues that got in the way of the care they provided. However, 31% stated that there were cultural or social issues.

Professionals working with Dementia engagement

- **There were 24 responses from professionals that work with people with Dementia. Of these responses, 19 were completed online and 5 were completed on paper.** Respondents were from a variety of services. **Ten of the 24 respondents** were managers within their services.
- **Nine respondents did not think the additional needs of people with Dementia using their services were being met.** The themes within the comments for this question included: **Services not able to be proactive when personalising services, individuals isolated due to lack of social facilities and the need for a carers information programme.**
- Fourteen respondents said they thought their service did meet the needs of adults currently using their service and four respondents said they did not think the needs were being met. **The comments provided by those that didn't think the needs were being met included: more courses and information programmes for carers required, more personalisation of services is required, a Dementia Café aimed at younger people with Dementia required and more staff/multi-agency working is required.**
- **Twelve respondents said that they were not aware of any changes or new trends in the needs for their current clients** and seven respondents said they were aware of changes or new trends. Five respondents said their service had the right skill mix and capacity to meet the future need. However, 9 mentioned they did not and provided comments on what they needed.
- **Some respondents said there were certain groups of people with Dementia that do not use their service but could benefit from extra support. These groups of people include those with early on-set Dementia, limited mobility and vision impairment, as well as carers and people from ethnic minorities.**
- Eight respondents said there were some cultural issues that needed addressing when working with their clients, which included:
    - **Meeting cultural and religious needs by creating more links with religious organisations**
    - **Encourage people with BME backgrounds to use services**
    - **Need to reach out to hard to reach communities, such as homeless and LGBT communities**
    - **Need a more ethnically diverse specialist workforce**

- **Improve awareness of services among communities where sight loss might be more prevalent**

Recommendations

- Raise awareness of services available to people with Dementia and their carers, in a formal, well-structured manner, especially among those with an ethnic minority background and those who may be harder to reach, such as LGBT and homeless.
- To provide and/or raise awareness of services which support those with Dementia and sight loss, whilst simultaneously raising awareness of the association between Dementia and sight loss.
- Increase awareness and provision of Dementia Café's. Increase provision of Dementia Café's for younger people with Dementia, aged under 65.
- Introduce provision of a Dementia friendly transport service, in order to improve accessibility of Dementia services.
- Service providers should aim to provide care/services that are personalised for the individual with Dementia and ensure their needs are considered when providing their service.
- Service providers need to ensure they are prepared to support an increasing number of clients and ensure that staff are better informed, by increasing the amount of support and training provided, especially for lower graded staff.
- Service providers should aim to provide forward thinking community based activities, support services and training to enable staff to help people continue to connect with the world, rather than 'just holding' people with Dementia.
    - What community assets do we have that could contribute to this?

Population group whose needs are to be assessed

This needs assessment will examine the needs of people with dementia and their family carers living in the City of Wolverhampton. This includes the area covered by the Royal Wolverhampton Hospital Trust and Wolverhampton Clinical Commissioning Group (CCG).

Aims and objectives

The overall aim of this Dementia needs assessment is to assess whether the services for people with dementia, their families and/or carers are meeting the current need and any future needs that may arise. The objectives of the needs assessment are to:

1. Determine the scope of dementia in Wolverhampton, through descriptive and comparative epidemiological analysis.
2. Map dementia services currently provided in Wolverhampton and identify potential gaps in provision.
3. Review evidence of best practice.
4. Conduct stakeholder engagement, including professionals that work with people with Dementia, those caring for people with Dementia and those diagnosed with Dementia, to identify the needs and discuss potential solutions.
5. Frame recommendations for processes that would address the unmet need identified, which would improve the quality of life of people living with dementia and those that care for them.

The 'need' of a population for a service can be defined as the capacity to benefit from that service. However, this may differ from a demand for a service or the supply of a service. This needs assessment aims to outline the needs of the population and consider any inconsistencies between need and supply.

What is Dementia and what is the impact of Dementia?

Dementia is a syndrome most commonly seen in older people and is characterised by impaired cognitive function. World Health Organization (WHO) define Dementia as *'Dementia is a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.' [http://www.who.int/en/news-room/fact-sheets/detail/dementia]*

Dementia is one of the world's major causes of disability and dependency in older people. It has an impact on the quality of life of not only those that have Dementia, but of their families and carers too. The Impact on carers and family can be physical, psychological, social and economical. There is often a lack of awareness and understanding of Dementia, which can result in stigmatisation of the disease and barriers to care and diagnosis.

Worldwide, the number of people with Dementia is estimated to triple by 2050. In 2015, the cost of Dementia to the global community was $818 Billion and is estimated to cost $2 Trillion by 2030. *[http://www.who.int/mediacentre/factsheets/fs362/en/]*

Types of Dementia

Alzheimer's Disease

Alzheimer's disease is the most common cause of dementia. There are thought to be more than 520,000 people in the UK with Alzheimer's disease. The disease causes proteins to build up in the brain to produce structures called plaques and tangles, causing the loss of connections between nerve cells, eventually leading to the death of nerve cells and loss of brain tissue. Alzheimer's disease is a progressive disease, which means that over time, more parts of the brain are damaged.

The vast majority of people who develop Alzheimer's disease will develop it after the age of 65, however some people do develop Dementia before reaching the age of 65. This is known as early-onset Alzheimer's disease, which is often reported under the umbrella term 'early onset dementia'. There are over 40,000 people with early onset dementia in the UK.

Age is the greatest risk factor for Alzheimer's disease. Above the age of 65, a person's risk of developing dementia doubles every 5 years. There are about twice as many females as males who have Alzheimer's disease, for which the reasons are not yet confirmed. This observation is not fully explained by the fact that women live longer than men, on average. Genetics can play a part in increasing the risk of developing Alzheimer's disease. A number of genes are known to affect a person's chances of developing Alzheimer's. In rare cases, early onset dementia can be passed down through generations of a family. Medical conditions such as diabetes, stroke, high blood pressure, high cholesterol and obesity in mid-life are all known to increase the risk of Alzheimer's disease. This risk can be reduced by keeping these conditions under control and adopting a healthy, active lifestyle.

Vascular Dementia

Vascular dementia is the second most common type of dementia and estimated to affect around 150,000 people in the UK. Vascular dementia is caused by disruption in blood supply to the brain. This disruption is due to diseased blood vessels, leading to the blood vessels leaking or becoming

blocked and causing brain cells to die. The death of these brain cells bring about the symptoms which are characteristic of dementia.

Vascular dementia can develop following a stroke. A stroke occurs when blood supply to the brain is suddenly cut off, due to a blood vessel in the brain either narrowing or being blocked by a clot. The severity of strokes depend on where the blocked vessel is and how long the disruption of blood supply is (could be permanent). This sudden disruption in blood supply reduces the oxygen supplied to the brain and leads to the death of a large volume of brain tissue. However, not everyone who has a stroke will develop vascular dementia, around 20% of people who have a stroke will develop dementia within the following six months. Consequently, once a person has suffered a stroke, they are at a higher risk of suffering another stroke, therefore increasing their risk of developing dementia.

Other types of vascular dementia include:

Single-infarct and multi-infarct dementia, which are caused by one or more smaller strokes. An infarct is a small area of brain tissue that has died due disruption of blood supply to the brain. A single infarct in an important part of the brain can cause dementia, but more often it is a number of infarcts spread around the brain that cause dementia (multi-infarct).

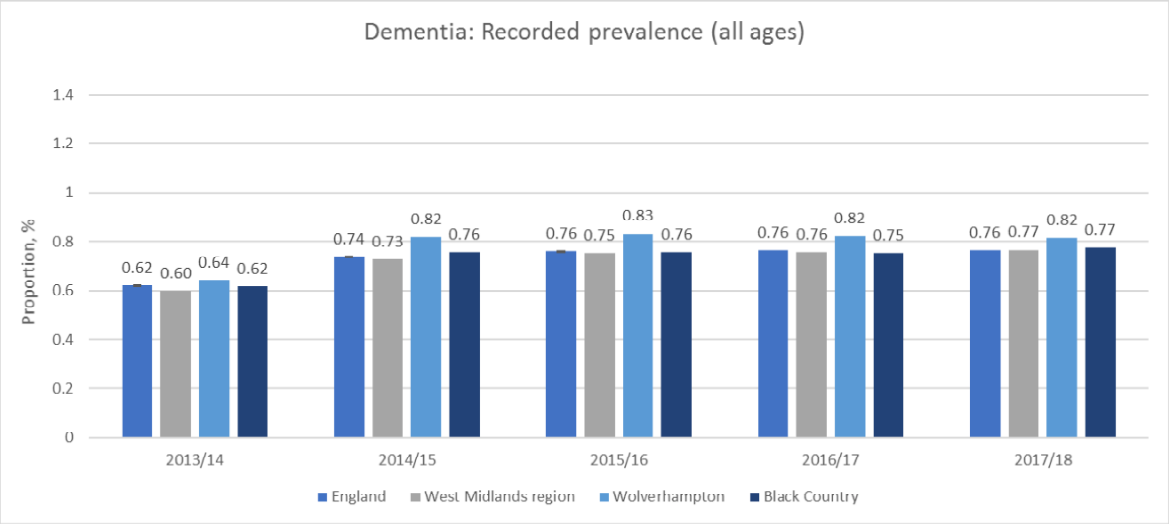
Subcortical dementia is caused by diseases of the very small blood vessels that lie deep in the brain, which cause them the vessel walls to thicken and vessels to become stiff and twisted. This causes damage to the nerve fibres that carry signals around the brain (white matter). It can also cause small infarcts around the base of the brain. Diseases of small vessels develop much deeper in the brain, compared to the damage caused by many strokes, therefore the symptoms are often different to stroke-related dementia.

Mixed Dementia

Around 10% of people with dementia are diagnosed with mixed dementia, which means that both Alzheimer’s disease and vascular dementia have caused the dementia. Symptoms of mixed dementia can vary between the symptoms of Alzheimer’s disease and vascular dementia.

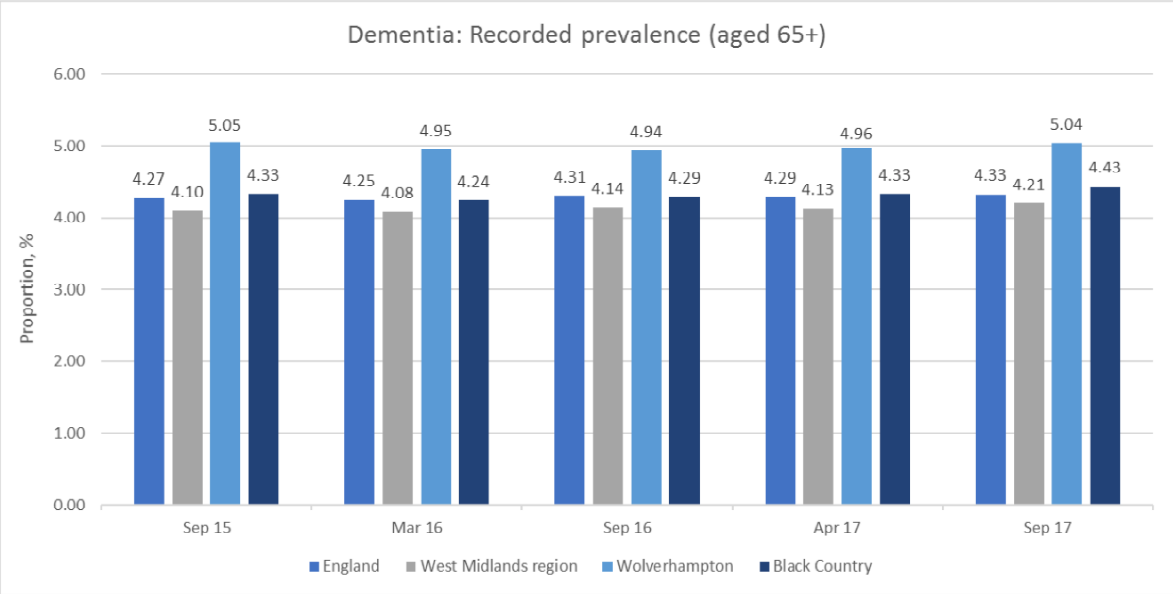
Dementia Indicators

Prevalence of Dementia



Source: Fingertips, PHE

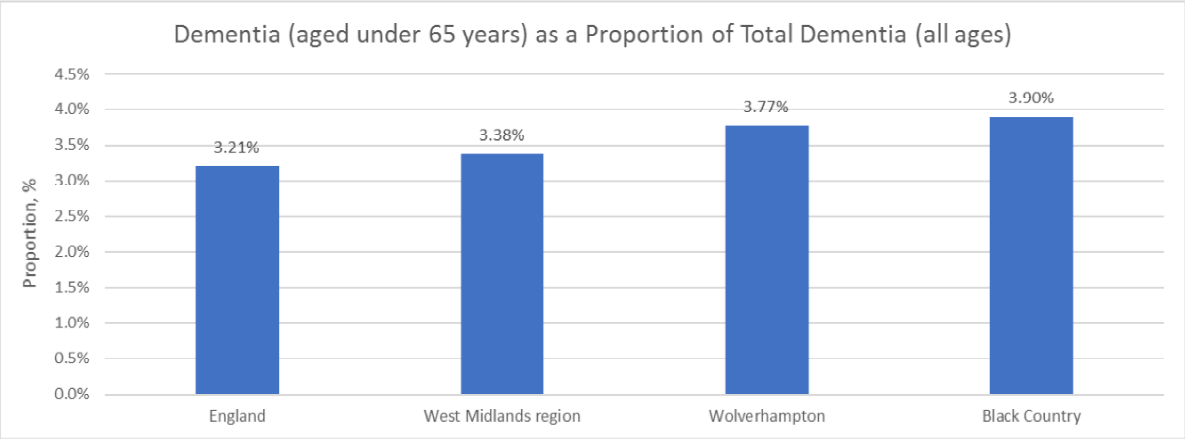
In Wolverhampton, the prevalence of Dementia in all ages has consistently been slightly higher than the prevalence in England, the West Midlands and the Black Country, however, this difference has only been statistically significant since 2014-15. In 2017-18, the proportion of the Wolverhampton population that had a diagnosis of Dementia was 0.82% (2,286 individuals), compared to 0.76% across England and 0.77% across the West Midlands. In Wolverhampton, the prevalence of Dementia increased significantly over a 5-year period from 0.54% (2011-12) to 0.83% (2015-16), an increase of 835 individuals and has remained steady since.



Source: Fingertips, PHE

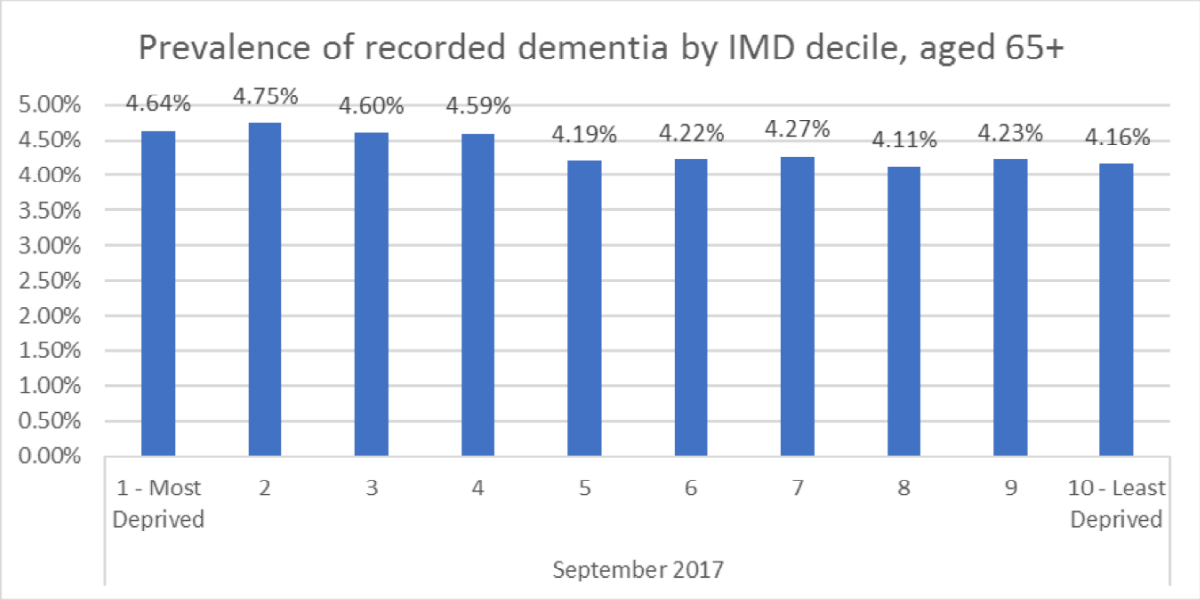
The prevalence of Dementia in Wolverhampton in the over 65 population has consistently been significantly higher than England, the West Midlands and the Black Country in the two-year period for which data was collected. In Wolverhampton, the proportion of over 65's with a diagnosis of Dementia has remained steady, ranging between 4.94% and 5.05%. The prevalence across England

and the West Midlands also remained steady across the two-year period, although the prevalence in England remained significantly higher than the West Midlands.



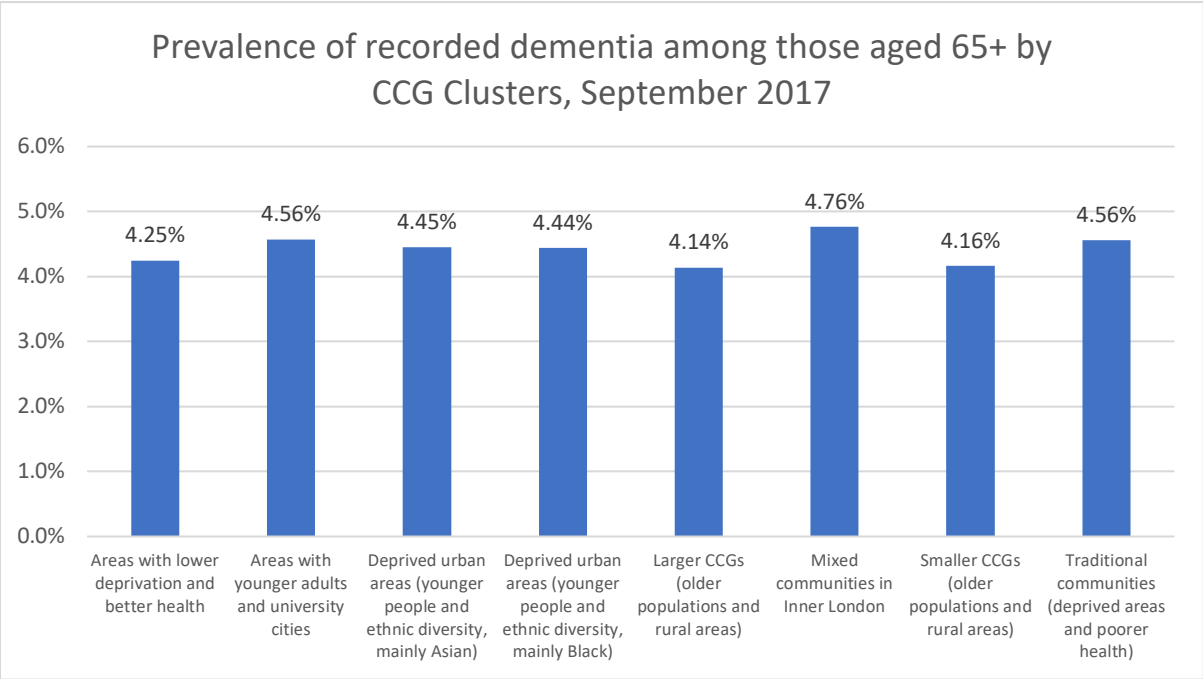
Source: Fingertips, PHE

As a proportion of Dementia in all ages, the population of under 65's with a diagnosis of Dementia in Wolverhampton is 3.77%, which is statistically similar to the proportion in England (3.21%), the West Midlands (3.38%) and the Black Country (3.90%). This accounts for 86 individuals in Wolverhampton, aged under 65 that have been diagnosed with Dementia.



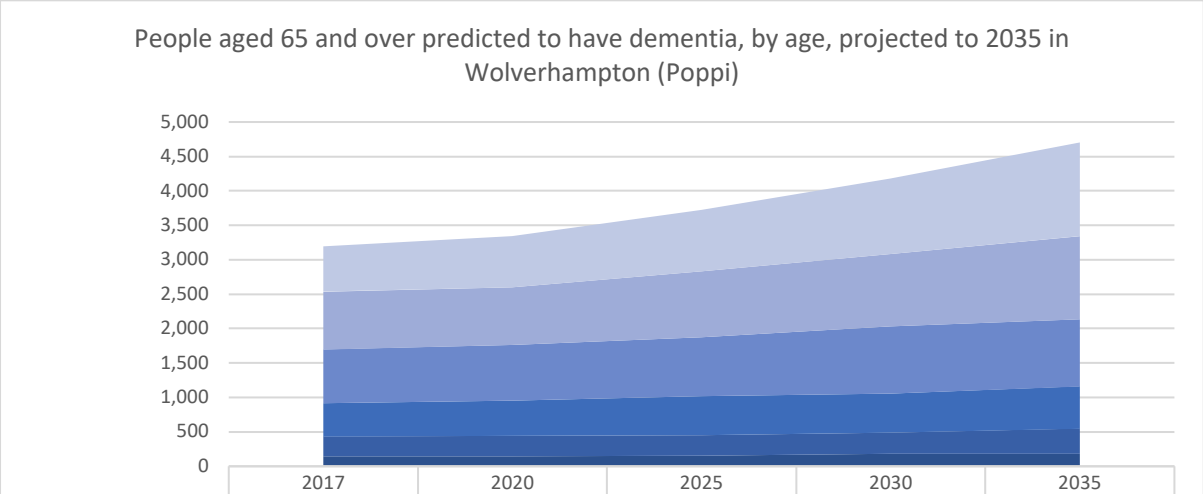
Source: Fingertips, PHE

The prevalence of recorded Dementia varies by Index of Multiple Deprivation in the 65+ population of England. This indicator is not available at Local Authority level, however in England the highest prevalence figures of Dementia are seen in the most deprived deciles, between 4.54% and 4.83% in the four most deprived deciles, compared to 4.19% in the least deprived decile. This trend remained similar at all three data points available: September 2015, March 2016 and September 2016.



Source: Fingertips, PHE

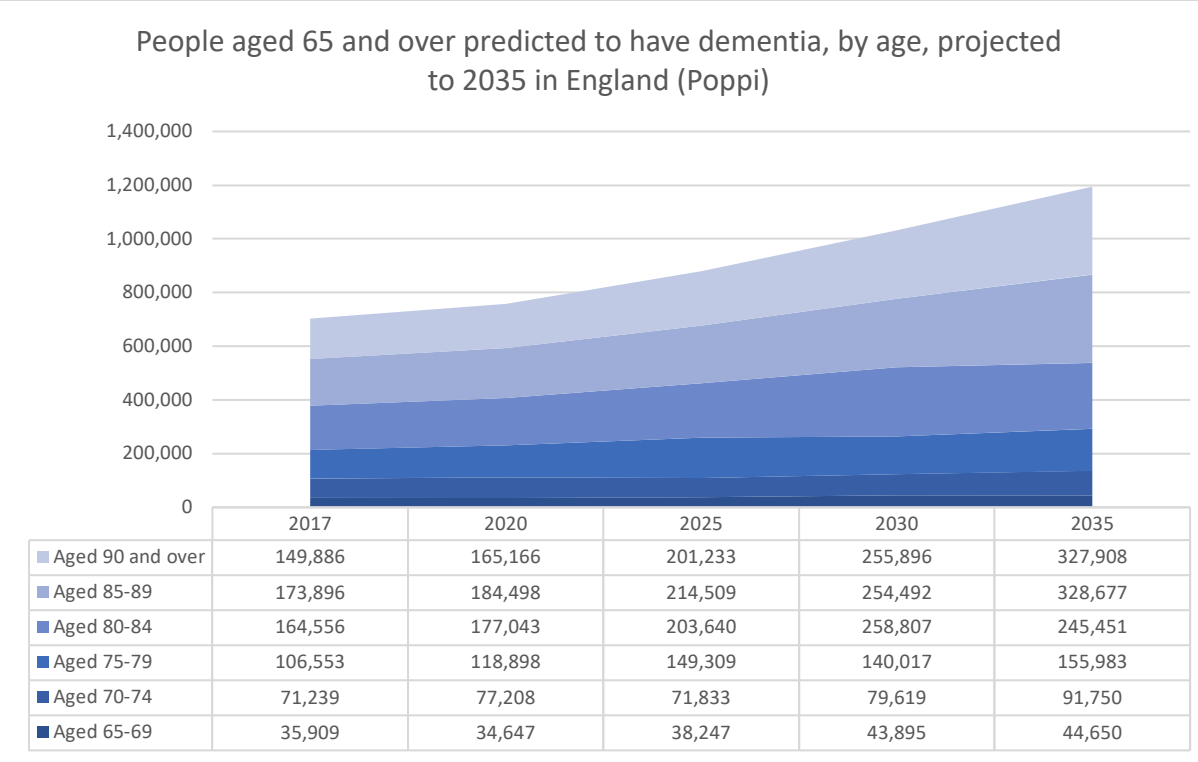
CCG Clusters are used to group CCGs with similar geographic and/or population characteristics across England. In England, the highest prevalence of Dementia is seen in 'Mixed communities in inner London' (4.76%), followed by 'Areas with younger adults and university cities' (4.56%). The lowest prevalence figures were seen in 'Smaller CCGs (older populations and rural areas)' (4.16%) and 'Larger CCGs (older populations and rural areas)' (4.14%). The characteristics of the population of Wolverhampton CCG would put it in the 'Deprived urban areas (younger people and ethnic diversity, mainly Asian).



	2017	2020	2025	2030	2035
Aged 90 and over	656	745	890	1,097	1,362
Aged 85-89	844	839	956	1,050	1,206
Aged 80-84	778	811	858	973	973
Aged 75-79	486	510	566	566	614
Aged 70-74	282	296	296	315	365
Aged 65-69	148	145	154	178	183

Source: Poppi

The number of Wolverhampton residents aged over 65 predicted to have Dementia is projected to increase by around 47.2% between 2017 (3,194) and 2035 (4,702). The largest increase is predicted to be in the 90 and over age group, with figures predicted to increase two-fold, from 656 in 2017 to 1,362 in 2035. The second largest increase is predicted to be seen in the 85-89 year age group, with an increase of 42.9% over the 18-year period.

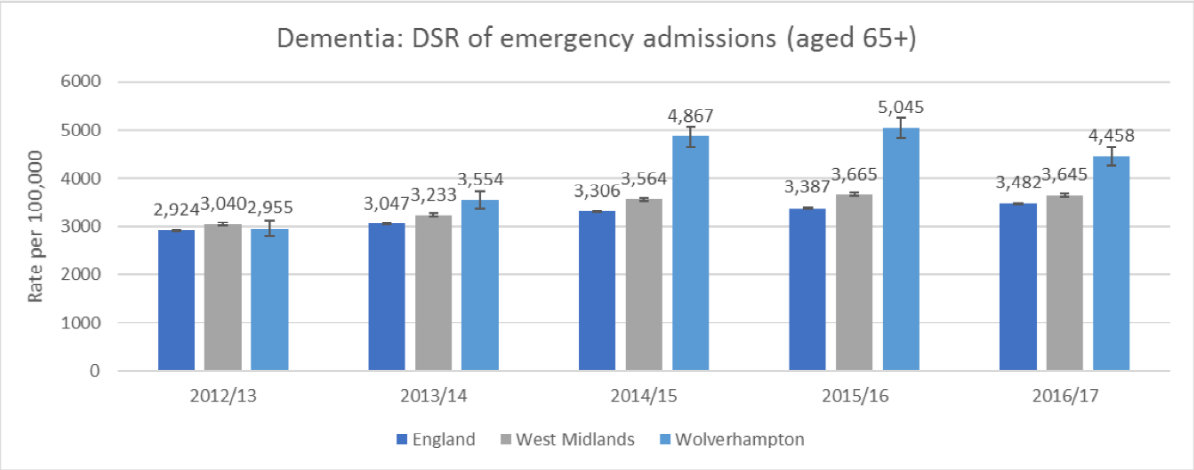


Source: Poppi

The number of people in England aged 65+ is projected to increase by 70.1% between 2017 and 2035, from 702,039 to 1,194,419. The largest increase is predicted to be in the 90 and over age group, with figures predicted to more than double over the 18-year period, from 149,886 to 327,908. The second highest increase is predicted to be in the 85-89 year age group, with an increase of 89.0%. The youngest age group presented, 65-69 years is projected to increase by 24.3% over the 18-year period.

The overall increase in Wolverhampton is predicted to be smaller compared to the national projections. The projections by Poppi suggest that the number of people aged over 65 predicted to have Dementia in England is to increase by 70.1% between 2017 and 2035.

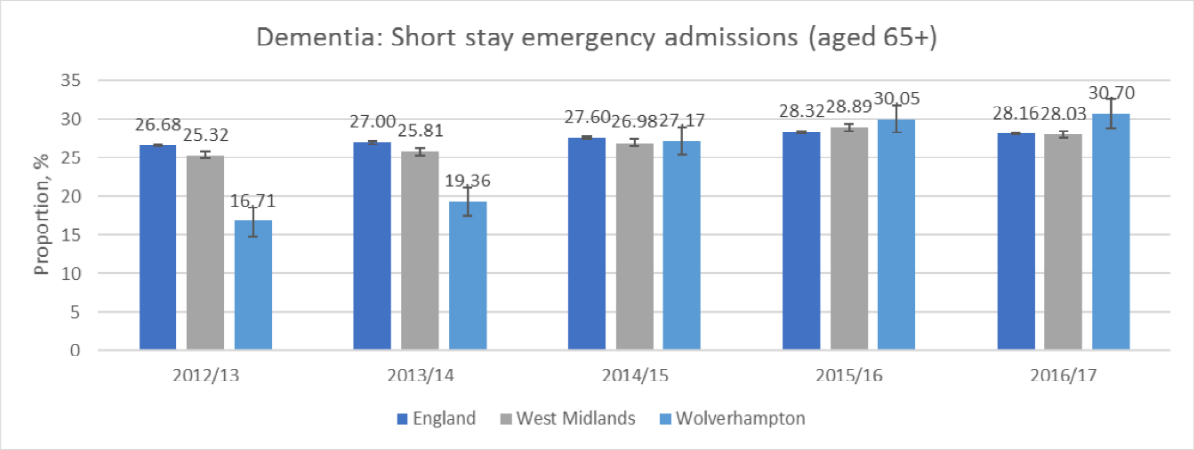
Hospital Admissions due to Dementia in Wolverhampton



Source: Fingertips, PHE

In Wolverhampton, the directly standardised rate (DSR) of emergency admissions with Dementia in over 65s increased significantly in a 5-year period from 2,955 per 100,000 (2012-13) to 4,458 per 100,000 (2016-17). In terms of numbers, the increase was from 1,307 in 2012-13 to 2,082 in 2016-17. The DSR for Wolverhampton consistently increased significantly between 2012-12 and 2014-15. In comparison to the England and West Midlands DSR's, in 2012-13, the Wolverhampton figure was not significantly different, however, the rate of increase over the following 3 years was much higher in Wolverhampton than England and the West Midlands. In the West Midlands, figure increased significantly from 3,040 per 100,000 in 2012-13 to 3,645 per 100,000 in 2016-17.

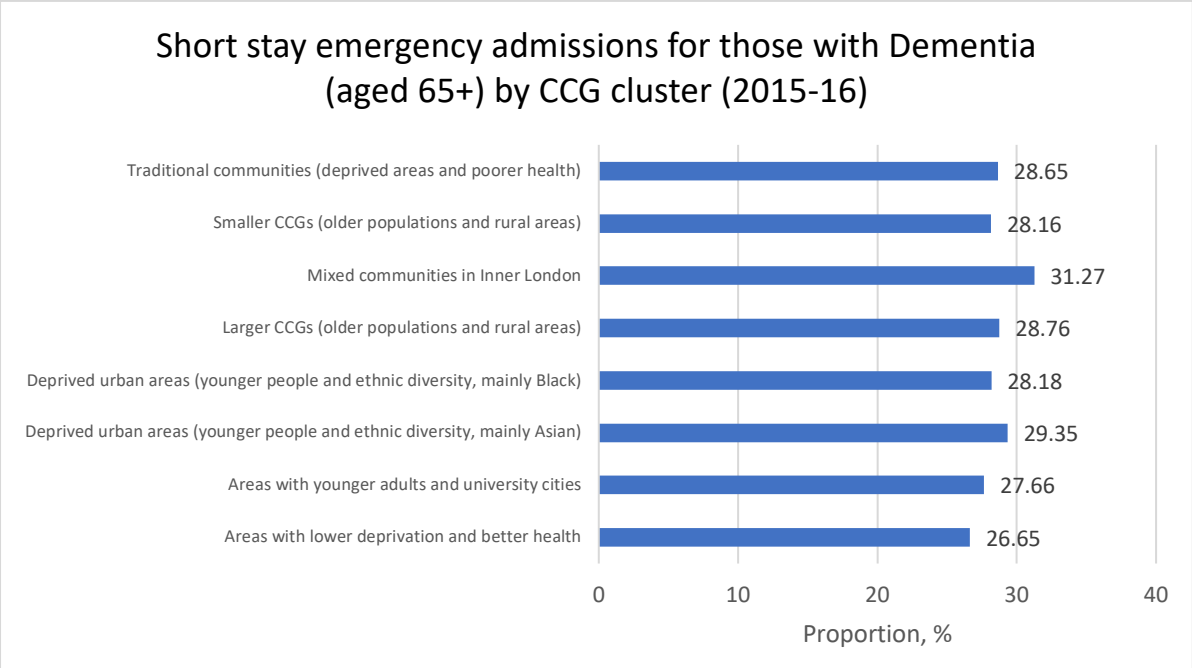
In England, the DSR for adults with dementia aged 65+ increased significantly year on year between 2012-13 and 2016-17. Overall, over the 5-year period, the rate of emergency admissions for Dementia in over 65's has increased by 16.0%, accounting for 558 admissions per 100,000 population.



Source: Fingertips, PHE

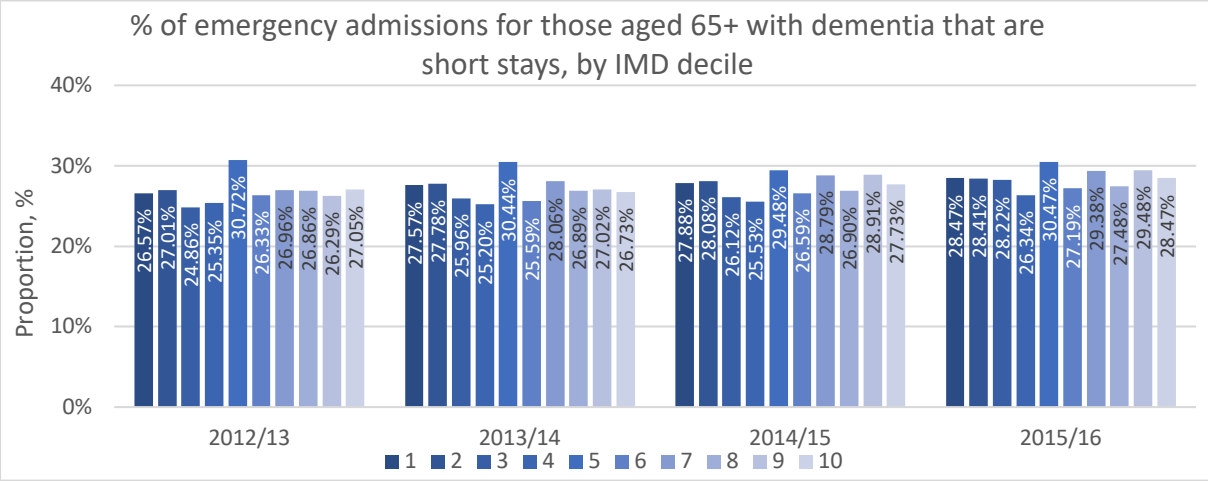
Short stay emergency admissions are defined as hospital admissions which last 1 night or less. Short stay emergency admissions are considered to potentially be detrimental to the health of individuals with Dementia. This is due to changes in the surrounding environment increasing the levels of anxiety and stress for an individual. Furthermore, people with dementia can be more susceptible to these changes, which can cause additional distress.

The proportion of emergency admissions for Dementia which were short stays (defined as a stay of less than 1 day) in Wolverhampton increased significantly from 16.71% (2012-13) to 30.70% in 2016-17. In terms of numbers this increase was from 243 in 2012-13 to 719 in 2016-17. The figures in England and the West Midlands also saw significant increases over the five-year time period, but at much smaller scales. In 2012-13 and 2013-14, the Wolverhampton figures were significantly lower than England and the West Midlands, however, following significant increases, Wolverhampton's figure in 2016-17 was significantly higher than England and the West Midlands figures. In England, there were two consecutive statistically significant increases in the four-year period, increasing from 27.00% in 2013-14 to 28.16% by 2016-17. Overall in England, there was an increase of 5.3% over the five-year period.



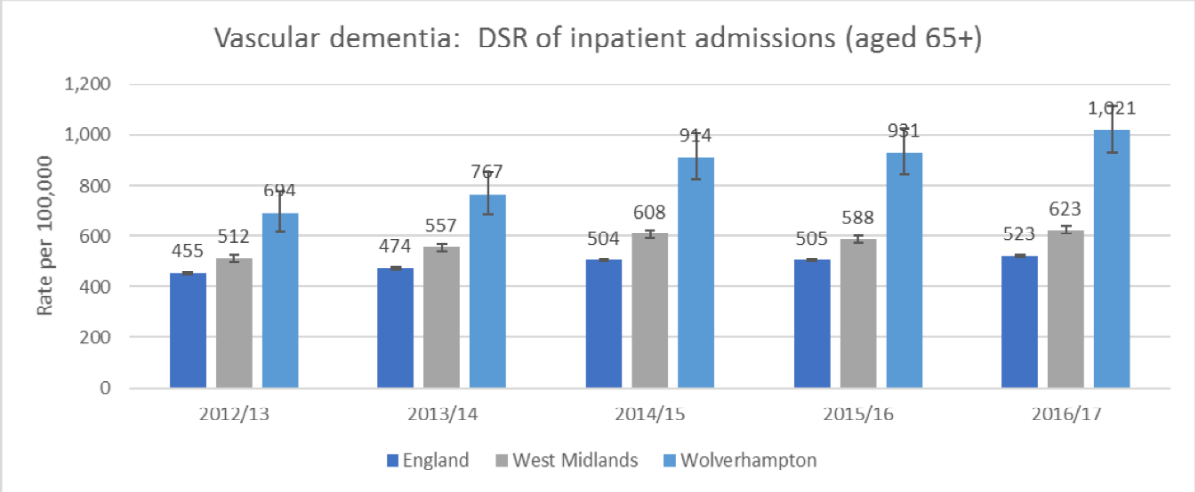
Source: Fingertips, PHE

CCG Clusters are used by the NHS to group together populations with similar characteristics. The population of Wolverhampton would be most similar to the 'Deprived urban areas (younger people and ethnic diversity, mainly Asian)'. In England, there is some variation between the CCG Clusters in regards to short stay emergency admissions for those with Dementia and aged 65+. The highest percentage of emergency admissions in those aged 65+ with Dementia is seen in 'Mixed communities in inner London' at 31.27%, followed by 'Deprived urban areas (younger populations and ethnic diversity, mainly Asian' at 29.35%. The lowest figure is seen in 'Areas with lower deprivation and better health' at 26.65%. The data would suggest that there is some association between higher deprivation and higher proportions of short stay emergency admissions for over 65's with Dementia. The figures for this indicator, in all of the CCG Clusters have experienced some level of increase over the three-year period between 2013-14 and 2015-16.



Source: Fingertips, PHE

The proportion of emergency admissions for those aged 65+ with Dementia that were short stays by IMD were not available at a Wolverhampton level. However in England, by IMD deciles there is no noticeable trend, with figures varying between 26.34% and 30.47% in 2015-16. Figures in the three previous time periods also varied to similar extents. One constant in the four data periods was that the percentage of emergency admissions for those aged 65+ with Dementia that were short stays, in the 5th most deprived decile was the highest. The figure varied slightly between 29.48% and 30.72% over the four-year period.

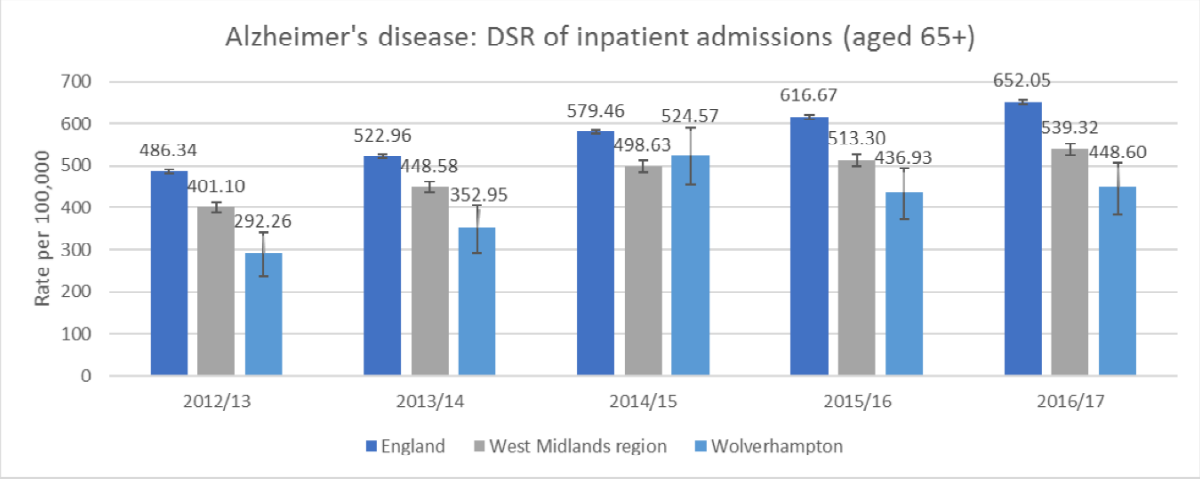


Source: Fingertips, PHE

Vascular Dementia is the second most common form of Dementia, affecting around 150,000 adults in the UK. The symptoms are often similar to Alzheimer's disease, though the issues affecting memory are often milder. The cause of Vascular Dementia is a reduced blood supply to the brain due to diseased blood vessels, resulting in the death of brain cells. The most common type of Vascular Dementia is thought to Subcortical Dementia, which involves reduced blood flow through the very small blood vessels deep in the brain. Vascular Dementia can also be caused by Strokes and Transient Ischaemic Attacks' (TIAs). [Alzheimers.org.uk]

The DSR of Vascular dementia in Wolverhampton has consistently been significantly higher than in England and the West Midlands, over the five-year period between 2012-13 and 2016-17. The rates

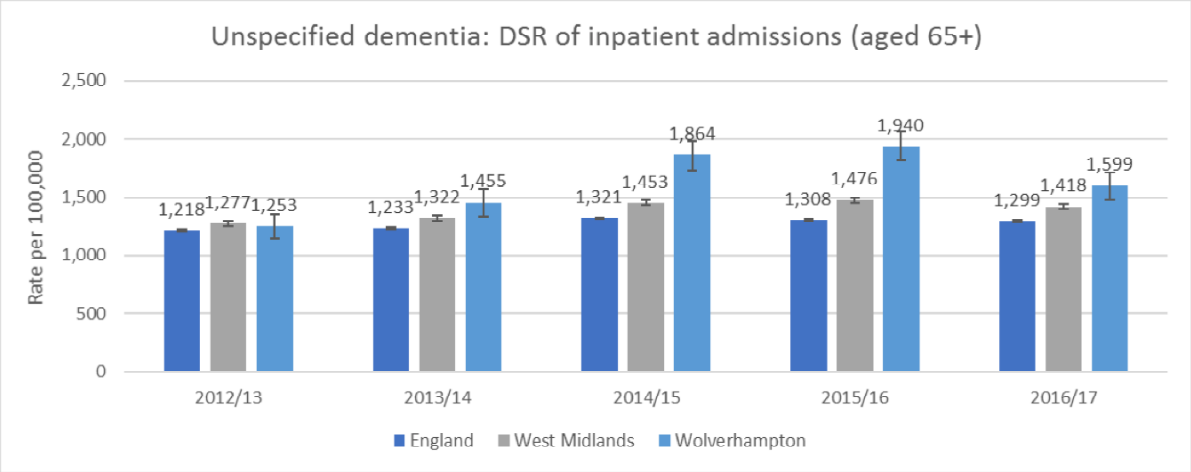
in all three geographies have significantly increased. The figures in Wolverhampton have increased from 693.7 per 100,000 (2012-13) to 931.3 per 100,000 (2015-16). In terms of numbers, the increase was from 308 in 2012-13 to 476 in 2016-17. In England, the directly standardised rate of inpatient admissions for Vascular Dementia in those aged 65+, increased significantly year on year between 2012-13 and 2014-15. Following this period of significant increase, figures continued to increase into 2016-17. In Wolverhampton, the rate of inpatient admissions in over 65's increased by almost a third (32.0%), equivalent to around 168 more admissions per year.



Source: Fingertips, PHE

Alzheimer's disease is the most common form of Dementia, with more than 520,000 people in the UK estimated to have Alzheimer's disease. Alzheimer's disease is a progressive disorder and the symptoms include: loss of short-term memory, language difficulties, visuospatial problems, orientation and difficulties in concentrating, planning and organising. [Alzheimers.org.uk]

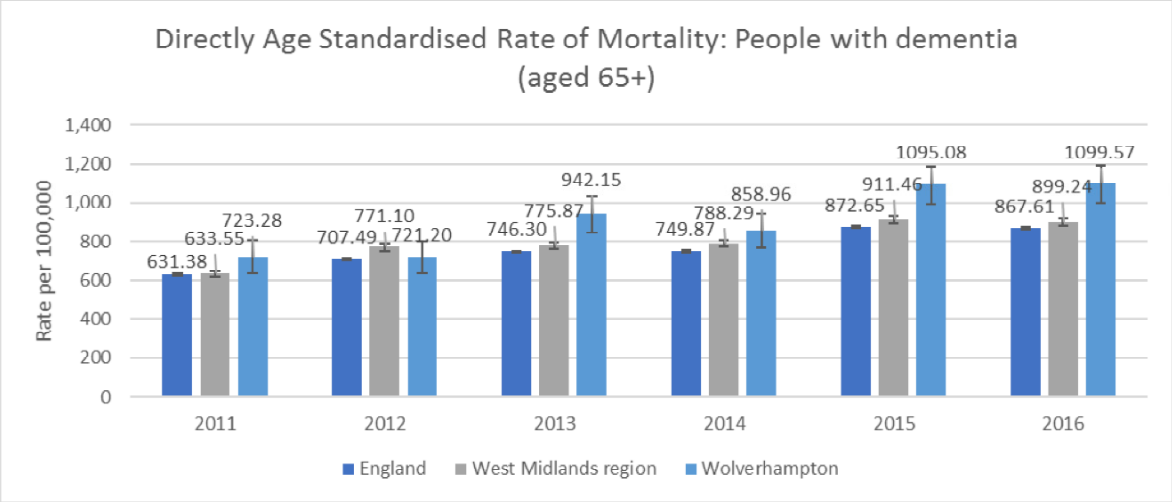
In 2016-17, the DSR of inpatient admissions for Alzheimer's disease in Wolverhampton (448.6 per 100,000) was significantly lower than the England figure (652.1 per 100,000) and the West Midlands figure (539.3 per 100,000). The Wolverhampton figures saw a significant increase between 2012-13 and 2014-15, followed by a slight non-significant decrease in 2015-16 and remained relatively constant going into 2016-17. Whereas, the England and West Midlands figures consistently increased significantly over the five-year period. The rate of inpatient admissions in England increased by 34.1%, accounting for around 166 more inpatient admissions per 100,000 adults aged 65+. In terms of numbers, in Wolverhampton, there were 208 inpatient admissions for Alzheimer's disease in people aged 65+, in 2016-17.



Source: Fingertips, PHE

Inpatient admissions for Unspecified Dementia are when the record of admission includes a mention of Unspecified Dementia in the diagnosis fields. The DSR of unspecified dementia in Wolverhampton increased significantly over a five-year period between 1,253 per 100,000 in 2012-13 to 1,599 per 100,000 in 2016-17, despite a fall in 2016-17. In terms of numbers, the increase in Wolverhampton was from 552 in 2012-13 to 748 in 2016-17. In comparison, the DSR's for England and the West Midlands also saw significant increases, but at much smaller scales. The Wolverhampton figures were significantly higher than England and the West Midlands between 2013-14 and 2016-17. In England, the directly standardised rate of inpatient admissions for Unspecified Dementia, in over 65's increased significantly between 2012-13 and 2014-15, followed by a significant decrease in 2016-17. In Wolverhampton, between 2012-13 and 2016-17, there was a 21.7% increase, equivalent to 196 more inpatient admissions per year in over 65's.

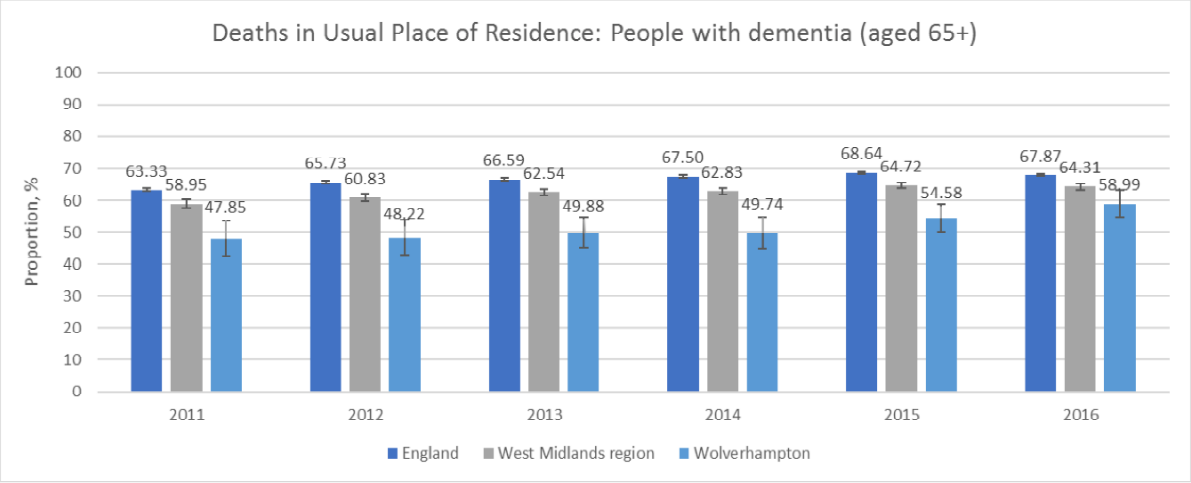
Mortality in people with Dementia



Source: Fingertips, PHE

In 2016, the DSR of mortality in people with Dementia aged over 65 was significantly higher in Wolverhampton at 1,099.6 per 100,000, than England (867.6 per 100,000) and the West Midlands (899.2 per 100,000). Over the five-year period between 2012 and 2016, the figures for Wolverhampton saw a general statistically significant increase from 721.2 per 100,000 to 1,099.6 per 100,000 (2016). Wolverhampton was significantly higher than England in four of five years (all but 2012), but only significantly higher than the West Midlands in three of the five years (2013, 2015 and 2016). In terms of numbers, there were 505 deaths of people with Dementia in 2015.

In England, the directly standardised rate of mortality with a mention of Dementia in those aged 65+, was 872.65 per 100,000 in 2015, which is significantly higher than each of the previous five years data points. The rate of mortality in those aged 65+ with Dementia increased significantly between 2011 and 2015, with figures increasing significantly year on year, except between 2013 and 2014. The cause of such an increase could be explained by looking at the increases in Dementia prevalence and diagnoses.

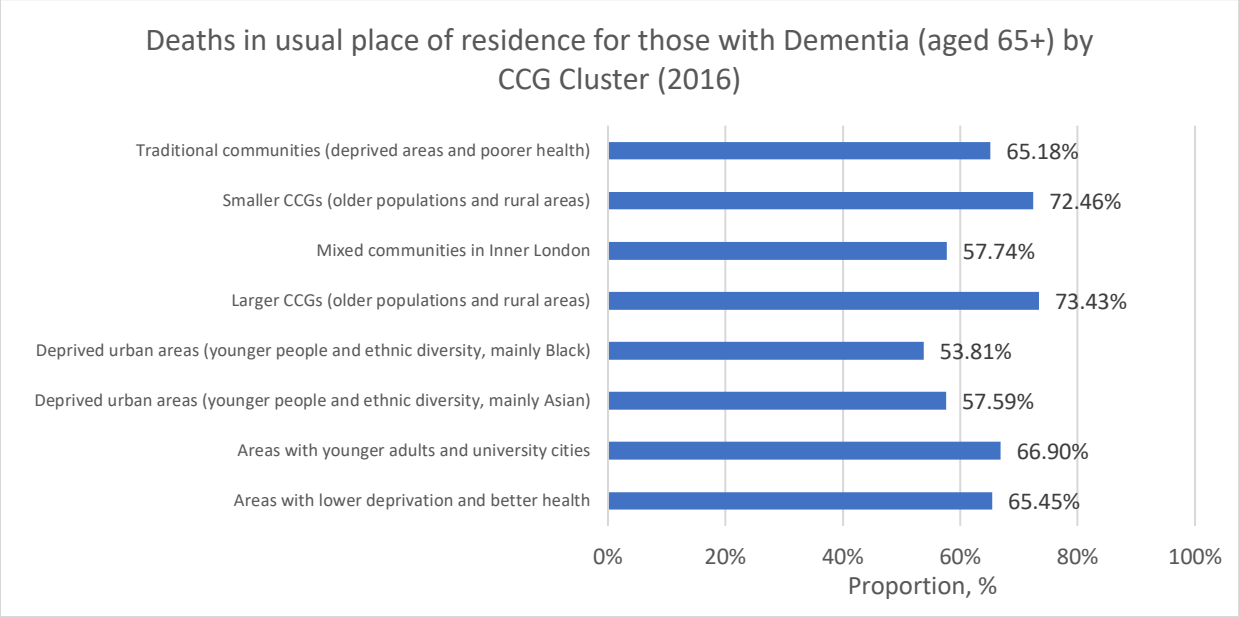


Source: Fingertips, PHE

End of life care for those with Dementia was a key objective in the National Dementia Strategy (2009) and a key measure of the quality of end of life care is 'death in usual place of residence'. The

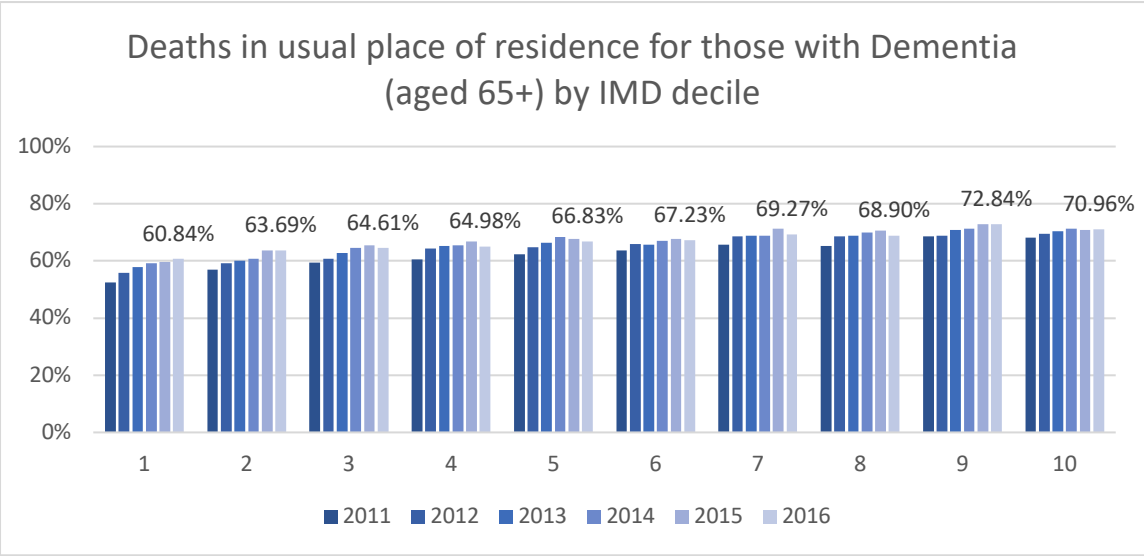
term 'usual place of residence' can refer to the individual's own home, a care home or other residential setting.

In Wolverhampton, the proportion of people who die with Dementia whose death occurs at the usual place of residence increased slightly over a five-year period from 48.22% (2012) to 58.99% (2016). In terms of numbers, this increase was from 149 in 2012 to 292 in 2016. However, throughout the five-year period, the Wolverhampton figure was significantly lower than the England and West Midlands figures. In England, the proportion of deaths in over 65's with Dementia that died in their usual place of residence consistently increased significantly, year on year, until 2016 when there was a slight decrease. Over the six-year period presented in the chart (2011 – 2016), there was a 4.54 percentage point increase, from 63.33% to 67.31%.



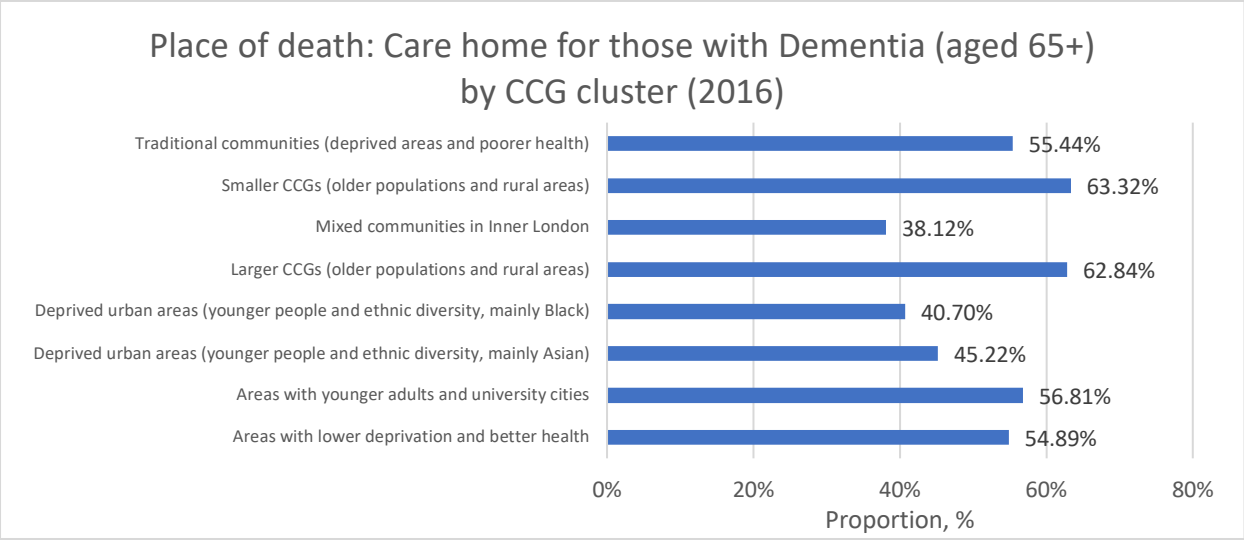
Source: Fingertips, PHE

In England, the proportions of deaths in over 65's with Dementia that occur in the individuals usual place of residence were highest among the Smaller CCG (72.46%) and Larger CCG (73.43%) CCG clusters. Both CCG clusters are described as having older populations and being predominantly rural areas. The lowest figures were seen in the 'Deprived urban areas (younger people and ethnicity diversity, mainly Black)' with 53.81% and 'Deprived urban areas (younger people and ethnicity diversity, mainly Asian)' with 57.59%. The figure for 'Mixed communities in inner London' is also considerably low, at 57.74%.



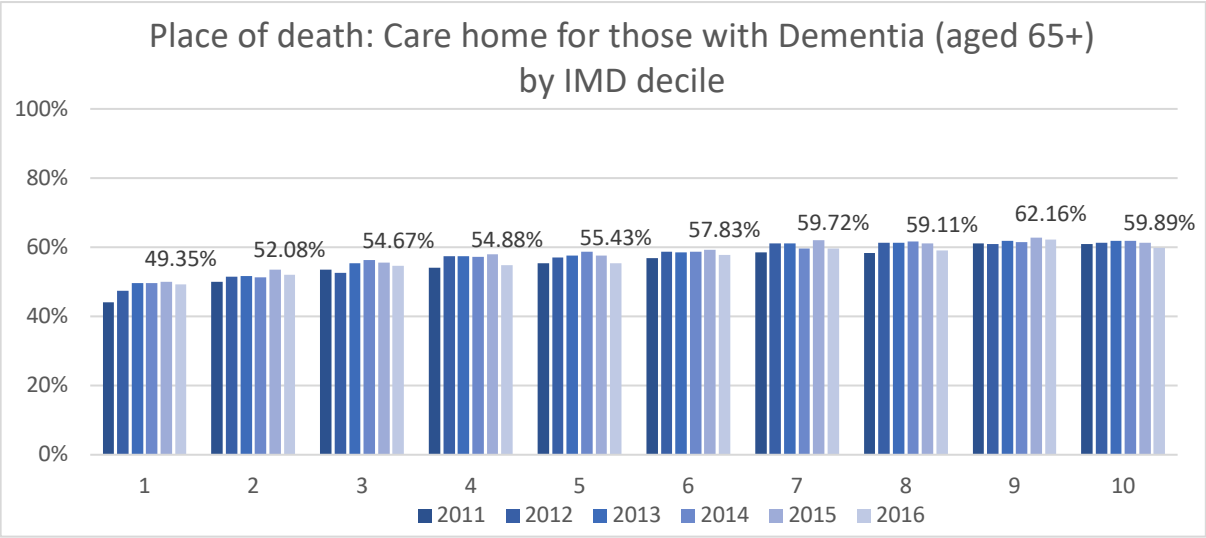
Source: Fingertips, PHE

The proportion of Deaths in usual place of residence for those with Dementia is not available by IMD deciles in Wolverhampton. However in England, over the six-year period between 2011 and 2016, the proportion of deaths of those aged 65+ with Dementia which occurred in the usual place of residence increased within each IMD decile. The largest increase was seen in the most deprived decile, an increase of 8.47 percentage points; the smallest increase was seen in the least deprived decile, an increase of 2.83 percentage points. In general, in each of the six years, the proportions of deaths in usual place of residence in those aged 65+ with Dementia increased and the level of deprivation decreased, with the highest figures in the most affluent deciles.



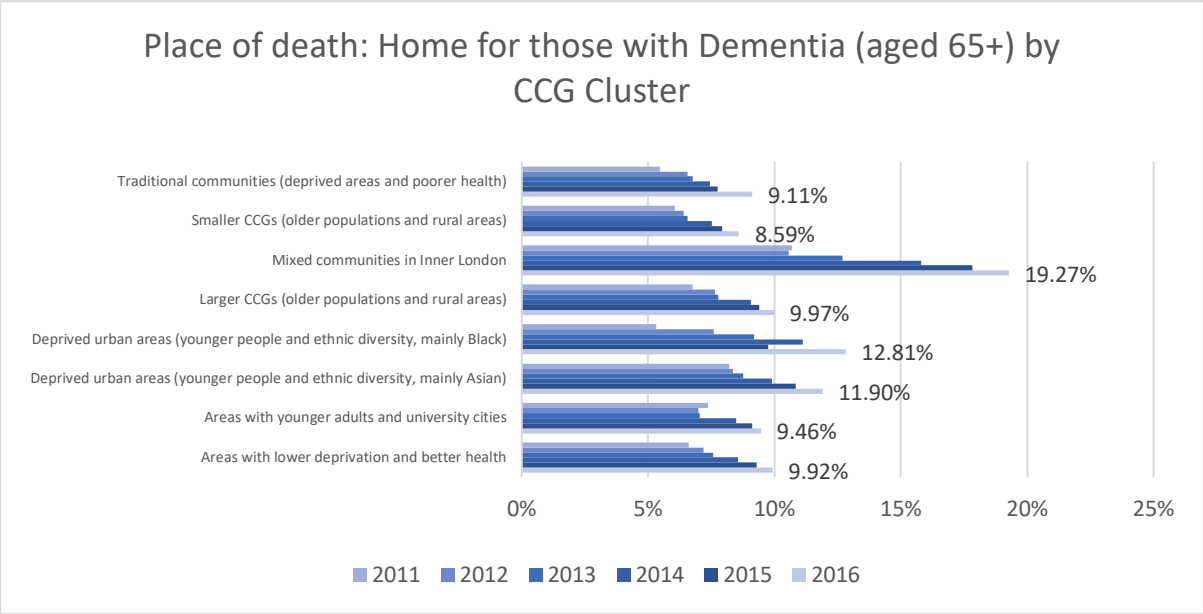
Source: Fingertips, PHE

In England, the proportion of deaths occurring in Care Homes, for individuals with Dementia and aged over 65 was highest among Smaller CCG's and Larger CCG's, which are both described as having an older population and rural areas. The lowest figures were seen in 'Mixed communities in inner London', 38.12%, Deprived urban areas (younger people and ethnic diversity, mainly Black), 40.70% and Deprived urban areas (younger people and ethnic diversity, mainly Asian), 45.22%. There were notable trends seen in the figures for the previous 6 data points (2011-2016).



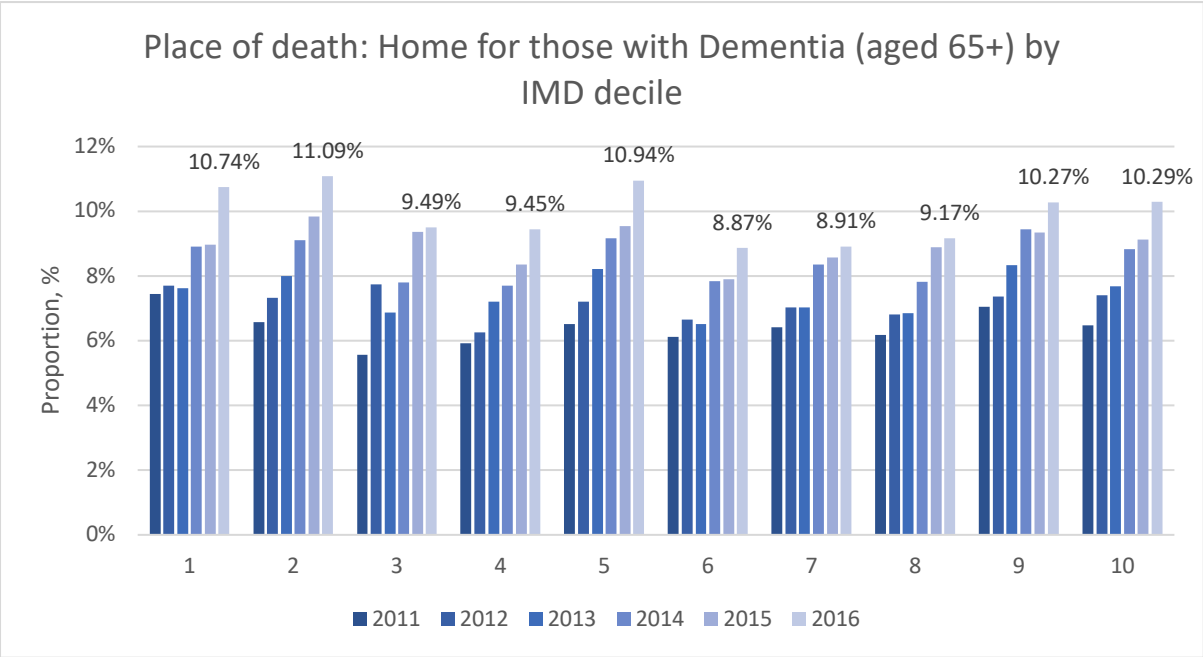
Source: Fingertips, PHE

The proportion of Deaths for those with Dementia that occurred in a care home is not available by IMD deciles in Wolverhampton. However in England, the proportion of deaths in those aged 65+ with Dementia that occurred in a care home increased as deprivation decreased, in 2016. There was a 10.54 percentage point difference between the most deprived and the least deprived areas of England. There have also been changes over time within each IMD decile, with figures within the majority of deciles increasing until 2014 and falling slightly by 2016.



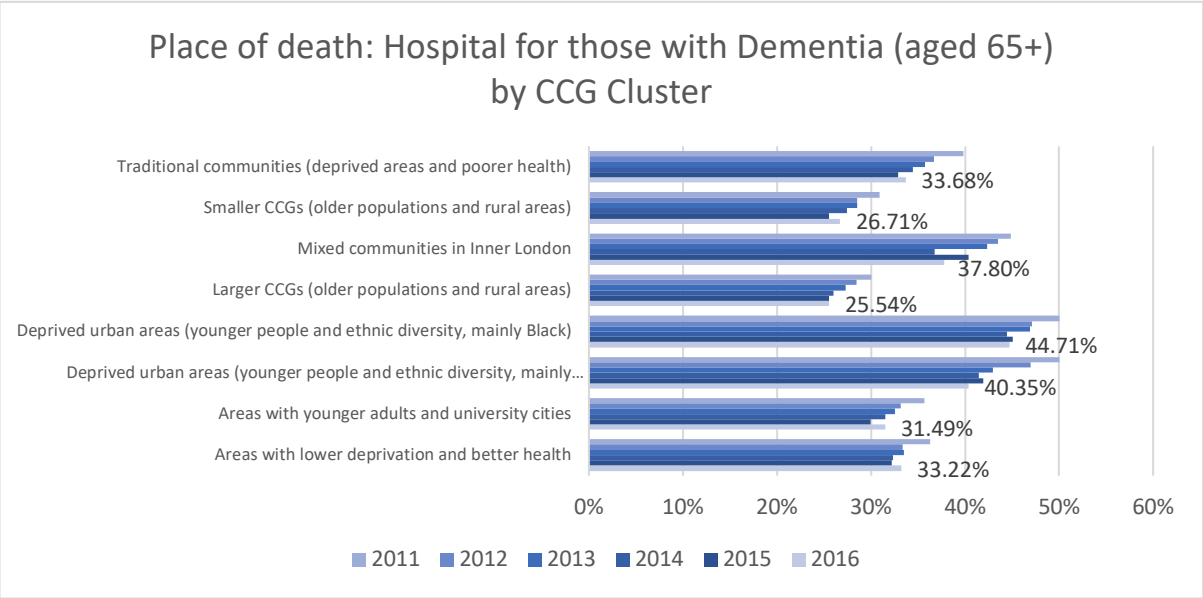
Source: Fingertips, PHE

In England, the proportion of deaths of over 65s with Dementia that occurred at home was, in 2016, highest in the 'Mixed communities in inner London' CCG cluster (19.27%). The rate in all other CCG clusters ranged between 9.11% in 'Traditional communities (deprived areas and poorer health)' and 12.81% in 'Deprived urban areas (younger people and ethnic diversity, mainly Black)'. Over the 5-year period between 2011 and 2016, the proportion of deaths, in those aged over 65 with Dementia, occurring at home increased in all of the CCG clusters. The largest percentage increases were seen in the 'Deprived urban areas (younger people and ethnic diversity, mainly Black)', with an increase of 140.3%. The smallest increase was seen in 'Areas with younger adults and university cities' with a 28.2% increase.



Source: Fingertips, PHE

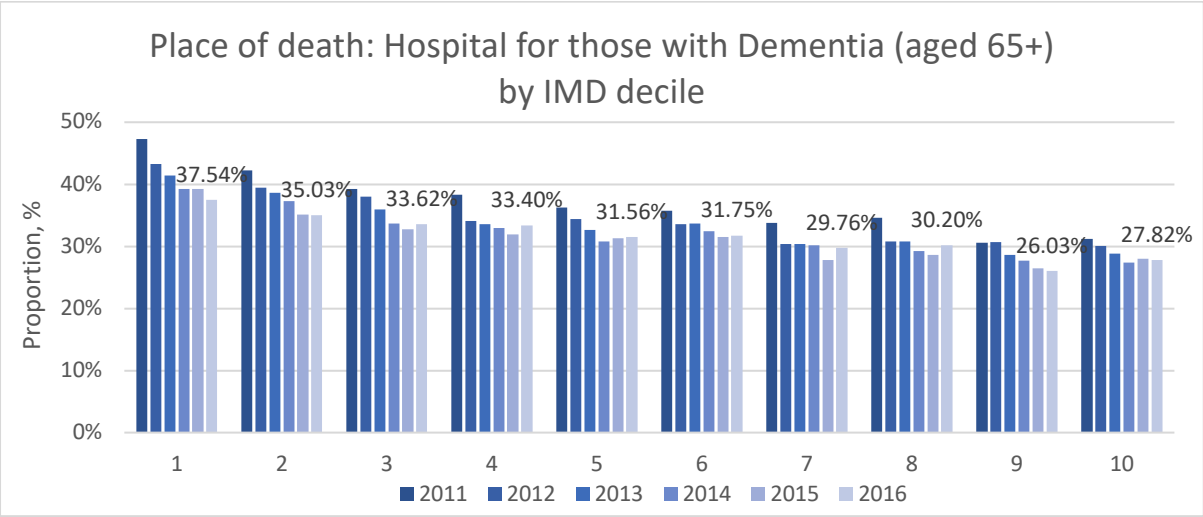
The proportion of Deaths for those with Dementia that took place within their own home, is not available by IMD deciles in Wolverhampton. However in England, there is slight variation and no notable trends between the proportions of deaths, of those aged 65+ with Dementia, occurring at home, in the different IMD deciles. The 2016 figures range from 8.87% in the 6th most deprived decile to 11.09% in the 2nd most deprived decile. However, over the five-year period, the figures have increased in every IMD decile between 2011 and 2015. The increases did not follow any notable trend, despite varying considerably between 38.8% and 70.4%.



Source: Fingertips, PHE

In England, the proportions of deaths, of those aged 65+ with Dementia, that occurred in a Hospital setting were highest in the 'Deprived urban areas (younger people and ethnic diversity, mainly Black)' (44.71%) and 'Deprived urban areas (younger people and ethnic diversity, mainly Asian)' (40.35%) CCG Clusters. The 2016 figure for the 'Mixed communities in inner London' CCG Cluster

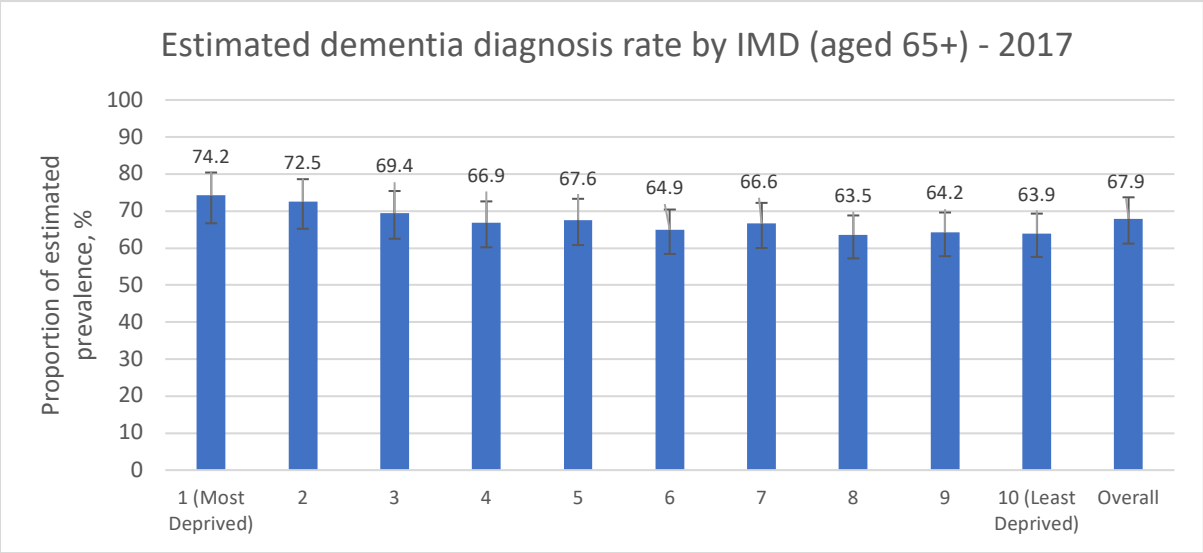
was also higher than average, at 37.80%. The lowest figures were seen in the 'Larger CCGs (older populations and rural areas)' CCG cluster, at 25.55%, and the 'Smaller CCGs (older populations and rural areas)' CCG cluster, at 26.71%. The figures also decreased in the six-year period between 2011 and 2016, with the largest percentage decreases seen in 'Traditional communities (deprived areas and poorer areas)' (17.36%) and 'Smaller CCGs (older populations and rural areas)' (17.25%). Therefore, suggesting that though numbers would be higher in the areas with older populations, there are increasingly higher proportions of over 65's with Dementia dying in hospitals in areas with younger populations.



Source: Fingertips, PHE

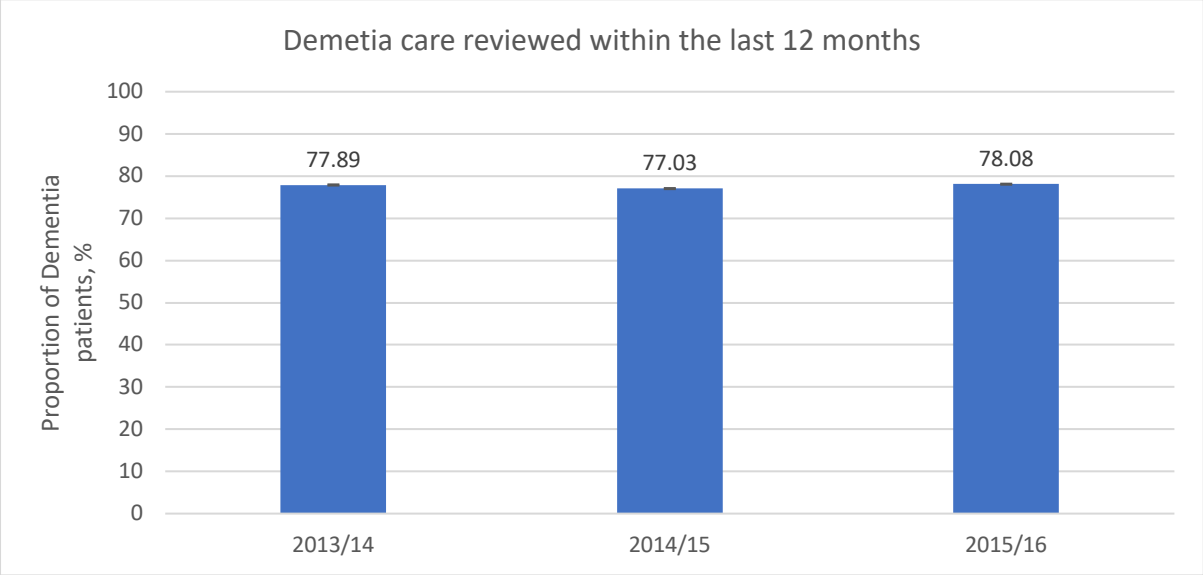
The proportion of hospital deaths for those with Dementia is not available by IMD deciles in Wolverhampton. However in England, the proportions of deaths of those aged 65+ with Dementia, that occurred in a Hospital setting were higher in the more deprived deciles, compared to the least deprived deciles. The proportions of deaths occurring in hospitals, for those with Dementia and aged 65+, in the three most deprived deciles were 37.54%, 35.03% and 33.62%, respectively; compared to the 30.20%, 26.03% and 27.82% in the three least deprived deciles. This suggests that the proportion of death is strongly associated with deprivation. Over the six-year period between 2011 and 2016, there were also decreases in figures within each decile. The smallest percentage decreases were seen in the least deprived deciles compared to the most deprived deciles, 11.96% in the least deprived decile compared to 25.87% in the most deprived decile.

Other Dementia indicators



Source: Fingertips, PHE

In England, around two-thirds (67.9%) of people aged 65+ estimated to have dementia, have received a diagnosis. This figure is known as the estimated diagnosis rate and is only available at a national level. The estimated diagnosis rate decreases slightly in line with decreases in deprivation, however, these decreases are not statistically significant. The figures suggest that there is poorer dementia diagnosis in the more affluent areas of the country, compared to the more deprived areas. Just under three-quarters (74.2%) of the people estimated to have dementia have been diagnosed in the most deprived decile, compared to less than two-thirds (63.9%) in the least deprived decile.



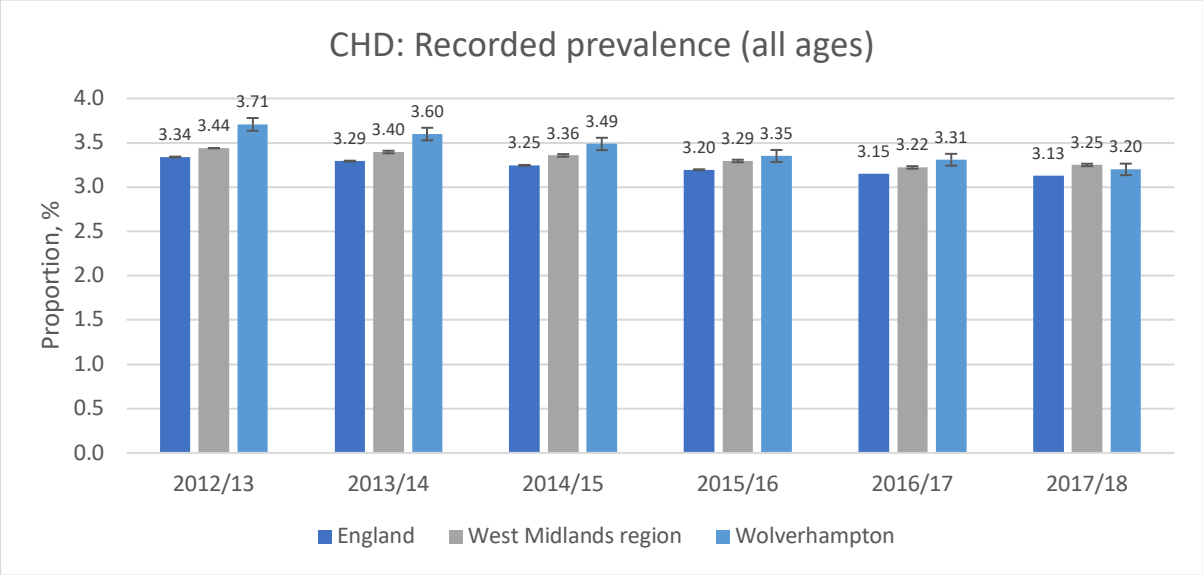
Source: Fingertips, PHE

The proportion of Dementia patients, in England, that had their care reviewed within 12 months of reporting ranged between 77.03% and 78.08%. This indicator is only available at a national level. Due to the variations between the three figures, a trend cannot be accurately reported. Although, the 2014/15 figure was significantly lower than both the 2013-14 and 2015-16 figures.

Risk Factors for Dementia

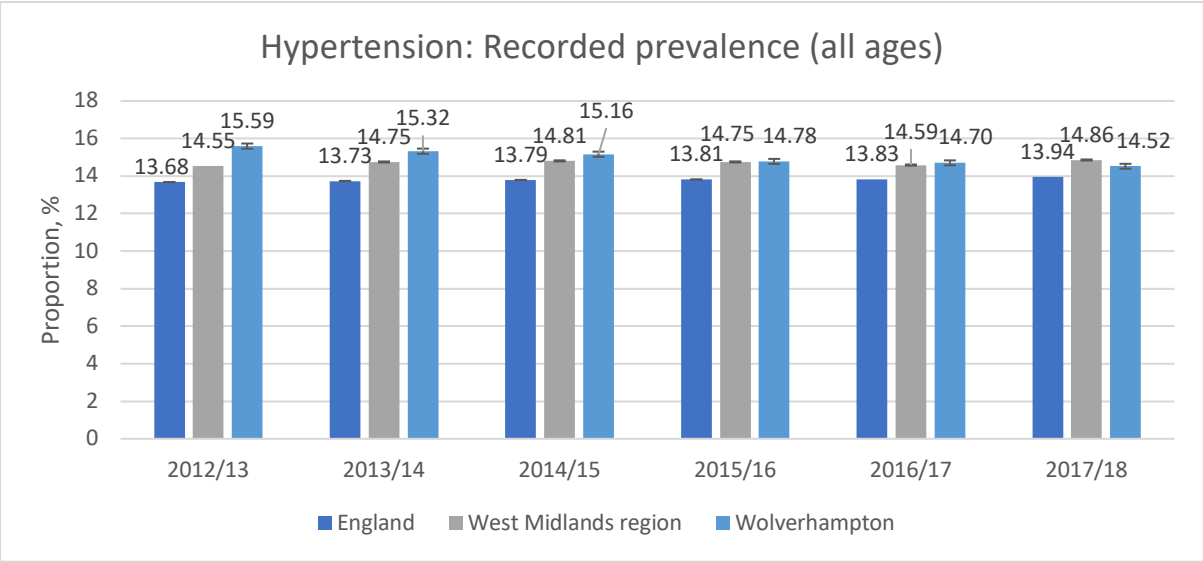
Research into Dementia have discovered a number of factors that affect the risk of developing Dementia. Some of these risk factors are genetic and age related, which are not controllable, but some are lifestyle factors which can be altered. Genetic and age-related risk factors include gender (females are more likely than males to develop Dementia, even when allowing for females living longer on average), ethnicity (there is some evidence that suggests South Asian people are more likely to develop Vascular Dementia than White Europeans) and inherited genes (there are around 20 genes which have been found to increase the risk of developing Dementia). Other risk factors are the presence of health conditions and lifestyle related, including: cardiovascular factors (such as type 2 diabetes, high blood pressure, high cholesterol levels and obesity), pre-existing mental health conditions (such as depression and Parkinson's disease), lack of physical activity, smoking and excessive alcohol consumption.

Detailed below is the prevalence of some of these risk factors in Wolverhampton.



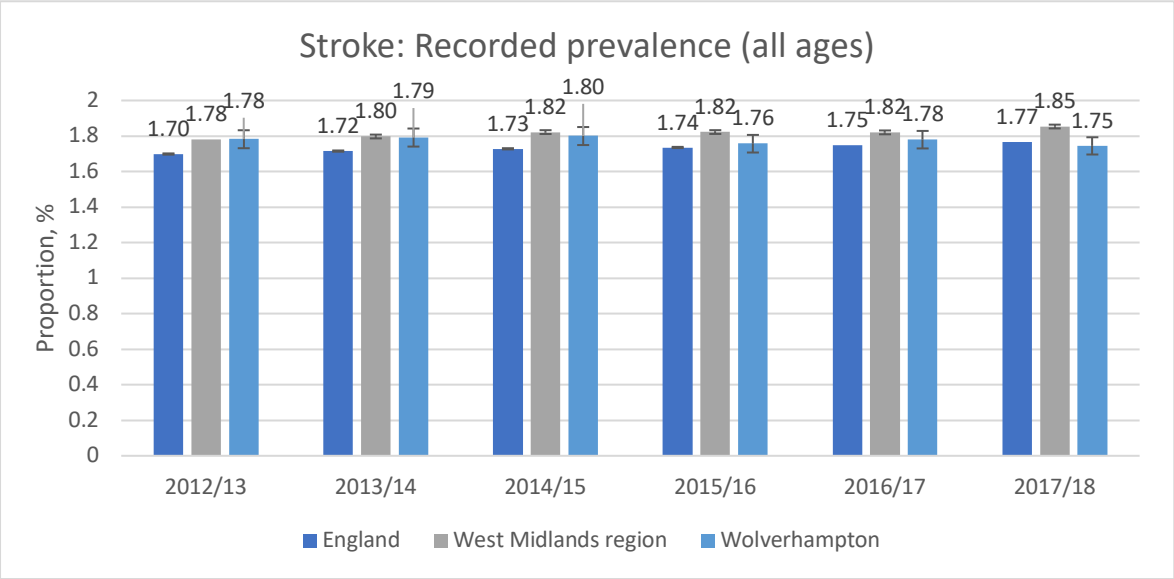
Source: Fingertips, PHE

The prevalence of Coronary Heart Disease, CHD, in Wolverhampton had consistently been significantly higher than England and the West Midlands, between 2012-13 and 2014-15, however figures in Wolverhampton have been consistently decreasing and since 2015-16 have statistically similar to the West Midlands. Over the six-year period, the figures in Wolverhampton decreased significantly, from 3.71% in 2012-13 to 3.20% in 2017-18. The figures for England and West Midlands also decreased significantly over the same time period. In terms of numbers, there were 8,969 people in Wolverhampton on the QOF register for CHD in 2017-18.



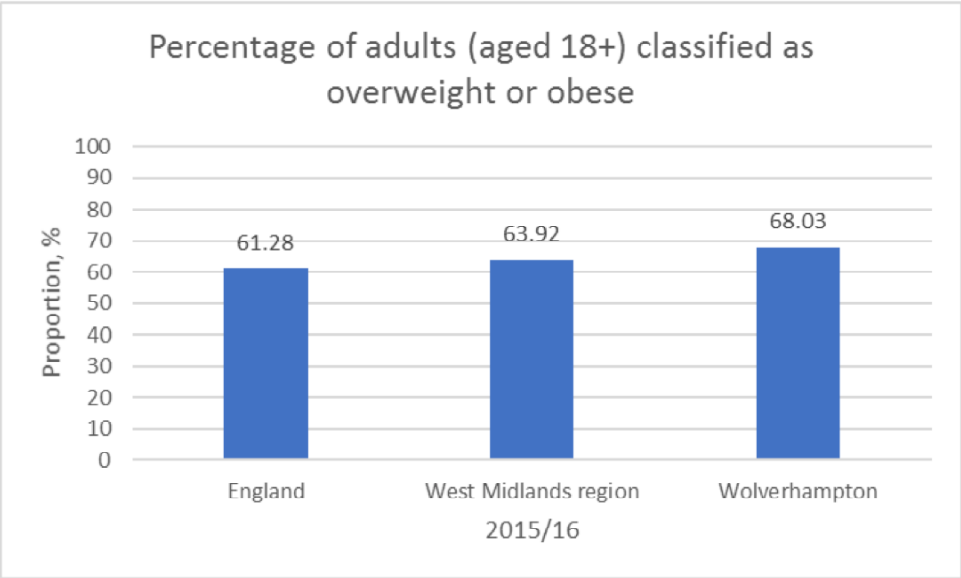
Source: Fingertips, PHE

Similarly, to the prevalence of CHD in Wolverhampton, the prevalence of Hypertension was consistently significantly higher than England and the West Midlands, prior to 2015-16, since which the prevalence has been similar to the West Midlands. The prevalence in Wolverhampton has reduced significantly over the six-year period from 15.59% in 2012-13 to 14.52% in 2017-18. However, during the same period, the prevalence of Hypertension in England and West Midlands significantly increased. In terms of numbers, there were 40,700 people in Wolverhampton on the QOF register for Hypertension in 2017-18.



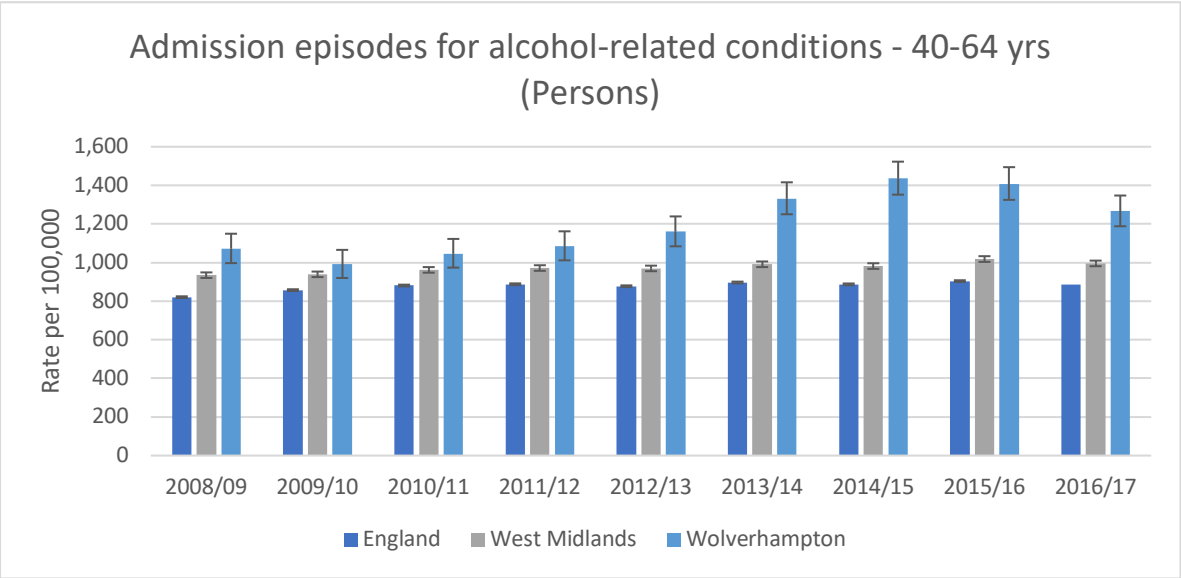
Source: Fingertips, PHE

In Wolverhampton the prevalence of people on the Stroke register was significantly higher than England in the 3 years between 2012-13 and 2014-15, but Wolverhampton was statistically similar to England between 2015-16 and 2017-18. The prevalence in Wolverhampton varied over the six-year period, between 1.75% in 2017-18 and 1.80% in 2014-15. However, in England and the West Midlands, the prevalence significantly increased over the same four-year period. In terms of numbers, there were 4,891 people in Wolverhampton on the QOF Stroke register in 2017-18.



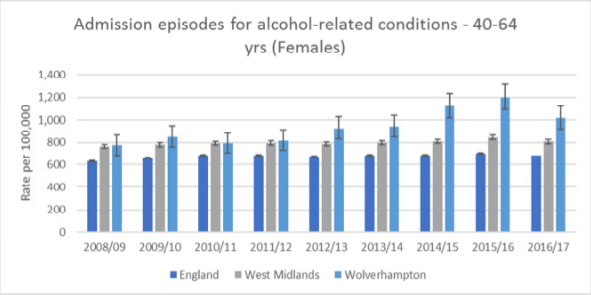
Source: Fingertips, PHE

In 2015-16, just over two-thirds of adults (68.03%) in Wolverhampton are overweight or obese, which is significantly higher than the England figure (61.28%), but not significantly different to the West Midlands (63.92%).

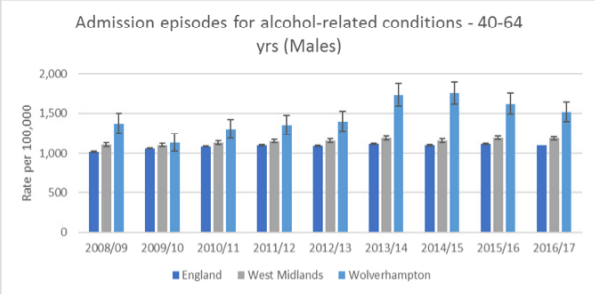


Source: Fingertips, PHE

The rate of admission episodes for alcohol-related condition in 40-64 year olds in Wolverhampton has increased significantly over the past nine years, from 1,071.2 per 100,000 (2008/09) to 1,265.8 per 100,000 (2016-17). This equates to an increase of 18.2%. The Wolverhampton figures were consistently significantly higher than England over the nine-year period, but only significantly higher than the West Midlands from 2011-12 to 2016-17.



Source: Fingertips, PHE

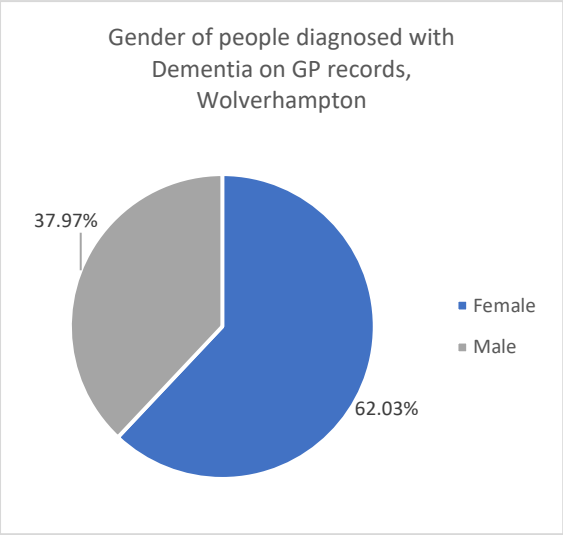


Source: Fingertips, PHE

When separated into males and females, the rates for males are considerably higher than females. In 2016-17, the rate of admission episodes for males was 1,516.6 per 100,000 and the rate for females was 1,018.4 per 100,000, a difference of 498.2 per 100,000. There have been notable increases in the rates for both genders, with figures for males increasing by 10.4% and females increasing by 32.0%, over the nine-year period.

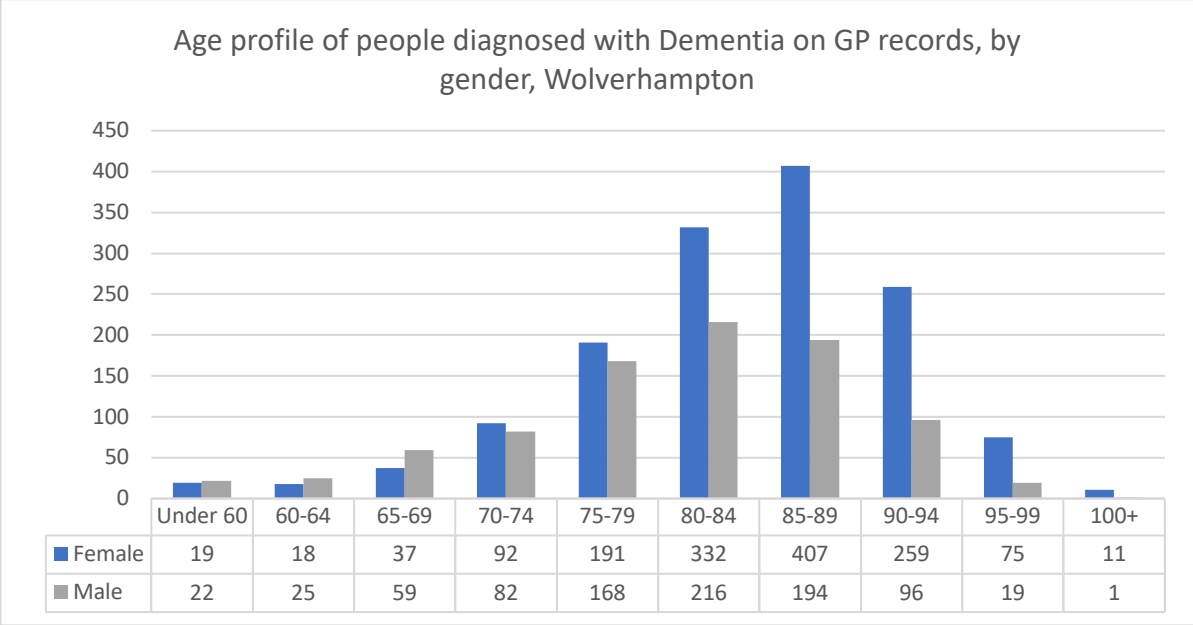
GP Records – Graphnet

In Wolverhampton, there were 2,323 people with a diagnosis of Dementia registered with a Wolverhampton GP.



Source: Graphnet

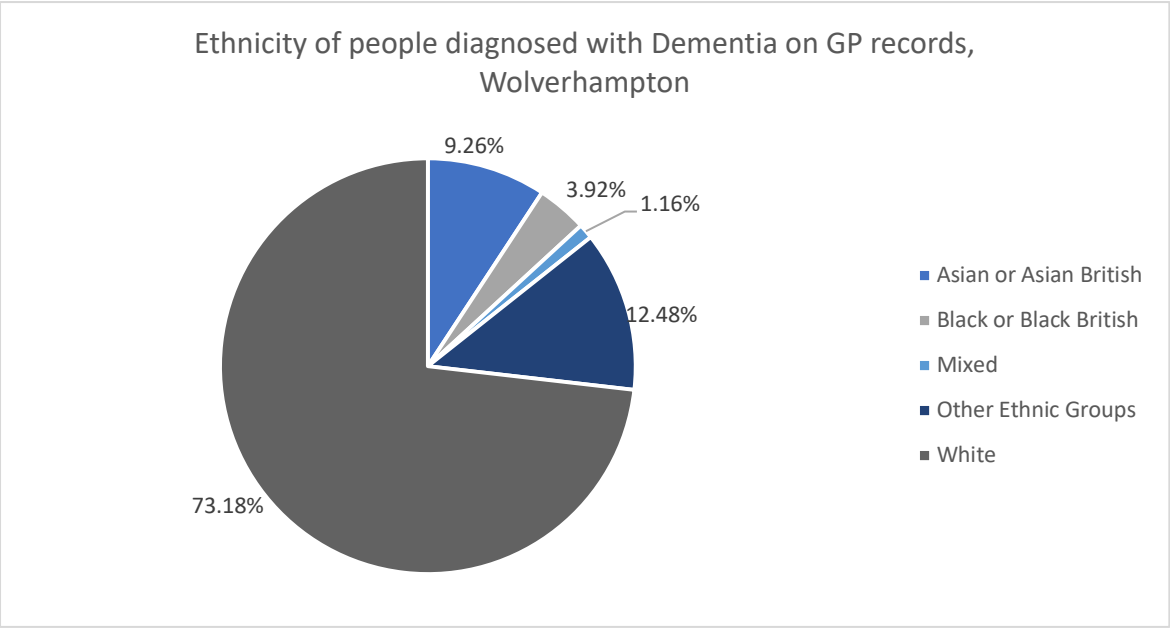
Of the 2,323 people with a diagnosis of Dementia in Wolverhampton, around 62.03% were Female and 37.97% were Male. This accounts for 1,441 Females and 882 Males.



	Under 60	60-64	65-69	70-74	75-79	80-84	85-89	90-94	95-99	100+
Female	19	18	37	92	191	332	407	259	75	11
Male	22	25	59	82	168	216	194	96	19	1

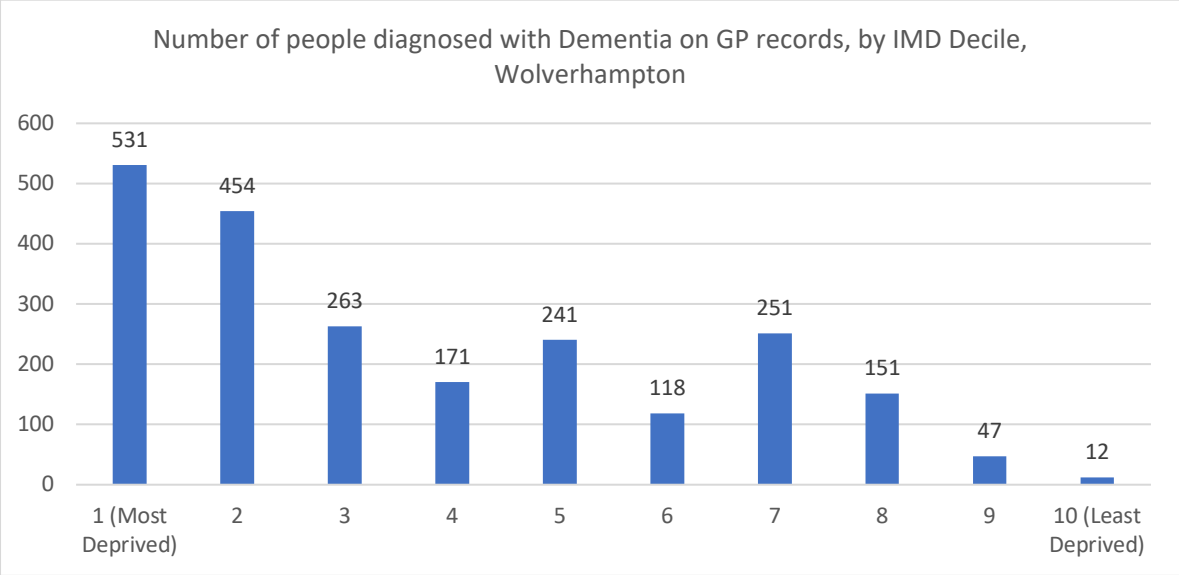
Source: Graphnet

The age profile of the population of Wolverhampton diagnosed with Dementia on GP records is slightly skewed towards older people. The most populous age group was 85-89 years, with 601 patients, making up just over a quarter of all patients (25.87%) with a diagnosis of Dementia. In the 85-59 year age group, there were more than two-times the number of Females (407), than there were Males (194). The 80-84 year age group was the second most populous age group, with 548 patients, making up 23.59% of all patients diagnosed with Dementia. The 80-84 year age group, was made up of 332 Females and 216 Males. The mean age of an individual with a diagnosis of Dementia was 82.51 years. The average age for Females was slightly higher (83.81 years) than Males (80.38 years).



Source: Graphnet

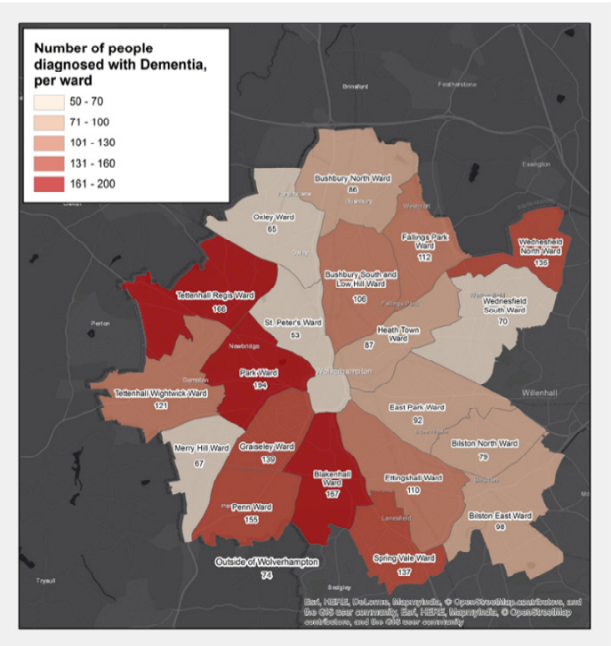
Almost three-quarters of people with a diagnosis of Dementia had a White ethnic background, 73.18%, which is significantly higher than the proportion of people with a White ethnic background in the general population of Wolverhampton. The second largest proportion was of those with an ethnic background listed as 'Other', which made up 12.48% of people with a diagnosis of Dementia. This is likely to a recording error, where the ethnicity of the patient was not correctly recorded. Just under a tenth of people diagnosed with Dementia had an Asian or Asian British ethnic background, which was significant lower than the proportion of people with an Asian or Asian British ethnic background in the general population of Wolverhampton. Similarly, the proportion of people with Dementia with a Black or Black British ethnic background (3.92%) is also significantly lower than the proportion in the general population.



Source: Graphnet

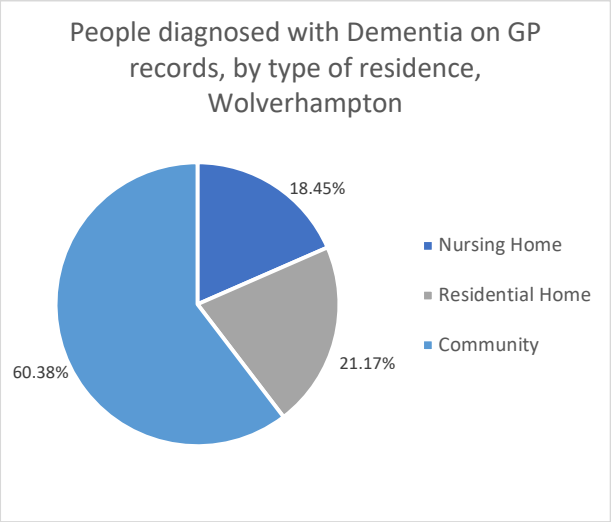
The number of people with a diagnosis of Dementia decreases as Deprivation decreases, in Wolverhampton. More than half of those diagnosed with Dementia (53.72%) in Wolverhampton reside in areas which are in the top 30% most deprived areas nationally. Whereas, only 9.04% of those with Dementia live in the top 30% most affluent areas nationally. This is due to there being a

smaller number of Lower Super Output Areas, LSOA's, in the top 30% most affluent areas when compared nationally. However, when IMD rankings are scaled to a Wolverhampton level, there is a much more even spread.



Source: Graphnet

In geographic terms, the highest number of people diagnosed with Dementia on GP records reside in West of the city, in wards such as Tettenhall Regis, Park and Blakenhall. Wards in the East and North of the city generally had lower figures, ranging from 65 in Oxley to 135 in Wednesfield North. There were also 74 people diagnosed with Dementia, who were registered to Wolverhampton GP's, but live outside of the Wolverhampton boundary.



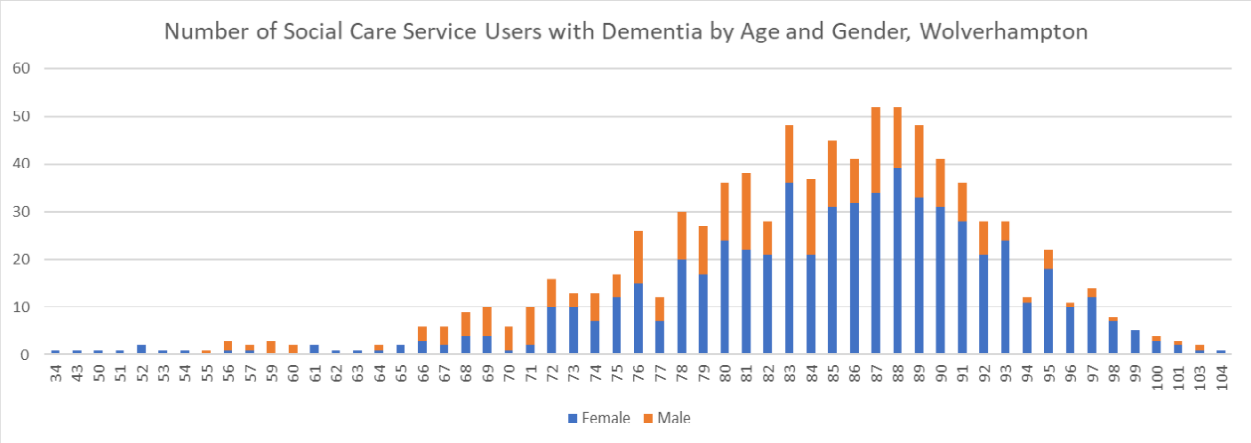
Source: Graphnet

The majority of people (60.38%) diagnosed with Dementia on GP records in Wolverhampton live in the community, accounting for 1,352 people. Around a fifth of people (21.17%) diagnosed with Dementia live in residential homes and 18.45% live in nursing homes, accounting for 474 and 413 people, respectively.

CareFirst – Service Users with Dementia Analysis

In Wolverhampton, there are 1,740 people known to social care service users that have a diagnosis of Dementia. Of these people, 874 are currently receiving services funded by the City of Wolverhampton Council. Of those currently receiving services, 601 service users are female and 273 service users are male.

Service User Demographics



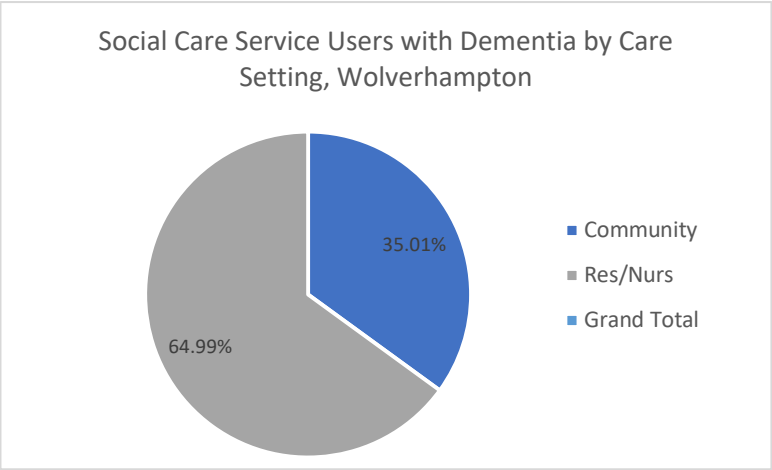
Source: CareFirst, CWC

The number of social care service users with Dementia are aged between 49 and 103 years of age. However, the numbers are less than 10 service users per year of age in the ages below 72 and above 95 years. The interquartile range is between 80 and 89 years of age, which is the range in which the middle 50% of service users reside and the median age is 85 years. The distribution of ages is slightly positively skewed, which means that the majority of service users are aged towards the older end of the 49 – 103 years age range.

	Female	Male
100+	58.82%	41.18%
90-99	48.78%	51.22%
80-89	59.41%	40.59%
70-79	68.94%	31.06%
60-69	81.46%	18.54%
Under 60	70.00%	30.00%

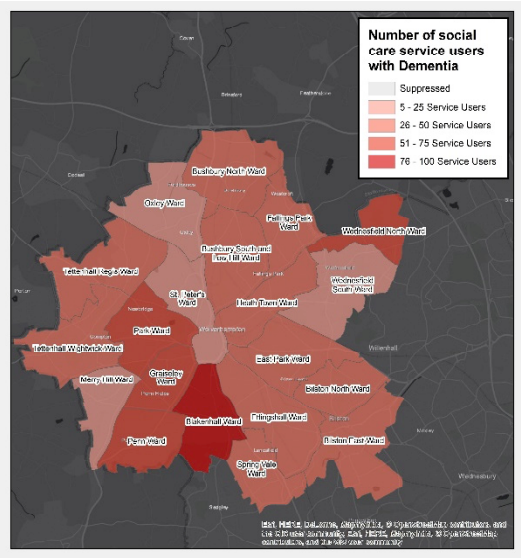
Source: CareFirst, CWC

In the most populated age groups, 70-79, 80-89 and 90-99, the proportion of service users that were female was higher compared to the proportion of males. The largest difference was seen in the 90-99 year age group, which was comprised of 81.5% female and 18.5% male service users. However, in the age groups with smaller numbers, the proportions varied, with a slightly higher proportion of males compared to females in the 60-69 year age group. In general, the proportion of female compared to male service users increased as the age groups got older.



Source: CareFirst, CWC

Of the 874 social care service users receiving services with Dementia in Wolverhampton, 306 live in the community either with family or in their own homes and 568 live in residential or nursing homes. Of those living in the community, around 64.7% are female, 35.3% are male. Of those service users living in residential or nursing homes, 71.0% are female and 29.0% were male. On average, service users who live in the community were on average 6 years younger, at 78 years, compared to those that live in residential or nursing homes, at 84 years.

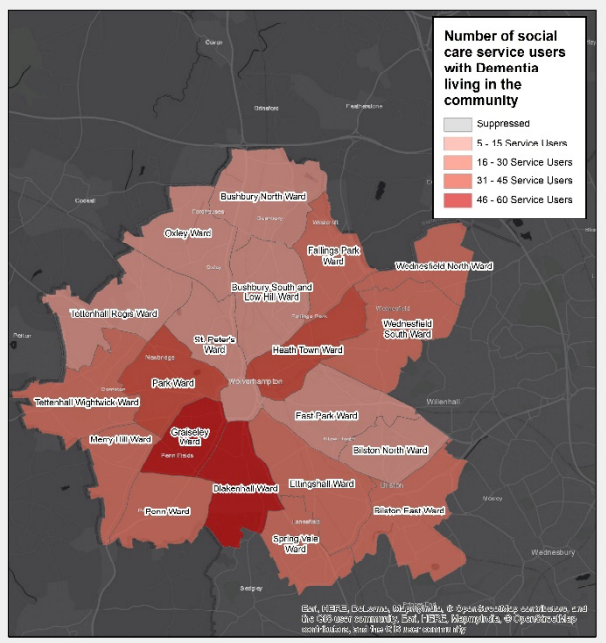


Source: CareFirst, CWC

The number of service users with social care needs with Dementia are highest in Blakenhall ward, with more than 75 service users, followed by Wednesfield, Park, Penn and Graiseley wards, with between 51-75 service users.

The wards with the highest number of service users are some of the more affluent parts of the city, except from Blakenhall which is in the 3rd most deprived IMD quintile. However, this is not a strong correlation, because the most deprived wards of Wolverhampton do not necessarily have the lowest numbers of service users.

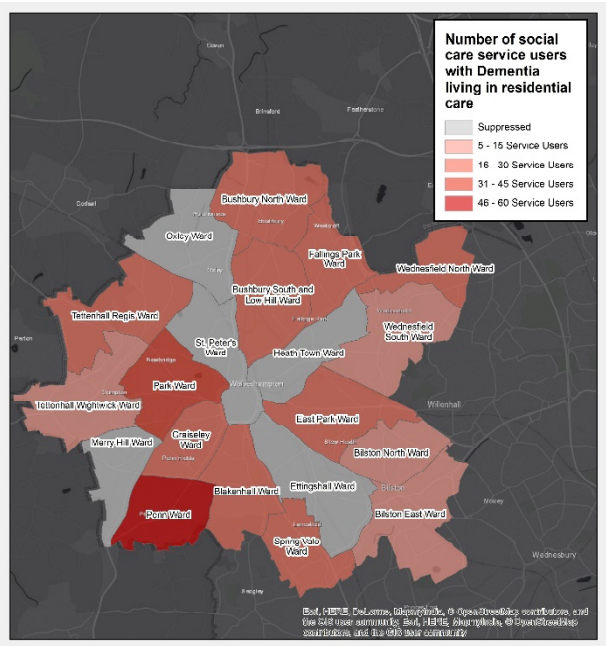
The geographical trend of social care service users does not have a strong correlation with the proportion of over 65's in each ward. Wednesfield North does indicate a correlation with over 50 service users and 24.56% of residents in the ward are aged 65+. However, Blakenhall ward contains over 75 service users, but the proportion of residents aged 65+ in the ward is considerably lower at 15.34%. The ward with the highest proportion of over 65's is Tettenhall Wightwick, 27.66%, but only has between 30-39 service users.



Source: CareFirst, CWC

However, when looking at service users that live in the community, the spread of service users varies considerably. The wards across the north east and south of the city have the highest number of service users living in the community.

This spread does not seem to be correlated with deprivation or proportion of over 65's.



Source: CareFirst, CWC

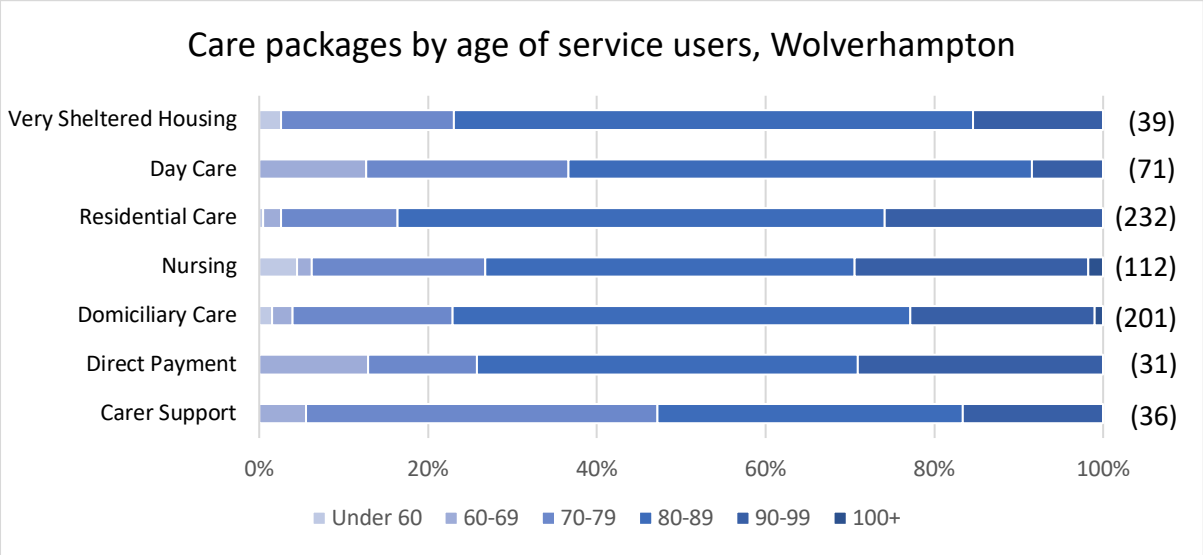
The geographical spread of the number of social care service users with dementia that live in residential/nursing homes is concentrated in two areas in Wolverhampton. In the south of the city, there is are five wards with at least 15 service users in each and North East of the city where there are 4 wards clustered together with more than 15 service users in each.

The geographical spread of social care service users in residential/nursing homes is dependent on the location of nursing homes and the type of service user the care homes cater for. The areas with the highest numbers of service users also have the highest density of care homes, as shown on the map.

Care Package Distribution

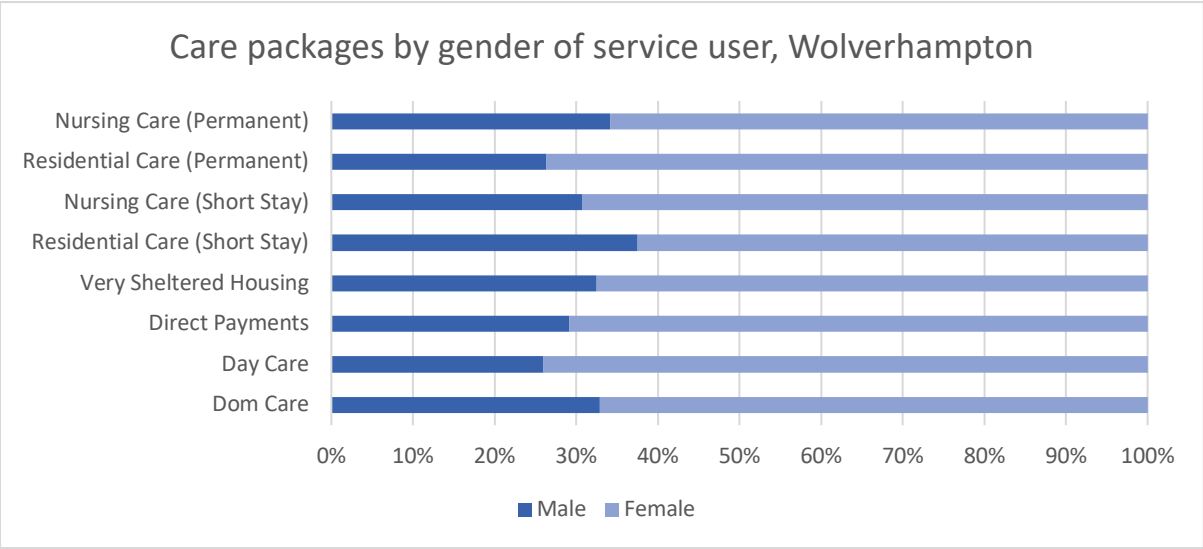
Service Setting	Number of Service Users
Dom Care	167
Day Care	73
Direct Payments	24
Individual Service Fund	<5
Supported Living	<5
Very Sheltered Housing	40
Shared Lives	<5
Residential Care (Short Stay)	24
Nursing Care (Short Stay)	52
Residential Care (Permanent)	369
Nursing Care (Permanent)	199
Carer's Services	50

In Wolverhampton, Social Care provide 952 services for the 874 service users. The table above shows the number of each type of care package. Around 38.76% of services provided were Residential Care (Permanent) services, this was the highest proportion of services. Just over a fifth (20.90%) of services were for Nursing Care (Permanent). Around 17.54% of services were for Domiciliary Care and 7.67% of services were for Day Care.



Source: CareFirst, CWC

For all types of care packages, except carer support, the highest proportion of service users are in the 80-89 year age group. More than half of service users that receive residential care and domiciliary care are aged between 80-89. The second largest proportions of service users that receive residential care, nursing and domiciliary care are aged 90-99.



For all types of care packages, the majority of service users are female. Day Care and Residential Care (Permanent) have the highest proportion of females for any of the care packages in the chart, with 74% of service users being female. Residential (Short Stay) has the lowest proportion of females of any of the care packages, with only around 63% of service users being female.

NHS Dementia Clusters Analysis

Care Cluster Definitions

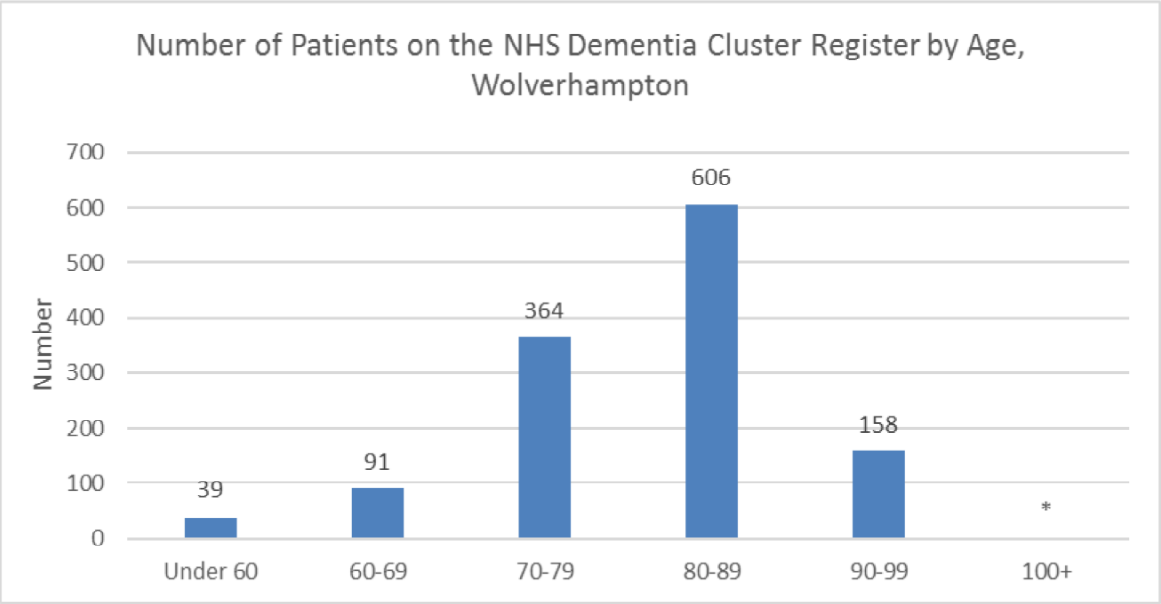
Care Cluster 18: People who may be in the early stages of dementia (or who may have an organic brain disorder affecting their cognitive function) who have some memory problems, or other low level cognitive impairment but who are still managing to cope reasonably well. Underlying reversible physical causes have been ruled out.

Care Cluster 19: People who have problems with their memory, and or other aspects of cognitive functioning resulting in moderate problems looking after themselves and maintaining social relationships. Probable risk of self-neglect or harm to others and may be experiencing some anxiety or depression.

Care Cluster 20: People with dementia who are having significant problems in looking after themselves and whose behaviour may challenge their carers or services. They may have high levels of anxiety or depression, psychotic symptoms or significant problems such as aggression or agitation. The may not be aware of their problems. They are likely to be at high risk of self-neglect or harm to others, and there may be a significant risk of their care arrangements breaking down.

Care Cluster 21: People with cognitive impairment or dementia who are having significant problems in looking after themselves, and whose physical condition is becoming increasingly frail. They may not be aware of their problems and there may be a significant risk of their care arrangements breaking down.

Patients registered to all clusters



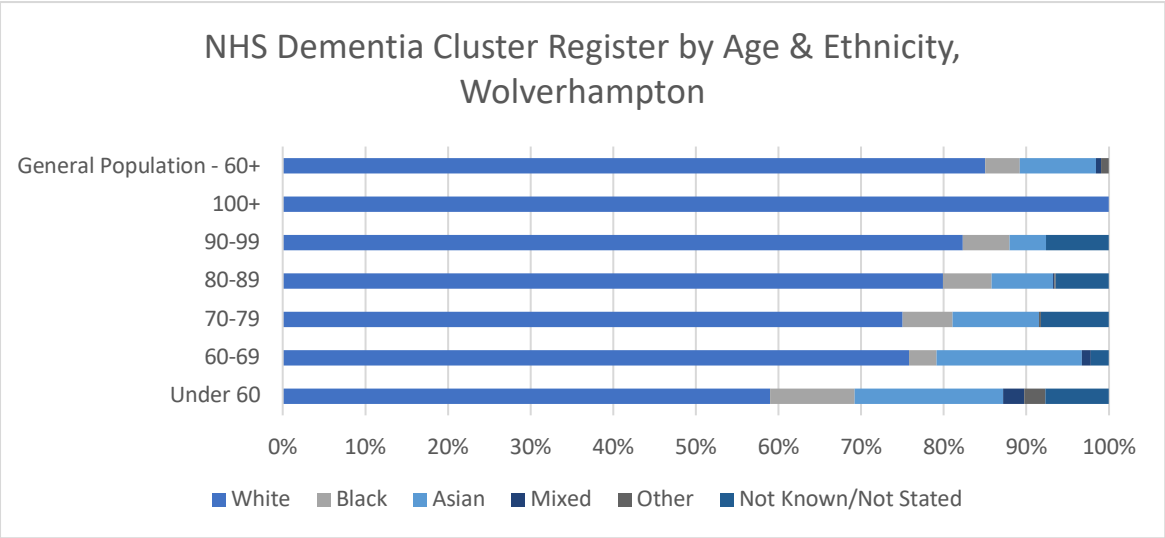
Source: NHS BCPFT

In Wolverhampton, there are around 1,250 patients registered to a cluster that is indicative of a diagnosis of Dementia. Just under half of all patients (606 patients) are in the 80-89 year age group. The second most populated age group is the 70-79 year age group, in which there are 364 patients.

	Population	Number in Cluster	Rate per 100,000
Under 60	199,144	39	19.58
60-69	24,397	91	373.00
70-79	18,303	364	1,988.75
80-89	10,384	606	5,835.90
90+	2,178	159	7,300.28

Source: NHS BCPFT

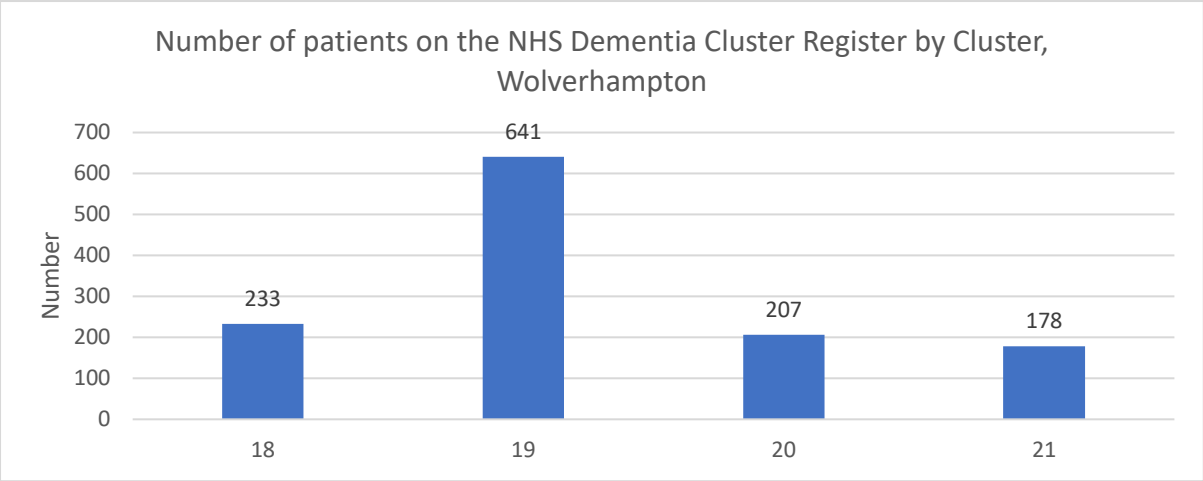
However, when the number of patients registered to a cluster are compared to the general population, the highest rate of residents registered to a cluster is in the 90+ age group, at 7,300 per 100,000. The rate for the 80-89 year age group, of which around 48% of all registered patients fall into, has the second highest rate of 5,836 per 100,000. The rates for the 70-79, 60-69 and under 60 age groups are considerable lower.



Source: NHS BCPFT

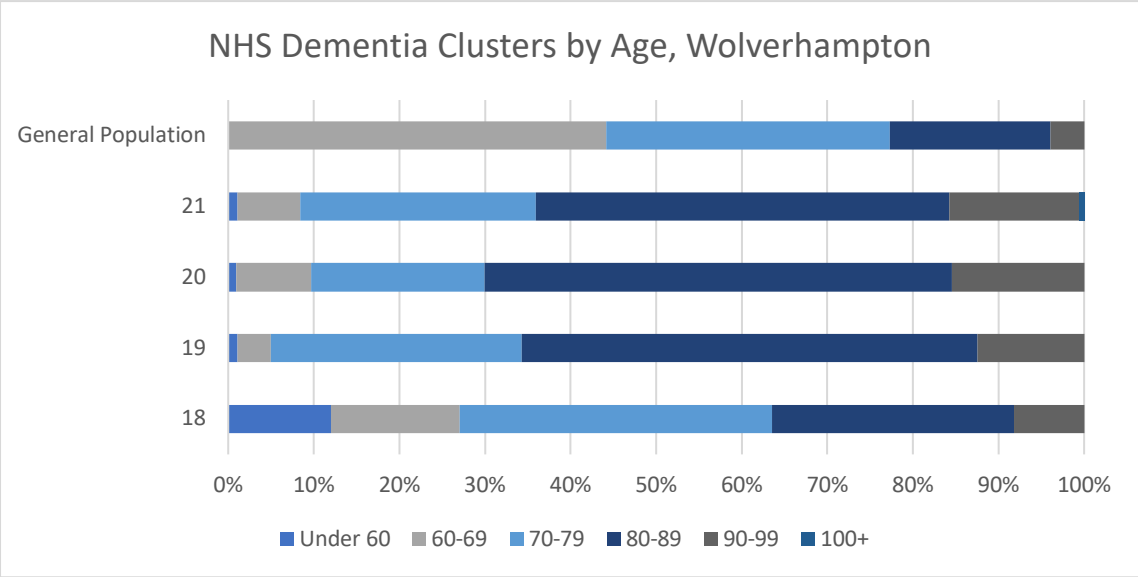
The majority of patients registered to clusters that are related to Dementia are of a White ethnicity. In the most populated age groups (70-79, 80-89 and 90-99), between 75.0% and 82.3% of those registered in clusters are of a White ethnicity. Compared to the general population of Wolverhampton aged 60+, the White ethnic group in the three most populated age groups is slightly under-represented. The Asian ethnic group is also slightly under-represented in the 80-89 and 90-99 year age group, but slightly over-represented in the 70-79 year age group. The Black ethnic group is slightly over represented compared to the general population of Wolverhampton aged over 60 (4.1%), with figures between 5.7% and 6.0% in the three most populated age groups.

Patients within clusters



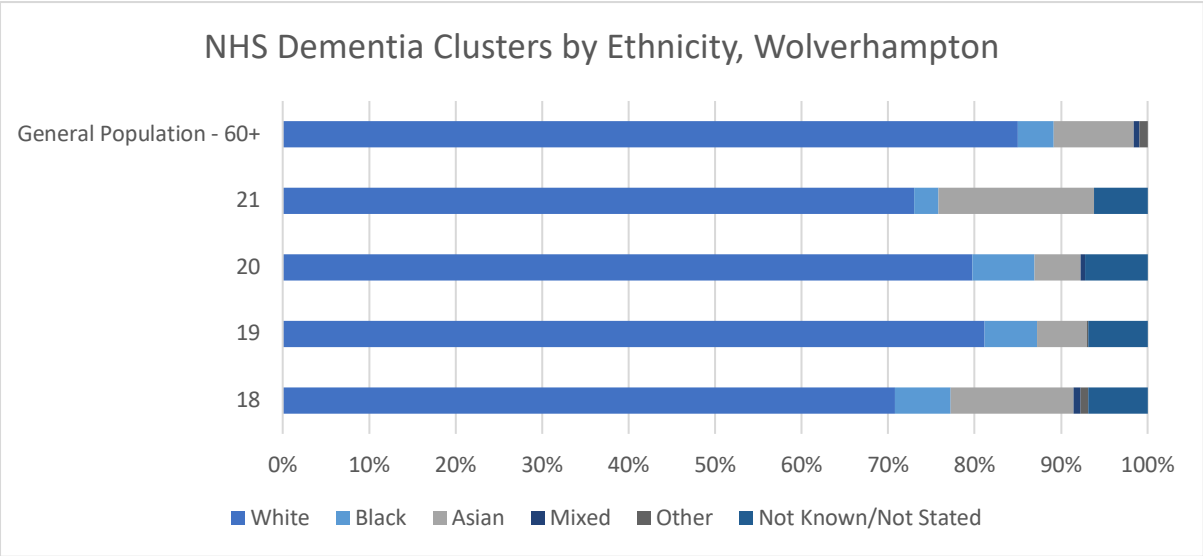
Source: NHS BCPFT

Just over half of all patients registered to a care cluster that suggest a diagnosis of Dementia fall into cluster 19. Patients in Cluster 19 are characterised by having moderate needs. The number in the cluster with the least needs, Cluster 18, have just under a fifth of all patients registered for Dementia related needs. The two clusters which contain patients with significant needs, Clusters 20 and 21, contain 16% and 14% of patients, respectively.



Source: NHS BCPFT

The age profiles for each of the dementia clusters vary slightly. Cluster 18, which is characterised as having the least severe cognitive symptoms, on average has the youngest patients, with a median of 76 years of age. Almost 40% of patients in Cluster 18 are aged between 70-79, the highest among the four clusters for that age group. Cluster 18 also has the highest proportion of under 60's and the lowest proportion of over 90's. In Clusters 19, 20 and 21 around half of patients are aged between 80-89. On average the patients in Clusters 19, 20 and 21 are older than the patients in Cluster 18, the median age is 83 years for Cluster 19 and 20, and 82 years for Cluster 21. The proportion of patients in the 90-99 age group increases as the severity of symptoms increases, with the highest proportions seen in Cluster 20 and 21, 15.5% and 15.2%, respectively.



Source: NHS BCPFT

The majority of patients registered to a dementia cluster were of a White ethnicity, although the proportion of patients with a White ethnicity was lower compared to the proportion of the White population in the Wolverhampton population aged 60+. The lowest proportions of patients of a White ethnicity are seen in clusters 18 and 21. The proportion of patients of an Asian ethnicity is highest in clusters 18 and 21, at 14.2% and 18.0%, respectively. Whereas, the proportions in clusters 19 and 20 were much lower at 5.8% and 5.3%, respectively. Compared to the general population of Wolverhampton, the Asian ethnicity is over represented in clusters 18 and 21; and underrepresented in clusters 19 and 20. There is also a slight data quality issue in this chart, with between 6.2% and 7.2% of patients in each cluster, with an ethnicity recorded as 'Not Known/Not Stated'.

Stakeholder Views

Surveys were conducted to obtain the views of service providers, professionals working with people with Dementia, carers and people diagnosed with Dementia on services provided for people with Dementia. Three separate surveys were conducted to obtain stakeholder views. One survey for professionals working with people with Dementia, one for carers of people with Dementia and one for people diagnosed with Dementia. The results of these surveys are only the views and opinions of the people who responded to the survey and should be interpreted with caution as they may not reflect the views of all the survey audience in Wolverhampton. A summary of the stakeholder engagement processes is presented below and a detailed stakeholder engagement report is available on request.

Methodology

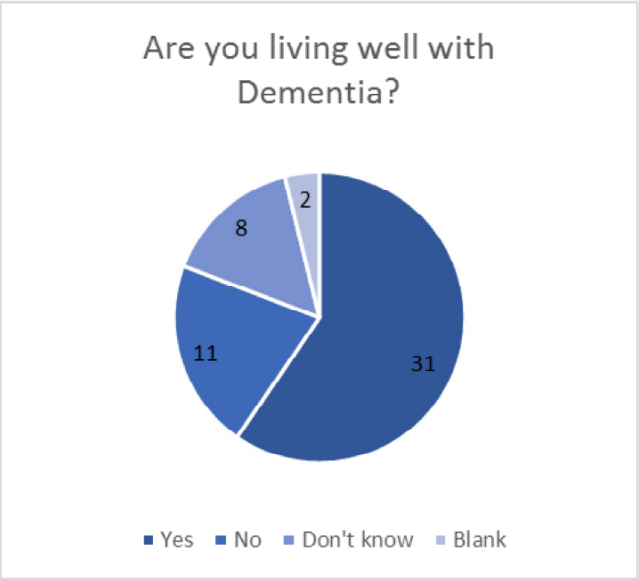
The three survey questionnaires were co-produced with colleagues from social care commissioning and with consultation of the JSNA Steering Group members, which includes membership from the Wolverhampton CCG, Royal Wolverhampton Trust and Black Country Partnership Foundation Trust. An implementation plan was agreed to ensure timely administration.

The questionnaire was sent to the stakeholders via a survey monkey link along with an email detailing the importance of the Dementia JSNA and how stakeholders could help to shape future services. There were also hard copies of each of the surveys for those respondents who were either unable to fill it online or did not wish to. The JSNA Steering Group supported dissemination to key stakeholders and there was additional direct distribution to further known networks. The links to the surveys were also disseminated via the City Council's communications team with press releases, articles on the Council's intranet and local newspapers. Colleagues from social care commissioning that were involved with Dementia Café's also took along hard copies of the surveys for people diagnosed with Dementia and asked service users to fill them in and assisted respondents with this.

Survey for people diagnosed with Dementia

There were 52 surveys returned from respondents that had been diagnosed with Dementia, of which 1 survey was completed online and 51 surveys were completed on paper. Of the 52 respondents, 35 reported their gender as Female, 13 as Male and 4 left the question blank.

Are you living well with Dementia?



The majority (59.62%) of respondents reported 'Yes' when asked 'Are you living well with Dementia?'. Around a 21.15% of respondents reported 'No' to the question, a further 15.38% said they 'Don't know' and 2 respondents left the question blank.

Alongside the response, respondents were asked for any comments they may have to along with their answer. Comments from those who responded 'Yes' included: 'With lots of help from carers and daughter', 'Yes, because my wife looks after me' and 'Best I can'. Comments alongside those that responded 'No' included: 'Every day it's different. You don't know what you are going to face. (People with Dementia do not feel comfortable around new people).' Other comments from those who reported to being unsure were around the themes of not being able to say how they were feeling.

What is your type of residency?

Type of Residency	Number	Percentage
Living alone at home	10	19.23%
Living at home with partner	23	44.23%
Living in residential care	2	3.85%
Living in supported accommodation	4	7.69%
Living with extended family	9	17.31%
Blank	4	7.69%

Respondents were asked about the living arrangements using a closed question: 'What is your type of residency?'. Almost half of the 52 respondents (44.23%) said they live at with their partner, a further 10 respondents said they live at home alone and 9 respondents said they lived with extended family.

Do you have enough family and friends around you that you can count on for support?

Responses	Number	Percentage
No	8	15.38%
Yes	36	69.23%
Don't know	6	11.54%
Blank	2	3.85%

Respondents were also asked whether they have enough family and friends around them that they could count on for support. Around two-thirds of respondents reported that they had enough family

and friends around for support, whereas a further 14 respondents reported that they either did not have enough (15.38%) or did not know (11.54%).

Of the 10 respondents that reported to living at home alone, 6 said they had enough family and friends around for support, 3 said they didn't and 1 said they did not know. There were 32 respondents who reported to living with either their partner or extended family, 4 of these respondents said they did not have enough family or friends around them and 3 said they did not know. None of the respondents living in either supported accommodation or residential care said they did not have enough friends or family around to count on for support.

Are you receiving any support to live well with Dementia?

Responses	Number	Percentage
No	13	25.00%
Yes	26	50.00%
Blank	5	9.62%
Don't know	8	15.38%

Respondents were asked if they received any support to live well with Dementia. This question had a text box alongside it for respondents to identify who they received support from and to explore what people with Dementia may identify as support.

Half of the respondents said they received some support to live well with Dementia, accounting for 26 respondents. In the comments, respondents elaborated on this. The common themes were:

- Support from carers from social services/council
- Nurse visits
- Carer support to carry out tasks such as getting changed and shopping
- Support from family

Do you feel involved enough in decisions about your care and support?

Responses	Number	Percentage
No	9	17.31%
Yes	23	44.23%
Blank	3	5.77%
Don't know	17	32.69%

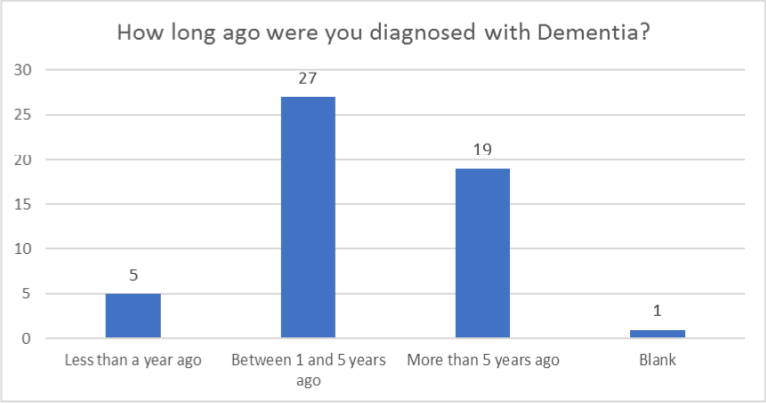
Respondents were also asked whether they felt involved enough in decisions about their care and support, via a closed question. Almost a third of respondents (32.69%) reported that they did not know if they were involved enough with decisions about their care and support. However, the majority of respondents said they did feel involved enough with decisions (44.23%) and just under a fifth (17.31%) said they did not feel involved enough.

If you have a carer (family or friend), do they receive help to care for you?

Responses	Number	Percentage
No	20	38.46%
Yes	25	48.08%
Blank	4	7.69%
Don't know	3	5.77%

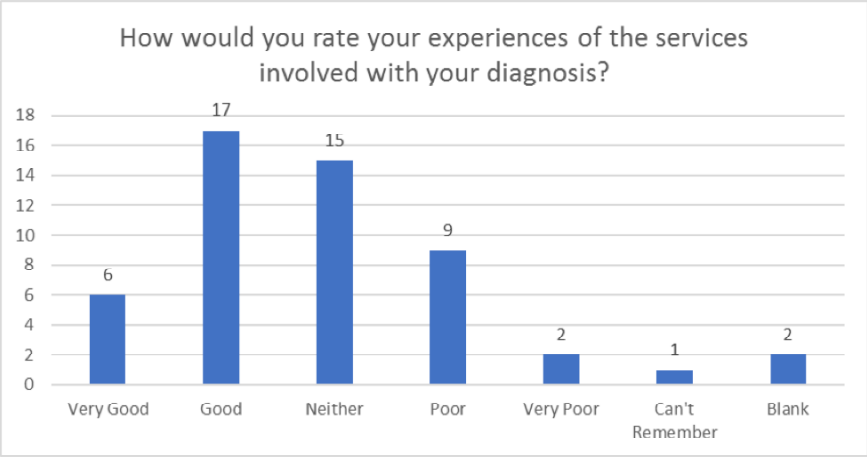
Respondents were asked if they had a carer (family or friend), whether that carer received help to care for them, with an open text box asking who the help was provided by. Just under half of all respondents (48.08%) reported that their carers received support to care for them. The common themes from the text within the free text box were financial support, additional carer support and family support. Around 38.46% of respondents said their carers did not receive any help and 5.77% said they did not know. None of the respondents who said their carers did not or they did not know whether their carers received any help, left any comments alongside their answer. Four respondents left the question blank, but did say that their family helped their carer in the text box.

How long ago were you diagnosed with Dementia?



Respondents were asked how long they had been living with a diagnosis of Dementia, via a closed question with three-time periods. Just over half of respondents (51.92%) had been diagnosed with Dementia for between 1 and 5 years, at the time of the survey. There were 19 respondents (36.54%) who reported to had been diagnosed more than 5 years ago and only 5 respondents were diagnosed less than a year ago.

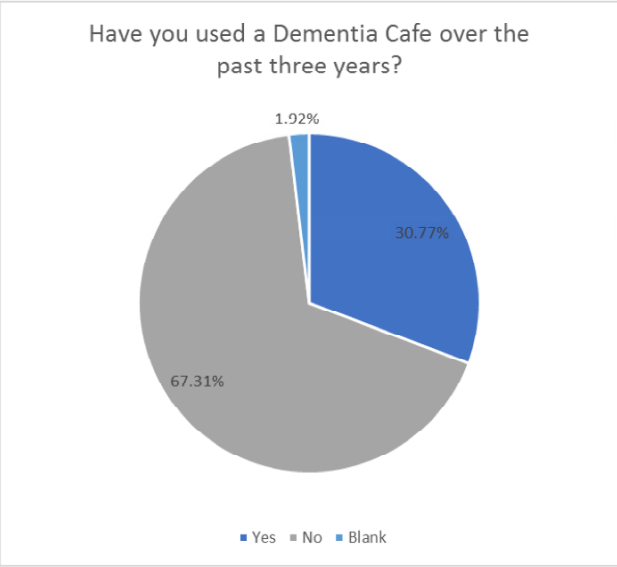
How would you rate your experiences of the services involved with your diagnosis?



Respondents were asked to rate their experiences of the services involved with their diagnosis. Just under half of respondents (44.23%) said their experience with the services involved with their diagnosis was either 'Good' or 'Very Good'. Over a fifth of respondents (21.15%) said their experience was 'Poor' or 'Very Poor'.

Of the respondents that were diagnosed more than five years ago (19 respondents), nine said they rated their experience of services as 'Good' or 'Very Good', whereas only 4 respondents rated it as 'Poor' or 'Very Poor'. A similar split was seen in respondents who were diagnosed between 1 and 5 years ago, with 13 rating their experience as 'Good' or 'Very Good'; 6 rating it as 'Poor' or 'Very Poor'. However, in respondents that were diagnosed less than a year ago, 60% rated their experience as 'Neither' (3 respondents).

Have you used a Dementia Café over the past three years?



Respondents were asked whether they have made use of the Dementia Café's based in Wolverhampton at any point over the past three years. Of the 52 respondents, only 16 (30.77%) said they had used the Dementia Cafe service. Over two-thirds of respondents (67.31%) said they had not used a Dementia café.

If not, what stops you using a Dementia Café?

A further question was asked to those respondents who said they had not used the Dementia Café service in order to explore the reasons why they did not use them, using a list of three potentially common reasons and an 'Other' option for respondents who had reasons that were not in the list. Respondents may have chosen more than one option for this question.

Reason	Responses
Isn't one near me	4
Have never heard of it	15
It is not useful	3
Other	14
Blank	16

The most common reason for not using Dementia Cafés was that respondents had not heard of the service. A small number of respondents reported that they did not have a Dementia Café near them (4 respondents) or that they did not think the service was useful (3 respondents). The common themes that were presented alongside the 'Other' category were:

- People with Dementia struggling to get out of the house
- Carers or family members unable to take them due to the opening times.

Do you have any comments about the Dementia cafes? What is useful/not useful?

There was also an opportunity for respondents to provide comments on Dementia Café's and which aspects of the service respondents thought were useful or not useful. Common themes arising from the responses to this question were:

- Positive:
    - Somewhere to meet and talk to people about their condition
    - Somewhere to share problems and get help
    - Volunteers and users are very good and very friendly
    - Social aspects and activities
- Negative:
    - All run in the morning, need some café's open in the afternoon in the local area
    - Lack of fellow younger attendees can unsettle younger attendees that do attend
    - No transport available

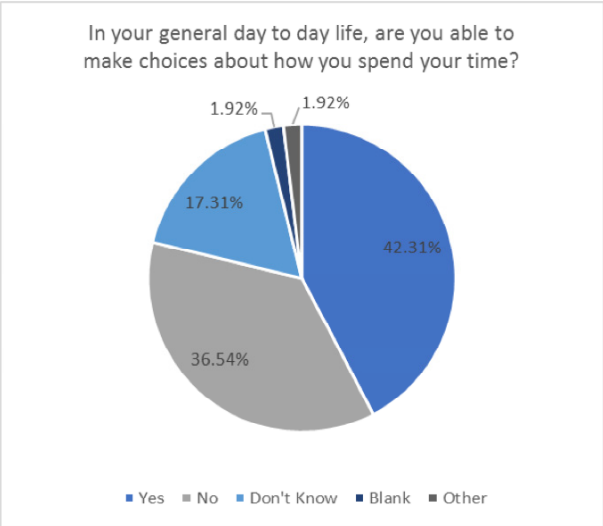
If you feel well supported with your Dementia in your local area, please tell us why?

Respondents were also asked if they felt supported to live well with Dementia in their local area, there were 14 responses to this question. This question was asked to explore which aspects of the respondent's environment support them to live well with Dementia. The responses to this question were quite diverse, the responses included:

- Carers are provided to support me
- Dementia cafes are good but more support is needed for more one to one [illegible] for dementia sufferers
- I attend Blakenhall Day Centre two days a week for dementia and feel well supported while I am there
- I feel well supported in my area because there is people to help you

- I have a number of Dementia cafes to choose from. However, there are non-catering for people from the Afro-Caribbean Community
- No - nothing in local area to me - just need to be with others i.e. social meetings - not organised facilities
- The dementia cafes are very supportive

In your general day to day life, are you able to make choices about how you spend your time?

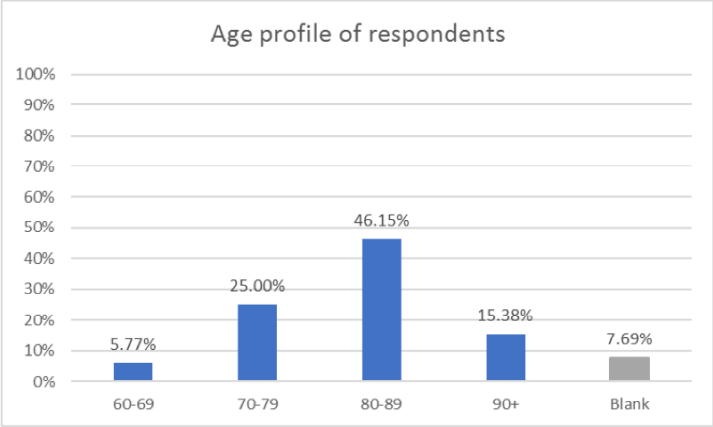


Respondents were asked whether they felt that they able to make decisions about how they spend their time, in their general day to day lives. There were 22 respondents who said they were able to make decisions, which was the highest proportion of responses (42.31%). Just over a third of respondents (36.54%) said that they were not able to make those decisions and 17.31% said they did not know. Two respondents did not select a response, but one of those wrote a comment to answer the question: 'Not always'.

Demographics of Respondents

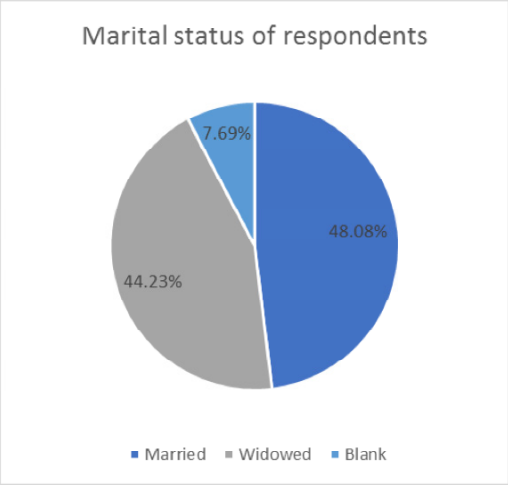
To complete this survey, we asked a set of demographic questions to understand the responses and to ascertain whether the current Dementia services provided in Wolverhampton are fair and accessible to a diverse range of people with dementia. Respondents were asked about a range of characteristics, such as gender, age, ethnicity and sexuality. This information will also allow us to determine how representative our sample of respondents is against the population of Wolverhampton with Dementia.

Age:



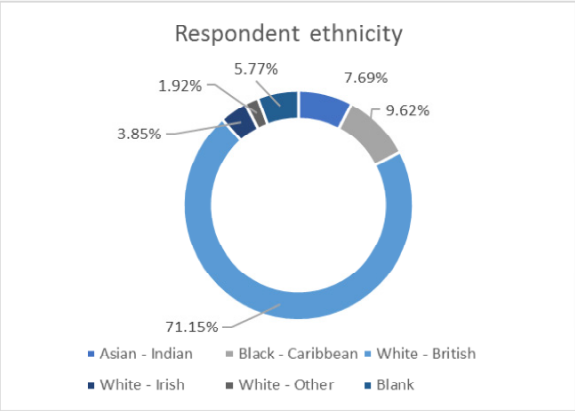
Just under half of all respondents said they were aged between 80-89 (46.15%). A quarter of respondents reported to being aged between 70-79, with lower proportions reporting to be aged below 70 and over 90.

Marital status:



Similar proportions of respondents reported to being Married or Widowed, at 48.08% and 44.23%, respectively. Four respondents did not leave a response and a number of options were left unticked (Civil Partnership, Co-habiting, Divorced, Single, Prefer not to say and Other).

Ethnicity:



The majority of respondents reported that their ethnicity was White – British (71.15%), whilst a further 3.85% said their ethnicity was White Irish and 1.92% said that it was White – Other. The second highest proportion of respondents reported that their ethnicity was Black – Caribbean (9.62%), followed by the proportion that said they were of an Asian – Indian ethnicity (7.69%).

Religion:

In addition to ethnicity, respondents were also asked which religion they followed, if any at all. The vast majority of respondents said they were Christian (including Catholic and Methodist), making up 78.85% of all respondents. Around 5.77% said they were Hindu, 1.92% said they were Sikh and 7.69% said they did not follow a religion. A further 5.77% left the question blank.

Sexuality:

Respondents were also asked about their sexuality, in order to see if there was any variation in the access and experience of living with Dementia between people with different sexualities. However, the vast majority reported their sexuality as Heterosexual/Straight (78.85%) and the remaining 21.15% either chose 'Prefer not to say' (4 respondents) or left the question blank (7 respondents).

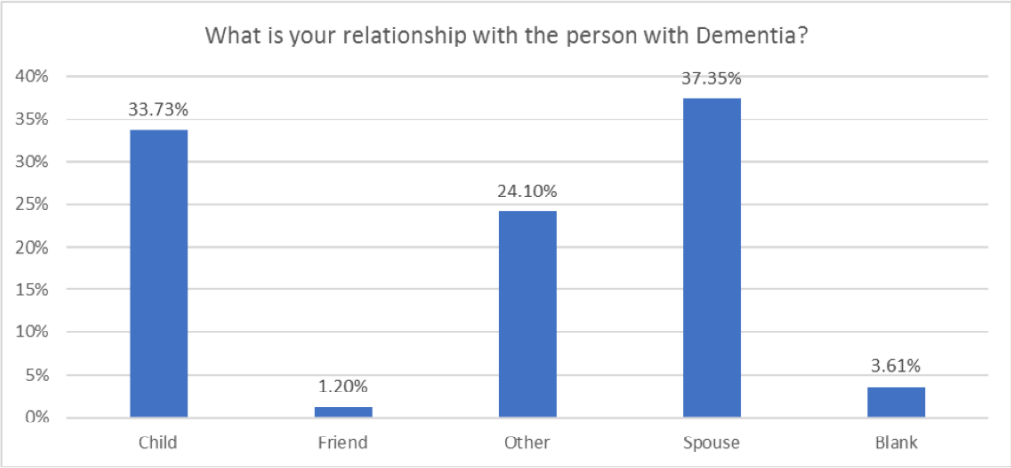
Further Comments:

Further comments were also placed at the end of some of the hard copies of the survey. Three of the comments were regarding completing the form, informing us that the person with Dementia was unable to complete the form, so a daughter filled it out with the person with Dementia. The other comment explained that the person with Dementia struggles to intercept letters and that due to English not being their first language, carers can struggle to communicate and understand her needs.

Survey for people caring for a person with Dementia

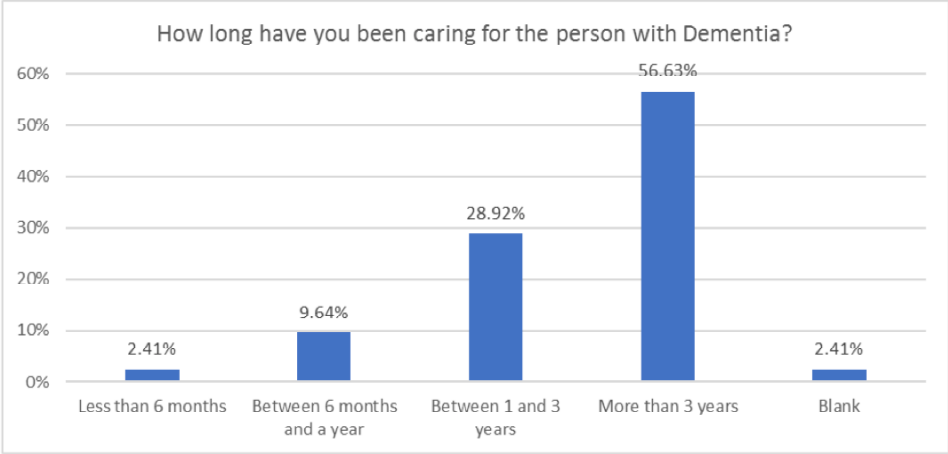
The survey aimed at carers generated 83 responses, 26 of the responses were done online and 57 were completed on paper. The 83 respondents consisted of 51 females, 24 males and 8 who either left their gender blank or said that they preferred not to say. The people with Dementia, that the 83 carers cared for, consisted of 44 females, 28 males and 11 people whose gender was not disclosed.

What is your relationship with the person with Dementia?



Respondents were asked what their relationship is with the person with Dementia that is cared for, the vast majority of carers were close relatives to the people they cared for. The most common relationship was 'Spouse', which made up 37.35% (31) of respondents, followed by carers that cared for a parent, with 34.94% (29) saying that they were the child of the person they cared for. Just under a quarter of respondents, 22.89% (19) of respondents said they were in the 'Other' category, which included other relatives and care workers.

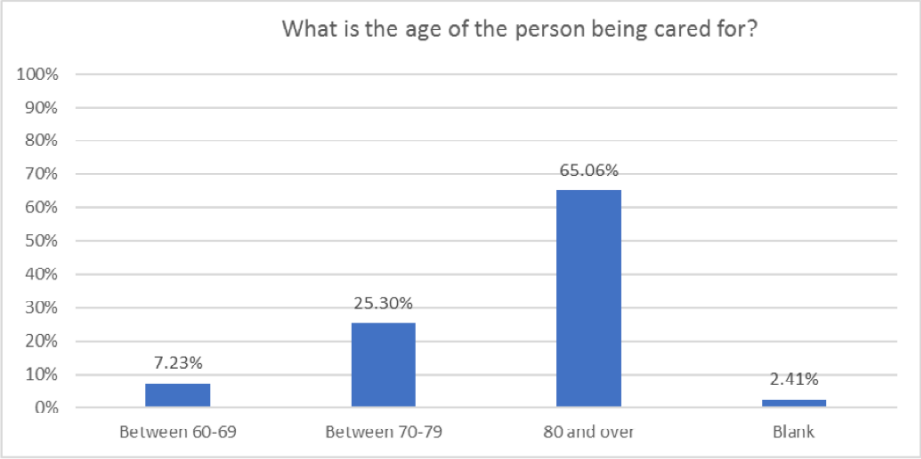
How long have you been caring for the person with Dementia?



Carers were asked how long they had been caring for the person with Dementia, more than half of the 83 carers said they had been caring for more three years (47 respondents). Over a quarter said they had been caring for between 1 and 3 years (24 respondents) and 9.64% said they had been caring for between 6 months and a year. Only 2 respondents said they had been caring for less than 6 months and a further two left this question blank.

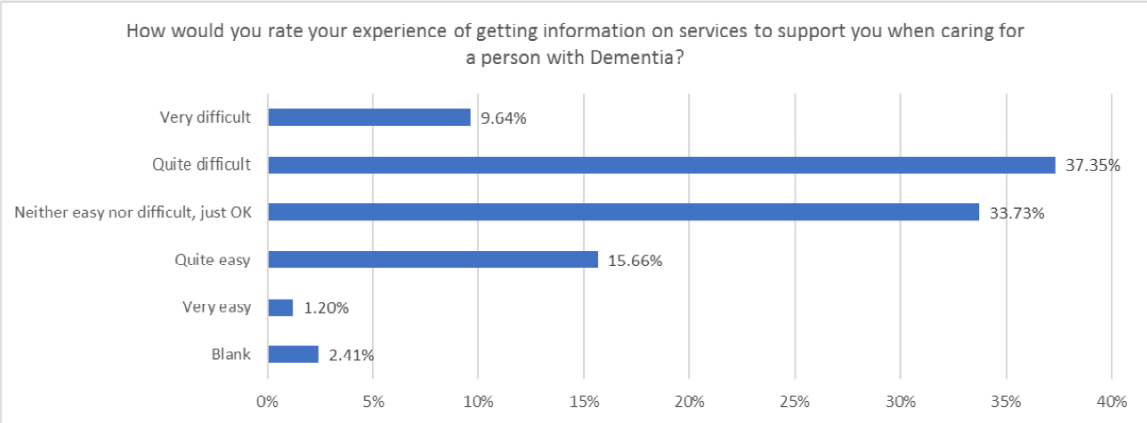
Around 60.71% of carers that care for a parent said they had been caring for them for more than 3 years and 32.14% said they had been caring for between 1 and 3 years. More than two-thirds (67.74%) of carers caring for a spouse said they had been caring for them for more than 3 years.

How old is the person with Dementia?



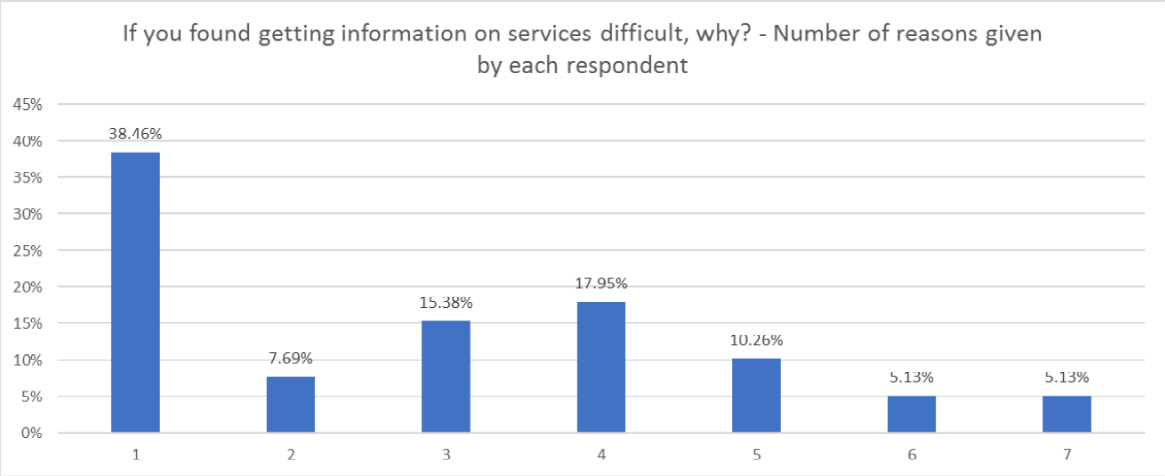
The majority (65.06%) of the people cared for by the respondents were aged 80 and over, accounting for 54 respondents. Around a quarter of those cared for were aged between 70-79, accounting for 21 respondents (25.30%). There were six respondents that said they were looking after someone aged between 60-69 (7.23%). None of the respondents reported to be caring for someone below the age of 60 with Dementia, however 2 respondents did not answer the question.

How would you rate your experience of getting information on services to support you when caring for a person with Dementia?



Carers responding to the survey were asked how they would rate their experience of getting hold of information on services to support them when caring for someone with Dementia. The responses were slightly skewed towards people finding it difficult to get hold of information, with 'Quite difficult' getting the most responses, 37.35% of responses. The second most common response was for 'Neither easy nor difficult, just OK', which was selected by 28 carers (33.73%). A further 8 respondents said they found it 'Very difficult', making up 9.64% of respondents. Only one respondent found it 'Very easy' to get hold of information and 13 found it 'Quite easy'.

If you found getting information on services difficult, why?



A follow up question was asked, looking into the reasons why respondents may have found getting information on services difficult, 21 respondents left this question blank. There were nine potential reasons provided, including an 'Other (please specify)' category and respondents could select as many as were appropriate. Around 38.46% of carers that found getting information difficult said they only had 1 reason. The proportion of respondents that said they had 2 reasons was much lower, at 7.69% and higher for respondents saying they had 3 or 4 reasons.

Reasons	Number
Not knowing where to get the information needed	24
Not knowing who to ask for the information needed	19
Not being told about something until it's too late	14
It takes too long to actually receive the information you need	14
Not knowing what services to look out for	9
Health and/or Social Care professionals have not been able to provide the information you need or where to get it from	8
The services for which you received information were not suitable	7
The information was in a format you couldn't use (e.g. online only)	5
Other (please specify):	17

The most commonly selected reason for finding it difficult to obtain information on Dementia services was 'Not knowing where to get the information needed', which was selected by 24 respondents, making up 38.71% of respondents that answered this question. The second most commonly selected reason was 'Not knowing who to ask for the information needed', which was selected by 19 respondents, (30.65%). The least selected reason was 'The information was in a format you couldn't use (e.g. online only)', selected by 5 respondents, making up 8.07% of respondents. The 'Other (please specify)' option was selected 17 times.

Common themes from the comments provided by those that selected the 'Other (please specify)' option included respondents saying that difficulties were a mixture of the option and provided specific examples of difficulties they encountered; lack of information provided around costs of care; fragmented information and support services; examples of difficulties involving multiple services, getting in touch with a certain support service was a 'waste of time' and that there is a lack of concern for individuals with Dementia and carers.

Which Dementia support services have you used?

Type of Service	Number
Dementia Café	26
Carer Support	21
Other	14
Memory Clinic	10
Social Services	10
None	9
Nursing Teams	9
Day Centre	6
Care Home	5
Telecare	3
GP	2

Respondents were asked to identify which services they had used to support them to live well with Dementia. This question had a free text box, so that we could also explore which services respondents thought supported them to live well with Dementia. The most commonly identified service by respondents were Dementia Café's, of which six individual Dementia Cafés were identified. The second most common form of support identified by carers was Carer Support, which was identified by 21 respondents. The least commonly identified services were GP's, with only two carers identifying them. However, it could be assumed that the majority of people that the respondents cared for visit their GP on a regular basis, but would not list them as a support service for Dementia.

Did you find accessing any of these services difficult?

A follow up question was asked looking to explore whether carers found accessing services difficult and if so, why they found it difficult. Of the 21 carers that said they had used Dementia Café's, the majority said they had no difficulties accessing the service. However, two difficulties were detailed in the responses in relation to difficulties accessing Dementia Café's. One respondents commented that the dates and times of Dementia Café's made it difficult for them to access the service and another respondents comment was unclear. Another respondent left a positive comment regarding the Dementia Café's, in which they suggested that the Café's provided information which opened doors to other services. A common theme among the answers for this question was that carers were unable to get the information required to access services from professionals, requiring them to either find the information themselves or get in contact with other support services to obtain the information. Other recurring themes were the initial diagnosis at the GP taking too long delaying the access to services, carers unable to contact either the service or the healthcare/social care professional who is working them and carers unable to access online only information.

What type of Dementia support have you found most useful? And why?

Respondents were asked which type of support they found most useful and why. This question was asked to explore what support carers find beneficial and the aspects of the support that has the most effect. The types of support identified in the responses to this question were similar. Respondents that found Dementia Café's the most useful type of support said they found the social aspects for people with Dementia useful. Carers also said Dementia Café's helped lift spirits, gave them somewhere to go and provided useful information. Respondents that found Carers Support

and Agency carers most useful said that they supported carers with challenging tasks, provided a break for carers and signposted to other support services. Carers said they found day care services useful because they provide respite and provide other support such as personal hygiene. Memory clinics were found to be useful to carers, however there was a lack of detail provided about which aspects of Memory clinics were most useful.

Do you think there are any needs that are not being met by Dementia services?

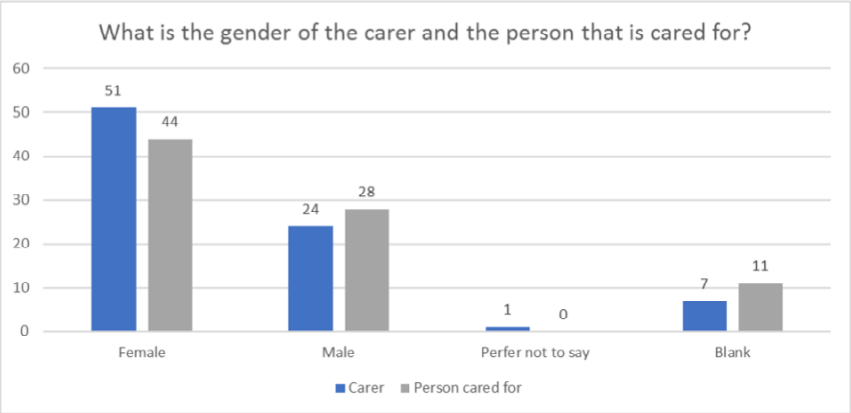
Respondents were also asked in an open question, whether they thought there were any needs that were unmet by current service provision. There was a diverse range of responses, however, some key themes did emerge. Carers said there was a lack of support for carers when exploring their options for services and care homes, with one respondent suggesting there should be a carers information support programme that is run in other areas. A number of respondents said that there was a lack of readily available information on what support was available to them, some saying that the onus was on the carer to find the information themselves. A number of respondents said they didn't think the level of support provided was adequate and in particular that there was a lack of quick response support either when newly diagnosed or in case of emergencies.

Are there any cultural or social barriers affecting the care you provide?

Respondents were also asked to comment on whether there were any cultural barriers that affect the care that they provide. The majority of respondents, 68.67%, either ticked the 'No' box or left the question blank, which means that just under a third of respondents, 31.33%, found that cultural issues affected the care they provided. There were nine responses from carers with a BME background, of whom six carers said there were cultural or social barriers. This suggests that those from a BME background are twice as likely to face cultural or social barriers that affect the care they give, although it should be noted numbers were small. There were a diverse range of comments and there were very few common themes. However, some themes which did stand out were that there was a lack of support in different languages for both carers and people with Dementia, a lack of Dementia friendly transport to/from services and a lack of understanding of the condition among the community.

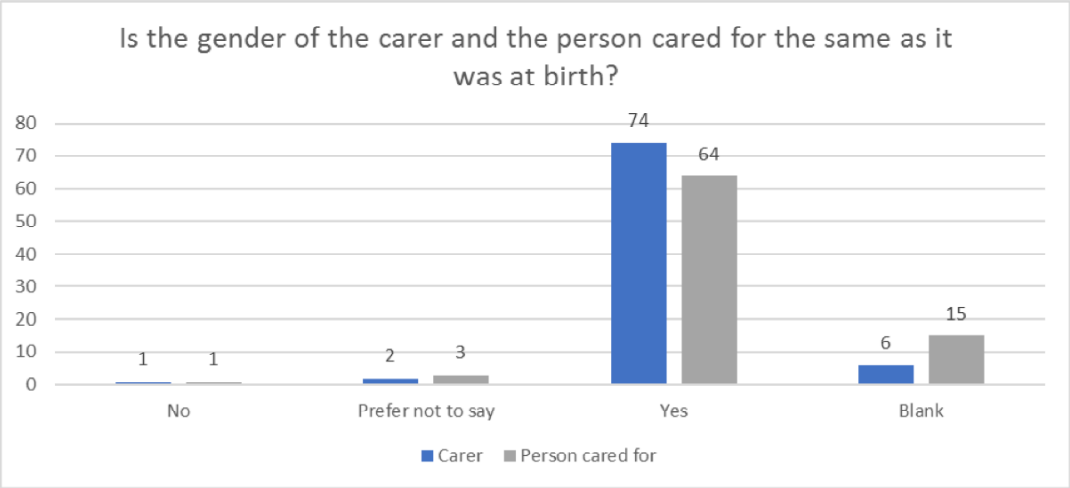
Demographic of carers and people cared for

Gender:



The majority of respondents (61.45%) said they were Female and around 28.92% said they were Male. When asked about the people they cared for, the majority said they cared for a female (53.01%) and around a third said they cared for a male (33.74%).

Is your gender identity the same as the gender you were assigned at birth?



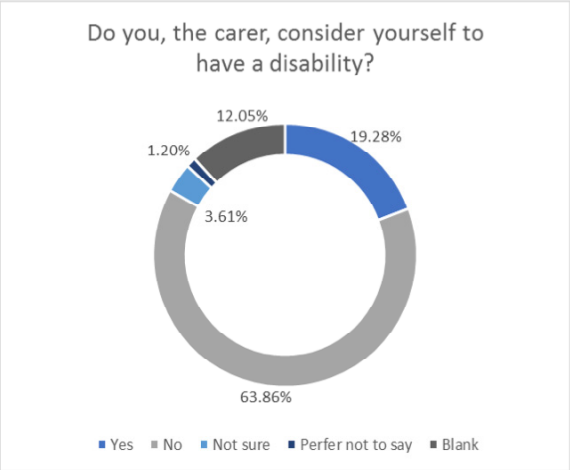
The majority of respondents said their gender and the gender of the person they cared for was the same as it was at birth, at 89.15% and 77.11%, respectively. There were 8 carers who either left the response about their gender blank or preferred not to say and 18 carers who either left the response about the person they cared for blank or preferred not to say.

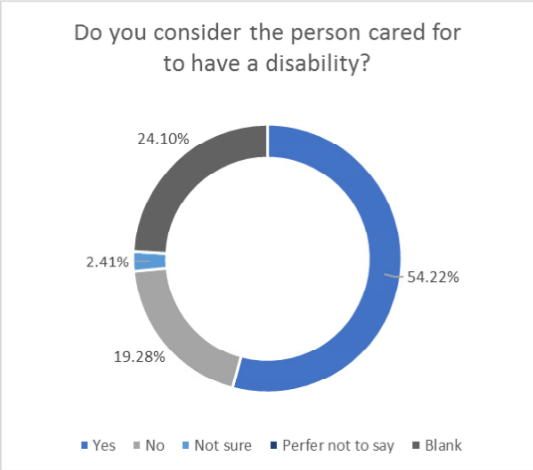
Marital Status:

Marital Status	Carer	Person cared for
Co-habiting	8	0
Divorced	4	5
Married	53	33
Single	10	1
Widowed	3	28
Prefer not to say	1	0
Blank	4	16

Almost two-thirds of carers stated that their marital status was 'Married' (63.86%) and a further 12.05% said they were 'Single'. Regarding the people cared for, the carers said that 39.76% of them were 'Married', 33.73% were 'Widowed' and 19.28% of responses were left blank.

Do you have a disability which affects your day to day activities, which has lasted, or you expect to last, at least a year?





Respondents were asked whether they considered, both themselves and the person they care for, to have a disability. There were 53 carers, making up almost two-thirds of carers (63.86%), that stated that they did not consider themselves to have a disability. There were 16 carers (19.28%) that considered themselves to have a disability and the remaining 14 respondents (16.87%) either were unsure, preferred not to say or left the question blank.

There were 45 carers that stated they considered the person they cared for to have a disability, making up 54.22% of responses. A further 16 respondents (19.28%) said they did not consider the person they cared for to have a disability and the remaining 22 respondents (26.51%) said they were either unsure or left the question blank.

Ethnicity:

Ethnicity	Carer	Person cared for
Asian – Indian	5	6
Asian – Pakistani	0	1
Black	3	4
White – British	67	61
White - Irish	1	1
White - Other	0	1
Other - Any Other	1	0
Blank	6	9

Respondents were asked to describe their ethnicity as well as the ethnicity of the people they cared for. The majority of carers said that their ethnicity and the ethnicity of the person they cared for was 'White – British', making up 80.72% of carers and 73.49% of people cared for. Respondents stated that around 6.02% of carers and 7.23% of the people cared for had an 'Asian – Indian' ethnic background. A further 3.61% of carers stated that their ethnic background was 'Black' and 4.82% of carers stated that the person they cared for had a 'Black' ethnic background.

Religion:

Religion	Carer	Person cared for
Christian	56	55
Sikh	3	4
Hindu	3	3
Muslim	1	1
Prefer not to say	4	1
No religion	9	4
Blank	7	15

Respondents were asked which religion they and the person they cared for followed. Around two-thirds of respondents said that they (67.47%) and the person they cared for (66.27%), followed Christianity. Around 10.84% of respondents said they did not follow any religion and 4.82% of respondents said that the person they cared for did not follow a religion. Around 8.43% did not leave an answer for their religion and 18.07% did not leave an answer for the person they cared for.

Survey for Professionals working with people with Dementia

There were 24 responses from professionals that work with people with Dementia, of these responses 19 were completed online and 5 were completed on paper.

What sector do you work in?

Sector	Number	Percentage
Health	3	12.00%
Social Care	6	24.00%
Private Sector	3	12.00%
Voluntary Sector	8	32.00%
Primary Care	1	4.00%
Other	3	12.00%
Blank	1	4.00%

The most responses came from professionals working in the Voluntary sector, making up just under a third of responses (32.00%). The second highest number of responses came from Social Care, making up just under a quarter of responses (24.00%) and there were 3 responses each from professionals who worked in the Health, Private and Other sectors.

At which level is your role?

Role	Number	Percentage
Carer	2	8.00%
Frontline	2	8.00%
Manager	10	40.00%
Nursing	3	12.00%
Volunteer	4	16.00%
Other	2	8.00%
Blank	2	8.00%

There were 10 responses from professionals who said they had a managerial role within their organisation, this made up 40.00% of the 25 responses. There were 4 responses from professionals who said they were volunteers within their organisation, two of whom stated that they were volunteers at Dementia Café's. There were two carers that responded to this survey, one of whom also said they were also a volunteer at a Dementia Café.

Brief description of service:

Respondents were also asked to provide a brief description of the service provided by the service they worked for. The three responses from professionals that worked in the Health economy stated that they provided:

- Dementia outreach service
- Provision of Dementia services across an acute hospital trust
- Work to improve the health and wellbeing of residents of the city

The responses from professionals that worked in Social Care stated that they provided:

- Community care for those living with Dementia, ranging from companionship to personal care
- Advising carers and people with Dementia how to live will with Dementia, delivering carers information support program and living well with Dementia programme for Dudley
- Domiciliary care for elderly within their own homes
- Day services
- Social care assessment for adults

The responses from professionals working in the private sector stated they worked for organisations which run care homes, providing care for elderly and frail people, including those with Dementia.

The responses from professionals working in the voluntary sector stated that they work for organisations that provided:

- Services for people of all ages living with sight loss across the Black Country and Staffordshire, which include a diverse range of on site and community based services with the aim of nurturing independence, reducing isolation, building confidence and physical and mental well-being. The service also provides residential care, including hospital to residential packages.
- Dementia Café's via Alzheimer's Society UK
- Providing day care to visually impaired who have pan disabilities
- Provision of Dementia Café's, Dementia support workers and providing access to the National Dementia Hotline and online forum.

There was one respondent that said they worked in a Primary Care organisation, the respondent stated that the organisation they worked for provided a day service for older adults with mental health conditions.

Three respondents classed the organisation they worked for as 'Other', these respondents said that their organisations provided:

- A ring and ride service transport service for people with limited mobility, to help individuals maintain independence and quality of life
- Listening to the effects on carers living with a partner with Dementia, watching their deterioration, acknowledging the impact on them and coming to terms with their loss
- Wolverhampton older adult mental health service

Age range you work with:

Sector	18-65	65-75	75-85	85+	Total Responses
Health	2	3	3	3	3
Social Care	3	6	5	5	6
Private Sector	2	2	3	2	3
Voluntary Sector	2	5	5	5	8
Primary Care	1	1	1	1	1
Other	3	3	2	2	3
All Sectors	13	20	19	18	24

Respondents were asked what age range their organisation worked with and the following age ranged were provided: 18-65 (working aged adults), 65-75, 75-85 and 85+. Out of the 24 respondents, 13 said their organisation worked with working aged adults (18-65), 20 worked with 65-75 year olds, 19 worked with 75-85 year olds and 18 worked with 85+ year olds. All three of the respondents in the Health economy said that their respective organisations worked with people aged 65-75, 75-85 and 85+, whereas only two respondents said they also worked with working aged adults. There were six respondents who said they worked in a Social Care organisation, of which only three said they worked with working aged adults, all six said they worked with 65-75 year olds, 5 respondents said they worked with 75-85 year olds and five said they worked with those aged 85+. Out of the eight respondents that worked in the Voluntary Sector, only two said that their organisation worked with working aged adults, whereas five respondents said their organisations worked with people in the 65-75, 75-85 and 85+ age groups.

How many adults diagnosed with Dementia do you work with, in a year (12 months)?

Sector	0-4	5-10	11-16	17-19	20+	All Ages
Health	-	-	-	-	2	3
Other	1	-	-	-	2	3
Primary Care	-	-	-	-	1	1
Private Sector	-	1	-	-	2	3
Social Care	1	-	1	-	4	6
Voluntary Sector	-	1	-	1	5	8
All Sectors	2	2	1	1	16	24

There were two respondents that said their organisation worked with less than 4 individuals that are living with Dementia, of which one respondent worked in Social Care and the other respondent classed their organisation as Other. There were also two respondents who stated that their organisation worked between 5-10 people with Dementia, of which one respondent worked in the Private Sector and one in the Voluntary Sector. Only one respondent said their organisation worked with 11-16 people with Dementia, which was a Social Care organisation, similarly only one respondent said their organisation worked with between 17-19 people with Dementia, which was a Voluntary Sector organisation. Two-thirds of respondents said their organisation worked with more than 20 people with Dementia. Of the 16 respondents that said their organisation worked with more than 20 people with Dementia, five worked in the Voluntary Sector, four worked in Social Care and 2 respondents each worked in the Health economy, Private Sector and in an Other sector. The only respondents from a Primary Care setting reported to work with more than 20 people with Dementia.

What are the referral routes into your service?

Referral Route	Number of times identified
Local Authority	10
Anyone Can Refer	8
Self-Referral	8
NHS Hospital	6
GP	5
NHS BCPFT	4
Other	3
CPN	2
Electronic Referral System	2
NHS	2
Alzheimer's Society	1
Carers	1
CCG	1
Church	1
NHS Eye Hospital	1
N/A	1

There were 56 referral routes identified by the 24 respondents. Due to the question requiring a free text response, the responses needed to be categorised into over-arching categories. The most common referral route was identified as Local Authority, which includes Social Care and other parts of the local authority. Local Authority was a referral route identified by 10 respondents. Self-referrals and 'Anyone can refer' were identified by 8 respondents each. NHS Hospitals were identified by 6 respondents, including one respondent who identified a specific ward that refers into their service. Referrals by GP's was also a commonly identified route into services, identified by 5 respondents. NHS BCPFT, who operate memory clinics, were also identified by 4 respondents as a common referral route.

How do you manage demand for your service (if applicable)?

Method	Number
Refer to other organisations for extra support	8
Criteria	7
Waiting Lists	6
Not seeing as often as preferred	4
Not applicable	4
Utilise varied grade of professional staff	2
Other	2
Shorter appointments	1

Respondents were asked how they managed the demand for their service, if applicable. This question had some potential answers provided, including an 'Other' option. There were 34 methods selected by the 24 respondents, although 8 respondents did not make a selection.

The most selected method of controlling demand was 'Refer to other organisations for extra support', which was selected by 8 respondents. The respondents who selected this option worked in a variety of areas, such as Social Care, in the Health economy and the Voluntary Sector. The second most selected option was 'Criteria', which means that clients must meet the criteria that a service has set to receive their support. Seven respondents selected Criteria as a method of managing the demand for their service, who worked in a variety of areas, including the health economy, social care and the voluntary sector. 'Waiting lists' was also a common method, selected by 6 respondents. Four respondents selected the 'Not applicable' option, which suggests that they have the capacity to deal with the demand for their service and do not need to implement any of these measures. The two respondents that selected 'Other' provided some further comments on the question, one respondent said their service works on a 'First come, first served basis' and the other respondent, working in social care, said they operate a continuous recruitment policy, but it is not clear whether this is in relation to staff or clients.

For the adults diagnosed with Dementia you see in your service, do you think their additional needs are being met?

Respondents to this survey were asked if the additional needs of adults they see with Dementia using their service were being met. Six respondents said they thought the additional needs were being met, nine respondents said they did not think additional needs were being met and eight of them left comments. Ten respondents did not select an answer, although one respondent did leave a comment.

The themes which arose from the comments written by respondents that did not think additional needs were being met were:

- Services are not able to proactive when personalising their services for individuals with Dementia
- Care assessments do not achieve helpful outcomes
- Many individuals with Dementia are isolated due to a lack of social facilities
- Lack of provision for under 65's with early on-set Dementia
- Smaller services do not have the time to spend therapeutically with patients
- Need for a carers information program and living well with Dementia program that is run in Dudley.

In your view, do you provide a service which meets the needs of adults diagnosed with Dementia currently using your service?

Respondents were also asked whether the service they provide meets the needs of adults with Dementia that are currently using their service. Fourteen respondents said they thought their service did meet the needs, whilst four stated they did not think the needs were being met and 5 respondents left the question unanswered.

The common themes which arose in the comments from respondents that thought their service met needs of adults using their service were:

- Provision of a personalised service that consider the individuals needs
- Providing the opportunity for social engagement for people with Dementia
- Well trained staff help meet the needs of people with Dementia and good access to GP's and interdisciplinary teams.

One respondent said that they thought their service met the needs of their service users, but the comments suggested that this may change in the future. The respondent's concerns were:

- Decisions are based on finances rather than clinical needs of people with Dementia
- Managers do not consider the vital opinion of clinicians
- Loss of resources and poor relationships with partners leading to loss of multi-agency working
- Currently the only place where an accurate diagnosis of Dementia can be made

The themes which arose from the comments left by respondents that did not think needs of adults using their service were being met were:

- More courses and information programmes are required for carers and people with Dementia to inform them about the condition and services available to them
- More personalisation and consideration of an individual's needs are needed by services
- A Dementia Café is required that is aimed at younger people with Dementia
- More staff and multi-agency working are required

Are there any key issues or needs for the adults diagnosed with Dementia you currently work with, which you don't provide, but wish to or someone else could deliver?

Respondents were asked whether they are aware of any key issues or needs for adults with Dementia that they work with, that they cannot support and would either like to support or someone else could support. Of the 24 respondents, five did not leave a response, eleven responded that they were aware of issues and needs and 8 respondents said they were not aware.

The common themes that arose from the comments provided by respondents who said they were are of issues and needs that they are not able to support were:

- Being able to raise more awareness of local services available to support people with Dementia
- Provision of forward thinking activities that socially stimulate people with Dementia rather than just 'holding them'
- Provision of more support for carers/family, including a sitting service to give carers a break and the Carers Information and living well with Dementia programs that are run elsewhere in the Black Country.
- Provision of services aimed at people with Dementia aged under 65

Are you aware of any changes or new trends in the needs for your current clients over the next 3-5 years?

Has your service got the right skill mix and capacity to meet this future need?

Respondents were asked whether they were aware of any changes or new trends over the next 3-5 years, in the needs of their current clients. Those that answered yes to this question were asked a follow up question, exploring whether services had the right skill mix and capacity to meet these future needs. Respondents who answered no to the follow up question were asked to elaborate on what they required to be prepared to meet the future need.

Twelve respondents said that they were not aware of any changes or new trends in the needs for their current clients. Whilst, seven respondents stated they were aware of changes or new trends and six did not respond. Although there were seven respondents who were asked to answer the follow up question, there were 14 responses.

There were 5 respondents that said 'Yes' their service had the right skill mix and capacity to meet the future need and 9 said they did not have the right skill mix and capacity. Those that said they did not have the right skill mix or capacity were asked to elaborate on what they would need to be prepared to meet future need. The comments provided were:

- Services need to be prepared to work with more clients, due to an aging population and be able to provide an accessible service with the needs of the customer at the centre
- Forward thinking community based outcomes, activities, support services and training to enable staff to help people continue to connect with the world
- Increase of capacity to provide support from point of diagnosis
- More support and training for staff, especially lower graded staff
- More local services
- Better informed staff
- More senior medical staff

Beyond the adults diagnosed with Dementia currently using your service, are there any further groups of adults diagnosed with Dementia that you feel would benefit from extra support from your service?

Respondents were asked whether there were any people with Dementia, beyond those that currently use the service, that would benefit from extra support from their service. Eleven of the respondents said 'No' and eight respondents said 'Yes' and five respondents did not answer the question. Respondents that said they did think there were people with Dementia that would benefit from extra support from their service were asked to elaborate on their answer. The themes which arose from the comments were:

- People with early on-set Dementia
- People with limited mobility
- People with vision impairments, due to the lack of awareness among services about the link between Dementia and sight loss.
- Carers
- Ethnic minorities

Are there adults who don't meet your service criteria but you think need some sort of support by your service?

Respondents were also asked whether there were any adults that did not meet their services criteria but they thought would need some support from their service. Four respondents said there were people that did not meet their service criteria that would need support, 12 said there were not any and 8 respondents did not answer the question. The four respondents that said there were adults who would need support were asked to elaborate on their answer, their comments included:

- Aging learning disability adults whose nursing needs are increasing and they are also a minority group that do not receive the appropriate care in hospital and most nursing homes
- Those in the early stages of Dementia, service provision could enable them to plan for the future and maintain independence
- Those who cannot afford to pay for the service

Are there any services or support you think your clients need, which are not being met by other services, including secondary diagnosis?

Respondents were asked whether there were any services or support that service users needed, but were not being provided by other services. Six respondents said there were services and support needed by their clients but were not being provided, 11 respondents said there were not aware of any and 7 respondents did not answer the question. The six respondents that said there were services and support not provided were asked to elaborate on their answer. Their comments included:

- More community based options are required, because people keep being referred into the same services
- More one to one support, rather than group support
- Clients with Dementia who have been hospitalised are not consistently assessed prior to discharge to ensure correct and appropriate care/support is in place, considering their reason for hospitalisation
- Other health care professionals may reassess clients, but no other help is provided even if it is deemed necessary
- Services for people with alcohol-related brain damage
- Because of the evidence between Dementia and sight loss, there needs to be a link between specialist organisations to ensure appropriate interventions are provided

Are there any social or cultural issues which need addressing to work with your current or any potential future adults diagnosed with Dementia?

Respondents were asked whether they thought there were any cultural issues that needed addressing to work with current clients or any future clients with Dementia. Eight respondents said there were some cultural issues that needed addressing, 12 respondents said there were no cultural issues and 4 respondents did not answer the question. The eight respondents that said there were some cultural issues were asked to elaborate on their answers, the comments include:

- Meeting cultural and religious needs by creating more links with religious organisations
- Encourage people with BME backgrounds to use services
- Need to reach out to hard to reach communities, such as homeless and LGBT communities
- Need a more ethnically diverse specialist workforce
- Improve awareness of services among communities where sight loss might be more prevalent.