

# **Swindon Dementia Needs Assessment 2017 - Update**

## Contents

Tables and Figures .....	3
Executive Summary.....	6
Main findings .....	6
1. Introduction and Context.....	9
Introduction .....	9
Dementia.....	10
National Policy .....	11
Local Context.....	11
A Snapshot of Swindon .....	12
2. Population – who is affected? .....	14
Introduction .....	14
Prevalence.....	15
Residential Status.....	18
Incidence .....	19
Memory Clinic Information .....	19
Mortality .....	20
Co-Morbidity.....	21
Inequalities.....	22
Deprivation .....	22
People with a Learning Disability .....	23
Black and Minority Ethnic (BME) Communities.....	23
Lesbian, Gay, Bisexual or Transgender (LGBT) communities.....	23
Comparators .....	24
3. Who is most at risk?.....	25
Introduction .....	25
Late Onset Dementia .....	26
Age .....	26
Mild Cognitive Impairment .....	28
Genetic inheritance.....	29
Hypertension, Diabetes, and High Cholesterol.....	29
Lifestyle Factors .....	30
Early onset dementia .....	31
4. Primary, Secondary and Social Care.....	32

Introduction .....	32
Health Services.....	33
Primary Care.....	33
Prescribing.....	34
Secondary Care .....	35
Social Care.....	38
4. What does the future look like? .....	41
Introduction .....	41
Population Projections.....	41
Costs of Dementia.....	44
5. Summary .....	45
Update on Recommendations .....	45
References .....	47

## Tables and Figures

Table 1: Swindon UA population in 2015 aged 65+ years by ten groups (decile groups) according to deprivation. (Deprivation in Swindon UA, as derived from Symphony Model 2015. 1= Most Deprived Group.) .....	13
Table 1: Expected prevalence of late onset dementia by age and gender in 2016 in the UK and in Swindon UA.....	15
Table 2: Estimated total numbers of people living with dementia and estimated total prevalence of dementia for Swindon .....	16
Figure 1: Expected late onset dementia by age group and gender in Swindon UA .....	16
Figure 2: Estimated prevalence of late onset dementia by ward in Swindon UA .....	17
Table 4: Estimates of proportion of people with dementia with each type of dementia, and of number of people over 65 in Swindon with each type of dementia.....	17
Figure 3: Estimated numbers of people aged over 65 living with dementia in Swindon by severity of dementia in Swindon UA 2016 .....	18
Table 5: Expected numbers of people with late onset dementia aged 65+ years by residential status and age in Swindon UA in 2016, based on 2014 consensus estimates. (Care Home here is defined as including residential or nursing care). .....	18
Table 6: Expected numbers of new cases of late-onset dementia among people aged 65+ years in Swindon UA in 2016, based on NICE incidence proportion (i.e. risk) figures for UK.....	19
Figure 4: Numbers of referrals to the Memory Service in Swindon for Swindon CCG patients from October 2015 to September 2017 inclusive (Source: Swindon CCG Finance).....	20
Table 7: Counts of dementia deaths in the Swindon CCG registered population aged 50+ years in years 2012 to 2015 inclusive.....	21
Figure 5: Percentage of deaths of Swindon CCG residents aged 50+ years in 2015 by place of death and underlying cause of death (dementia versus all causes) (Source: ONS/PCMD) .....	21
Figure 6: The five most common co-morbidities of people with dementia in Swindon UA in 2015, and the proportion with each, as predicted by the Symphony Model.....	22

Figure 7: Rate of hospital admissions of people with dementia (diagnosis in any position) per 1,000 people among people aged 65+ years in Swindon UA by deprivation quintile in the three year period from 2014/15-2016/17 .....	23
Table 8: Number and proportion of people living in Swindon UA by gender and age group in 2016. 26	
Figure 8: Population pyramid for Swindon based on the 2016 Census (Swindon UA) .....	27
Figure 9: Percentage of population over the age of 65, 75 and 85 respectively compared to other South West Local Authorities.....	27
Figure 10: Percentage of people over the age of 65, 75 and 85 respectively by ward in Swindon UA in 2015 .....	28
Table 9: The five wards with the greatest proportions of people aged over 65 and 85 respectively in Swindon UA in 2015.....	28
Figure 11: Rates of diabetes and hypertension by primary care practice as a percentage of the practice population in Swindon CCG in 2016 (in ascending order for diabetes).....	30
Figure 12: Rates of CHD and stroke by primary care practice as a percentage of the practice population in Swindon CCG in 2016 (in ascending order for CHD).....	30
Figure 13: Estimates of the percentage of people with dementia aged 65+ who have a formal diagnosis, in England, Swindon UA and comparator areas in 2017 .....	33
Figure 14: Estimated dementia diagnosis rates among people aged 65+ years predicted to have dementia in Swindon CCG and other CCGs in South West, as compared with England in 2017 .....	34
Table 10: Number and cost of drugs prescribed for dementia by year.....	35
Table 11: Number and cost of a basket of drugs prescribed for dementia in Swindon CCG, BANES CCG and Wiltshire CCG by year .....	35
Figure 15: Frequency of different durations of Lengths of Stay in days for admissions with a diagnosis of dementia (in any position) of Swindon UA residents in the three year period from 2014/2015-2016/2017.....	36
Table 12: The ten most frequent primary diagnoses (main reason for admission) for admissions of Swindon UA residents where dementia was a secondary diagnosis in the three year period from 2014/2015-2016/2017.....	37
Figure 16: Rate of admissions with dementia as a diagnosis (in any position) in people aged 60+ years per 1,000 people aged 65+ years by ward in Swindon UA in the three year period from 2014/2015-2016/2017.....	38
Table 13: Gross expenditure by Primary Support reason in people aged 65+ in Swindon UA in 2015/16.....	39
Table 14: Number of Mental Health Assessments carried out in Swindon UA in people aged 65+ years over three years from 2015/2016-2017/2018(Source: SWIFT) .....	39
Table 15: Number of clients aged 65+ funded by Swindon UA with Mental Health or Memory & Cognition needs by type of care in Swindon UA over three years from 2015/2016-2017/2018 (Source: Swift).....	39
Table 16: Number of clients aged 65+ with Mental Health or Memory & Cognition needs accessing services in Swindon UA by service type in 2016/17 (Source: Swift).....	39
Table 33: Swindon UA population aged 65+ years by sex and age-group, with actual 2016 population and projection of population numbers to 2031 .....	41
Table 34: Swindon UA numbers of people aged 65+ years by sex and age-group estimated to have dementia in 2016 and expected to, as projected to 2031.....	42
Table 35: Swindon UA numbers of people aged 30 to 64 years by sex and age-group estimated to have dementia in 2016 and expected to, as projected to 2030 .....	43

Table 36: Forecast of number of men and women aged 65+ years expected to be living alone in Swindon UA in the period 2016 to 2031.....	43
Table 37: Projection of number of people aged 65+ years from Swindon UA living in a care home (with or without nursing care) in selected years to 2031.....	44
Table 38: Average annual cost of dementia per person with dementia, by severity and setting (2012/2013 prices in pounds) Dementia UK Report 2014.....	44
Table 39: Variations in measures of dementia in Swindon taken from the period 2016 to 2017, showing estimates of prevalence, incidence and service use .....	45

DRAFT

## Executive Summary

This report is an update of the 2013 Joint Strategic Needs Assessment (JSNA) for dementia in Swindon (available at <http://www.swindonjsna.co.uk/dna/dementia-needs-assessment>) and should be read together with the latter, which gives more background and context on the issue. The aim of this update report is to inform the priorities and future strategy of the Dementia Steering Group and other stakeholders, by understanding the current epidemiology of dementia in Swindon and future need.

## Main findings

- Dementia is a clinical syndrome (i.e. a group of symptoms) rather than a specific disease, in which there is a decline in cognitive function severe enough to interfere with daily life and function. There are many possible causes and types of dementia. It is estimated that about 80% of dementia cases are caused by either Alzheimer's disease or vascular lesions in vascular dementia, or a combination of both types of pathology.
- Dementia affects people differently depending on the type of dementia, stage of illness (mild, moderate or severe) and individual. People with mild dementia can live independently and cope well with day-to-day living.
- Locally, a multi-agency Swindon Dementia Strategy for the period 2014-2019 was developed based on the 2013 dementia JSNA. The 12 priorities set out in this strategy are largely based on those of the 2009 National Dementia Strategy, and include improving public and professional awareness of dementia and reducing stigma, improving timely diagnosis and treatment of dementia, and developing services that support people to maximise their independence.
- Swindon Borough Council serves a resident population of 217,905 people. In all, 33,733 of people (15.5% of the population) are aged 65 years or more. BME groups accounted for 8% of all people aged 65 years or over in the 2011 Census. Life expectancy in Swindon UA from 2013 to 2015 inclusive was 79.6 years for males and 82.8 years for females. The difference in life expectancy between the most deprived group and the least deprived group was 8 years less for males and 4 years less for females during the period 2013-2015.

## Who is affected?

- In this JSNA update, prevalence has been estimated by applying prevalence rates from the Dementia UK Report (2014), which were estimated by an expert consensus panel (the Delphi consensus method), to ONS population figures.
- It was estimated that there were about 2,316 people over the age of 65 living with dementia within local authority boundaries in Swindon in 2016, and about 140 living with early onset dementia. This equates to about 1.8% of all those aged 30+ in the borough. This estimated prevalence rate is 3 times higher than the recorded prevalence in 2015/2016 for all ages of 0.6% (based on 1,395 cases on Swindon CCG registers).
- Actual numbers were estimated to be highest amongst those aged 80-89. At ward level, the estimates suggested that St Margaret and South Marston, Blunsdon and Highworth, and Wroughton and Wichelstowe had the highest numbers of people with dementia, which is not surprising as these wards have higher numbers of older people living there.
- Severity of disease is important to take into account as it indicates the potential level of care needed. Even with over 2,000 people in Swindon estimated to have dementia, nearly two thirds of these are estimated to be mild cases (1,283) and so would be able to function independently in a community that is sympathetic and supportive.

- Estimates suggest that 1,405 people with late onset dementia live in the community. The dementia population in care homes in 2016 in Swindon was estimated to lie between a maximum of 885 people and a minimum of about 610.
- Based on national incidence proportion figures, derived from the Cognitive Function and Ageing Study, it was estimated that, in 2016, 216 men and 383 women (599 persons in all) aged 65 years or more in Swindon UA developed dementia.
- There is little evidence for a direct link between deprivation and dementia. However many of the risk factors are more prevalent in more deprived areas.

#### *Who is most at risk?*

- Recent research (July 2017) from the Lancet Commission on Dementia Prevention, Intervention and Care identified that there are risk factors for dementia throughout the life course and tackling those which are modifiable would delay or prevent a third of dementia cases. Addressing modifiable risk factors for dementia would involve focusing on reducing hypertension, childhood education, exercise, maintaining social engagement, reducing smoking and management of hearing loss, depression, diabetes, and obesity.
- The Lancet Commission also found that nearly 85% of costs are related to family and social, rather than medical, care. In addition, the paper highlighted that recent studies in the USA, UK, Sweden, the Netherlands and Canada have found a lower incidence of dementia than expected.
- Age is an obvious risk factor for dementia; it is estimated that risk doubles for every additional 5 years after the age of 30, although it starts very low. According to 2016 population estimates, 15.5% of the Swindon population are aged 65 or over (33,733 people). With estimates of the number of people with dementia at around the 2,300 mark, this means that currently there are approximately 31,000 people aged 65 or over who do not have the disease.
- NICE guidance recommends that hypertension, diabetes and high cholesterol be identified and treated in middle age to reduce problems in later life. In Swindon, as of March 31st 2016, there were 31,729 people (13.7% of the CCG registered population) recorded as having hypertension and 12,924 people (7.1% of the population, only people aged 17 or over) recorded as having diabetes (7.1%, only people aged 17 years or over). Diabetes UK data suggest that a further 830 people in Swindon may have undiagnosed diabetes.
- Modifiable lifestyle risk factors for dementia include smoking, excessive alcohol consumption and having excess weight. Risk factors for early onset dementia (people who are under 65) include alcohol abuse, traumatic brain injury (although evidence for this is mixed), HIV and other neurological illnesses. It is estimated that about 10% of dementia cases in younger people are alcohol related.

#### *Primary, Secondary and Social Care*

- This chapter explores the services that people with dementia may access in their journey from diagnosis to end of life care – however it is not a comprehensive service review and rather focuses on updating data in the 2013 JSNA. There is currently no cure for dementia, although there are medical and psychosocial interventions which can help people to maintain independence. Because there is no cure, demand for social care can be significant particularly at the severe stage of the illness.
- The pathway for dementia care usually starts when someone approaches their GP with concern about their memory and is then referred to the memory clinic for assessment. Estimates suggest that people wait up to 3 years to see their GP after first noticing symptoms. In Swindon, the estimated diagnosis rate among people aged 65+ years with dementia is 64%, which is slightly lower than the national rate of 67.9%.

- Regarding medical interventions to reduce dementia symptoms, NICE recommends AChE inhibitors including Donepezil, Galantamine and Rivastigmine for mild to moderate Alzheimer's disease and Memantine for moderate or severe Alzheimer's disease. In Swindon, the number of items prescribed for all of these drugs, except Galantamine, has risen each year over the period 2013/2014-2016/2017. However, overall costs have come down in this period, as generic (unbranded) versions of these drugs have become available. This pattern mirrors that observed for England as a whole for the same period.
- Over the three year period from 2014/2015-2016/2017, there were 2,887 hospital admissions (representing 1,574 individual persons) with dementia coded in any diagnosis position (as either primary diagnosis or any of twelve secondary diagnoses). The number of admissions rose year-on-year, from 828 in 2014/2015 to 970 in 2015/2016 to 1,089 in 2016/2017.
- Dementia was comparatively rare as a primary diagnosis (2.7% of the total number of admissions). For admissions with a secondary diagnosis of dementia, the most frequently occurring primary diagnoses were urinary tract infections, pneumonia and problems related to falling.
- Social care provides crucial support for some people with dementia to maintain their independence and 'live well' with their condition. Swindon Borough Council commission both mental health support and community based services, including day services, domiciliary care, respite, and nursing care either at home, in the community or in residential care.
- In general the cost of adult social care services is substantial. According to the national NASCIS system, expenditure for people aged 65+ years in 2015/2016 in Swindon UA represented approximately 40% of the total gross expenditure on adult social care services.

*What does the future look like?*

- The number of people aged 65 and over is predicted to increase by over 20,000 over the next 15 years to nearly 55,000.
- According to POPPI (Projecting Older People Information System) numbers of people with dementia are estimated to increase by about 2000 by 2030 reflecting the increase in population of those over 65 and that age is the greatest risk factor for dementia.
- Data from POPPI predicts significant increases in the number of older people living alone over the next 20 years. However older people living alone is not necessarily a marker of increased dementia or demand for services as it may encourage people to maintain independence.
- The Alzheimer's Society estimated the formal and informal cost (i.e. unpaid carers) of dementia based on 2012/13 costs. This shows that costs depend on the severity of dementia, and that costs are highest for people with severe dementia in the community due to the high estimate of cost of informal care.



## 1. Introduction and Context

- This report is an update of the 2013 Joint Strategic Needs Assessment (JSNA) for dementia in Swindon and should be read together with the latter, which gives more background and context on the issue. The aim of this update report is to inform the priorities and future strategy of the Dementia Steering Group, by understanding the current epidemiology of dementia in Swindon and future need.
- Dementia is a clinical syndrome (i.e. a group of symptoms) rather than a specific disease, in which there is a decline in cognitive function severe enough to interfere with daily life and function. There are many possible causes and corresponding types of dementia. It is estimated that about 80% of dementia cases are caused by either Alzheimer's disease or vascular lesions in vascular dementia, or a combination of both types of pathology.
- Dementia affects people differently depending on the type of dementia, stage of illness (mild, moderate or severe) and individual. People with mild dementia can live independently and cope well with day-to-day living.
- Locally, a multi-agency Swindon Dementia Strategy for the period 2014-2019 was developed based on the 2013 dementia JSNA. The 12 priorities set out in this strategy are largely based on those of the 2009 National Dementia Strategy, and include improving public and professional awareness of dementia and reducing stigma, improving timely diagnosis and treatment of dementia, and developing services that support people to maximise their independence.
- Swindon Borough Council serves a resident population of 217,905 people. In all, 33,733 of people (15.5% of the population) are aged 65 years or more. BME groups accounted for 8% of all people aged 65 years or over in the 2011 Census.
- Life expectancy in Swindon UA from 2013 to 2015 inclusive was 79.6 years for males and 82.8 years for females. The difference in life expectancy between the most deprived group and the least deprived group was 8 years less for males and 4 years less for females during the period 2013-2015.

### Introduction

In 2013 a Joint Strategic Needs Assessment (JSNA) for dementia in Swindon was completed. This document set out knowledge about dementia at the time, including the prevalence and incidence of dementia based on available data and research. Four years on our knowledge about dementia, its risk factors, and what is effective in supporting people has improved, although there is no available cure as yet. This update report should be read together with the full 2013 JSNA, which gives more background and context. This report provides current estimates and insight into the scale of dementia in Swindon.

A JSNA is a process for understanding the current and future health and wellbeing needs of the local population. This involves gathering different types of information, interpreting it and pointing to the priorities for improving health and wellbeing in Swindon. Understanding Swindon's changing population, the factors that affect health and wellbeing, the town's assets and the implications for future services are important in setting priorities and planning future services.

The objectives for this JSNA update are:

- To inform the priorities and future strategy of the Dementia Steering Group
- To provide current incidence and prevalence data for dementia in Swindon
- To describe the population at risk of dementia in Swindon based on current knowledge and identified risk factors
- To understand future population projections for Swindon and what this may mean in terms of the needs of local people and demand for services

## Dementia

Dementia causes damage to the brain resulting in a progressive decline in more than one area of function, including memory, reasoning, communication skills and the skills needed to carry out daily activities. In medical terms, dementia can be defined in terms of both clinical aetiology and diagnosis and / or severity, but is a broad umbrella term often used to cover a number of diseases which have different causes and symptoms. The main types of dementia are<sup>1</sup>;

- **Dementia due to Alzheimer's disease**, in which small clumps of protein develop and accumulate around brain cells and disrupt the normal working of the brain – usually a gradual onset.
- **Vascular dementia**, in which problems with blood circulation result in parts of the brain not receiving enough blood and oxygen – can have a sudden onset, often after a stroke or series of strokes.
- **Dementia with Lewy bodies**, in which abnormal structures, known as Lewy bodies, develop inside the brain.
- **Fronto-temporal dementia**, in which the frontal and temporal lobes of the brain begin to shrink. This is rare and tends to affect younger people.

In terms of severity, it is generally categorised as mild, moderate or severe based on a psychometric test assessment<sup>2</sup>. The distinctions between these categories are not always clearly defined.

According to a general dementia needs assessment produced by the HCNA Group<sup>3</sup>, the characteristics defining each level of severity are:

- Mild – impairment of attention and memory, forgetting recent information, occasional confusion, able to cope with daily routine, but needing help with changes to routine
- Moderate – amnesia for recent events, disoriented about time and place, very poor reasoning and understanding of events, dependent on others for help with personal care and daily routine
- Severe – speech incoherent, unable to recognise close relatives, incontinence, completely dependent on others for personal care.

There is also a descriptive term used known as Mild Cognitive Impairment<sup>4</sup> which is not part of the dementia diagnosis, but recognises that for some people as they get older they may have mild problems with memory and recall, which may or may not be an early sign of dementia. MCI can affect people of any age as a result of stress, depression or another physical condition and usually involves only memory loss rather than affecting a range of cognitive functions.

It is estimated that about 80% of dementia cases are caused by either Alzheimer's disease or vascular dementia, or a combination of both – however people can have pathological damage in the brain without having cognitive impairment. Dementia can also be the result of an underlying neurological illness such as Parkinson's disease.

In terms of day to day living with dementia;

- Many people with mild dementia live independently and lead active, fulfilled lives
- Difficulty retaining memories of recent events is often one of the first symptoms, but this depends on the type of dementia
- There is no common journey for people with dementia – it affects everyone differently

- Some apparent symptoms of dementia in later stages (e.g. aggression, disorientation, paranoia) can be a response to the illness rather than part of the prognosis, although some people do have behavioural and psychological symptoms.

### National Policy

Dementia is a national priority - the Department of Health has given a Government commitment to improving the care and experience of people with dementia and their carers, via a focus on awareness, early diagnosis and appropriate treatment<sup>5</sup>. This approach was set out in the National Dementia Strategy (NDS) in 2009 and was followed up in 2012 by a personal dementia challenge set by the Prime Minister David Cameron. The Prime Minister's "Challenge on Dementia 2020", published in February 2015, sets out what the Government wants to see in place by 2020 in order for England to be:

- the best country in the world for dementia care and support and for people with dementia, their carers and families to live in
- the best place in the world in which to undertake research into dementia and neurodegenerative diseases.

In 2015, an implementation plan to 2020 was published focusing on 4 themes: risk reduction, health and care, awareness and social action, and research.

This is also within the context of strategies on end of life care, dignity in care, adult social care, carers and mental health overall. A House of Commons Briefing Paper on dementia policy, services and statistics gives more detail on UK Government activity to date and that which is planned for the future (<http://researchbriefings.parliament.uk/ResearchBriefing/Summary/SN07007>).

NICE (National Institute for Health and Care Excellence) has published new or updated guidance on dementia over the last few years:

- CG42 is a clinical guideline on supporting people with dementia and their carers in health and social care which was updated in September 2016 (<https://www.nice.org.uk/guidance/cg42>).
- NG16 focuses on dementia, disability and frailty in later life, as well as on mid-life approaches to delay or prevent onset and was published in October 2015 (<https://www.nice.org.uk/guidance/ng16>).
- Quality Standards (QS30) on dementia, independence and wellbeing were produced in April 2013 (<https://www.nice.org.uk/guidance/qs30>).
- Three summaries relating to medication were published in 2015 on low-dose antipsychotics (<https://www.nice.org.uk/advice/ktt7>), and management of aggression, agitation and behavioural disturbances in dementia with carbamazepine (<https://www.nice.org.uk/advice/esuom40/chapter/Key-points-from-the-evidence>) and valproate preparations (<https://www.nice.org.uk/advice/esuom41/chapter/Key-points-from-the-evidence>).
- New guidelines on dementia specifically, on assessment, management and support for people living with dementia and their carers - are being developed (<https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0792>) and are due for publication in June 2018.

### Local Context

Following on from the last Dementia JSNA in Swindon, a multi-agency Swindon Dementia Strategy for the period 2014-2019 was developed (<http://www.swindonjsna.co.uk/dna/dementia-needs-assessment>). This has 12 priorities, largely based on the national strategy, which are outlined below

- 1: Improve public and professional awareness of dementia and reduce stigma
- 2: Improve timely diagnosis and treatment of dementia
- 3: Increase access to a range of flexible day, home based and residential respite options

- 4: Develop services that support people to maximise their independence
  - 5: Increase community clinical support for patients experiencing dementia
  - 6: Improve the skills and competencies of the workforce
  - 7: Improve access to support and advice following diagnosis for people with dementia and their carers
  - 8: Reduce avoidable hospital and care home admissions and decrease hospital length of stay
  - 9: Ensure that the needs of younger people with dementia are addressed
  - 10: Improve the quality of dementia care in care homes and hospitals
  - 11: Improve end of life care for people with dementia
  - 12: Safeguard people living with dementia
- The Great Western Hospital also have a dementia strategy which was refreshed in 2017.

### A Snapshot of Swindon<sup>6</sup>

Swindon Borough Council (Swindon UA) serves a resident population of 217,905 people (ONS population estimates for mid-2016), with broadly similar numbers of men (108,651) and women (109,254). In all, 33,733 people (15.5% of the population) are aged 65 years or more, with 15,033 (6.9%) aged 75 years or more, and 4,508 (2.1%) aged 85 years or over. Swindon continues to grow - its population expanded by 16% in the decade between the 2001 and 2011 censuses, which was the highest growth rate in South West England. The NHS Swindon CCG registered population at 230,844 (people registered with a Swindon CCG GP) is larger than the Swindon UA population, but the age-sex profiles of the two populations are broadly similar.

(Population figures for Swindon can vary depending on the geographical boundary considered. For example, Watchfield and Shrivenham ward contributes to the CCG population, but comes under Oxfordshire rather than Swindon Borough Council. Also, some patients registered with Swindon CCG live outside Swindon UA and Watchfield and Shrivenham. Most figures in this report relate to the Swindon UA resident population, but the population being considered will be referenced in the text as appropriate.)

The proportion of people in Swindon who reported being from a non-White British group in the 2011 Census was 15.4% (32,128 people). The largest Black and Minority Ethnic (BME) group was Asian/Asian British at 5.9%, closely followed by White non-British people (mainly Europeans) at 5.2%. At present, BME groups in Swindon UA are relatively young. BME groups accounted for 8% of all people aged 65 years or over in the 2011 Census, but in younger age-groups, the proportion was higher - at 10% of people aged 50 to 64 years, 18% of people aged 16 to 49 years and 18% of people aged 0 to 15 years. The Asian/Asian British Group was at its greatest extent (8%) in people aged 0 to 15 years and in people aged 16 to 49 years, but it made up only 2% of the population aged 65 years or over. It would therefore be wise always to view age-group together with ethnic group, when considering matters of ethnicity in the population.

The overall deprivation score for Swindon UA on the Indices of Multiple Deprivation 2015 was 17.9, which was lower than the score for England as a whole of 21.8. At the same time, 16.3% of children are estimated to live in low income families in Swindon, which again is better than the figure for England of 20.1% (deprivation figures from Health Profile 2016). Although Swindon is less deprived than the average Upper Tier Local Authority, the levels of deprivation vary considerably across the town, and many different grades of affluence and poverty are present within the population.

The table below shows, using 2015 population figures, the number and proportion of people aged 65 years or over in each of ten groups in Swindon UA, according to level of deprivation based on the IMD 2015. In total, 4,340 people aged 65 years or more were categorised as being in the two most deprived groups (Groups 1 and 2), but this represents only 13.1% of the 65+ population. In fact, 15,597 people, or nearly half, of this age-group, were categorised as being in the three least deprived groups (Groups 8, 9 and 10.)

**Table 1: Swindon UA population in 2015 aged 65+ years by ten groups (decile groups) according to deprivation. (Deprivation in Swindon UA, as derived from Symphony Model 2015. 1= Most Deprived Group.)**

<b>Group of Deprivation</b>	<b>Population aged 65+</b>	<b>Percentage of all people aged 65+ in this group</b>
1 (Most deprived)	1,555	4.7%
2	2,785	8.4%
3	2,421	7.3%
4	2,107	6.4%
5	2,385	7.2%
6	2,580	7.8%
7	3,636	11%
8	8,331	25.2%
9	5,398	16.3%
10 (Least deprived)	1,868	5.6%
All	33,066	-

Life expectancy in Swindon UA from 2013 to 2015 inclusive was 79.6 years for males and 82.8 years for females. The Slope Index of Inequality (from ONS) is a standard method of establishing the difference in life expectancy between segments of a population. It divides a population into ten equal groupings according to level of deprivation, plots the life expectancy of each group graphically and then draws a line of best fit through these values. In Swindon UA the difference in life expectancy between the most deprived group and the least deprived group according to this method was 8.0 years less for males and 4.0 years less for females (from 2013 to 2015.)

## 2. Population – who is affected?

- There is no conclusive diagnostic test for dementia, apart from post-mortem examination of brain tissue, which makes it difficult to measure the number of people with dementia. In this JSNA update, prevalence has been estimated by applying prevalence rates from the Dementia UK Report (2014), which were estimated by an expert consensus panel (the Delphi consensus method), to ONS population figures.
- It was estimated that there were about 2,316 people over the age of 65 living with dementia within local authority boundaries in Swindon in 2016, and about 140 living with early onset dementia. This equates to about 1.8% of all those aged 30+ in the borough. This estimated prevalence rate is 3 times higher than the recorded prevalence in 2015/2016 for all ages of 0.6% (based on 1,395 cases on Swindon CCG registers).
- Actual numbers were estimated to be highest amongst those aged 80-89. At ward level, the estimates suggested that St Margaret and South Marston, Blunsdon and Highworth, and Wroughton and Wichelstowe had the highest numbers of people with dementia, which is not surprising as these wards have higher numbers of older people living there.
- Severity of disease is important to take into account as it indicates the potential level of care needed. Even with over 2,000 people in Swindon estimated to have dementia, nearly two thirds of these are estimated to be mild cases (1,283) and so would be able to function independently in a community that is sympathetic and supportive.
- Estimates suggest that 1,405 people with late onset dementia live in the community. The dementia population in care homes in 2016 in Swindon was estimated to lie between a maximum of 885 people and a minimum of about 610.
- Based on national incidence proportion figures, derived from the Cognitive Function and Ageing Study, it was estimated that, in 2016, 216 men and 383 women (599 persons in all) aged 65 years or more in Swindon UA developed dementia.
- There is little evidence for a direct link between deprivation and dementia. However many of the risk factors (see chapter 4) are more prevalent in more deprived areas.

### Introduction

Measuring the number of people with dementia is difficult. Whilst there are a number of different official sources, data from each depends on which interpretation of dementia diagnosis is used. There is no conclusive diagnostic test apart from post-mortem examination of brain tissue. However, for many people, diagnosis is based on behaviour and an ability to cope or not with daily activities. Formally, NICE guidance requires a mental health assessment which includes<sup>7</sup>:

- a detailed history from the patient and carer
- cognitive tests and an assessment of symptoms
- medical examination to exclude reversible causes of cognitive impairment such as depression, infection, adverse medication reaction or drug/alcohol abuse;
- brain imaging (either via a CT (computerised tomography) or MRI (magnetic resonance imaging) scan).



Official statistics identify those people who have been through this process (for example Quality Outcomes Framework (QOF) data<sup>1</sup> records all those on a register of patients with dementia held at a GP surgery, and all those who are reviewed regularly). However people may cope for a long time at home or with the support of family and friends, or there may be waiting lists for an official diagnosis: both of which may disguise the true prevalence.

In 2014, the Dementia UK organisation updated the consensus estimates developed in 2007. These are derived by a Delphi consensus method (used to estimate prevalence that you can't measure directly. The Delphi consensus process involved a preliminary review of all the available evidence, which was then submitted to an expert panel. The panel reviewed the evidence and used their judgment to estimate prevalence. After a second round of reviews (during which the panel could re-adjust their estimations in light of the anonymised responses of other experts) an average was calculated from the individual responses of the panel, which formed the basis for the estimations of prevalence published.

For this updated JSNA, prevalence has been estimated by applying consensus prevalence rates from the Dementia UK Report (2014) to ONS population figures.

### Prevalence

Based on estimated prevalence rates from the Dementia UK Report (2014) consensus exercise, there were about 2,316 people over the age of 65 living with dementia in Swindon in 2016 within local authority boundaries, and about 140 living with early onset dementia. This equates to about 1.8% of all those aged 30+ in the borough. Using the CCG registered population figure, this estimate increases to 2,390 in the over 65 age-group and 145 for early onset dementia.

**Table 1: Expected prevalence of late onset dementia by age and gender in 2016 in the UK and in Swindon UA**

	Estimated prevalence derived by Delphi consensus method of late onset dementia in the UK by age and gender (%)			Estimated numbers of people living with dementia in Swindon UA (derived by applying consensus prevalence rates to Swindon UA population in 2016)		
Age (years)	Male	Female	Overall	Male	Female	Overall
65-69	1.5	1.8	1.7	78	99	176
70-74	3.1	3	3	119	127	245
75-79	5.3	6.6	6	147	211	359
80-84	10.3	11.7	11.1	206	298	503
85-89	15.1	20.2	18.3	177	355	532
90-94	22.6	33	29.9	98	270	368
95+	28.8	44.2	41.1	24	109	132
TOTAL				848	1469	2316

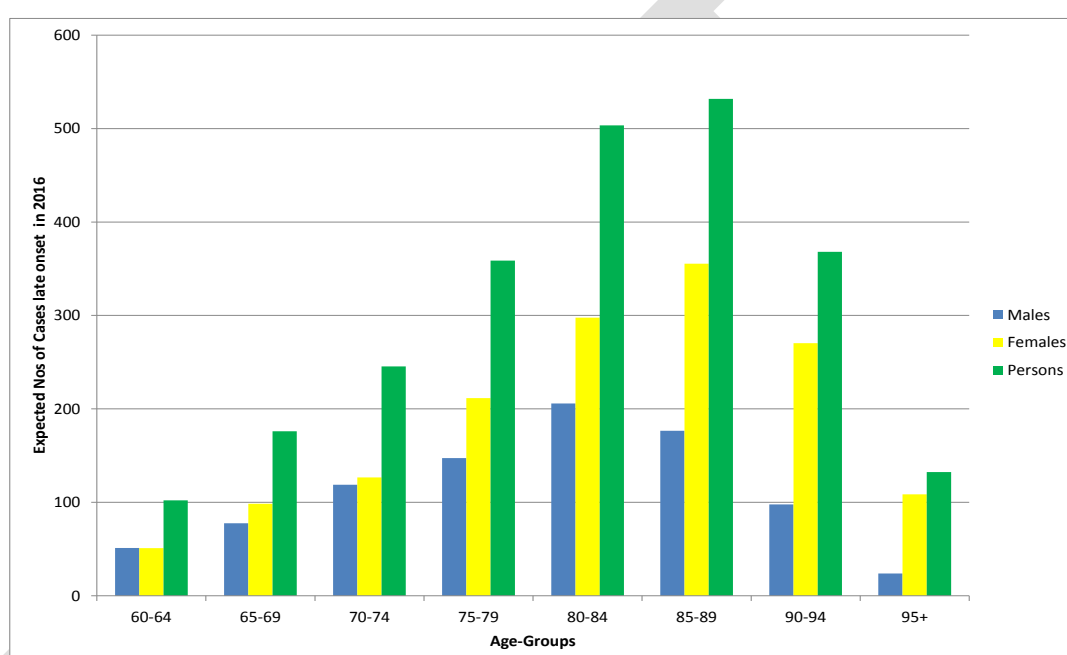
Sources: Dementia UK 2014, ONS.

Note: Expected numbers are rounded up to whole numbers within each cell and so do not appear to sum to the totals.

<sup>1</sup> The advantages of QOF are that robust and accurate data is available for those people on the register and they will have had a formal diagnosis. Its disadvantages are that it can be a more accurate reflection of the effect or interest of a GP practice in targeting a particular group of people rather than of the true prevalence in an area, that it also reflects the make-up of the local population, for example if that population is predominantly constituted of older people, and that it reflects only those aspects of care that are measurable.

**Table 2: Estimated total numbers of people living with dementia and estimated total prevalence of dementia for Swindon**

	Number with early onset dementia	Number with late onset dementia	Total estimated number with dementia	Prevalence of dementia among those aged 30+ <sup>8</sup>	Prevalence of late onset dementia among those aged 65+
Swindon (local authority boundary)	140	2316	2456	1.7%	6.9%
Swindon (CCG registered population)	145	2390	2535	1.7%	6.9%



**Figure 1: Expected late onset dementia by age group and gender in Swindon UA**

Actual numbers are highest amongst those aged 80-89. Estimates of numbers of men with dementia peak between ages 80-84 whereas the peak for women occurs between ages 85-89.

Applying the prevalence estimates at ward level suggests that the highest number of people with dementia will be in St Margaret and South Marston, Blunsdon and Highworth, and Wroughton and Wichelstowe wards. This is not surprising as it will obviously reflect those wards which have higher numbers of older people living there.



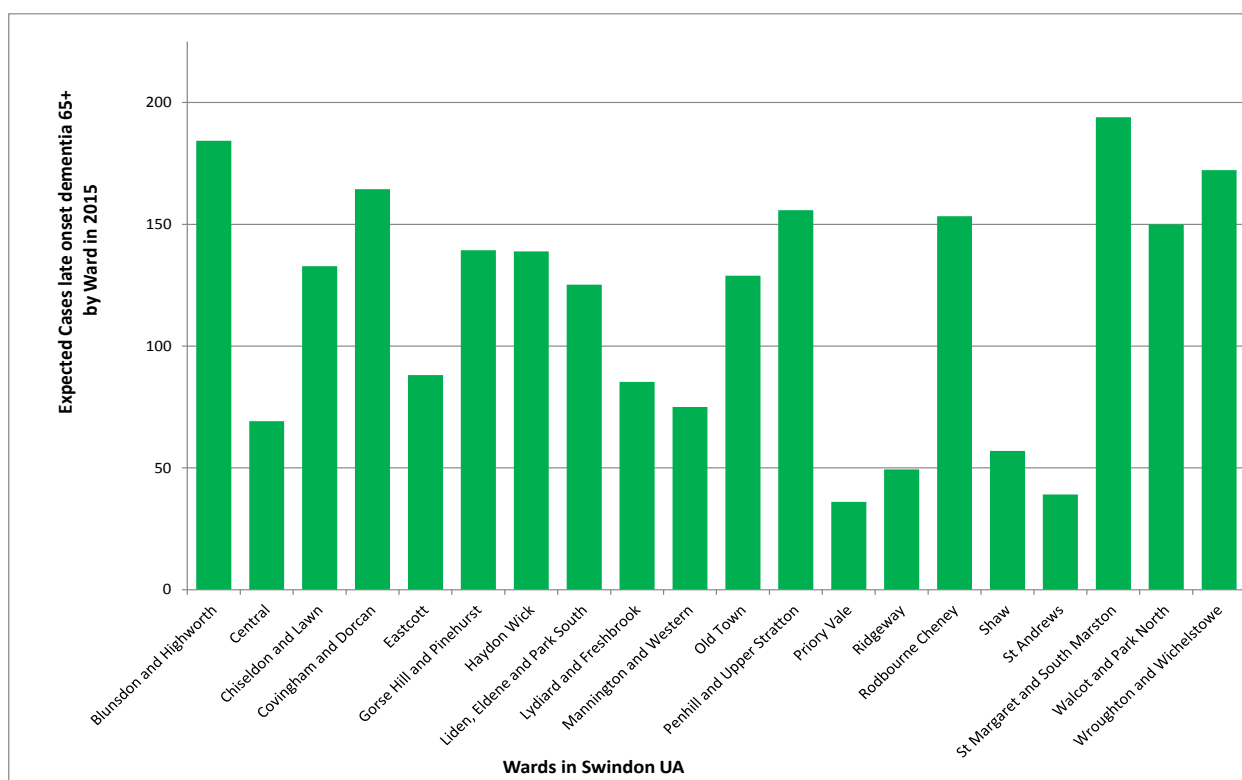


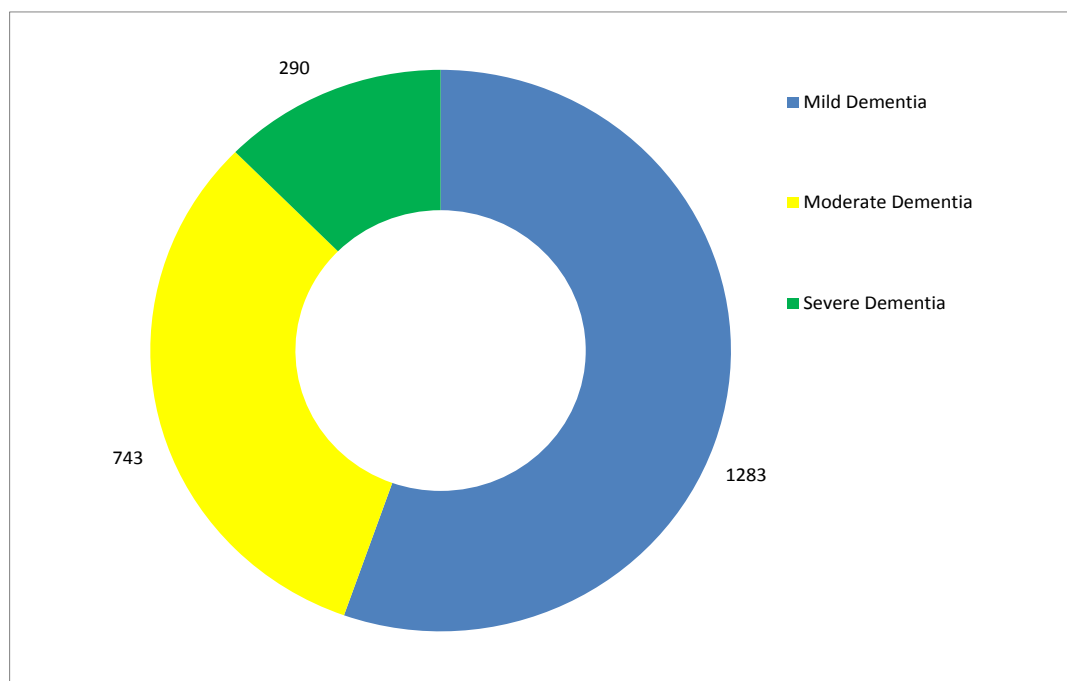
Figure 2: Estimated prevalence of late onset dementia by ward in Swindon UA

The estimated proportions of all people with dementia with each type of dementia from the Dementia UK report are shown below. These proportions were applied to the Swindon population aged over 65 to estimate the number of people living with each type of dementia – these estimates are also shown below.

Table 4: Estimates of proportion of people with dementia with each type of dementia, and of number of people over 65 in Swindon with each type of dementia

Type of dementia	Proportion of people with dementia (Dementia UK 2014)	Proportions applied to Swindon (SBC boundaries) Age 65+ population
Alzheimer's Disease	62%	1436
Vascular dementia	17%	394
Mixed (AD and VD)	10%	232
Dementia with Lewy bodies	4%	93
Frontotemporal dementia	2%	46
Parkinson's dementia	2%	46
Other	3%	69
Total		2316

Estimates of the proportions of people with dementia who have mild, moderate or severe dementia, again from the Dementia UK report, are 55.4%, 32.1% and 12.5% respectively. Applying these proportions to the Swindon population aged over 65, the estimated numbers with mild, moderate and severe dementia are 1,283, 743 and 290 respectively.



**Figure 3: Estimated numbers of people aged over 65 living with dementia in Swindon by severity of dementia in Swindon UA 2016**

Severity of disease is important as it indicates the potential level of care needed. Even with over 2000 people in Swindon estimated to have dementia, nearly two thirds of these will be mild and so would be able to function independently in a community that is sympathetic and supportive.

### ***Residential Status***

Having dementia does not mean that people cannot live independently and Dementia UK estimates that 63.5% of people with late onset dementia live in their own home. This varies according to age.

**Table 5: Expected numbers of people with late onset dementia aged 65+ years by residential status and age in Swindon UA in 2016, based on 2014 consensus estimates. (Care Home here is defined as including residential or nursing care).**

Age group	Estimated Percentage in Care Homes in UK	Estimated Percentage in Community in UK	Expected Number in Care Homes In Swindon	Expected Number in Community in Swindon
65-69	17.3%	82.7%	31	146
70-74	25.9%	74.1%	64	182
75-79	31.4%	68.6%	113	246
80-84	33.6%	66.4%	169	334
85-89	63.8%	36.2%	339	193
90-94	42.0%	58.0%	155	214
95+	31.2%	68.8%	41	91
Total	39.1%	60.9%	911	1405

The table above shows the estimated percentages in the UK of people with dementia aged 65 years or more by residential status. We have applied these percentages to the Swindon UA population to calculate expected numbers by residential status in Swindon. This suggests there are 1405 people with late onset dementia living in the community and 911 in care homes. The location of care homes will clearly impact any geographical assessment of dementia prevalence as some wards will tend to have more than others.

However, at the 2011 census, which was an actual headcount, there were 763 people aged 65 years or more living in care homes in Swindon. Allowing for 16% growth from 2011 to 2016 in the population aged 65 years or over, the expected number of people aged 65 years or over living in care homes, based on the census figure, would be 885 people. The 2014 consensus report suggests that about 69% of these would have dementia. Thus, even allowing for population growth, the predictions of care home numbers with dementia in Swindon in the above table (911 in total) look higher than may be actually the case.

The Adult Social Care Profile reports the rate of adults in permanent residential care as 431 per 100,000 adults in Swindon UA in 2013/2014, about a tenth lower than in England as a whole, while admissions of adults to permanent residential care in 2013/2014 was 81.3 per 100,000, about a quarter below the all-England level. (Source: Public Health England Adult Social Care Profile.) This suggests that Swindon uses residential care slightly less than England as a whole, and that a figure below the predicted 911 in the table would be more credible.

Thus, the dementia population in care homes in 2016 in Swindon may be somewhere between a maximum of 885 people (763 at 2011 census plus 16% population growth) and a minimum of about 610 (69% of 885, since not everyone in a care home will have dementia).

### Incidence

The NICE Costing Report provided estimates of annual incidence of dementia (i.e. the number of new cases each year) by age and gender. These were based on findings from the Medical Research Council Cognitive Function and Ageing Study.

**Table 6: Expected numbers of new cases of late-onset dementia among people aged 65+ years in Swindon UA in 2016, based on NICE incidence proportion (i.e. risk) figures for UK**

Age (years)	UK Annual Incidence Proportion Male (%)	UK Annual Incidence Proportion Female (%)	Swindon Expected Number of New Cases Male	Swindon Expected Number of New Cases Females	Swindon Expected Number of New Cases Totals
65-69	0.4	0.4	21	22	43
70-74	0.9	0.6	35	25	60
75-79	1.4	1.7	39	54	93
80-84	2.3	4.4	46	112	158
85+	4.5	6	76	169	245
			216	383	599

The NICE incidence proportion figures suggest that, in 2016, 216 men and 383 women (599 persons in all) aged 65 years or more in Swindon UA developed dementia.

### Memory Clinic Information

Memory services are recommended by NICE guidance as a single point of referral for early diagnosis of dementia. They can be provided in a number of different settings, including within a psychiatric or general hospital, as part of community mental health services or in primary care.

In Swindon, a memory clinic was formed in 1994 to facilitate research and provide diagnostic services for patients. It is currently provided at the Victoria Centre next to the Great Western Hospital and is overseen by psychiatric consultants.

The graph shows a count of referrals of Swindon CCG patients to the Avon and Wiltshire Mental Health Partnership (AWP) Memory Service in Swindon, provided mainly at the Victoria Centre at GWH. The increase in numbers from September 2016 to November 2016 was due to an initiative to reduce the size of the waiting list. Over the 2 years from October 2015 - September 2017, 1,709 people were referred to memory services, with an increase from 815 to 894 referrals from one year to the next.

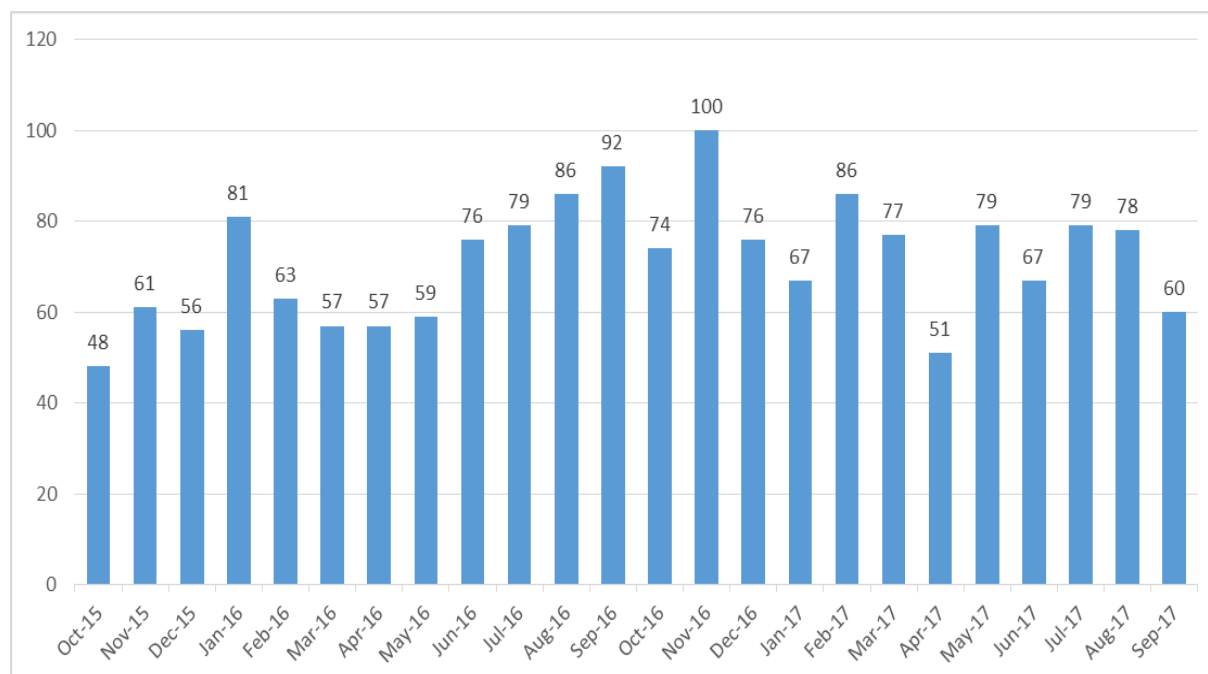


Figure 4: Numbers of referrals to the Memory Service in Swindon for Swindon CCG patients from October 2015 to September 2017 inclusive (Source: Swindon CCG Finance)

### Mortality

The Mortality data in the tables are from the Primary Care Mortality Database for the years 2012 to 2015 inclusive and relate to the CCG registered population in Swindon. Numbers are based on people aged 50 years or more at time of death. Records including dementia were selected using the following ICD 10 codes:

- F00.\* (Alzheimer's disease);
- F01.\* (vascular dementia);
- F02.\* (other forms of dementia);
- F03.\* (unspecified dementia.)

In fact, no death certifications with Alzheimer's disease were identified for this period. Each death certificate contained nine possible diagnoses, (first position diagnosis, second position diagnosis and so on), but an underlying cause of death was also given in a separate field. The two different counts in the table are based on counts from the underlying cause field and counts from any of the other diagnostic positions. Some people could feature in both counts, that is have dementia as a cause of death among other causes, but also have it highlighted as the underlying cause.

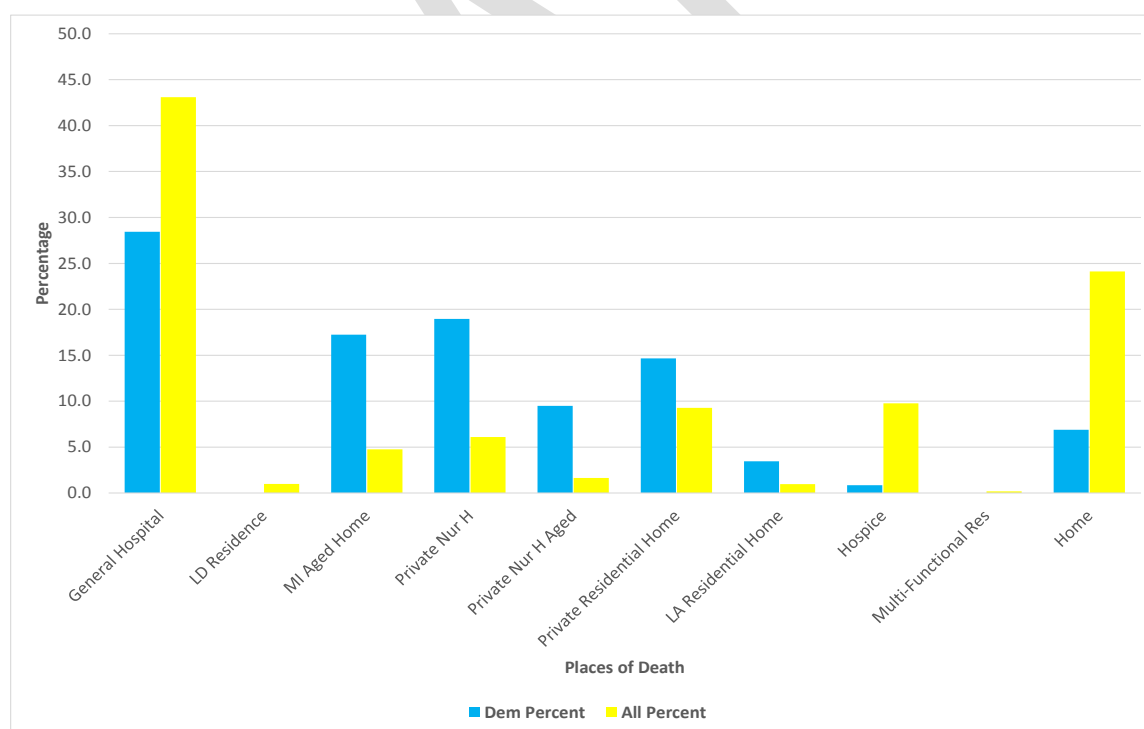
Around 11% of deaths in 2015 had dementia somewhere on the death certificate: the increase year on year may be due to coding rather than an actual increase in the incidence of people dying with dementia.

**Table 7: Counts of dementia deaths in the Swindon CCG registered population aged 50+ years in years 2012 to 2015 inclusive**

	Year of death registration			
	2012	2013	2014	2015
a) Dementia as underlying cause	107	97	111	116
b) Dementia in any diagnostic position	148	176	181	180
c) Total deaths (all diagnoses included)	1,524	1,632	1,544	1,638
Percentage of deaths with dementia in any position on death certificate (b/c x 100)	9.7%	10.8%	11.7%	11.0%

According to the Dementia Public Health Profile, in 2015, 67.0% of people with dementia recorded on their death certificate (in any diagnostic position) aged 65 years or more in Swindon died in their usual place of residence. This was at a similar level to that in England as a whole (68.6%), but was noticeably lower than the percentage for the South West (76.9%).

As the chart shows, people in Swindon who die from a dementia related cause are more likely to die in a care home of some type (63.8%) than people who die from other causes (22.8%). Very few people with dementia are recorded as dying in a hospice. Only 6.9% are recorded as dying at home compared to 24.1% of deaths from any cause, but this may again be influenced by coding practice. It is also increasingly recognised that the place of death is an imperfect proxy for the quality of end of life care.



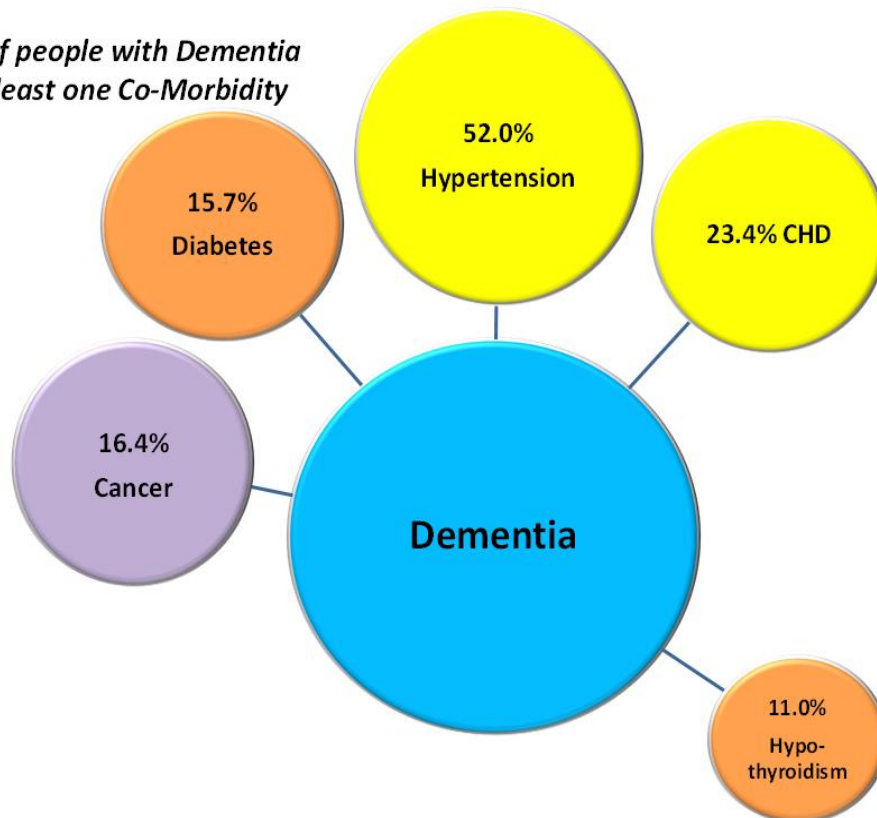
**Figure 5: Percentage of deaths of Swindon CCG residents aged 50+ years in 2015 by place of death and underlying cause of death (dementia versus all causes) (Source: ONS/PCMD)**

### Co-Morbidity

The Symphony Model (see the Long Term Conditions JSNA <http://www.swindonjsna.co.uk/dna/LTC> for more detailed explanation and analysis) suggests that it is very common for people with dementia also to have co-morbidities, usually physical conditions. The model, based on epidemiological patterns in the Somerset population, but applied to the Swindon UA population, suggests that about 80% of people in Swindon who have dementia will have at least one other

condition. In the model for Swindon, dementia tends to be co-morbid with four of the most common chronic diseases, namely, cancer, diabetes, hypertension and CHD. For instance, the model predicts that 52% of people with dementia in Swindon will also have hypertension (raised blood pressure). More details of the model used can be found in the JSNA profile of Long Term Conditions for Swindon available at [www.swindonjsna.gov.uk](http://www.swindonjsna.gov.uk).

**81.3% of people with Dementia had at least one Co-Morbidity**



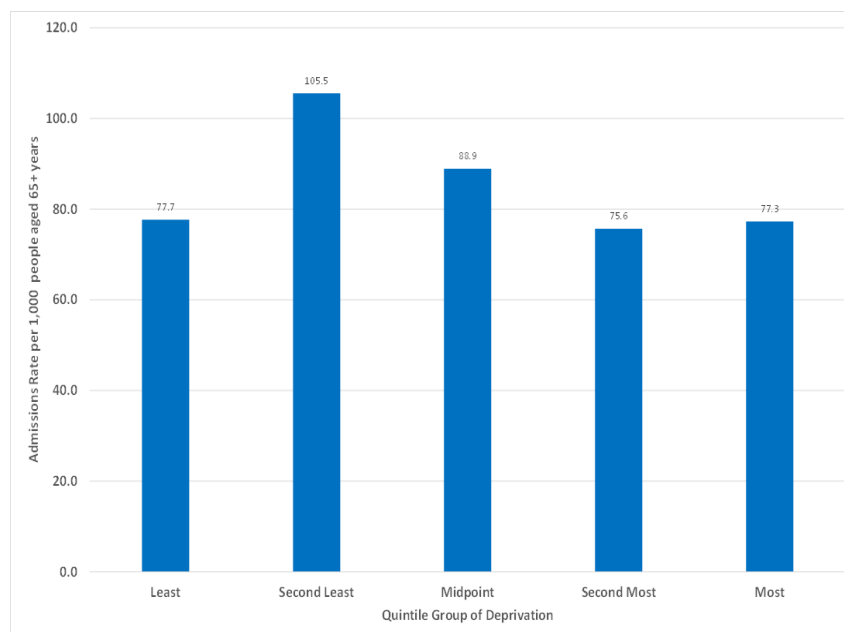
Source: Imputed through Symphony Matrix Model 2015.

## Inequalities

### Deprivation

There is little evidence for a direct link between deprivation and dementia. However many of the risk factors (see chapter 4) are more prevalent in more deprived areas because people have more challenges to overcome in order to adopt and maintain a healthy lifestyle. Although there is little evidence that the prevalence of dementia varies by socio-economic status or deprivation, there is some suggestion that access to services may vary. For example, national research in 2016 found that people from the least deprived areas (generally the richest) were 25% more likely to be started on 'anti-dementia' drugs than people in the most deprived areas.

The graph shows the rate of admissions for the electoral wards grouped according to level of deprivation into five groups (quintile groups) covering the period 2014/15 to 2016/17. The rates of admission are fairly similar, with Least Deprived at 77.7 per 1,000 people aged 65+ years, Second Most Deprived at 75.6 per 1,000 and Most Deprived at 77.3 per 1,000. The Midpoint group had a higher rate of admissions at 88.9 per 1,000, close to the overall Swindon UA figure of 86.5. However, the most notable rate was for the Second Least Deprived group (Lawn and Chiseldon, Haydon Wick, Old Town, St Margaret and South Marston), which was the highest at 105.5 per 1,000 people. This was probably due to the relatively old populations in these wards.



**Figure 7: Rate of hospital admissions of people with dementia (diagnosis in any position) per 1,000 people among people aged 65+ years in Swindon UA by deprivation quintile in the three year period from 2014/15-2016/17**

### *People with a Learning Disability*

People with Down's Syndrome are at risk of developing Alzheimer's Disease 30-40 years earlier than the rest of the population, although the risk across a lifetime is thought to be similar. The peak incidence of dementia occurs around 55 years, but 10% of people with Down's Syndrome aged 40-49 are estimated to have dementia.

The PANSI (Projecting Adult Needs and Service Information System) estimates that 34 men and 24 women with Learning Disability in Swindon UA in 2017 will also have early onset dementia. This is based on the rates from the Dementia UK 2007 report.

### *Black and Minority Ethnic (BME) Communities*

The Social Care Institute for Excellence (SCIE) estimate that more than 25,000 older black and minority ethnic (BME) people live with dementia in the UK, in part due to vascular risk factors such as hypertension, often found in African-Caribbean and South Asian UK populations. People from BME communities tend to access services later and at a more advanced stage.

The proportion of people in Swindon who reported being from a non-White British group in the 2011 Census was 15.4% (32,128 people). At present, BME groups in Swindon UA are relatively young. BME groups accounted for 8% of all people aged 65 years or over in the 2011 Census, but in younger age-groups the proportion was higher, at 10% of the 50-64 age-group, 18% of the 16-49 age-group and 18% of the 0-15 age-group. The school census in Swindon indicates that children in Swindon schools probably speak, between them, over 500 languages. About 13% of schoolchildren may have a language other than English which they regard as very important, but this does not mean that they are not able in the English language.

Little is known about the risk of dementia in the traveller community although increased risk of poor vascular health increases vulnerability to some types of dementia.

### *Lesbian, Gay, Bisexual or Transgender (LGBT) communities*

LGBT communities are affected by dementia both as patients but also as carers. The Equalities Action Plan for the National Dementia Strategy (Department of Health) suggests that, by applying national prevalence rates for dementia to estimates that 5-7% of the population is LGBT, over 34,000 LGBT people are living with dementia. The Alzheimer's Society estimates that between 35,000 and

70,000 lesbian, gay and bisexual people care for a person with dementia in the UK. People from this community face additional challenges in terms of getting appropriate support and understanding. This may be finding appropriate residential care in later stages of the disease or accessing support groups in early stages where other older people are comfortable discussing same sex partnerships.

There is not a local figure for the size of the LGBT community in Swindon, but the percentage of people belonging to a LGBT group is commonly taken by the public sector and the third sector as being about 6% in the UK, as this allows for people who are reluctant to report on their sexuality in surveys, or whose feelings of attraction are not necessarily captured well by survey techniques. If we apply that percentage to the local population in 2016, it would suggest that approximately 13,000 people in Swindon UA belong to a LGBT group, and for the Swindon CCG registered population the figure is about 14,000 people.

### Comparators

The following indicators are from the PHE Dementia Profile and are mainly based on recorded dementia cases in the QOF registers in primary care. Not all cases of dementia are identified and so an estimated diagnosis rate is also given- the estimated diagnosis rate was based on the MRC Cognitive Function and Ageing Study II (CFAS II). This may account for the difference between these prevalence figures and those based on the Dementia UK estimates.

- Recorded prevalence in 2015/2016 for all ages: Swindon UA significantly lower than England (0.6% v. 0.8%, 1,395 cases in Swindon CCG)
- Recorded prevalence in Sept 2016 for those aged 65+ years: Swindon UA significantly lower than England (4.0% v. 4.3%)
- Estimated diagnosis rate in 2017 for those aged 65+ years: Swindon similar to England (64.0% v. 67.9%)
- Ratio of inpatient use to recorded diagnoses in 2015/2016 for all ages (People with dementia using inpatient hospital services as a percentage of the total recorded diagnoses of dementia.): Swindon similar to England (55.9% v. 53.8%)



### 3. Who is most at risk?

- Recent research (July 2017) from the Lancet Commission on Dementia Prevention, Intervention and Care identified that there are risk factors for dementia throughout the life course and tackling those which are modifiable would delay or prevent a third of dementia cases. Addressing modifiable risk factors for dementia would involve focusing on reducing hypertension, childhood education, exercise, maintaining social engagement, reducing smoking and management of hearing loss, depression, diabetes, and obesity.
- The Lancet Commission also found that nearly 85% of costs are related to family and social, rather than medical, care. In addition, the paper highlighted that recent studies in the USA, UK, Sweden, the Netherlands and Canada have found a lower incidence of dementia than expected.
- Age is an obvious risk factor for dementia; it is estimated that risk doubles for every additional 5 years after the age of 30, although it starts very low. According to 2016 population estimates, 15.5% of the Swindon population are aged 65 or over (33,733 people). With estimates of the number of people with dementia at around the 2,300 mark, this means that currently there are approximately 31,000 people aged 65 or over who do not have the disease.
- NICE guidance recommends that hypertension, diabetes and high cholesterol be identified and treated in middle age to reduce problems in later life. In Swindon, as of March 31<sup>st</sup> 2016, there were 31,729 people (13.7% of the CCG registered population) recorded as having hypertension and 12,924 people (7.1% of the population, only people aged 17 or over) recorded as having diabetes (7.1%, only people aged 17 years or over). Diabetes UK data suggest that a further 830 people in Swindon may have undiagnosed diabetes.
- Modifiable lifestyle risk factors for dementia include smoking, excessive alcohol consumption and having excess weight. Risk factors for early onset dementia (people who are under 65) include alcohol abuse, traumatic brain injury (although evidence for this is mixed), HIV and other neurological illnesses. It is estimated that about 10% of dementia cases in younger people are alcohol related.

#### Introduction

Recent research (July 2017) from the Lancet Commission on Dementia Prevention, Intervention and Care<sup>9</sup> identified that there are risk factors throughout the lifecourse and tackling those which are modifiable would delay or prevent a third of dementia cases. Addressing modifiable risk factors for dementia would involve:

- Reducing hypertension
- Childhood education
- Exercise
- Maintaining social engagement
- Reducing smoking
- Management of hearing loss, depression, diabetes, and obesity.

Other findings included:

- Nearly 85% of costs are related to family and social, rather than medical, care.
- The more physical illnesses someone has, the more likely they are to develop dementia.
- Brains can be resilient – some people with neuropathological changes of Alzheimer’s Disease do not have the clinical symptoms of dementia.
- Pre-clinical signs of Alzheimer’s Disease pathology can be identified in mid-life but “many or even most” people found to be at risk of dementia will die in good cognitive health.
- Hypertension can reduce the cognitive reserve buffer and hence increase vulnerability to dementia.
- People of African origin in the UK / USA with high rates of hypertension have increased rates of dementia at a young age.
- Recent studies in the USA, UK, Sweden, the Netherlands and Canada have found a lower incidence of dementia than expected.

## Late Onset Dementia

### Age

Age is an obvious risk factor for dementia; it is estimated that risk doubles for every additional 5 years after the age of 30, although it starts very low.

According to 2016 population estimates, 15.5% of the Swindon population are 65 or over (33,733 people). With estimates of the number of people with dementia at around the 2,300 mark, this means there are approximately 31,000 older people who do not have the disease in total across all age groups over 65.

**Table 8: Number and proportion of people living in Swindon UA by gender and age group in 2016**

Age-Group	Males	Females	Population (Persons)	Persons as Percentage of Total Population
0-14 years	21,560	20,386	41,946	19.2%
15-44 years	42,160	42,021	84,181	38.6%
45-64 years	29,463	28,582	58,045	26.6%
65-74 years	9,007	9,693	18,700	8.6%
75-84 years	4,777	5,748	10,525	4.8%
85+ years	1,684	2,824	4,508	2.1%
Totals	108,651	109,254	217,905	100%

Source: ONS

As the population pyramid below shows, the most populous age groups are those between 40-55. This suggests that potentially over the next 20 years there will be increasing numbers of older people in Swindon – however, the reality of this depends on whether people stay in Swindon for their retirement.

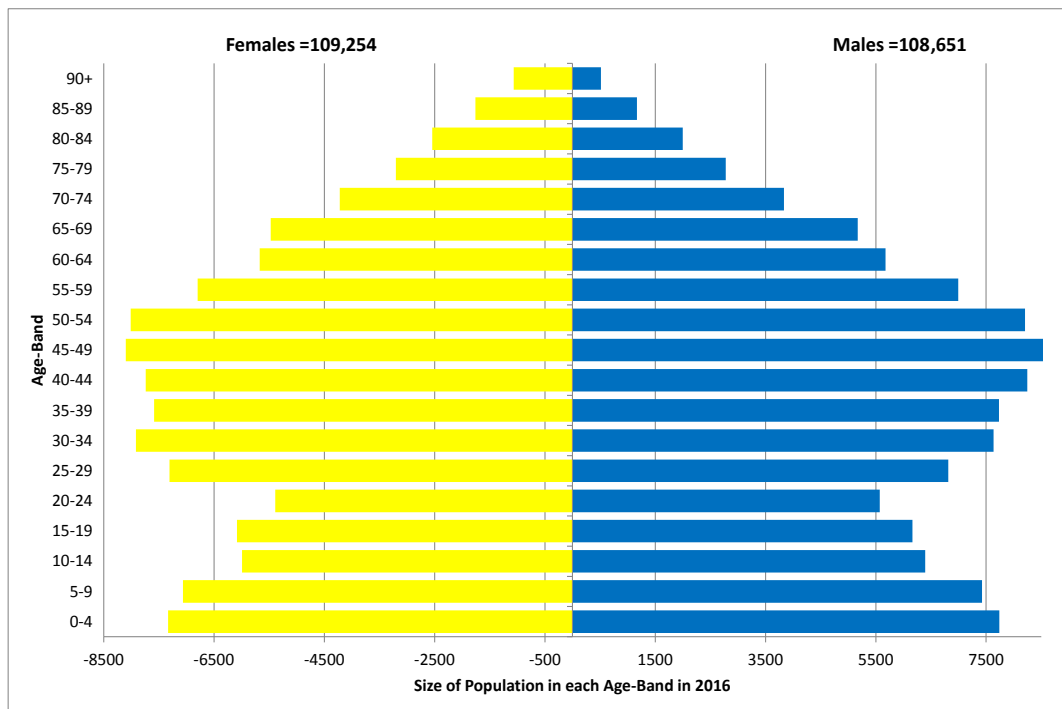


Figure 8: Population pyramid for Swindon based on the 2016 Census (Swindon UA)

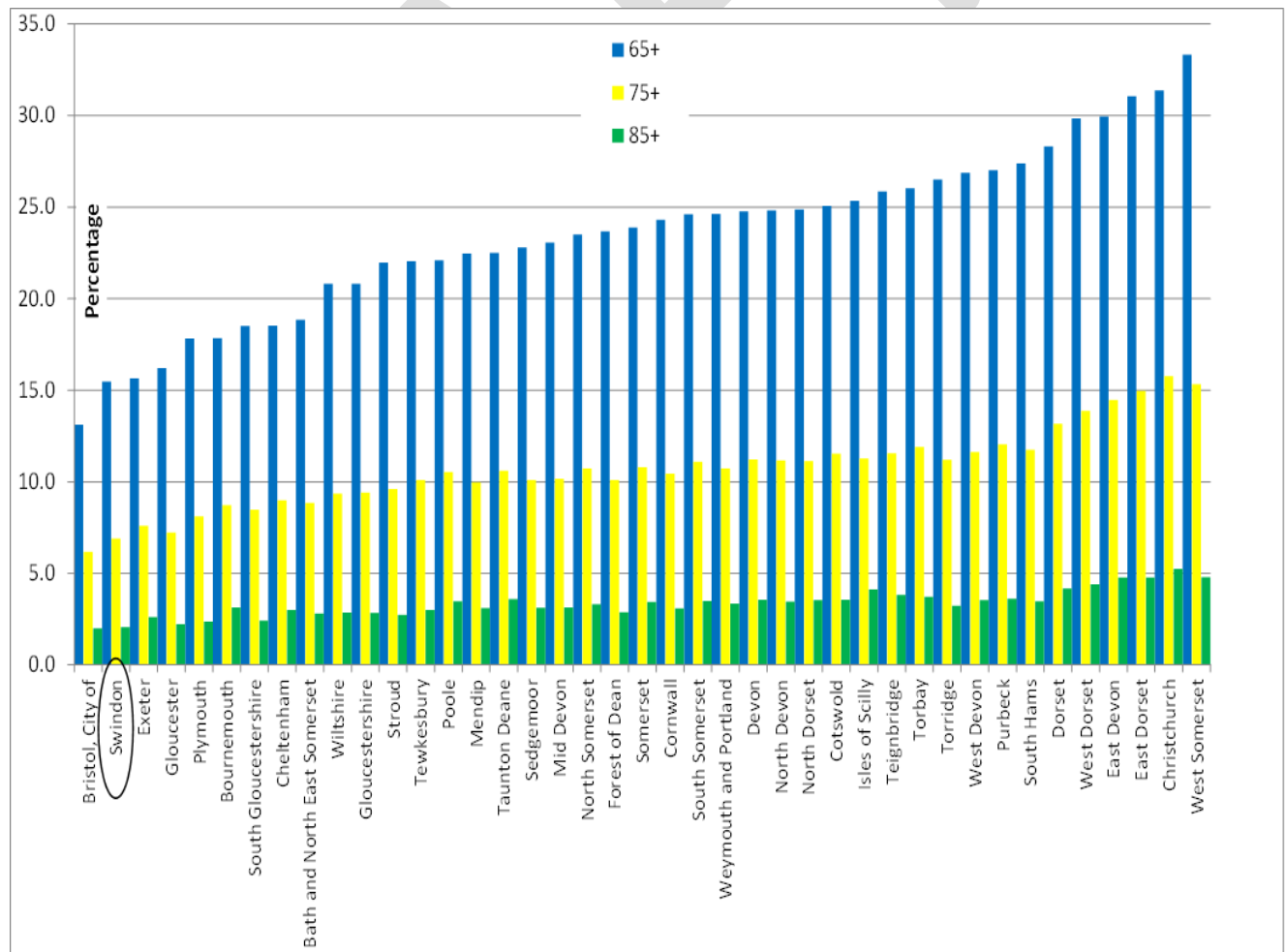
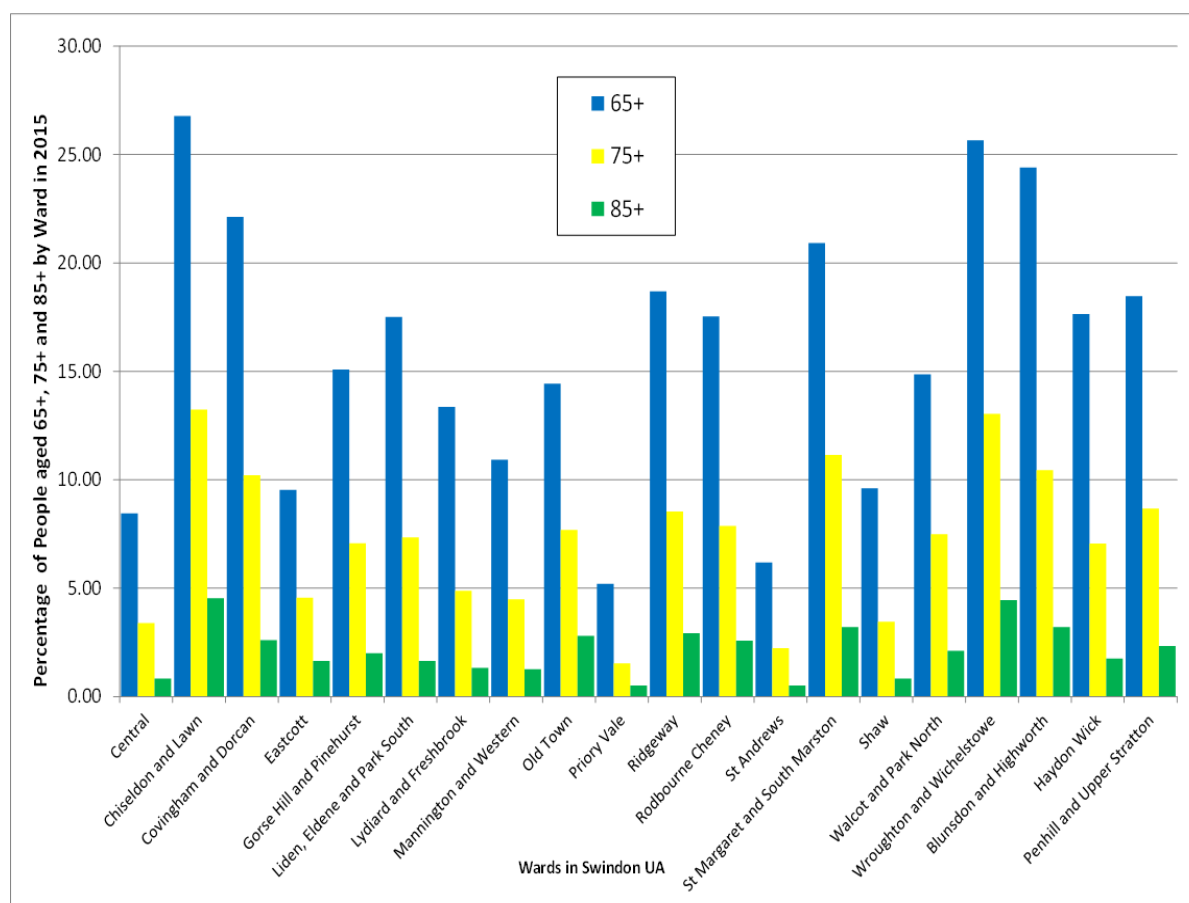


Figure 9: Percentage of population over the age of 65, 75 and 85 respectively compared to other South West Local Authorities

Compared to other LAs in the South West, Swindon UA has the smallest proportion of people aged 65+ years (15.5%), with the sole exception of Bristol (13.1%). West Somerset had the highest at 33.3%, while the proportion for the South West Region overall was 21.6%. For people aged 85+ years, the order of proportions in the Local Authorities was approximately the same; the proportions were 2.1% for Swindon UA, 2.0% for Bristol, 5.2% for Christchurch (the largest, with West Somerset the second largest) and 3.1% for the South West as a whole.

At ward level, there are some wards with higher numbers of people over 65 and over 85 than others. As the chart shows, Chiseldon and Lawn and Wroughton and Wichelstowe have higher proportions of people over 65 than other wards.



**Table 9: The five wards with the greatest proportions of people aged over 65 and 85 respectively in Swindon UA in 2015**

Over 65's				Over 85's		
	Ward	Number	Proportion	Ward	Number	Proportion
1	Chiseldon & Lawn	1,625	26.8%	Chiseldon & Lawn	275	4.5%
2	Wroughton & Wichelstowe	2,082	25.7%	Wroughton & Wichelstowe	361	4.4%
3	Blunsdon & Highworth	2684	24.4%	St Margaret & South Marston	372	3.2%
4	Covingham & Dorcan	2398	22.1%	Blunsdon & Highworth	352	3.2%
5	Ridgeway	626	18.7%	Ridgeway	98	2.9%

### *Mild Cognitive Impairment*

As explained in the introduction, mild cognitive impairment (MCI) can affect people as they get older, but does not affect someone's usual daily activities, and does not reach the threshold for a

diagnosis of dementia. Although people with MCI are more likely to develop dementia (for example it is estimated that people with MCI are 15 times more likely to develop Alzheimer's disease than those without MCI<sup>10</sup>), nearly 50% of those with MCI do not go on to develop it.

### *Genetic inheritance*

Some people may be more vulnerable to certain types of dementia because of the presence of a particular gene. For example, it is thought there may be a genetic link for familial autosomal dominant Alzheimer's disease, Pick disease and other causes of frontotemporal dementia, Huntington's disease, and cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy (CADASIL). NICE guidance recommends that people likely to be in this risk group are referred for genetic counselling.

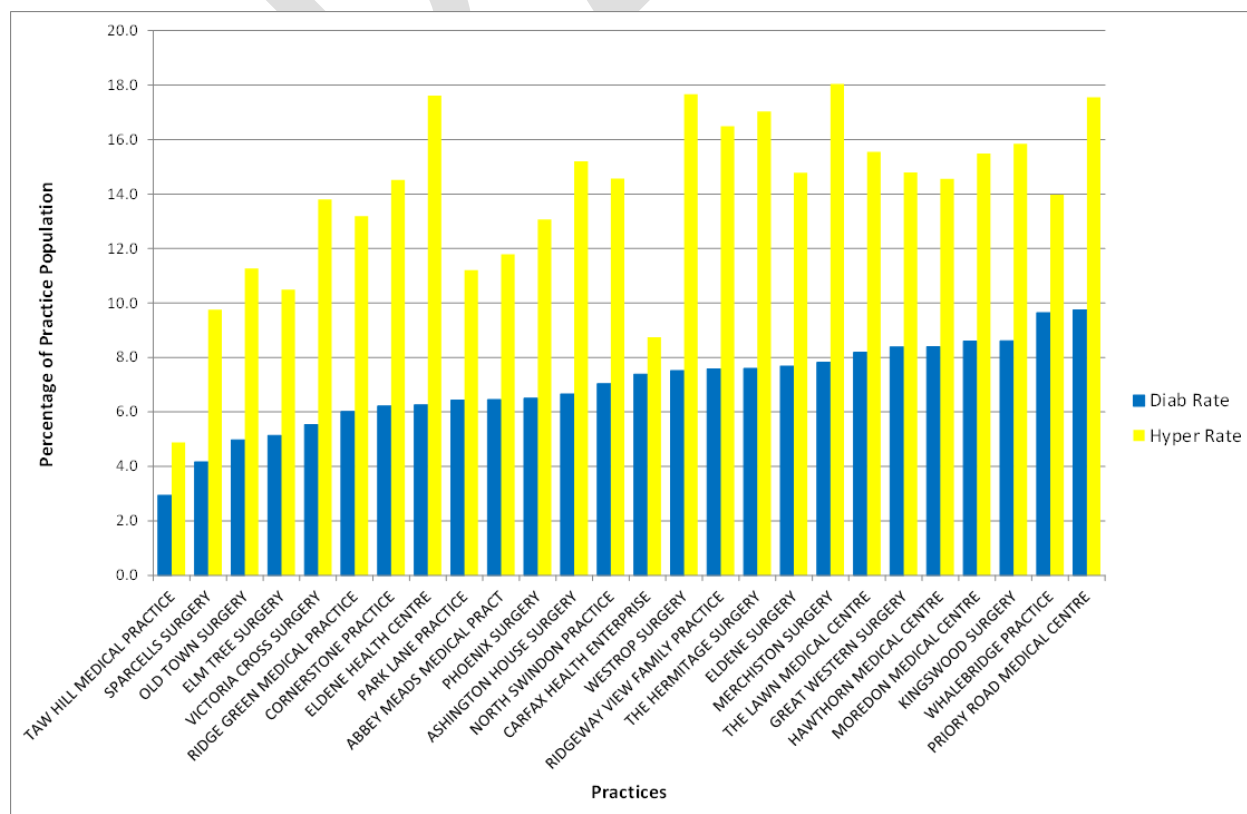
### *Hypertension, Diabetes, and High Cholesterol*

NICE guidance recognises the potential link between hypertension, diabetes, high cholesterol and problems in later life, recommending that these are identified and treated in middle age.

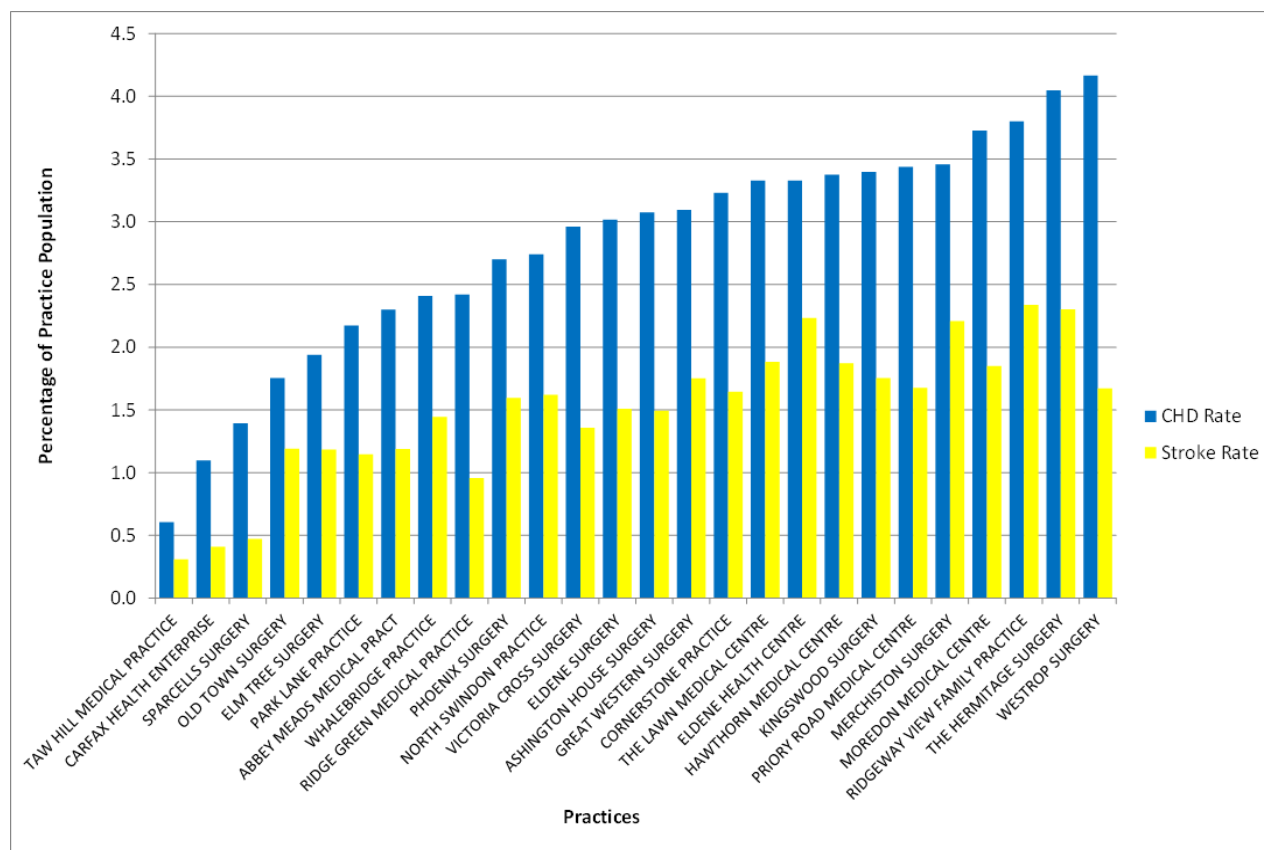
Quality Outcome Framework (QOF) data based on the population registered at 31<sup>st</sup> March 2016 with Swindon CCG shows that:

- 3,395 people were recorded with stroke and/or Transient Ischaemic Attack (1.5%).
- 31,729 people were recorded with hypertension (raised blood pressure) (13.7%)
- 1,398 people were recorded with heart failure (0.6%)
- 6,370 people were recorded with Coronary Heart Disease (2.8%)
- 12,924 people were recorded with diabetes (7.1%, only people aged 17 years or more)

Diabetes UK data suggest that a further 830 people in Swindon may have undiagnosed diabetes.



**Figure 11: Rates of diabetes and hypertension by primary care practice as a percentage of the practice population in Swindon CCG in 2016 (in ascending order for diabetes)**



### Lifestyle Factors

The overall smoking prevalence in adults in Swindon UA in 2016 was 14.9%, an encouraging reduction from 21.5% in 2012. The smoking prevalence for adults in England as a whole was 15.5% in 2016, although this was not different at a statistically significant level from the Swindon rate. In both Swindon and England, however, the prevalence rates of smoking in people in the most deprived groups were higher. In the period 2013 to 2015 inclusive, 917 people (aged 35 years and over) died in Swindon of a smoking-related illness, a directly standardised rate of 299 per 100,000 per annum, which was not different at a statistically significant level from the rate for England as a whole. (Source: Health Profiles.)

With regard to alcohol, the percentage of adults consuming more than 14 units a week in the period 2011 to 2014 inclusive was 20.5% in Swindon UA, which was not significantly different from the level in England as a whole at 25.7%. 11.9% of adults in Swindon in 2011 to 2014 were binge-drinking on their heaviest drinking day, not significantly different from the level in England, 16.5%. However, Swindon did compare unfavourably to England where admissions for alcohol-related conditions (narrowly defined with alcohol as a prominent feature) were concerned in 2015/2016; the directly standardised admissions rate for Swindon was 721 per 100,000, which was significantly higher than the rate for England at 647 per 100,000. (Source: Local Alcohol Profiles.)

People in Swindon eat an average of 2.5 portions of fruit a day and 2.3 portions of vegetables a day. This is similar to the levels recorded for England as a whole for 2015. (Source: Health Profiles.)

With respect to maintaining a healthy weight, and avoiding being overweight (BMI = 25 to 29.9) or obese (BMI = 30 or more), Swindon faces a considerable challenge, having a comparatively high percentage of adults with excess weight. In the period 2013 to 2015, 70.8% of adults in Swindon were categorised as either overweight or obese. This was significantly higher than the figure for England as a whole (64.8%). At national level, around two-thirds of women and three-quarters of

men aged 65 years or over are overweight or obese, and the proportions increase further with age for men but decrease for women. It is likely that a similar pattern is present in people aged 65 years or more in Swindon. (Source: Health Profiles.)

The level of childhood obesity in Swindon UA in 2015/2016 in children aged 4 to 5 years was at a similar level to that in England as a whole at 8.5% of the population of 4-5 year olds compared with 9.3% nationally. At the same time, the level of obesity in 10 to 11 year olds in 2015/2016 was lower in Swindon UA when compared with England, at 17.3% of the population of 10-11 year olds compared to 19.8% nationally. (Source: Child and Maternal Health Profiles.)

The Chief Medical Officer for England recommends that adults should undertake at least 150 minutes of moderate intensity physical activity per week. In Swindon in 2015, 56.4% of adults achieved this, in comparison with 57.0% of adults in England as a whole- these proportions did not differ significantly from each other. National data suggests that people living in the least prosperous areas are twice as likely to be physically inactive as those living in more prosperous areas. (Source: Health Profiles.)

### Early onset dementia

Studies show that there are few differences in terms of demographics and background between early and late onset dementia<sup>11</sup>, but for those people who do develop early onset dementia the main risk factors are:

- Traumatic brain injury (although evidence for this is mixed)
- Alcohol abuse
- Another neurological condition e.g. Huntingdon's disease
- HIV

It is estimated that about 10% of dementia cases in younger people are alcohol related<sup>12</sup>. Korsakoff's syndrome is caused by a lack of vitamin B1 in the body brought on by heavy alcohol consumption over a long term period. There is also some debate about whether 'alcoholic's dementia' is a separate condition. Both of these are different from usual dementias as, with abstinence, high doses of B1, an improved diet and increased support, people can show improvement.



#### 4. Primary, Secondary and Social Care

- This chapter explores the services that people with dementia may access in their journey from diagnosis to end of life care – however it is not a comprehensive service review and rather focuses on updating data in the 2013 JSNA. There is currently no cure for dementia, although there are medical and psychosocial interventions which can help people to maintain independence. Because there is no cure, demand for social care can be significant particularly at the severe stage of the illness.
- The pathway for dementia care usually starts when someone approaches their GP with concern about their memory and is then referred to the memory clinic for assessment. Estimates suggest that people wait up to 3 years to see their GP after first noticing symptoms. In Swindon, the estimated diagnosis rate among people aged 65+ years with dementia is 64%, which is slightly lower than the national rate of 67.9%.
- Regarding medical interventions to reduce dementia symptoms, NICE recommends AChE inhibitors including Donepezil, Galantamine and Rivastigmine for mild to moderate Alzheimer's disease and Memantine for moderate or severe Alzheimer's disease. In Swindon, the number of items prescribed for all of these drugs, except Galantamine, has risen each year over the period 2013/2014-2016/2017. However, overall costs have come down in this period, as generic (unbranded) versions of these drugs have become available. This pattern mirrors that observed for England as a whole for the same period.
- Over the three year period from 2014/2015-2016/2017, there were 2,887 hospital admissions (representing 1,574 individual persons) with dementia coded in any diagnosis position (as either primary diagnosis or any of twelve secondary diagnoses). The number of admissions rose year-on-year, from 828 in 2014/2015 to 970 in 2015/2016 to 1,089 in 2016/2017.
- Dementia was comparatively rare as a primary diagnosis (2.7% of the total number of admissions). For admissions with a secondary diagnosis of dementia, the most frequently occurring primary diagnoses were urinary tract infections, pneumonia and problems related to falling.
- Social care provides crucial support for some people with dementia to maintain their independence and 'live well' with their condition. Swindon Borough Council commission both mental health support and community based services, including day services, domiciliary care, respite, and nursing care either at home, in the community or in residential care.
- In general the cost of adult social care services is substantial. According to the national NASCIS system, expenditure for people aged 65+ years in 2015/2016 in Swindon UA represented approximately 40% of the total gross expenditure on adult social care services.

#### Introduction

There is currently no cure for dementia. However, there are both medication and psychosocial interventions which can help to maintain independence and slow progression for some people. Following diagnosis, people may have changing needs for health and social care over time, but because of the lack of a cure, demand for social care can be significant particularly when the illness is



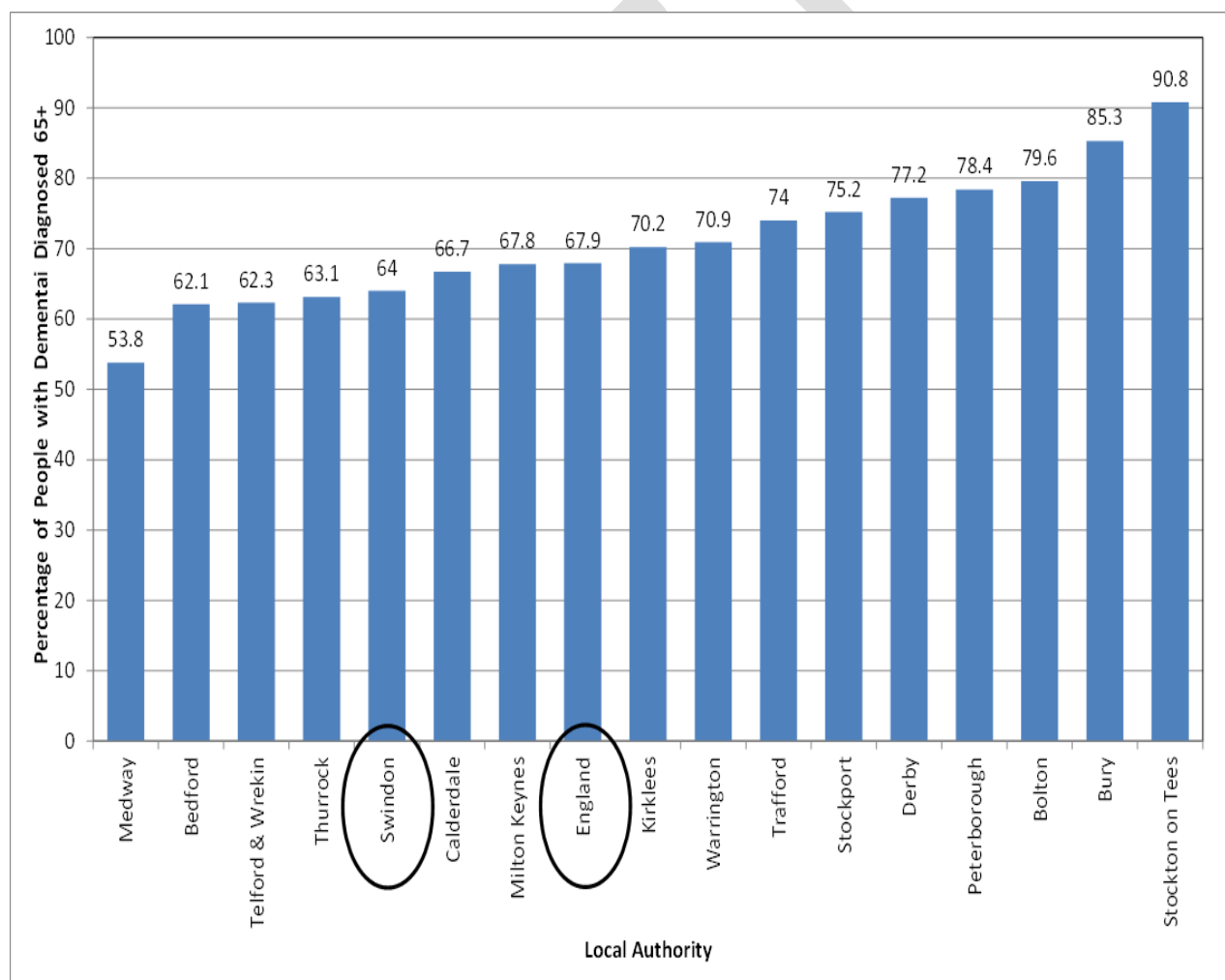
severe. There is also a significant burden on carers, both for those with a formal diagnosis, but also for people who do not access the system.

The previous chapter considered people who are at risk. This chapter looks at those who already have symptoms and the services they may access to support them in their journey from diagnosis to end of life care. It concentrates on updating data rather than on providing a service review – more detailed information about services is available in the 2013 JSNA.

## Health Services

### Primary Care

GPs are often the first point of contact for an individual or family member with concerns about memory loss or symptoms. Estimates suggest that people wait up to 3 years<sup>13</sup> to see their GP after first noticing symptoms and 70% of carers were unaware of symptoms before diagnosis. There continues to be a lack of evidence that a formal screening programme for dementia would be beneficial. In Swindon, 64% of people estimated to be living with dementia over the age of 65 have a formal diagnosis, which is slightly lower than the national average of 67.9%.



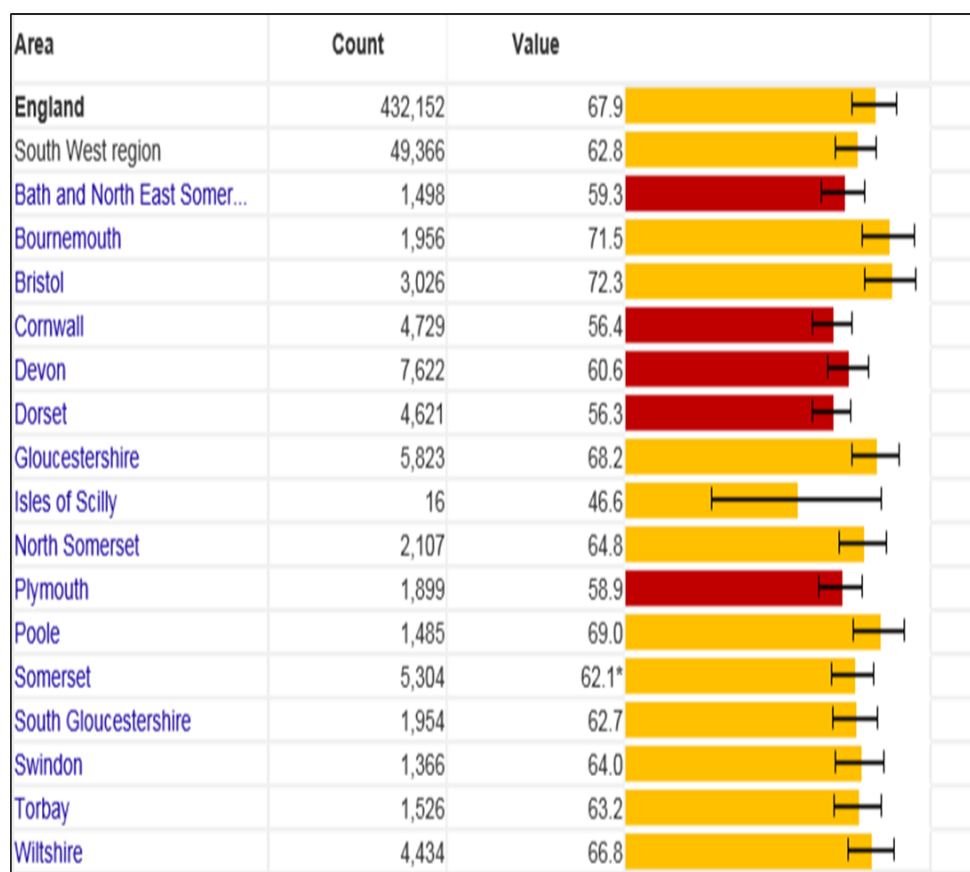


Figure 14: Estimated dementia diagnosis rates among people aged 65+ years predicted to have dementia in Swindon CCG and other CCGs in South West, as compared with England in 2017

The figure shows, for England, the South West and the CCGs of the South West, the proportion of people predicted to have dementia aged 65+ years who have probably been identified and diagnosed. The age and sex-specific 65+ prevalence rates of the Cognitive Function and Ageing Study II (CFAS II) population (the reference rates) were applied to the age and sex structure of the registered patients in these populations. Dividing the observed number of cases actually recorded in each population (the numerators) by the expected number (the denominators) gives the estimated diagnosis percentages.

### Prescribing

The following drugs are recommended by NICE:

- For mild to moderate Alzheimer's: AChE Inhibitors are available, including donepezil, galantamine, rivastigmine.
- As an alternative in moderate Alzheimer's, or for severe Alzheimer's: Memantine.

These drugs are mainly used for dementia, although the item numbers and costs shown in the table below will include prescription for conditions other than dementia.

The number of items prescribed each year in Swindon has risen for all of these drugs, except Galantamine, although the rise for Rivastigmine has been small. Yet overall costs for Rivastigmine and Memantine have come down in this period, as generic (unbranded) versions of these drugs have become available.

**Table 10: Number and cost of drugs prescribed for dementia by year**

	Donepezil		Galantamine		Rivastigmine		Memantine	
Year	Annual Number of Items	Total Annual Cost	Annual Number of Items	Total Annual Cost	Annual Number of Items	Total Annual Cost	Annual Number of Items	Total Annual Cost
2013/14	1207	1907	270	10639	415	14722	325	9223
2014/15	1299	1769	178	8344	361	10015	461	4850
2015/16	2900	3951	72	6866	442	7922	621	3719
2016/17	3813	4633	52	2176	431	7236	1424	3478

Another source of data is that from the NHS Information Centre which provides data on 'drugs for dementia' as defined in the British National Formulary (BNF) 2008. This is not the same as the local data provided above. According to this data source, compared to Wiltshire and similar areas such as Milton Keynes and Peterborough, Swindon has a clearer downward trend in the number of items prescribed for dementia and the cost.

The table below provides an alternative way of measuring prescribing for dementia, by looking at a basket of drugs as a whole which can be used for dementia. This table shows the number of items prescribed and costs per annum for Swindon CCG and two geographical neighbours (Bath & North East Somerset (BANES) CCG and Wiltshire CCG). From this perspective as well, the number of prescriptions has been increasing, while costs have been coming down. Swindon CCG seems to have relatively low prescription levels for dementia in primary care. (Note that Wiltshire's population is about twice the size of Swindon's, but its prescription numbers in 2016/2017 were over 4 times as great; BANES has a smaller population than Swindon, but its prescription levels in 2016/2017 were about 3 times as great). The same pattern has been seen for England as a whole, with number of items prescribed rising from 2.4 million to 3.5 million over the period from 2013/2014-2016/2017, and costs falling from 45.4 million pounds to 25.1 million pounds over this period.

**Table 11: Number and cost of a basket of drugs prescribed for dementia in Swindon CCG, BANES CCG and Wiltshire CCG by year**

	Swindon CCG		BANES CCG		Wiltshire CCG	
Year	No of items	Cost £	No of items	Cost £	No of items	Cost £
2013/2014	2,217	36,500	13,591	206,000	8,619	64,900
2014/2015	2,299	25,000	15,857	161,800	21,271	71,100
2015/2016	4,035	22,500	17,248	117,000	24,646	54,700
2016/2017	5,720	17,500	18,440	127,300	28,410	47,600

### Secondary Care

The analysis reported here is based on hospital activity for Swindon patients over a three year period from 2014/2015-2016/2017. Hospital records were selected for analysis where dementia was coded as a primary diagnosis or as one of the secondary diagnoses (twelve secondary diagnoses were possible for each admission). ICD 10 codes used were: F00.\* (Alzheimer's disease), F01.\* (Vascular dementia), F02.\* (Other forms of dementia) or F03.\* (Dementia not specified as to type).

For simplicity, patient numbers are reported as "hospital admissions", though these are based on a count of episodes in hospital which ended with a discharge. One person could be admitted as a patient on several occasions and thus counted more than once. The years covered are 2014/2015, 2015/2016, 2016/2017 and data are for Swindon UA residents unless otherwise specified.

In all, there were 2,887 admissions during the three years with dementia coded in any diagnosis position. Of these, 1,738 were female admissions and 1,149 were male admissions. In all, 2,632 (91.2% of the total number) were emergency admissions (including requests for admission by a GP).

The number of admissions rose year-on-year, from 828 in 2014/2015 to 970 in 2015/2016, to 1,089 in 2016/2017. Of the total number of admissions over the 3 year period, 21 patients were aged under 60 years, 86 were aged 60 to 69 years, 508 were 70 to 79 years, 1,548 were aged 80 to 89 years, and 724 were aged 90 years or older.

Dementia was comparatively rare as a primary diagnosis, with 77 primary diagnoses (2.7%) compared with 2,842 secondary diagnoses (i.e. where dementia was not the main reason for admission and dementia was coded as a secondary diagnosis in at least one of the secondary positions.)

Where dementia was a primary diagnosis, the majority of these admissions (60 out of 77) were coded as unspecified dementia, with 2 coded as Alzheimer's disease, 14 as vascular dementia and 1 as other forms of dementia. In the case of secondary diagnoses, larger numbers of patients were assigned to the specific codes, but the majority were still coded to the unspecified category.

Analysing the pattern of hospital admissions found:

- In the three year period, 2,787 admissions were to GWH, 14 were to the BMI Ridgeway hospital in Swindon, while 86 were to hospitals outside Swindon. There were no admissions to the local psychiatric trust, AWP.
- The mean length of stay was 9.0 days, with an average of 13.0 days where dementia was the primary diagnosis and 8.9 days where dementia was a secondary diagnosis. For 509 admissions, the length of stay was zero i.e. the patient was discharged without staying the night.
- There were 2,887 admissions, but 1,574 individual persons admitted to hospital. Thus, in terms of individual people, 675 (42.9%) had more than one admission. Breaking this down further, 372 (23.6%) had two admissions, 162 (10.2%) had three admissions, 69 (4.4%) had six admissions, and 72 (4.5%) had five or more admissions. Of the latter group, six people had ten or more admissions.

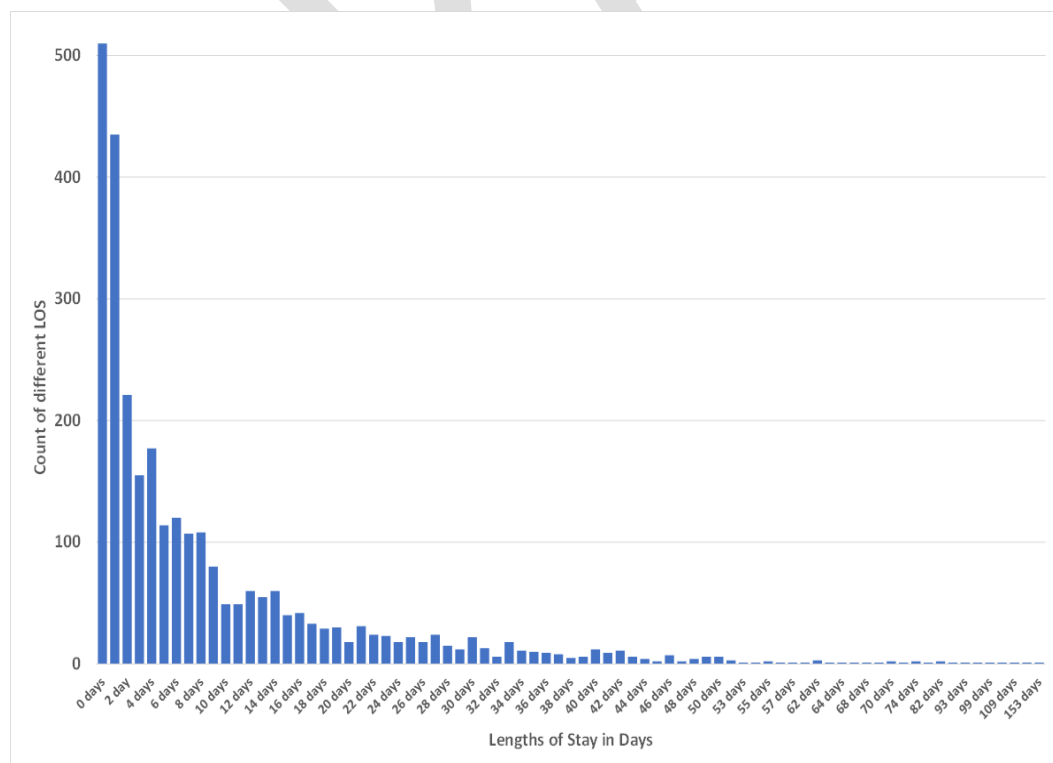


Figure 15: Frequency of different durations of Lengths of Stay in days for admissions with a diagnosis of dementia (in any position) of Swindon UA residents in the three year period from 2014/2015-2016/2017

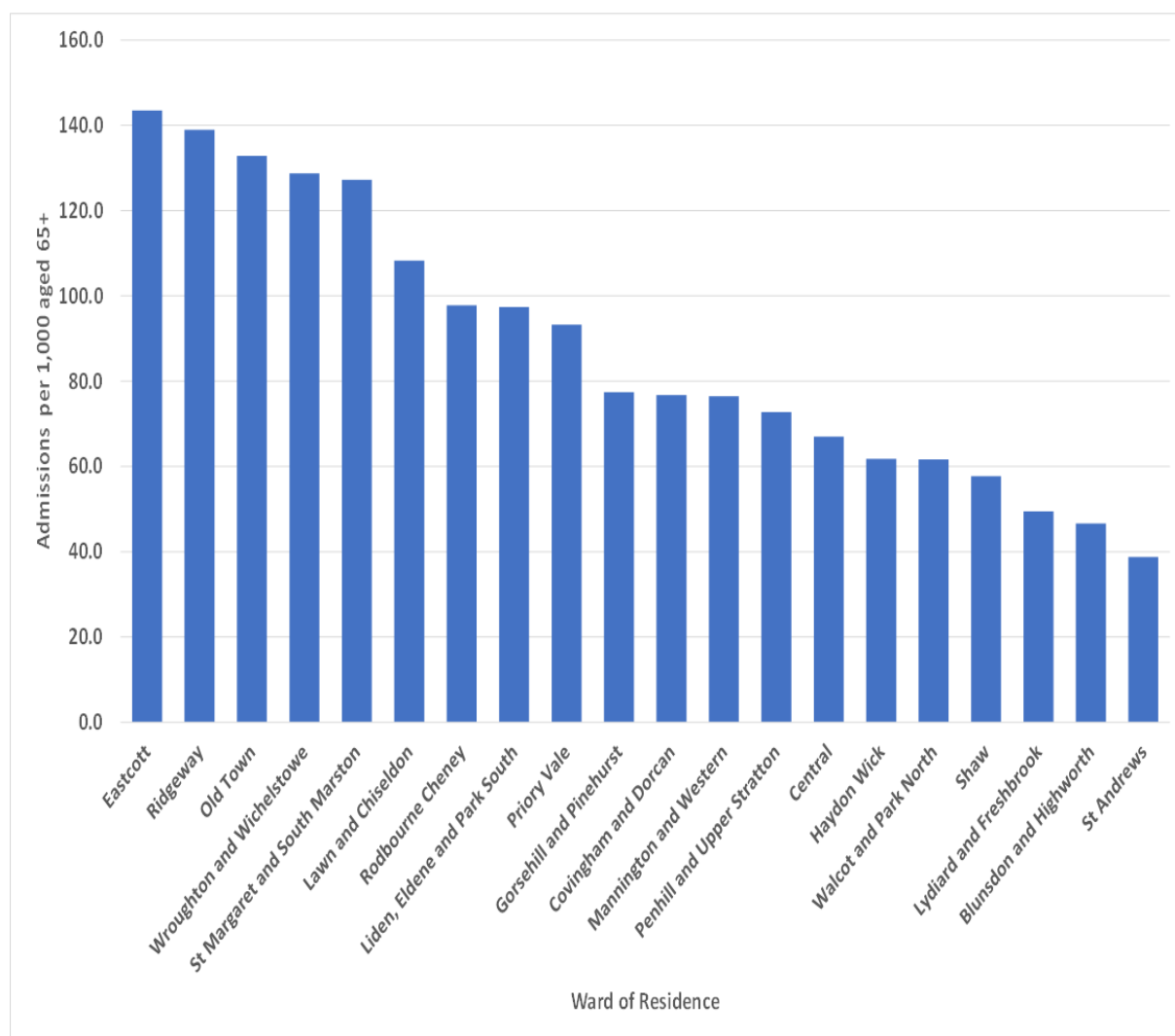
The table below shows the top 10 primary diagnoses for people admitted to hospital with a secondary diagnosis of dementia between April 2014 and March 2017. The “top 10” accounts for about a third of all admissions for dementia patients. Urinary tract infections, pneumonia and problems related to falling are prominent in the table. Note that if the three pneumonia categories and lower respiratory infection are added together they sum to 415 admissions. Likewise, if diagnosis categories related to falling (tendency, the two fracture categories, syncope) are added together, they amount to 311 admissions. The numbers for these types of problem will actually be higher if detailed diagnoses not in the top 10 are also counted in.

**Table 12: The ten most frequent primary diagnoses (main reason for admission) for admissions of Swindon UA residents where dementia was a secondary diagnosis in the three year period from 2014/2015-2016/2017**

ICD Code	Primary Diagnosis	Number of Admissions
N390	Urinary tract infection site not specified	222
J181	Lobar pneumonia unspecified	192
R296	Tendency to fall	127
J189	Pneumonia unspecified	94
A419	Sepsis unspecified	85
J22X	Unspecified acute lower respiratory infection	81
S7200	Fracture of neck of femur	74
R55X	Syncope and collapse	56
S7210	Pertrochanteric fracture (neck of femur)	54
J690	Aspiration pneumonia	48

Costs for admissions for Swindon UA residents with a diagnosis of dementia (in any position) in the three year period are drawn from the PBR (Payment By Results) Tariff assigned to each admission. This is the amount of money charged by the hospital to Swindon CCG.

In all, 550 admissions were recorded with a zero cost - this number includes virtually all patients with dementia as a primary diagnosis. Overall, the range of costs was from zero to £45,579 per admission. The mean cost per admission was £2,330 and the median was £1,880. The total cost for all admissions was £6,726,624, which gives an annual average cost of £2,330,208 over the three year period.



aged 65+ years by ward in Swindon UA in the three year period from 2014/2015-2016/2017

At ward level the number of admissions relates generally to the number of older people in the ward or the number of care homes concentrated in particular areas. 308 admissions were from residents from St Margaret and South Marston, 272 from Wroughton and 207 from Rodbourne Cheney.

Data for Shrivenham are not included in the other figures given here, but can be summarised as follows:

- There were 32 admissions with dementia as a diagnosis, but these were all secondary diagnoses.
- 17 admissions took place in 2014/2015, 10 in 2015/2016 and 5 in 2016/2017.
- 6 admissions were of people in the age-range 60 to 79 years, with 26 admissions of people aged 80 to 99 years (the majority of these were aged 80 to 89 years).

### Social Care

Social care provides crucial support for some people with dementia to maintain their independence and 'live well' with their condition. Swindon Borough Council commission both mental health support and community based services, including third sector commissioning.

Services include day services, domiciliary care, respite, and nursing care either at home, in the community or in residential care. The need for social support is often perceived to be greatest at the early stages of the disease (when social needs outweigh health care needs) and at the later stages.

As the disease progresses, people may have behavioural issues that need specialist healthcare intervention such as medication.

In general the cost of adult social care services is substantial. According to the national NASCIS system, expenditure for people aged 65+ years in 2015/2016 in Swindon UA was £25,137,000 for Long Term care and £991,000 for Short Term care, equating to around 40% of the total gross expenditure on adult social care services.

**Table 13: Gross expenditure by Primary Support reason in people aged 65+ in Swindon UA in 2015/16**

Primary Support Reason	Expenditure (£1,000s)
Physical Support	16,876
Sensory Support	183
Support for Memory and Cognition	4,895
Learning Disability Support	3,089
Mental Health Support	1,085
All	26,128

In terms of the actual number of people supported by social care, data is available from the national NASCIS system and local systems. At the end of year 2015/2016, out of 757 service users (long term community support) aged 65+ in Swindon UA, 592 (78.2%) were receiving a full or partial Direct payment or personal budget. If only direct payments are considered, there were 94 people out of 757 (12.4%) in this category.

In 2015/2016 there were 182 carers aged 65 to 84 receiving carer-specific services in Swindon UA and 48 (26.4%) were receiving direct payments or partial direct payments.

**Table 14: Number of Mental Health Assessments carried out in Swindon UA in people aged 65+ years over three years from 2015/2016-2017/2018 (Source: SWIFT)**

Year	No. of Mental Health Assessments	No. of Memory & Cognition Assessments
2015/2016	266	108
2016/2017	323	160
2017/2018 (6 months)	169	102

**Table 15: Number of clients aged 65+ funded by Swindon UA with Mental Health or Memory & Cognition needs by type of care in Swindon UA over three years from 2015/2016-2017/2018 (Source: Swift)**

Year	Mental Health or Memory & Cognition Needs	Residential Care	Nursing Care	Community Care	Total Clients
2015/2016	MH	90	45	97	212
2016/2017	MH	37	7	105	119
2017/2018 (6 months)	MH	45	17	172	118
2015/2016	M&C	117	60	155	249
2016/2017	M&C	83	45	87	181
2017/2018	M&C	N/A	N/A	N/A	N/A

**Table 16: Number of clients aged 65+ with Mental Health or Memory & Cognition needs accessing services in Swindon UA by service type in 2016/17 (Source: Swift)**

**Notes:** Not a client count as clients may access more than one service. To avoid potentially disclosive

<b>Service Type</b>	<b>Number with Mental Health Needs</b>	<b>Number with Memory &amp; Cognition Needs</b>
<b>Equipment</b>	<b>13</b>	<b>21</b>
<b>Domestic Care</b>	<b>12</b>	<b>13</b>
<b>Direct payments</b>	<b>6</b>	<b>0</b>
<b>Day care; temporary residential care; intermediate domiciliary; residential reablement</b>	<b>6</b>	<b>14</b>
<b>Professional support includes advocate/ deputyship</b>	<b>30</b>	<b>23</b>
<b>Nursing permanent</b>	<b>17</b>	<b>45</b>
<b>Residential permanent</b>	<b>45</b>	<b>83</b>
<b>Planned Short Term breaks</b>	<b>5</b>	<b>9</b>
<b>Total</b>	<b>134</b>	<b>208</b>

low numbers, some rows have been adjusted slightly, together with the totals, and some categories have been combined.



#### 4. What does the future look like?

- The number of people aged 65 and over is predicted to increase by over 20,000 over the next 15 years to nearly 55,000.
- According to POPPI (Projecting Older People Information System) numbers of people with dementia are estimated to increase by about 2000 by 2030 reflecting the increase in population of those over 65 and that age is the greatest risk factor for dementia.
- Data from POPPI predicts significant increases in the number of older people living alone over the next 20 years. However older people living alone is not necessarily a marker of increased dementia or demand for services as it may encourage people to maintain independence.
- The Alzheimer's Society estimated the formal and informal cost (i.e. unpaid carers) of dementia based on 2012/13 costs. This shows that costs depend on the severity of dementia, and that costs are highest for people with severe dementia in the community due to the high estimate of cost of informal care.

#### Introduction

The number of people with dementia in any area will increase as the population ages and people live longer. It is also important to differentiate between need and demand. Whilst there is some overlap, there will always be some people who need services or support but do not access them (until perhaps a crisis point is reached), and also people who demand services who could be supported in other ways or via a different level of provision.

#### Population Projections

The number of people in Swindon aged 65+ is predicted to increase from 33733 in 2016 to 54976 in 2031. Although numbers are smallest than in other age groups, the number of people aged 90 and over will more than number for both males and females.

**Table 2: Swindon UA population aged 65+ years by sex and age-group, with actual 2016 population and projection of population numbers to 2031**

<b>Males by age</b>	<b>2016 Actual</b>	<b>2020</b>	<b>2025</b>	<b>2030</b>	<b>2031</b>
<b>65-69</b>	5,173	5,287	6,296	7,516	7,613
<b>70-74</b>	3,834	4,593	4,854	5,795	6,058
<b>75-79</b>	2,779	3,190	4,110	4,379	4,519
<b>80-84</b>	1,998	2,356	2,722	3545	3,613
<b>85-89</b>	1,169	1,441	1,731	2,059	2,183
<b>90-94</b>	432	713	1,028	1,401	1,455
<b>95+</b>	83	136	196	267	278
<b>All Males 65+</b>	15,468	17,717	20,938	24,961	25,717
<b>Females by age</b>	<b>2016 Actual</b>	<b>2020</b>	<b>2025</b>	<b>2030</b>	<b>2031</b>
<b>65-69</b>	5,473	5,489	6,415	7,755	7,956
<b>70-74</b>	4,220	52,20	5,382	6,299	6,575
<b>75-79</b>	3,204	3,789	48,77	5,059	5,199
<b>80-84</b>	2,544	2,778	3,330	4,313	4,404

<b>85-89</b>	1,759	1,968	2,159	2,653	2,797
<b>90-94</b>	819	1,071	1,389	1,736	1,790
<b>95+</b>	246	321	417	521	537
<b>All Females 65+</b>	18,265	20,635	23,968	28,335	29,259
<b>All Persons 65+</b>	33,733	38,352	44,906	53,296	54,976

Numbers of people with dementia are estimated to increase by about 2000 by 2030 due to the increase in population of those over 65. This forecast is purely based on the changes in demographics rather than reflecting individual or generational risk. The highest percentage increases are in the 90+ age groups. For early onset dementia the prevalence amongst 30 to 64 year olds is likely to increase from 0.1 to 0.2% over the next 15 years with an estimated increase in numbers from 140 to 191 people.

**Table 3: Swindon UA numbers of people aged 65+ years by sex and age-group estimated to have dementia in 2016 and expected to, as projected to 2031**

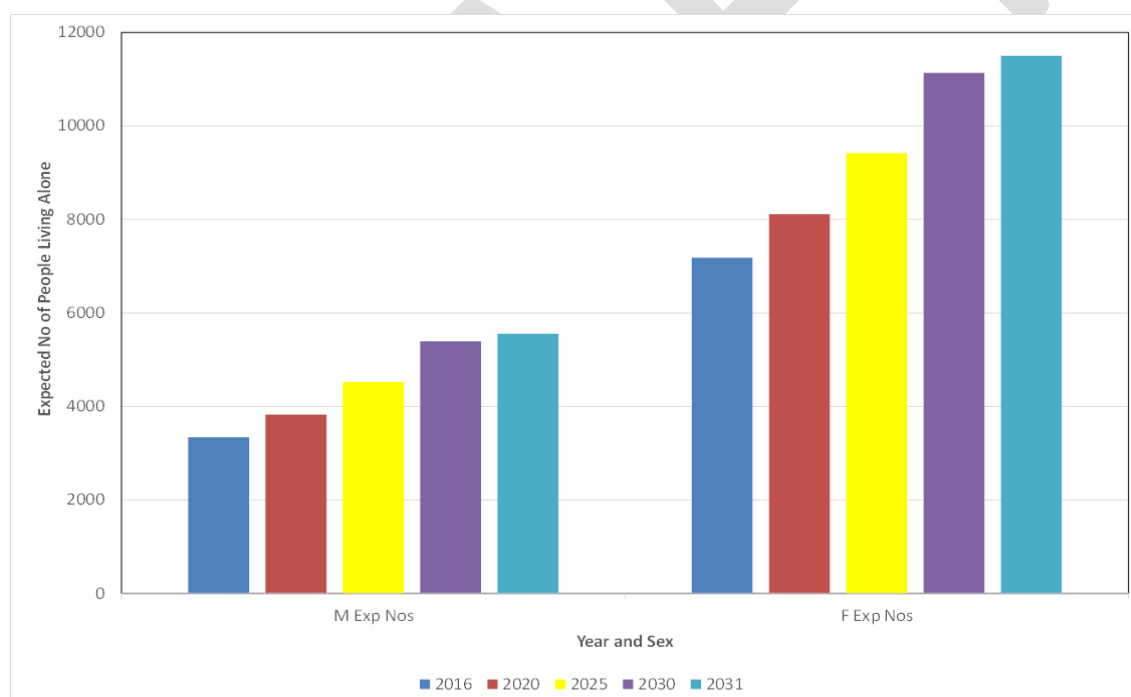
<b>Males by age</b>	<b>2016</b>	<b>2020</b>	<b>2025</b>	<b>2030</b>	<b>2031</b>
<b>65-69</b>	78	79	94	113	114
<b>70-74</b>	119	142	150	180	188
<b>75-79</b>	147	169	218	232	239
<b>80-84</b>	206	243	280	365	372
<b>85-89</b>	177	218	261	311	330
<b>90-94</b>	98	161	232	317	329
<b>95+</b>	24	39	57	77	80
<b>All Males 65+</b>	848	1,051	1,294	1,594	1,652
<b>All Males 65+ Crude Prevalence</b>	5.5%	5.9%	6.2%	6.4%	6.4%
<b>Females by age</b>	<b>2016</b>	<b>2020</b>	<b>2025</b>	<b>2030</b>	<b>2031</b>
<b>65-69</b>	99	99	115	140	143
<b>70-74</b>	127	157	161	189	197
<b>75-79</b>	211	250	322	334	343
<b>80-84</b>	298	325	390	505	515
<b>85-89</b>	355	397	436	536	565
<b>90-94</b>	270	353	458	573	591
<b>95+</b>	109	142	184	230	237
<b>All Females 65+</b>	1,469	1,723	2,067	2,506	2,592
<b>All Females 65+ Crude Prevalence</b>	8.0%	8.4%	8.6%	8.8%	8.9%
<b>All Persons 65+</b>	2,316	2,775	3,361	4,100	4,244
<b>All Persons 65+ Crude Prevalence</b>	6.9%	7.2%	7.5%	7.7%	7.7%

**Table 4: Swindon UA numbers of people aged 30 to 64 years by sex and age-group estimated to have dementia in 2016 and expected to, as projected to 2030**

Age groups	2016	2020	2025	2030
30-39		4	4	4
40-49		7	7	8
50-59		32	32	32
60-64		118	142	147
Total population aged 30-64	140	161	185	191

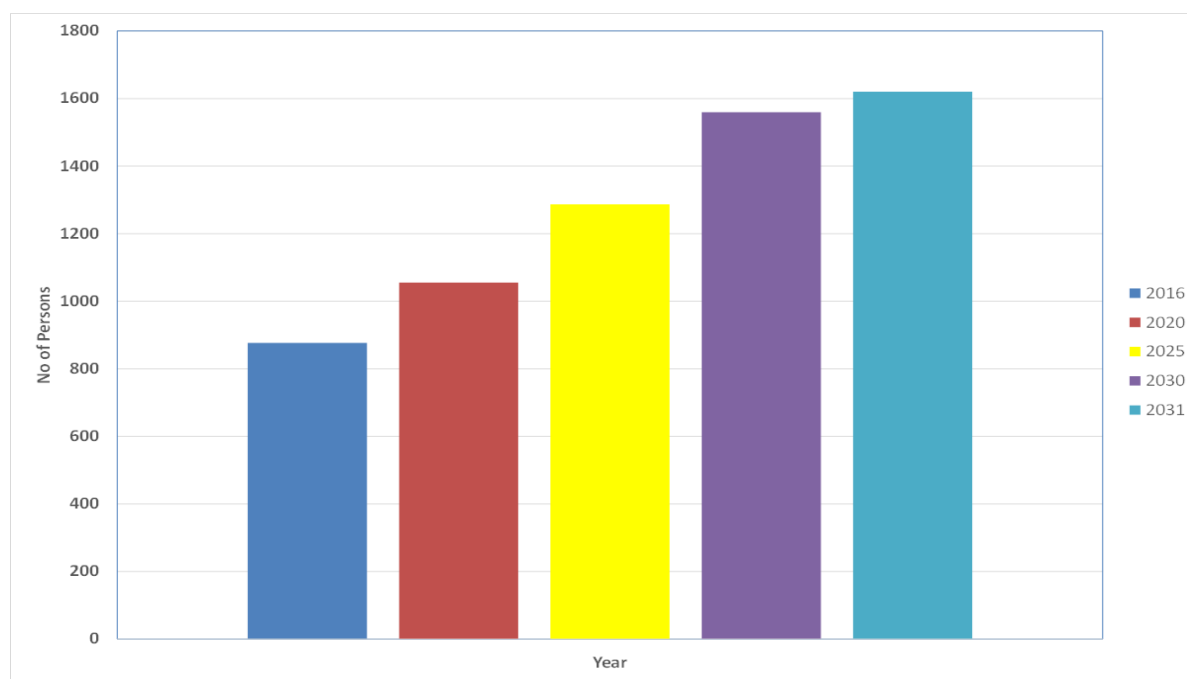
Data from POPPI predicts significant increases in the number of older people living alone over the next 20 years. The graph shows the numbers of people aged 65+ years, by sex, expected to be living alone in selected years from 2016 to 2031. These estimates are based on figures in the 2011 Census which suggested that 21.6% of men aged 65+ and 39.3% of women aged 65+ years were living alone. These proportions were applied to the actual population of Swindon UA in 2016 and to the population projections for years up to and including 2031. According to this method 3,341 men and 7,178 women aged 65+ years were living alone in 2016, by 2025 this is expected to be 4,523 and 9,419 respectively and by 2031, 5,555 and 11,499 respectively.

**Table 5: Forecast of number of men and women aged 65+ years expected to be living alone in Swindon UA in the period 2016 to 2031**



The graph shows projections to 2031 of numbers of people aged 65+ years from the Swindon UA population who are likely to be resident in a local authority or private care residence in the years to 2031. This projection allows for the differential changes in growth by age-group within the elderly population, but does not take account of differentials between the sexes. In this projection the care home population would virtually double from 876 in 2016 to 1,620 in 2031, driven mainly by a doubling of the size of population aged 85 years or more in this period. The major assumption of this prediction is that patterns of care home use will remain the same as they did in the base year 2011 (when the census took place), for instance, with about 11% of people aged 85 years or being cared for in this way. This may not be the case and it is conceivable that in the future a more people in later old age will maintain a level of fitness that will enable them to live in their own homes.

**Table 6: Projection of number of people aged 65+ years from Swindon UA living in a care home (with or without nursing care) in selected years to 2031**



### Costs of Dementia

The costs of dementia are estimated by the Alzheimer's Society in the table below and include informal care by family and friends as well as healthcare costs. The costs are based on 2012/13 and so may have increased since then. Data is not available on the cost of early onset dementia. Costs vary depending on the severity of dementia and the setting. For example the cost of severe dementia in the community is mainly in informal care whereas cost in a residential setting is predominantly social care.

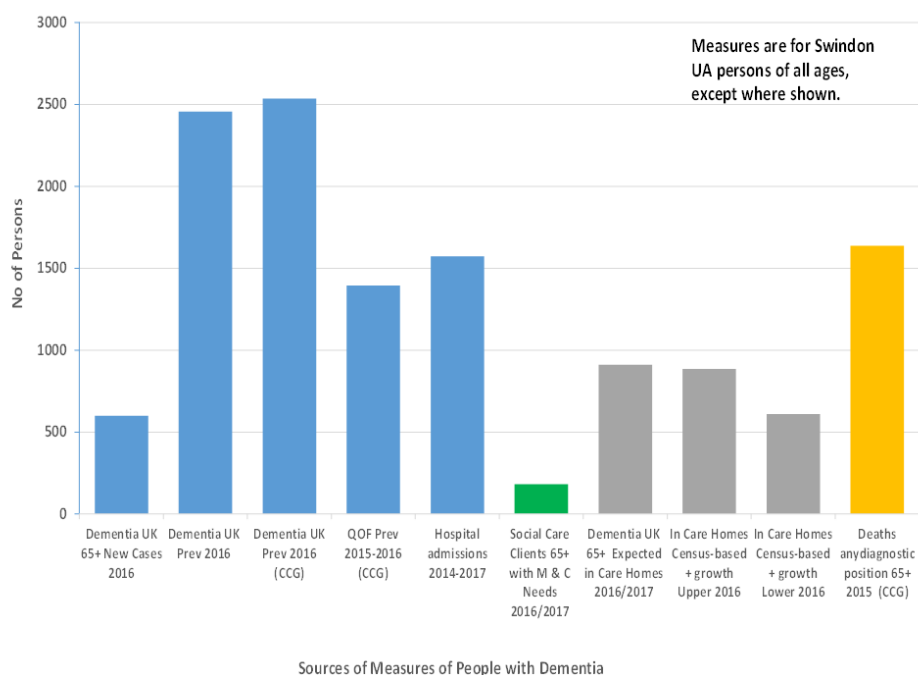
**Table 7: Average annual cost of dementia per person with dementia, by severity and setting (2012/2013 prices in pounds) Dementia UK Report 2014**

£	Cost of mild dementia in the community	Cost of moderate dementia in the community	Cost of severe dementia in the community	Cost of dementia in a residential care setting
NHS	2,751	2,695	11,258	8,542
Social Care	3,121	7,772	10,321	25,610
Informal Care	19,714	32,237	33,482	2,450
Other costs	137	137	136	136
Total Cost	25,723	42,841	55,197	36,738

## 5. Summary

In Swindon it is estimated there are currently over 2000 people with dementia and this is predicted to increase to over 2700 by 2020 based on population alone and current incidence rates. As the figure shows there is variation in different measures of people with dementia and demand for services.

**Table 8: Variations in measures of dementia in Swindon taken from the period 2016 to 2017, showing estimates of prevalence, incidence and service use**



The current Swindon dementia strategy covers the period to 2019 and reflects the priorities outlined in the National Dementia Strategy. This JSNA does not include any new recommendations but outlined below is a brief update on the recommendations from the 2013 JSNA. The Dementia Steering Group has produced two reports providing an overview of work on dementia in Swindon which were presented to the Council's Adult Overview and Scrutiny Committee. These provide a more comprehensive update of work on dementia across Swindon over the last 3 years.

### Update on Recommendations

**A dementia steering group will be established to take work in this area forward.**

The Swindon Dementia Steering Group (DSG) was established in 2014 to oversee the implementation of the Swindon Dementia JSNA and Dementia Strategy 2014-2019. It is a multi-agency group which meets quarterly with current membership including Swindon Borough Council (Public Health, Housing and Social Care), NHS Swindon Clinical Commissioning Group, Swindon Carers Association, Great Western Hospital, Alzheimer's Society, SEQOL, Avon & Wiltshire Mental Health Partnership, Swindon Dementia Action Alliance, and Wiltshire Police Service.

**Continue to develop a more detailed understanding of the role of carers and ensure the additional funding SBC are putting into caring services reflects carers' needs, recognising that people need different support at different times.**

Swindon Carer's Centre has continued to develop its role in supporting carers and offers a wide range of activities and support. The Alzheimer's Society have a dementia advisor (funded by One Swindon) and dementia support worker, who offer support on diagnosis and after to people living with dementia and their carers.

**Develop campaigns to promote awareness of risk factors for dementia and in particular that lifestyle factors such as healthy eating, physical activity and not smoking can benefit cognitive ability as well as protecting against cardiovascular disease**

More is known about the benefits of a healthy lifestyle and reducing the risk of dementia. This is promoted both nationally via the Public Health England One You campaign and in our local health promotion work with a 'Good for the heart, good for the brain' campaign planned for 2018/19.

**Develop the Swindon Dementia Action Alliance and Swindon as a dementia friendly community**

Swindon gained Alzheimer's Society accreditation for its work in working towards a dementia friendly community in 2017. We now have a Dementia Friendly Swindon Co-ordinator and the role includes working with businesses, leisure, voluntary services, education and other partners to promote dementia awareness. The Dementia Action Alliance has continued to develop and provide a community voice for people wanting to be more dementia friendly.

**Work in partnership to improve the speed of diagnosis from referral to diagnosis**

Time from referral to diagnosis in Swindon has improved significantly over the last 3 years.

**Encourage all staff in public sector organisations, including GPs, have dementia awareness training**

There has been an active programme of dementia friends sessions over the last 3 years across Swindon Borough Council and other public sector organisations as well as for the general public. This is ongoing and we continue to promote the sessions with businesses, schools and other partners.

**Develop a briefing paper on best practice around supported and extra care housing for people with dementia to inform the planning and development of this type of housing in the future**

Dementia Friendly Housing Guidance has been produced and work is ongoing with housing and planning to include good dementia design in future developments.

**Work in partnership to extend the support for social activities and opportunities for people to benefit from others experiencing the same challenges, and reducing the risk of social isolation**

There are a range of social activities available in Swindon including Singing for the Brain, memory cafes, lunchtime get-togethers, walks, and craft groups. The ongoing work to make Swindon more dementia friendly is also looking at how to make everyday activities more accessible for people living with dementia.

## References

- <sup>1</sup> [http://www.sheffield.ac.uk/polopoly\\_fs/1.207026!/file/SheffieldDementiaInformationPack.pdf](http://www.sheffield.ac.uk/polopoly_fs/1.207026!/file/SheffieldDementiaInformationPack.pdf)
- <sup>2</sup> The Mini Mental State Examination is routinely used which asks a series of questions to test cognitive functioning e.g. recalling objects, simple numerical calculations, and questions about dates and current location
- <sup>3</sup> <http://www.birmingham.ac.uk/Documents/college-mds/haps/projects/HCNA/HCNAV02chap14sh5L.pdf>
- <sup>4</sup> [http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=120](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=120)
- <sup>5</sup> <http://www.dh.gov.uk/health/category/policy-areas/social-care/dementia/>
- <sup>6</sup> A detailed picture of Swindon is available in the JSNA, available at <http://www.swindon.gov.uk/sc/sc-healthmedicaladvice/jsna/Pages/Joint-Strategic-Needs-Assessment.aspx>
- <sup>7</sup> Parliamentary Office of Science and Technology Diagnosing Dementia January 2010 Number 349 [www.parliament.uk/briefing-papers/POST-PN-349.pdf](http://www.parliament.uk/briefing-papers/POST-PN-349.pdf)
- <sup>8</sup> Census 2011 estimates are rounded and so summing male and female totals does not equate to total persons. Total person figures have been used to calculate percentages.
- <sup>9</sup> Lancet Commission on Dementia Prevention, Intervention and Care (Jul 2017) *The Lancet* DOI: (10.1016/S0140-6736(17)31363-6)
- <sup>10</sup> [http://www.cks.nhs.uk/dementia/background\\_information/epidemiology\\_and\\_societal\\_burden#-406359](http://www.cks.nhs.uk/dementia/background_information/epidemiology_and_societal_burden#-406359)
- <sup>11</sup> McMurtray A, Clark DG, Christine D, Mendez MF Early-onset dementia: frequency and causes compared to late-onset dementia. *Dement Geriatr Cogn Disord*.2006;21(2):59-64. Epub 2005 Nov 4
- <sup>12</sup> [http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=164](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=164)
- <sup>13</sup> Chrisp TAC, Thomas BD, Goddard WA, Owens A Dementia timeline: Journeys, delays and decisions on the pathway to an early diagnosis *Dementia* (2011) 10(4); 555-570