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Somerset Clinical Commissioning Group

FINAL DRAFT

SOMERSET DEMENTIA STRATEGY

2016 – 2020

26 May 2016
V17

CONTENTS

Somerset Dementia Strategy 2016 to 2020

Our Vision

Our vision is that by 2020 Somerset will be in step with the national ambition to be the best country in the world for dementia care, support, research and awareness.

People with dementia and their carers and families in Somerset will:

- Be supported to live well with dementia, irrespective of the stage of their condition or where they live
- Be supported by communities that are working towards becoming dementia friendly
- Be able to access timely, high quality and appropriate care and support
- Be supported by a workforce that is skilled, experienced and knowledgeable in dementia

Outcomes for people living with dementia

- I have personal choice and control or influence over decisions about me
- I know that services are designed around me and my need
- I have support that helps me live my life
- I have the knowledge and know-how to get what I need
- I live in an enabling and supportive environment where I feel valued and understood
- I have a sense of belonging and of being a valued part of family, community and civic life.
- I know there is research going on which delivers a better life for me now and hope for the future

Well Pathway for Dementia

The public and care professionals are well informed about dementia; and Dementia Friendly communities and organisations are 'the norm'.

	2016 – 2020 Key Ambitions
Preventing well →	Raise awareness of how lifestyle factors can contribute to dementia
Diagnosing well →	Timely diagnosis and treatment is the rule rather than the exception
Living well →	People have access to personalised, appropriate care and support to optimise wellbeing
Supporting (carers) well →	Carers are supported to have a life of their own during and after caring for a person with dementia
Dying well →	People with dementia at end of life and their carers have choice and access to personalised, appropriate, advance care planning and support

SOMERSET DEMENTIA STRATEGY

2016 – 2020

1 INTRODUCTION

What is dementia?

1.1 Dementia is a term used to describe the symptoms that occur when the brain is affected by certain diseases or conditions which impact on its function. These result in a progressive decline in function, including memory, reasoning, communication skills and the skills needed to carry out daily activities. More information is available at the following website: https://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200120 and in the Health Needs Analysis at Appendix 1

Purpose of the Strategy

1.2 The Somerset Dementia Strategy was produced in July 2010, following public consultation, in response to the National Dementia Strategy (February 2009) as a key step towards achieving the goal of building health and social services for dementia that are fit for the 21st century.

1.3 A refreshed Strategy was published in 2013 taking account of a successful bid for funding from the Prime Minister's Challenge fund 2012 for £415,000 to implement a number of initiatives including training for health and social care staff; development of Dementia Friendly Communities; and a local bid for £56,000 to implement an intergenerational project called 'Archie's Story'.

1.4 This new strategy is fundamentally based on the new Prime Minister's Challenge on Dementia 2020 (PMCD 2020) and the national commitments it sets for the next 4-5 years; together with the NHS England 'Well Pathway for Dementia'. Dementia remains a high priority for all stakeholders within Somerset who continue to strive for quality and outcome improvements within dementia services. This strategy also has at its core the key principle of individual 'wellbeing' as set out in the Care Act 2014. Appendix 2 provides an overview of Dementia Wellbeing 'Crosswalks' linking guidance to delivery across all sectors.

The Somerset Vision

1.5 The vision of this strategy is that by 2020, Somerset is in step with the national ambition to be the best country in the world for dementia care, support, research and awareness.

- Be supported to live well with dementia, irrespective of the stage of their condition or where they live
- Be supported by communities that are working towards becoming dementia friendly
- Be able to access timely, quality and appropriate care and support

- Be supported by a workforce that is skilled, experienced and knowledgeable in dementia

1.6 People with dementia, their family and carers can be helped to improve the quality of their life. They will have access to personalised care and support, and in addition:

- The public and professionals are well informed about dementia; and the fear and stigma associated with the illness has been dispelled by changing public and professional attitudes, understanding and behaviour
- Families affected by dementia will know where to go for help and what services are available and where the quality of care is exceptional
- Timely diagnosis and treatment is the rule rather than the exception
- People with dementia and their carers are enabled to live well with their condition by the provision of good quality support for all from diagnosis to the end of life, in the community, in hospitals and in care homes'

1.7 As a health and care community, Somerset will organise the delivery of the vision, and PMCD 2020, under the Well Pathway sections:

- Preventing well
- Diagnosing well
- Living well
- Supporting (carers)well
- Dying well

Engagement

1.8 Engagement activity which has taken place within the last year is summarised in Appendix 3 and has been at the various levels shown below.

- A large event for health and care professionals, patients, carers, voluntary and charitable organisations
- A stakeholder workshop which included members of the Dementia Strategy Group and others who signed up at the large event to be involved further
- A public engagement event led by Somerset County Council in the community
- Contractual service level engagement (service user surveys)
- Informal engagement in a number of settings and agencies

1.9 The implementation of this strategy will have engagement at its core and this will continue to inform service commissioning and provision, building on the 'I' statements developed by the Dementia Action Alliance (DAA) in its National Dementia Declaration (see Figure 1 below and Appendix 2).

Figure 1. Demential Action Alliance (DAA) 'I' statements

The National Dementia Declaration is based on 7 'I' Statements:

1. I have personal choice and control or influence over decisions about me.
2. I know that services are designed around me and my needs.
3. I have support that helps me live my life.
4. I have the knowledge and know-how to get what I need.
5. I live in an enabling and supportive environment where I feel valued and understood.
6. I have a sense of belonging and of being a valued part of family, community and civic life.
7. I know there is research going on which delivers a better life for me now and hope for the future.

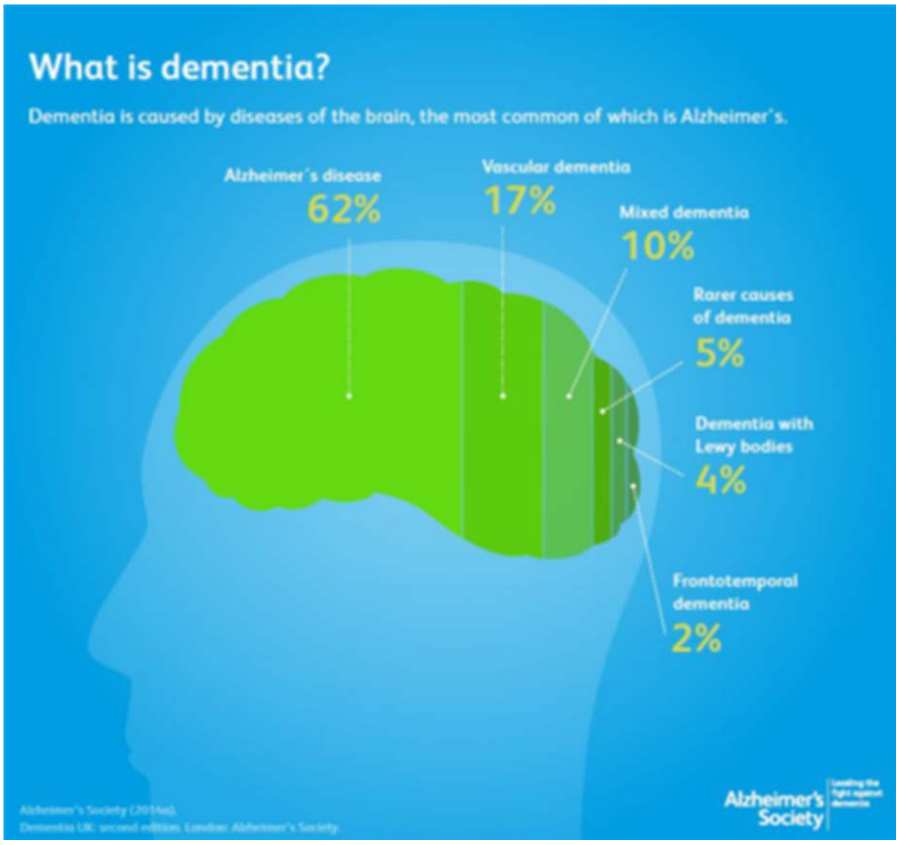
http://www.dementiaaction.org.uk/nationaldementiadeclaration

2 DEMENTIA HEALTH NEEDS ANALYSIS

2.1 Somerset Public Health has undertaken a Dementia Health Needs Analysis (see Appendix 1) which references national and local data on dementia, drawing on recent policy and guidance.

2.2 Figure 2 below shows percentages attributed to the different types of dementia nationally.

Figure 2. Types of dementia



2.3 Dementia is a progressive condition becoming worse over time however it is important to appreciate the course of the illness and people's symptoms may appear at different stages and is an individual experience, based on many factors including; health, emotional wellbeing, support and medication. People may be able to continue their normal life, including work, however when someone reaches a late or severe stage of dementia they will require significant support.
(https://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200342)

Risk factors for dementia

2.4 There are a number of risk factors for dementia and is often not the only condition a person lives with. Key risk factors are detailed in Appendix 1 and relate to:

- Aging
- Gender
- Genetics
- Learning disabilities
- Ethnicity
- Lifestyle

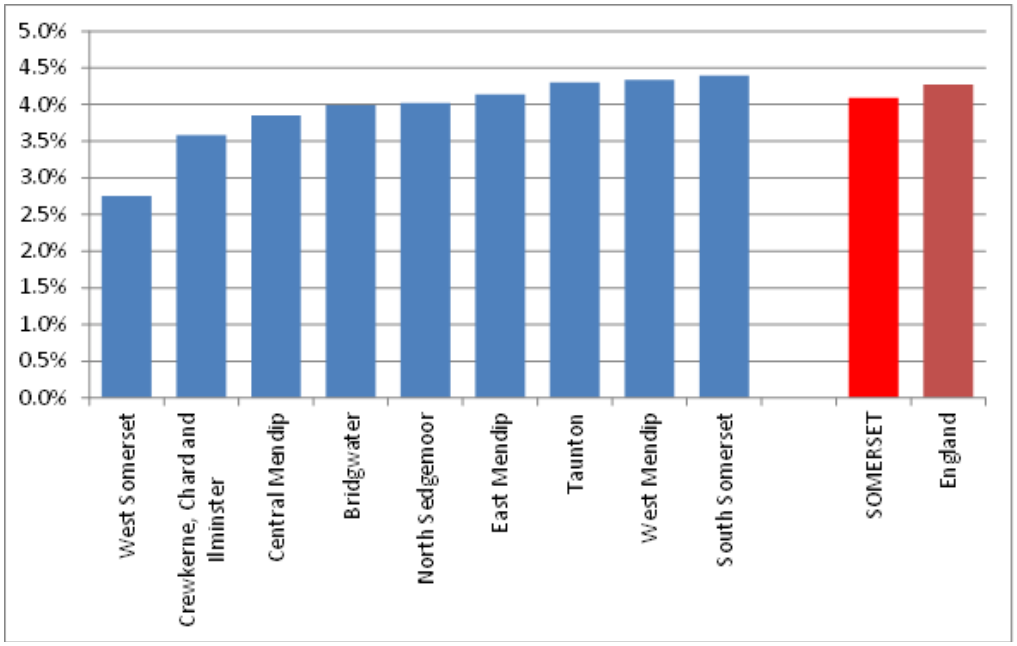
Local Context

2.4 In Somerset 1 in 24 adults over the age of 65 are diagnosed with dementia, as shown in Figure 3. The 65+ diagnosis rate of 4.09% in Somerset is slightly lower than the England average of 4.27% but slightly higher than the average rate in the South West of 4.02%.

Figure 3. Dementia ratio over 65 years

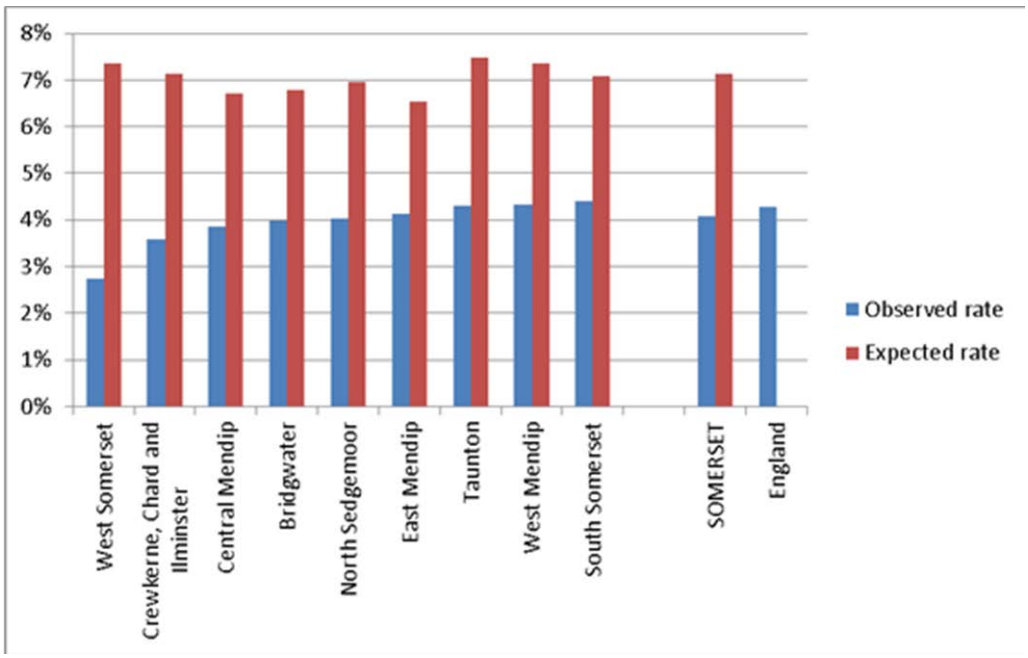
2.5 Recorded diagnoses of dementia vary considerably between areas of Somerset, from a low rate of 2.75% in West Somerset to a high of 4.39% in South Somerset as shown in Figure 4.

Figure 4 Recorded diagnosis of dementia for people aged 65 and over by commissioning locality (2015).



2.6 Overall it is modelled that there are almost 9000 people living with dementia in Somerset compared to the just over 5300 recorded. West Somerset has the highest proportion of people over age 75 and rates of dementia might be expected to be higher, yet the gap between expected and observed is highest in this area (see Figure 5).

Figure 5. Observed and expected rates of dementia (2015)



2.7 Below in Figure 6 is a non-specific example of how a diagnosis can make a real difference to people's care.

Figure 6 Dementia Diagnosis and post diagnostic support – 'sliding doors' - Mr Smith aged 79 with urinary tract infection (UTI) (Prof. A. Burns; 20.1.16)

What can happen…….	What could happen…….
Becomes distressed and agitated one Saturday night	**Identified as having dementia two years ago**
Seen by on call GP and admitted to hospital	**Supported by a Dementia Advisor**
Diagnosed with delirium secondary to UTI	**Wife notices he is "not himself" one Tuesday**
History of two years memory loss, wife not managing well	**GP who knows him visits and prescribes antibiotic for a UTI**
Sedated on admission, discharged to care home	**Recovers – no need for hospital admission**

3 THE IMPACT OF DEMENTIA IN SOMERSET

3.1 It is possible that the number of people living with dementia may double in the next 20 years; however there is emerging research which may indicate that preventative strategies for may reduce this rate of increase. These initiatives include medication, stimulating brain activity, and support to achieve a healthy lifestyle. Table 1 below shows the numbers of people with dementia currently and expected numbers in line with population.

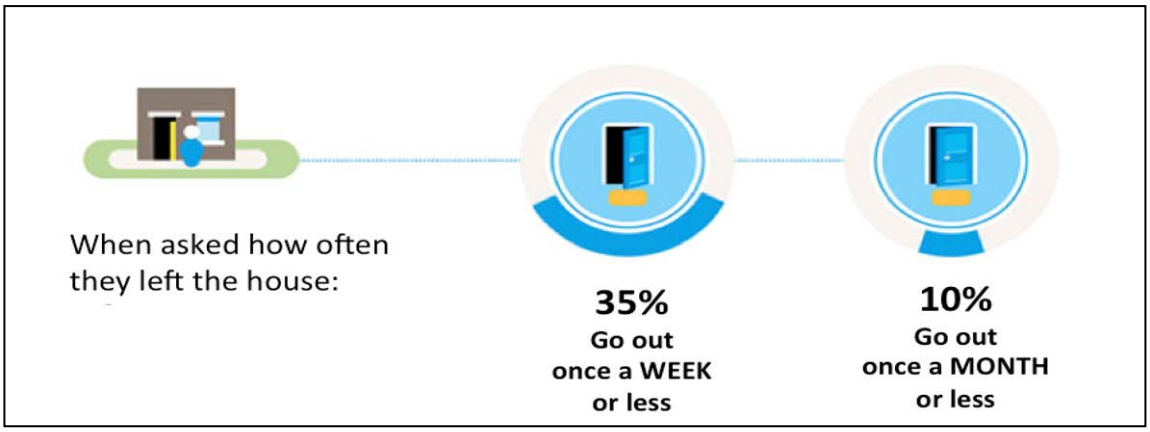
Table 1 Projected numbers of those with dementia in Somerset 2015-2035.

Age	2015	2020	2025	2030	2035
30-59	95	100	95	87	84
60-69	966	928	1,008	1,099	1,058
70-79	2,293	2,813	3,165	3,080	3,383
80-89	4,029	4,529	5,413	6,844	7,635
90+	2,279	2,768	3,439	4,377	5,730

Quality of Life

3.2 A question in the 2014 Alzheimer's Society survey provides the following alarming numbers regarding how often people 'go out' (Figure 7). Yet the activities people with dementia enjoy most are not costly – they enjoy the natural environment especially places with water and wildlife (Natural England, 2016). See also 3.22 below.

Figure 7 Alzheimer's Society 2014



3.3 The demands of caring for someone with dementia cannot be underestimated, whether provided by a husband/wife/partner of a similar age who may have significant health issues of their own or a family member or friend who is still in employment. We will continue to see a rise in older carers as this age group is predicted to rise significantly in the coming years, for example from 2013 to 2021 it is estimated there will be a 46% increase in those carers aged 90 and over from 6,700 to 9,900.

3.4 Unplanned admission to hospital is distressing for anyone; however the impact is magnified for a person with dementia due to the nature of the condition. Supporting a person's wellbeing when they have dementia is best done in familiar surroundings with people they know.

Health and Social impact

3.5 People with dementia are sometimes in hospital for conditions for which, were it not for the presence of dementia, they would not need to be admitted. It is estimated that 25% of hospital beds are occupied by people with dementia (DoH, 2013). In addition people admitted to hospital who also have dementia stay in hospital for longer, are more likely to be readmitted and more likely to die than patients without dementia who are admitted for the same reason.

3.6 Dementia is more common among some population groups and services should ensure services are planned with them in mind:

- Asian and black-Caribbean communities are more prone to risk factors for vascular dementia such as cardiovascular disease, hypertension and diabetes
- People with learning disabilities are more likely to develop dementia
- People with early onset dementia may still be working

3.7 Data also suggests around 3,500 unpaid carers are themselves in bad or very bad health, and almost half of those provide at least 50 hours of care a week.

This can be further broken down to show that 780 people in Somerset aged 65 or over and in bad or very bad health were providing at least 50 hours of unpaid care.

3.8 Figures produced by Alzheimer's Society which suggests that 11.2% of all carers look after someone with dementia; we can estimate that approximately 6500 carers in Somerset currently care for someone with dementia. We also estimate that in Somerset more than one in five people aged 55-64 provide unpaid care and 58% of unpaid carers are women, this is in line with the national average. About 12,300 people provide at least 50 hours of unpaid care a week, of these, more than 5,300 are aged 65 or older and an estimated 1,600 are 85 or older.

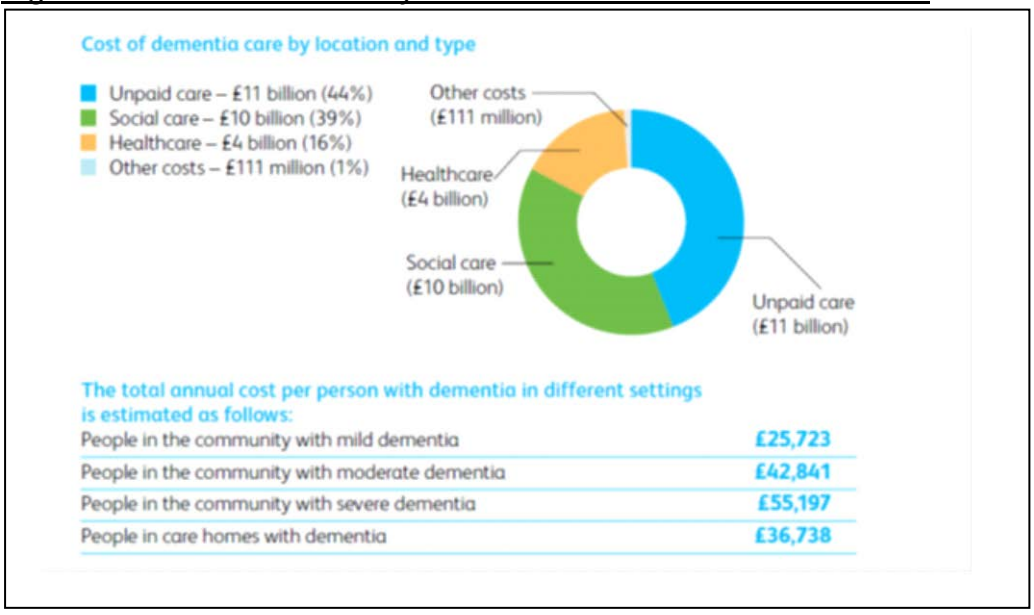
3.9 It was reported at the public engagement event that there are instances where people are unfortunately told by their care professional to stop driving before it is necessary. This came up as one reason why people might resist a diagnosis of dementia. In a rural county where bus routes continue to be affected by limited budgets, the loss of the ability to drive will seriously impact on a person's ability to go out. If care professionals agree with individuals and carers it may no longer be safe for a person to drive, they should signpost people and carers to alternatives such as community transport.

Cost of care

3.10 It is estimated dementia costs society an estimated £26 billion a year nationally; more than the costs of cancer, heart disease or stroke (Alzheimer's Society, 2014).

3.11 Figure 8 below shows the estimated annual cost distribution of care for people with dementia (Alzheimers Society); the value of unpaid care can be seen clearly here .

Figure 8 Alzheimer's Society Cost Distribution for Dementia Care



3.12 Within the Somerset Symphony dataset, which captures costs across the health and social care system, a person who only had dementia (and no other long term disease or illness) would cost the health and social care system on average just over £11,500 per year. When a person has three or more major disease conditions, the presence of dementia produces the highest cost across the healthcare economy; e.g. above cancer, heart disease, COPD or stroke.

3.13 The 2011 census showed that in Somerset one in nine people, or just over 58,000, said they provided unpaid care for a friend or relative (for a variety of reasons, not solely dementia). This is approximately 8,000 more than the number identified in the 2001 Census.

Housing

3.14 It is estimated approximately two thirds of people with dementia live in their own home and one third in care homes. A YouGov poll for Alzheimer's Society in 2014 found that 85% of people would want to stay at home as long as possible following a diagnosis of dementia. Evidence shows that changes of environment can be particularly unsettling for people living with dementia, so maintaining familiar settings is very important. The Prime Minister's Challenge on Dementia sets a goal that by 2020 there should be a greater focus on independent living with more people being able to live in their homes for as long as it is in their best interests to do so.

3.15 As the remaining one third of people with dementia live in residential care it is essential care homes are able to meet the needs of someone with dementia and provide high quality, personalised care to enable someone to live as full a life as possible. Ensuring staff have appropriate training is crucial. It is thought that approximately 69 per cent of care home residents are currently estimated to have dementia, which again emphasises the need for competent well trained staff and dementia friendly environments (Alzheimer's Society, 2014).

3.16 Care in people's own home may also have a positive impact on costs. It is known that people with dementia living in a care home are more likely to go into hospital with avoidable conditions (such as urinary infections, dehydration and pressure sores) than similar people without dementia.

Unplanned Care Services

3.17 Emergency hospital admissions (all trusts), with any dementia code, are increasing significantly year on year: see Table 2 below which shows an 23.5% increase over two years. These admissions may not all be due to dementia itself, but having dementia will add to the level of care needed. The average cost for an emergency admission where dementia has been coded is £2,524. It cannot be assumed that these are all additional admissions as it may just be improved coding of dementia. However if the 23.5% increase in these

admissions with dementia were additional, they would have cost an additional £126,200 in 2015-16 compared to 2013-14.

Table 2 Numbers of Emergency Hospital Admissions with dementia

Financial Years				
2011-2012	2012-2013	2013 - 2014	2014 - 2015	2015 - 2016 (Apr-Feb)
145	238	213	238	263

3.18 Average length of stay for emergency admissions with a primary diagnosis of dementia is a mixed picture in terms of growth but has increased in the community and mental health trust over the last five years from 56 days in 2011-12 to 73 days in 2015-16 thereby suggesting an increasing the pressures on overall system capacity.

Employers

3.19 The Centre for Economics and Business Research (2014) suggests dementia costs UK business £1.6 billion per year and 89% of employers believe that dementia will become a bigger issue for their organisation and their staff. However this study indicates businesses are making changes and showing a willingness to make society more dementia friendly, with most businesses already providing or would consider providing a range of support to carers of someone living with dementia. In addition more than half of businesses would consider providing a range of support to dementia carers such as flexible working hours (63%), extended leave (61%), working from different locations (53%) and counselling and support (51%).

3.20 Another aspect linked to the economic impact of dementia is the working age profile in Somerset over the coming 20 years, as this declines markedly especially in rural areas such as West Somerset. This is likely to have an impact on the numbers of staff available to support an ageing population including people with dementia, in provision of both domiciliary care and staff in residential settings.

3.21 Although a relatively small number of younger people (those with onset before the age of 65) are identified in Somerset, evidence shows they often struggle to access appropriate care and support as dementia services are often designed to meet the needs of older people. As a result, dementia services may not be appropriate to the needs of younger people who are more likely to work, have family and financial commitments and rarer forms of dementia.

Community

3.22 The 2014 Alzheimer's Society survey reported 35% of people living with dementia ' go out once a week or less' and 10% 'go out once a month or less. People with dementia feel their biggest barriers to participating in their local area are:

- Lack of confidence
- Worried about becoming confused
- Getting lost
- Mobility difficulties
- Physical health
- Not wanting to be a burden
- Transport
- Lack of opportunity

3.23 A Natural England commissioned report 'Is it nice outside? – Consulting people living with dementia and their carers about engaging with the natural environment; indicates the natural environment is a highly valued activity. The report highlighted the particular appeal of staying local and close to home; the presence of water, walking and wildlife. This would suggest that in combination with the development of Dementia Friendly Communities this is a low cost social and fitness activity which could increase opportunities to 'go out' more often than reported in 3.2 above.

4 KEY PROGRESS ACHIEVED FROM THE SOMERSET DEMENTIA STRATEGY 2013-16

4.1 Somerset has made steady progress in increasing dementia diagnosis rates over the last few years, the national ambition that two-thirds of people living with dementia should have a diagnosis remains a target and Somerset GP practices are benefiting from individual support, which aims to address this. The Clinical Commissioning Group has extended its target to 69% by end of March 2017.

4.2 The Somerset Dementia Strategy 2013-16 set out the vision for dementia services for Somerset. The Strategy described in detail four key areas of focus to improve services for people with dementia and their carers:

- Raising awareness and understanding
- Timely diagnosis and support
- Living well with dementia
- Workforce and Training

4.3 Table 3 below provides a summary of the significant progress against the key priority areas described in the Somerset Dementia Strategy 2013-16.

Table 3. Key progress achieved from the Somerset Dementia Strategy 2013-16

2013-16 Priority Area: Raising Awareness and Understanding
Yeovil Hospital: • Increased staff awareness training • Dementia friendly organisation • Staff encouraged to become Dementia Friends • Annual Dementia Awareness Week activities

2013-16 Priority Area: Raising Awareness and Understanding
Musgrove Park Hospital: • Annually hosts events within Dementia Awareness week and 'Remember, remember' event on 5 November • Publish quarterly magazine 'Corridors' sharing best practice with Dementia Champions • The Dementia team have a training plan which includes raising awareness and understanding with all new staff • The hospital has over 60 Dementia Champions who raise awareness across their specialty areas
Somerset Partnership NHS Foundation Trust (community and mental health services) • Provided two day training on supporting behaviours that challenge • Training places available to other care providers • Working with care homes to improve diagnosis rates and awareness • GP and Community Hospital Dementia Toolkit reference source
Reminiscence Learning: • Created 'Archie Project' and delivered to over 30 primary schools; linking with care homes, sheltered housing schemes and the community to help create dementia friendly communities and reduce fear and stigma associated with dementia • Archie dementia friendly stickers for vans (350 in use) • Provided dementia awareness training for GP surgeries; Taunton Deane Council staff; and other local businesses
The Alzheimers Society: • Dementia Awareness Roadshows (includes Dementia Friends sessions) • Since April 2015 – 185 awareness raising events held
Age UK: • Volunteers and staff attend Dementia Friend sessions • Information on risk reduction distributed • Partnership working with local communities and organisations to raise awareness of the support needs of people living with dementia
Somerset County Council (SCC): • Adult Social Care – increased information and resources shared with practitioners • Social work workshops included dementia awareness sessions resulting in referrals to Alzheimer's Society • Staff attended Somerset Partnership's two day training which focusses on supporting behaviours that challenge • Proposal agreed for SCC to become a Dementia Friendly Organisation • Dementia Friends session held for staff and more planned for councillors
Somerset CCG: • Dementia Friends training for CCG staff • Somerset Diagnosing Dementia Event (public)
Care Focus: • Have been delivering half day dementia awareness courses which are accessed by a range of services including approximately 12 libraries and housing staff.

2013-16 Priority Area: Timely Diagnosis and Support
Yeovil Hospital: • Collaborative working with Somerset Partnership and Alzheimemer's Society: o Discharge planning o Direct referrals to memory assessment service and Dementia Adviser Service •
Musgrove Park Hospital: • Dementia screening remains a priority in patients over 75 years • Dementia team have supported Somerset changes to streamline the diagnosis of dementia through communications direct to Memory Assessment Service and GPs.
Somerset Partnership: • Memory Assessment Service across the county with home or clinic appointments • Information, advice, support and onward referral/signposting • Multidisciplinary assessments including for emerging memory concerns for individuals with learning disabilities (with and without Down's Syndrome
Reminiscence Learning: • The Archie Project encourages early diagnosis by educating primary school children who permeate the information back to family members who can then access more information themselves
Age UK • Advocacy department provides support with paperwork • Information and Advice sessions provide signposting
Somerset CCG • Somerset Diagnosing Dementia Event 20.1.2016 • Individual practice support to identify and formally diagnose people living with dementia

2013-16 Priority Area: Living Well with Dementia
Yeovil Hospital: • Dementia friendly garden completed and open • Signed up as dementia friendly organisation • Development of team of dementia volunteers to support meals and tea rounds; activity sessions etc • Team development to include physio falls lead and OT • Reminiscence and life story therapeutic activity with patients and carers started Carers' survey; packs and welcome programme supporting carers to remain involved in hospital
Musgrove Park Hospital: • Now has a dementia friendly orthopaedic ward • Dementia friendly design included in both interior and exterior design strategies including signage • Carers Policy, charter, strategy and 'Carers Information Hub' in place

2013-16 Priority Area: Living Well with Dementia
linked to Compass Carers. Carers badges initiated on feedback from a carer via the Memory Café in Chard • From January 2016, visiting hours extended to 10am-9pm with carers supported to stay overnight using overnight chairs • 25 dementia buddy volunteers currently on the wards. In a year they recorded 475 patient visits and 700 hours spent with patients • Pet as Therapy Service on two wards (plans to expand) • Staff initiate access to 'This is me' document, and complete it with patients
Somerset Partnership: • Advice and training for care staff and family carers • Medication reviews • Peer support/post diagnostic support • Key role in Continuing Health Care and Funded Nursing Care assessments and reviews • Community mental health multidisciplinary teams provide hospital liaison and offer advice and support to care homes • Secondary care in-patient individual and group activity programmes; dementia friendly garden • Community Hospitals awarded Level 2 Standards by South West Dementia Partnership o Dementia Champions o Dementia Activities Co-ordinators and volunteers on wards to support patients and carers o Open visiting for carers to support patients/loved ones who have dementia • Liaison with other services regarding End of Life and palliative care.
Alzheimer's Society: • Established Befriending (Side BY side) • Additional Singing for the Brain groups in Frome and Axbridge making 7 across the county (mostly fortnightly) • Memory Cafés in 6 locations across the county (mostly fortnightly) • 94 CrisP (Carers Education) sessions across Somerset • 50% increase in annual referrals to Dementia Adviser Service over three years • Established self-supporting groups in Mendip,Yeovil, Chard, Ilminster and Crewkerne areas • Established the annual 'Big Sing' event which brings together all the Singing for the Brain groups • Established Living Well With Dementia course
Reminiscence Learning: • Weekly community sessions in Wellington and monthly media coverage to promote them • The Archie Project has regular activity sessions that enable people within care homes to live well with dementia • Activity Angels provide a wide range of activities in a number of care homes and day centres

2013-16 Priority Area: Living Well with Dementia
• Provide bespoke activity cushions for people in late stage dementia • Provide training and books for activities for late stage dementia; sessions on 'behaviour we find difficult' and end of life
Age UK • Group activities and peer support which include people with dementia • Partners in Care - partnering with other organisations in providing services and providing support and advice to people prior to discharge from hospital
Dementia Friendly Communities (DFCs) • Now in place in Chard, Ilminster, Crewkerne, Wells, Bridgwater, Watchet and Minehead • Taunton, Yeovil, Wellington and Langport are developing • Gaps have been identified in Burnham on Sea, Williton and Exmoor • Network of DFCs is developing through an Avon and Somerset Forum
Compass Carers (not dementia specific): • Carer support workers • Carers Newsletter

2013-16 Priority Area: Training and Workforce
Yeovil Hospital: • Training delivered via: various groups; induction; 'Snack Box' training. • Specific training courses and the web page provides a direct link to resources and an online training booklet • In 2015 approximately 1066 staff received training • Clinical Nurse Specialists training in use of Advance Care Planning documents
Musgrove Park Hospital: • There is a training and education plan in place • One day dementia training includes specialist input from: End of Life Team; Safeguarding Team; Nutrition; and Falls • Dementia Champions have a handbook and quarterly support days • Top Ten Tips are used in a number ways for training informally and formally • Collaborating with University West of England (UWE) to offer post registration staff a dementia module (CPD days) • Participation in the National Audit of Dementia • Anti-psychotic audit 2016
Somerset Partnership: • Provide training programmes for Dementia Friendly Community • Dementia training linked with Falls training • Training courses available to other care providers • Older Persons Mental Health provider of bespoke packages
Age UK: • Training for volunteers who support people living with dementia (incuding early onset) • Staff updates on available services and support for patients and carers.
Somerset CCG • Dementia Friends Sessions for staff

2013-16 Priority Area: Training and Workforce
• Medicines Management support to reduce anti-psychotic prescribing

5 STRATEGIC PLAN

5.1 There are joint plans in development called 'Somerset Together' which will significantly change the way health and care services are commissioned from April 2017. Providers will work together to deliver improved outcomes for the population of Somerset within the current funding available. Funding for the public sector is not expected to increase significantly in the foreseeable future: and together with workforce shortages it is more important than ever for health and care organisations to work 'smarter' and collaboratively. This will also be reflected in the System Transformation Plan.

5.3 Dementia is a key priority for many organisations in Somerset and there is a real commitment to continue to work together and this will continue to ensure that people with dementia and their carers receive a positive experience and the workforce is appropriately trained.

5.4 A high level gap analysis has been undertaken of the current position for dementia care in Somerset (Appendix 4) and identifies some key ambitions:

- **Awareness and Workforce**
  - *The public and care professionals are well informed about dementia; and Dementia Friendly communities/organisations are 'the norm'*
- **Preventing Well**
  - *Reduce risks of newly diagnosed lifestyle related dementias*
- **Diagnosing Well**
  - *Timely diagnosis and treatment is the rule rather than the exception*
- ***Living Well***
  - *People have access to personalised and appropriate care and support to optimise their wellbeing*
- **Supporting (Carers) Well**
  - *Carers are supported to have a life of their own during and after caring for a person with dementia*
- **Dying Well**
  - *People with dementia and carers have choice and access to personalised, appropriate, advance care planning and support*

6 FRAMEWORK FOR DELIVERING THE NEW STRATEGY

Partnership working

6.1 Somerset is renowned for excellent partnership working and commissioners, providers and the voluntary sector organisations have worked together for a number of years to improve dementia services. The Somerset Dementia Strategy Group comprises of the following organisations:

- Age UK
- Alzheimer's Society
- Care Focus
- Compass Carers
- Local Pharmaceutical Committee
- Public Health
- Reminiscence Learning
- Somerset Clinical Commissioning Group
- Somerset County Council
- Somerset Partnership NHS Foundation Trust
- Somerset Strategic Housing Officers Group
- Yeovil District Hospital NHS Foundation Trust

6.2 The Somerset Dementia Strategy Group is chaired by the Somerset CCG GP Lead for Dementia and reports progress to the CCG Clinical Operations Group the Somerset Joint Commissioning Group, which feeds into the Somerset Health and Wellbeing Board.

6.3 A detailed collaborative four year implementation plan will be developed by the Dementia Strategy Group setting out further improvements to help realise the Somerset Vision and related ambitions for Dementia, which are in line with the Dementia Well Pathway, and the PMCD 2020. Progress will be reported on annually and activities in the first year are likely to be:

- Increasing awareness of healthy lifestyle to reduce risk of developing dementia
- Supporting and maintaining increased diagnosis rates – increasing confidence to diagnose appropriately in primary care
- Reducing the use of antipsychotic medicines
- Reviewing the dementia pathway (diagnosis and follow up)
- Increasing schools' participation in awareness raising activities
- Supporting increased numbers of Dementia Friendly Communities and Dementia Friendly Organisations/Employers
- Finding ways to enable people with dementia and their carers to 'go out' more
- Ensure service user and carer participation is built into the workstreams which will deliver the Somerset Dementia Strategy

7. APPROVAL AND ADOPTION OF THE NEW SOMERSET DEMENTIA STRATEGY

7.1 Somerset organisations are requested to consider and approve this joint Somerset Dementia Strategy 2016-2020; adopt it; and actively support collaborative implementation.

References
(links accessed 24.5.16)

1. Alzheimer's Society website https://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=2000120
2. National Dementia Strategy 2009 https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy
3. Prime Minister's Challenge on Dementia 2012 https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia
4. Prime Minister's Challenge on Dementia 2020 https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020 and https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/507982/PM_Dementia_Annex_2_acc.pdf
5. NHS England 'Well Pathway for Dementia http://dementiapartnerships.com/resource/sharing-knowledge-and-learning-across-the-well-pathway-for-dementia/
6. The Care Act 2014 http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted
7. Dementia Action Alliance 'I' Statements http://www.dementiaaction.org.uk/nationaldementiadeclaration
8. Dementia 2014: Opportunity for Change (Alzheimer's Society) https://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1484
9. Dementia: a state of the nation report on dementia care and support in England (Department of Health 2013 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/262139/Dementia.pdf
10. Centre for Economics and Business Research (2014) http://www.cebr.com/reports/cost-of-dementia-to-business/
11. Is it nice outside? – Consulting people living with dementia and their carers about engaging with the natural environment http://publications.naturalengland.org.uk/publication/5910641209507840
12. Department of Health Policy Paper – Joint declaration on dementia post diagnostic care and support https://www.gov.uk/government/publications/dementia-post-diagnostic-care-and-support/dementia-post-diagnostic-care-and-support#contents

APPENDIX 1

Somerset Dementia Health Needs Assessment

March 2016

Contents

Executive Summary

Dementia will continue to have growing impact in Somerset, with more people receiving a diagnosis and the consequences this has for their families, our workplaces, communities, and services that provide support. In Somerset 1 in 24 adults over the age of 65 has dementia and although there has been a steady increase in diagnosis, this varies across the county and a continued focus on promoting diagnosing is important to ensure people receive timely support.

The prevalence rate of dementia is estimated to be considerably more than the numbers of people actually diagnosed with dementia, in addition over the coming years our ageing population will lead to a significant increase in the number of people with dementia. By 2035 it is anticipated there will be around 18,000 people with dementia in Somerset, with the largest increase in people aged 90 and over.

Providing care and support for people with dementia in the future requires in depth consideration as we anticipate costs across the health and social care system to almost double in line with the expected rise in rates, evidence also shows additional health conditions someone experiences adds further complexity. There are certain people with dementia who may require services to meet their specific needs, such as those with early-onset dementia or with a learning disability and it is important that services can respond appropriately to their needs.

Currently plans for people diagnosed with dementia to receive appropriate follow up and review appears to vary across the county, this is essential to ensure people and their families are supported to live well with dementia.

The contribution provided by the estimated 6,500 family carers of someone with dementia across Somerset is an essential element of support. It is important to recognise many carers will have a longstanding illness, be older themselves and provide significant levels of support, therefore carer support is essential.

In addition to supporting people with dementia, focusing on prevention and minimising people's risk of developing dementia requires further attention, especially within midlife, as lifestyle factors are shown to increase the risk of developing dementia considerably.

Introduction

The Health Needs Assessment incorporates national and local data on dementia, drawing on recent policy and guidance.

This document aims to inform the development of the revised Somerset Dementia Strategy by understanding the risk factors, the population, and projected growth in Somerset to assist with future service provision and to help ensure people with dementia and their families are supported to live well with dementia.

In addition themes cover the Prime Minister's challenge on dementia 2020 priorities for people with dementia, their families and society, which will be considered in the local context.

Dementia is an important topic due to its prevalence within the older population, it's impact on individuals, their families and on the health and social care economy. It is one of the top five underlying causes of death, one in three people who die after the age of 65 have dementia and with the ageing population in Somerset dementia rates will continue to rise.

Sources of Data

In January 2016 PHE released Dementia Profiles – this is a summary of how Somerset compares with the other CCGs in the cluster of *'Larger CCGs, rural with more older people'* and also, where possible for the Commissioning Localities within Somerset. This is available at: http://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia

A number of useful sources of data have been collated by the National Dementia Intelligence Network within a Dementia Data Catalogue. This is available at: http://www.yhpho.org.uk//resource/view.aspx?RID=222222

Other data is drawn from Public Health Outcomes Framework indicators and the Primary Care Web Tool.

Public Health England has produced a webinar '*Using data and tools to understand dementia in the South West: Prevention, prevalence, screening and treatment'* which demonstrates various data sources and list other resources, visit: http://www.swpho.nhs.uk/resource/item.aspx?RID=119599

Data throughout the document may be displayed in different ways, some is shown at CCG commissioning locality level, for information there are nine commissioning localities in Somerset, previously GP Federations.

1. Background

1.1 Different types of dementia

Dementia is a term used to describe the symptoms that occur when the brain is affected by certain diseases or conditions which impact on its function. Dementia causes resulting in a progressive decline in function, including memory, reasoning, communication skills and the skills needed to carry out daily activities. There are many different types of dementia. The most common type of dementia is that caused by Alzheimer's disease (62%), the next most common type is vascular dementia (17%) as shown in Figure 1. Vascular dementia results from problems with the blood supply to the brain and lack of blood supply to the brain causes death of brain cells. Mixed dementia shows a combination of characteristics of both Alzheimer's disease and vascular dementia.

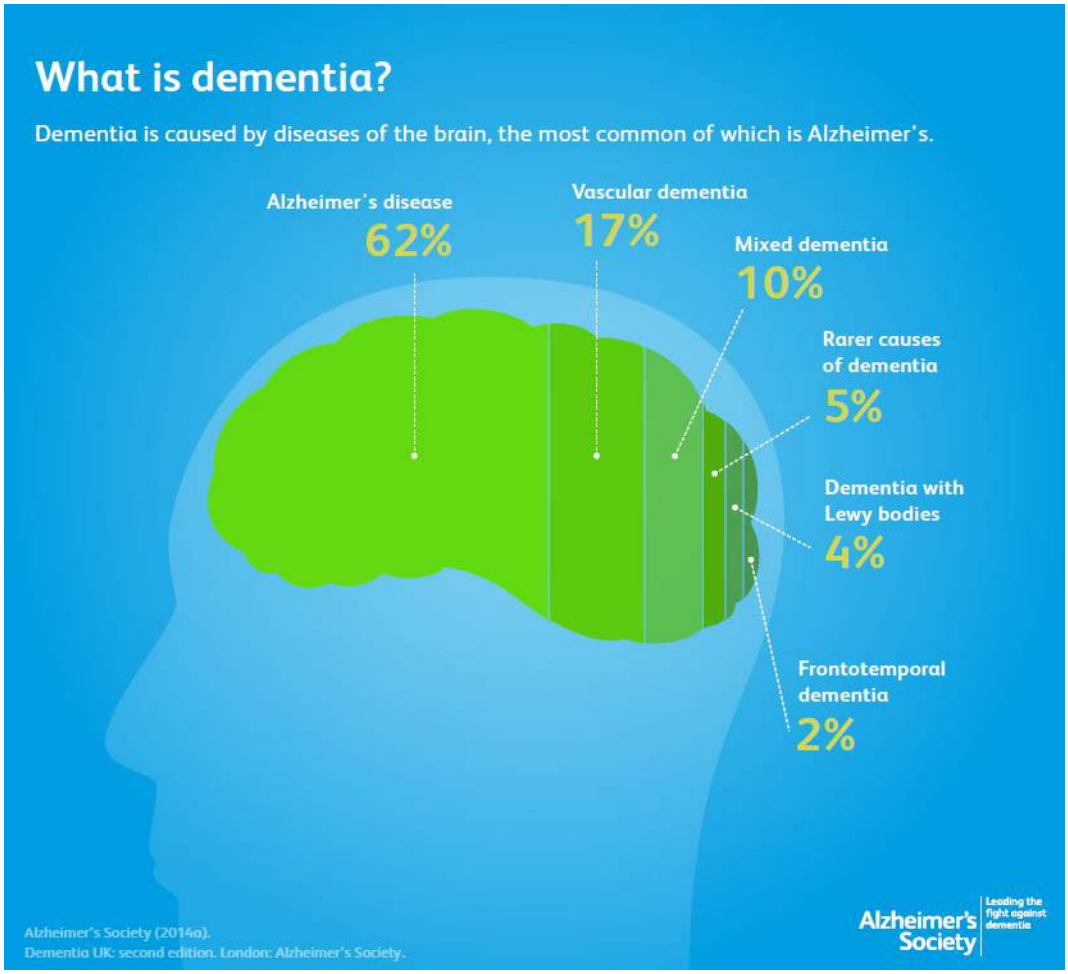


Figure 1

Dementia is generally seen as an irreversible and progressive condition becoming worse over time. Severity of dementia can be categorised into:

- Mild dementia which includes impaired attention and memory, short term memory loss, occasional confusion, coping with daily activities and living independently but with assistance

- Moderate dementia which includes recent amnesia, disorientation in time and place, poor reasoning and understanding of events, requiring some help with personal care and daily routine
- Severe dementia which includes incoherent speech, inability to recognise close relatives, full support required with all aspects of daily living and personal care

Categorising dementia can be a useful way of understanding the changes that occur over time, however, it is important to appreciate this view of dementia provides a rough guide to the course of the illness as people's symptoms may appear at different stages and is an individual experience, based on many factors including; health, emotional wellbeing, support and medication. However when someone reaches the severe or late stage of dementia they will require significant support and eventually will be totally dependent on others for all their care.

1.2 Risk factors for dementia

1.2.1 Ageing

The most significant risk factor for development of dementia is increased age. Development of Alzheimer's disease and Vascular dementia are strongly linked to increased age. After the age of 65, the risk of developing Alzheimer's disease doubles approximately every five years. It is estimated that one in 14 people over the age of 65 and one in six over the age of 80 have a form of dementia (but may not all have received a diagnosis). Early-onset dementia, ie with an onset before the age of 65 is rare, accounting for just over 5% of cases. The range of types of dementia seen in early onset cases is similar to that seen in typical onset dementia but rare causes of dementia are slightly over-represented in early onset cases.

1.2.2 Gender

In the UK 62% of those diagnosed with dementia are female and 38% are male, this is a likely consequence of their longer life expectancy and dementia is a leading cause of death among women – higher than heart attack or stroke. In addition women are more likely to be caring for someone with dementia or another condition, evidence shows this can lead to them becoming isolated and depressed which is a risk factor for dementia[i].

1.2.3 Genetics

Early onset dementias are more likely to have a genetic cause than late-onset dementias and it is estimated that perhaps up to 10% of all people with early onset dementia may inherit this. There is also a wider range of diseases that cause early or young onset dementia and a younger person is much more likely to have a rarer form of dementia.

1.2.4 Learning disabilities

People with learning disabilities have a greater risk of developing dementia than other people and usually develop the condition at a younger age. This is particularly true of people with Down's syndrome, one in three of whom will develop dementia in their 50s and the specific association between Down's syndrome and Alzheimer's disease is well recognised.

1.2.5 Ethnicity

Early-onset dementia (affecting people under 65) is more frequent among people from Black, Asian and Minority Ethnic (BAME) groups. While just two per cent of people with dementia from white-British backgrounds have the early onset form, the equivalent rate for BAME groups with dementia is six per cent [ii]. Dementia is more common among Asian and black-Caribbean communities as this group are more prone to risk factors for vascular dementia such as cardiovascular disease, hypertension and diabetes, although there is no data on incidence within different ethnic groups.

1.2.6 Lifestyle

A number of lifestyle factors are associated with risk of developing dementia, primarily through their association with cardiovascular disease and damage to the blood vessels in the brain (leading to vascular dementia), however there is growing evidence that Alzheimer's disease in approximately one third of cases might be attributable to potentially modifiable lifestyle risk factors [iii]. The Public Health England Dementia Profile illustrates the distribution of lifestyle risk factors in Somerset which will be explored within the Preventing Well section of this needs assessment.

2. Somerset population in relation to types of dementia and risk factor

2.1 Recorded numbers of those with Dementia in Somerset

In Somerset 1 in 24 adults over the age of 65 are diagnosed with dementia, as shown in

Figure 2. The 65+ diagnosis rate of 4.09% in Somerset is slightly lower than the England average of 4.27%, but slightly higher than the average rate in the South West of 4.02%.

Figure 2 Recorded levels of dementia in those aged 65+ in Somerset

Recorded diagnoses of dementia vary considerably between commissioning locality areas, from a low observed rate of 2.75% in West Somerset to a high of 4.39% in South Somerset as shown in Figure 3.

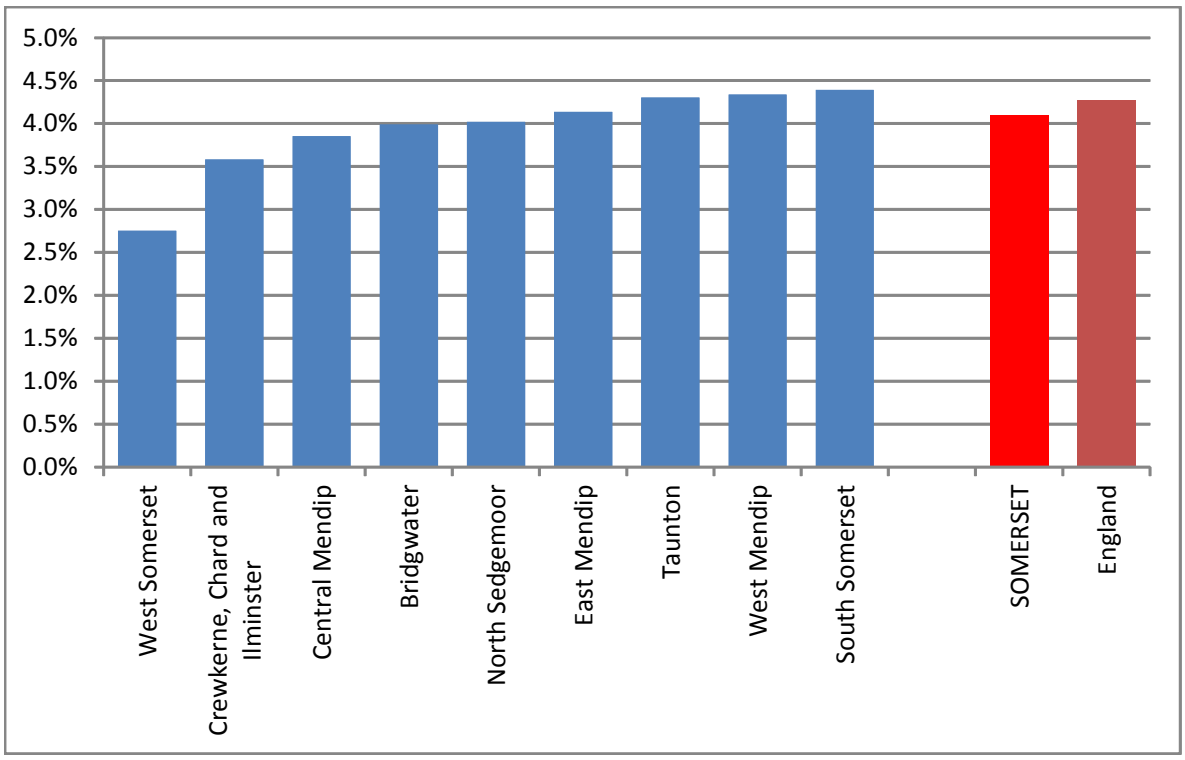


Figure 3 Recorded diagnosis of dementia for people aged 65 and over by commissioning locality

The overall (all age) crude rate of recorded prevalence of dementia is 0.96% in Somerset, compared to 0.74% in England and 0.88% in the South West. These rates are crude and take no account of the age profile, so Somerset with its higher proportion of older people will naturally tend to have a higher rate. As dementia rates in those aged over 65 are similar in Somerset to the rest of the country, this recorded prevalence rate is likely due to population structure rather than inherent differences in disease susceptibility.

However it is a valid indication of the higher need for dementia services per head of the population in Somerset than in the rest of the South West and England

Over the past few years increasing diagnosis of dementia has been a focus for CCGs across England in response to Department of Health requirements, this has driven a steady rise in recorded diagnosis in Somerset, for reasons including; an increase in the number of people being diagnosed, improved recording of diagnoses, the rise in the ageing population, or a combination of these factors.

Therefore when we look at the actual numbers of people recorded on GP dementia registers over the past few years we can see this has risen each year and for 2014/15 there were 5,317 people recorded, see Table 1 below, although within Somerset there are variations as mentioned previously. This is higher than the South West and England prevalence and is rising with a similar pattern when compared against the England recorded prevalence, Figure 4.

Table 2 Numbers of cases of dementia on disease registers in Somerset

Period		Count	Value	Lower CI	Upper CI	South West	England
2010/11	○	3,211	0.60	0.58	0.62	0.55	0.48
2011/12	○	3,681	0.68	0.66	0.70	0.62	0.53
2012/13	○	4,178	0.76	0.74	0.79	0.68	0.57
2013/14	○	4,494	0.81	0.79	0.84	0.75	0.62
2014/15	○	5,317	0.96	0.93	0.98	0.88	0.74

Source: Quality Outcomes Framework (QOF), Health and Social Care Information Centre (HSCIC)

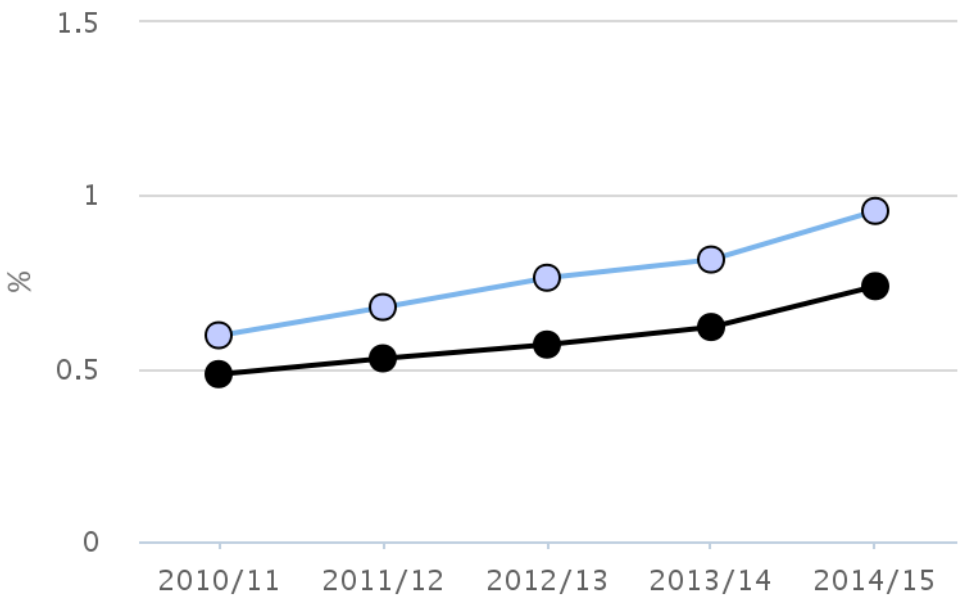


Figure 4 Dementia recorded prevalence (all ages) Somerset (blue) in comparison to England rates (black) 2010/11 – 2014/15

2.2 Modelled rates of dementia in Somerset

Modelled rates of incidence or prevalence (numbers we would expect to see) across Somerset takes account of the age profile of the population. In 2015 it was estimated that there are about 2,550 new cases of dementia each year in Somerset. The estimate for each commissioning locality is shown in Figure 5.

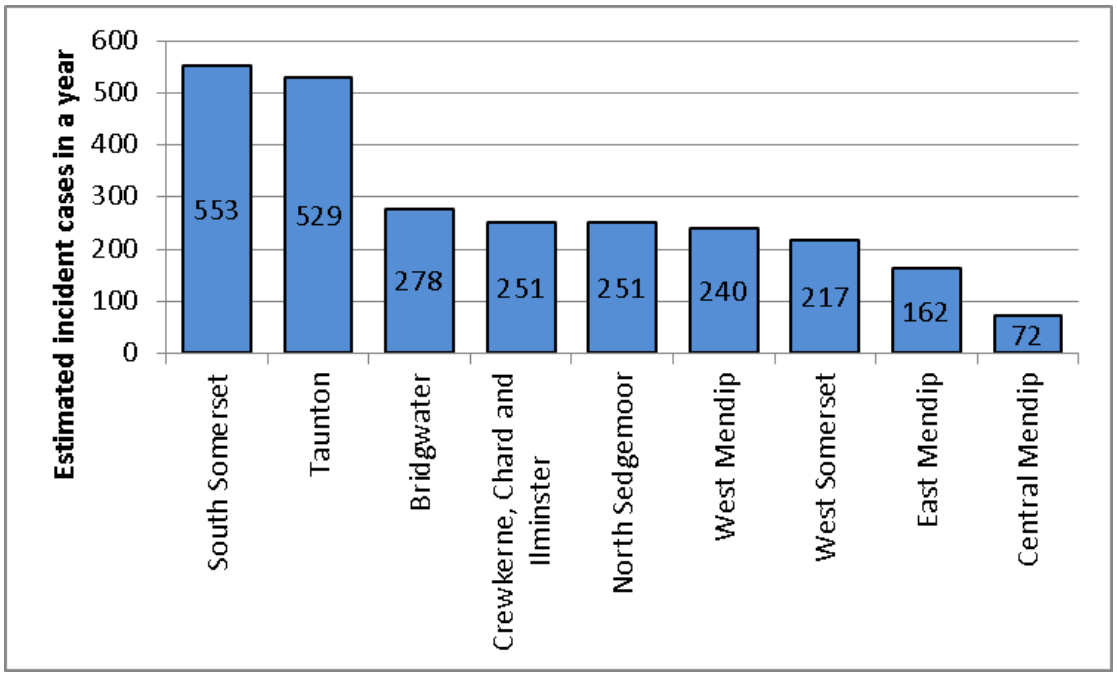


Figure 5 Estimated new cases of dementia in 2015

However the modelled rates of dementia in Somerset, as in the rest of England, are still much higher than the recorded rates, the government and NHS England set a target for 66% of patients to have a formal diagnosis by March 2015. As at November 2015 Somerset CCG had a diagnosis rate of 61.1%, which has been steadily increasing.

Overall it is modelled that there are almost 9000 cases of dementia in Somerset compared to the just over 5300 recorded diagnoses. West Somerset has the highest proportion of those over age 75 where rates of dementia would be higher so if anything rates would be expected to be highest in this area and the gap between expected and observed is highest in this commissioning locality as shown in Figure 6 below.

In addition we can see some variations in the expected rate depending on the demographic of the commissioning locality area, this clearly demonstrates West Somerset as having the largest difference between these rates.

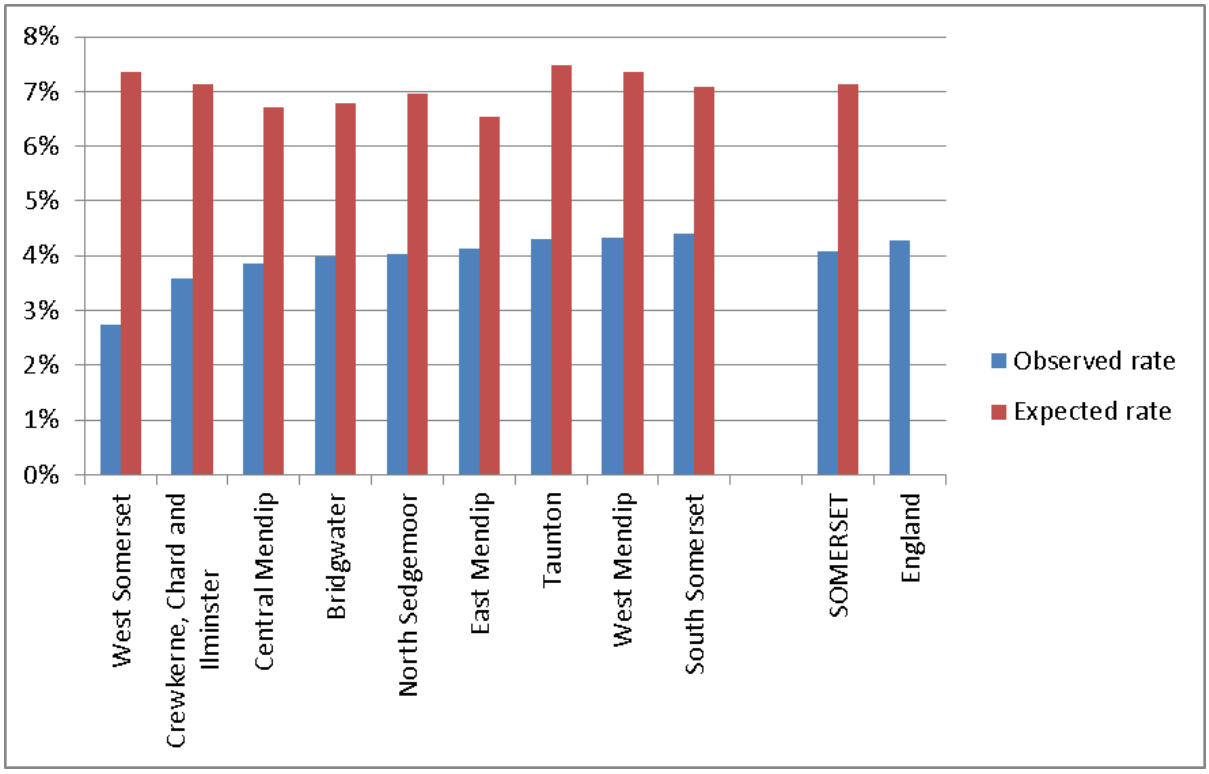


Figure 6 Somerset commissioning localities observed and expected rates of dementia 2015

In terms of service planning, the highest numbers of those with dementia are modelled to be in the urban areas where population density is highest. The modelled prevalence rate of dementia across the county is shown in the maps below for 2014, 2024 and 2034 showing the number of expected cases per 1000 population aged 65 and over in each Lower Super Output Area (a geographic area). We can see the highest modelled rates of dementia cases are found in areas with a greater proportion of older people. By 2034 the number of areas where 9% or more of the population over 65 is expected to have dementia is anticipated to increase substantially.

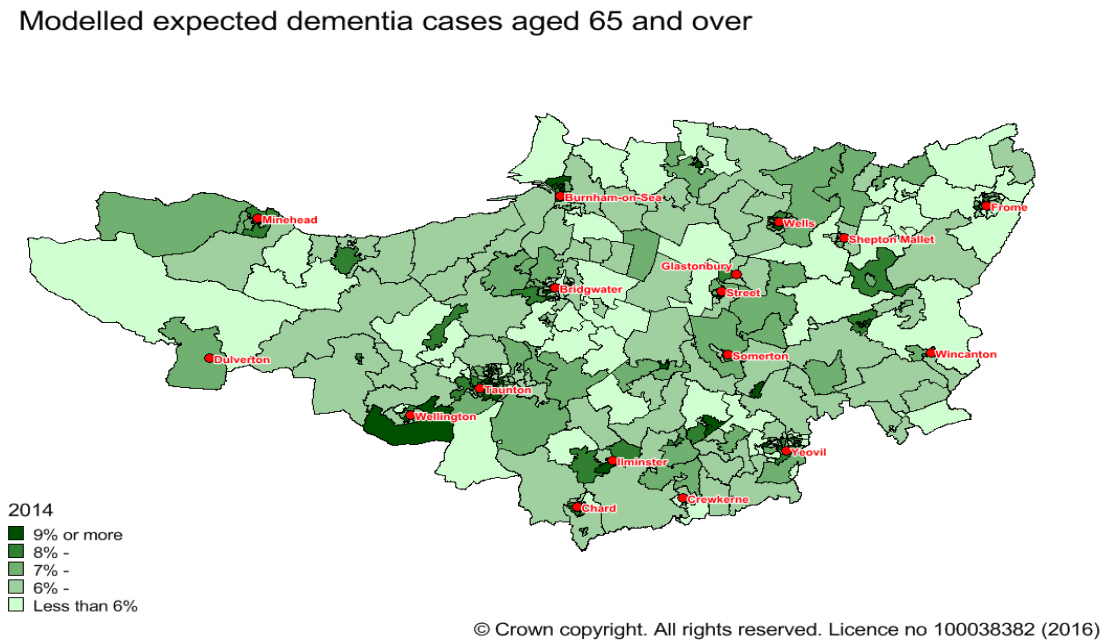


Figure 7 Modelled expected dementia cases aged 65 and over, Somerset 2014

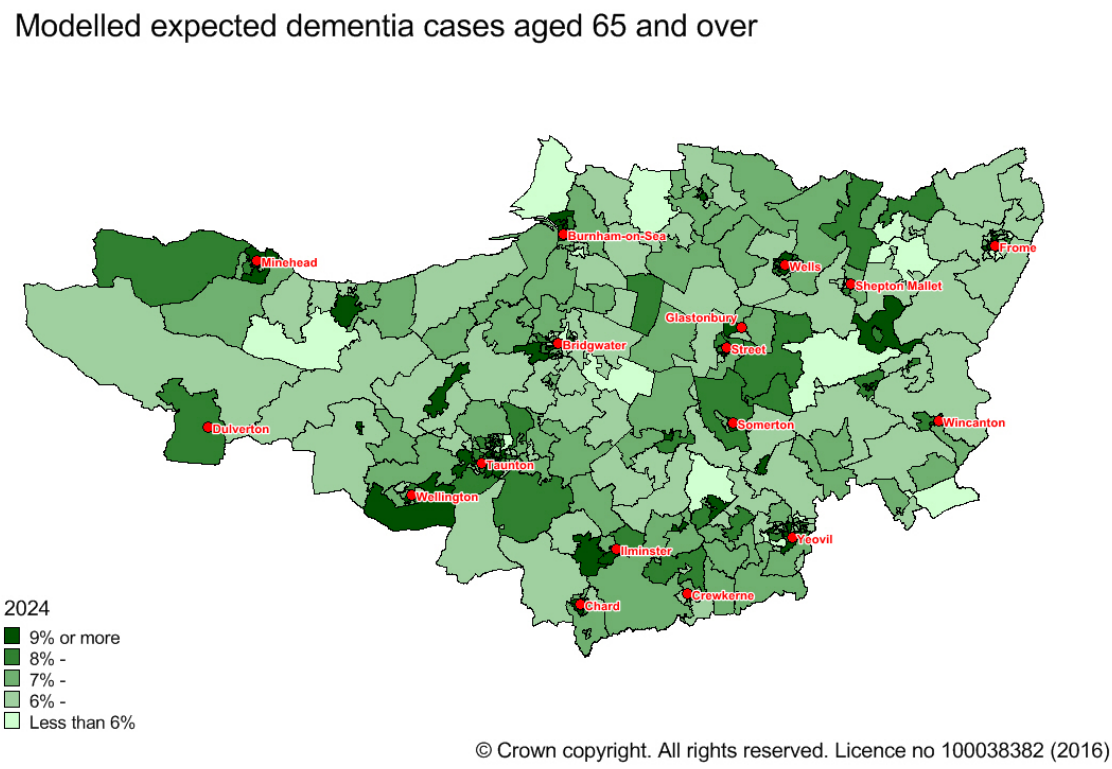


Figure 8 Modelled expected dementia cases aged 65 and over, Somerset 2024

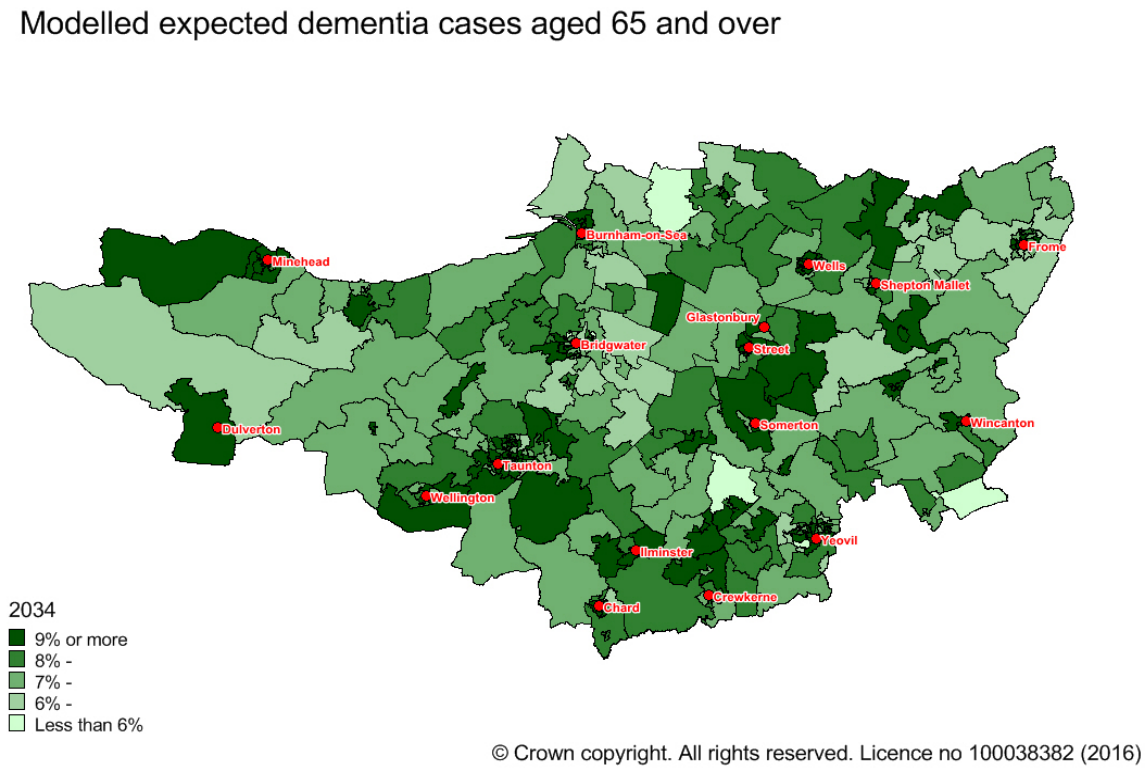


Figure 8 Modelled expected dementia cases aged 65 and over, Somerset 2034

Using the prevalence given in the Alzheimer Society's Dementia Report 2007 for the different types of dementia, we can estimate the number of cases of different types of dementia in Somerset, see Table 2.

National proportions	Type	Bridgwater	Central Mendip	Crewkerne, Chard and Ilminster	East Mendip	North Sedgemoor	South Somerset	Taunton	West Mendip	West Somerset	SOMERSET
62%	Alzheimer's disease	572	152	530	347	546	1,165	1,269	531	428	5,542
17%	Vascular dementia	157	42	145	95	150	320	348	146	117	1,519
10%	Mixed (AD and VD)	92	25	85	56	88	188	205	86	69	894
4%	Lewy body Dementia	37	10	34	22	35	75	82	34	28	358
2%	Fronto-temporal dementia	18	5	17	11	18	38	41	17	14	179
2%	Parkinson's dementia	18	5	17	11	18	38	41	17	14	179
3%	Other	28	7	26	17	26	56	61	26	21	268
	Total	**923**	**246**	**854**	**560**	**881**	**1,880**	**2,047**	**857**	**690**	**8,938**

Table 2 Modelled numbers of different types of dementia in Somerset, 2015

The PHE Dementia Profile tool also shows the estimated proportions of mild, moderate and severe dementia. Perhaps because this is modelled data the proportions are very similar in Somerset (54.6% mild, 32.5% moderate, 12.4% severe) and England (55.0% mild, 32.5% moderate, 12.9% severe).

3. Impact and cost to the health and social care system

The economic impact of dementia in the UK is considerable and it is estimated dementia costs society an estimated £26 billion a year, more than the costs of cancer, heart disease or stroke as demonstrated in Figure 9 from Alzheimer's Society[iv].

The Centre for Economics and Business Research [v] suggests dementia costs UK business £1.6 billion per year and 89% of employers believe that dementia will become a bigger issue for their organisation and their staff. However this study indicates businesses are making changes and showing a willingness to make society more dementia friendly, with most already providing or they would consider providing a range of support to carers of someone living with dementia. In addition more than half of businesses would consider providing a range of support to dementia carers such as flexible working hours (63%),

extended leave (61%), working from different locations (53%) and counselling and support (51%).

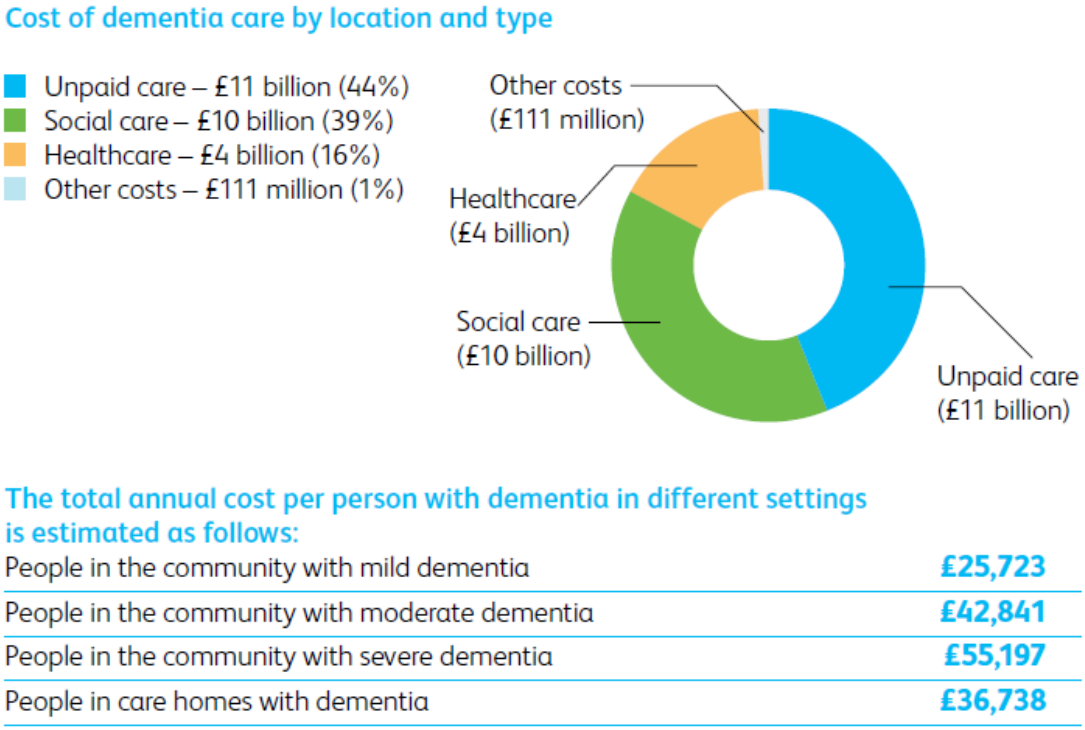


Figure 9 Alzheimer's Society Opportunity for Change (2014)

Within the Somerset Symphony dataset, which captures costs across the health and social care system, a person who only had dementia (and no other long term disease or illness) would cost the health and social care system on average just over £11,500 per year. The major costs fall approximately on continuing health care £4.5k, mental health services £3k and social care £3k, with about £1k across other health areas.

Not surprisingly, these costs increase where additional morbidities (disease or illness) are experienced by individuals. In Figure 10, a comparison of costs of the different major morbidities when they occur with 3 other major morbidities, it can be seen that the presence of dementia produces the highest average costs per year.

Figure 11 compares costs across health and social care for major disease conditions (where 3 or more other morbidities are present) and shows that dementia has the highest costs particularly for social care and acute hospital inpatient services (Acute IP/DC).

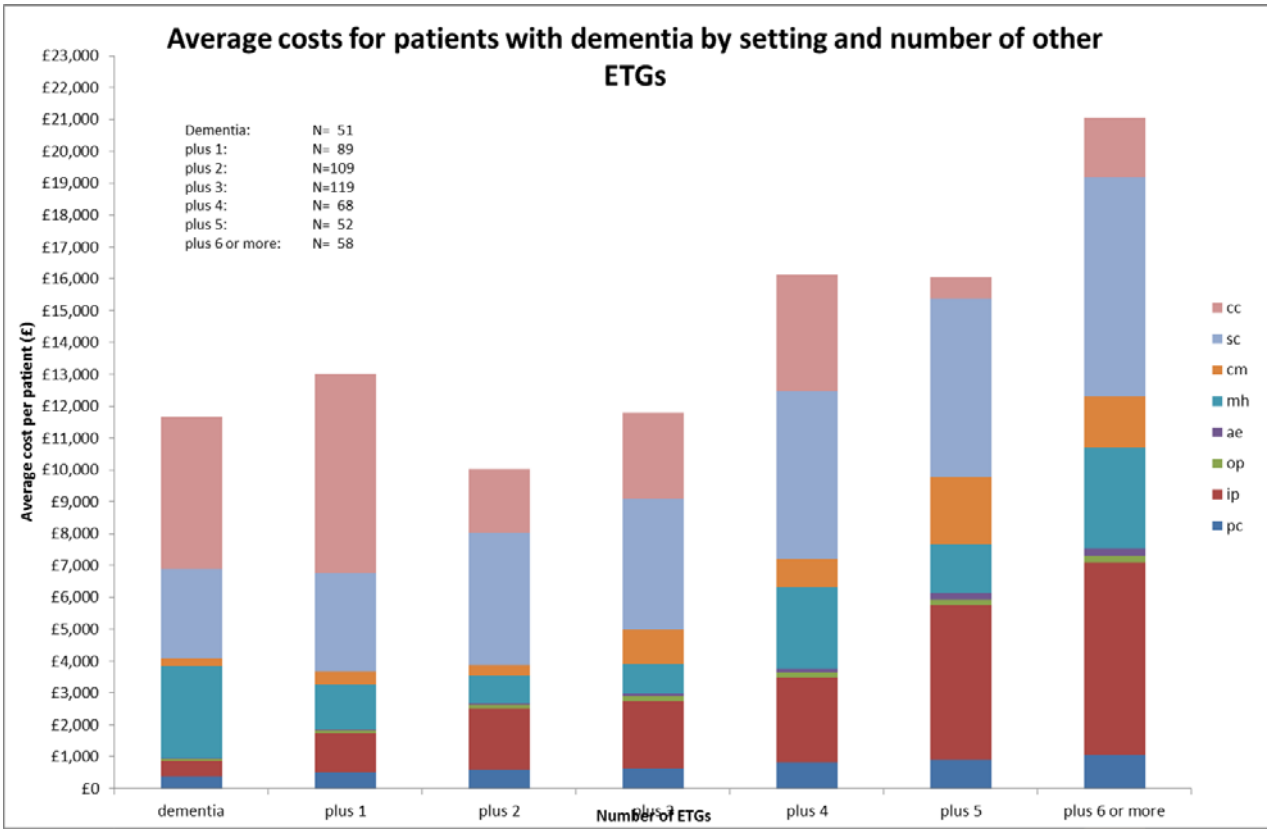


Figure 10 Costs across the healthcare economy of dementia plus other morbidities (Hudson, 2015)

(ETG = Episode Treatment Group classifying patients episodes of care using software)

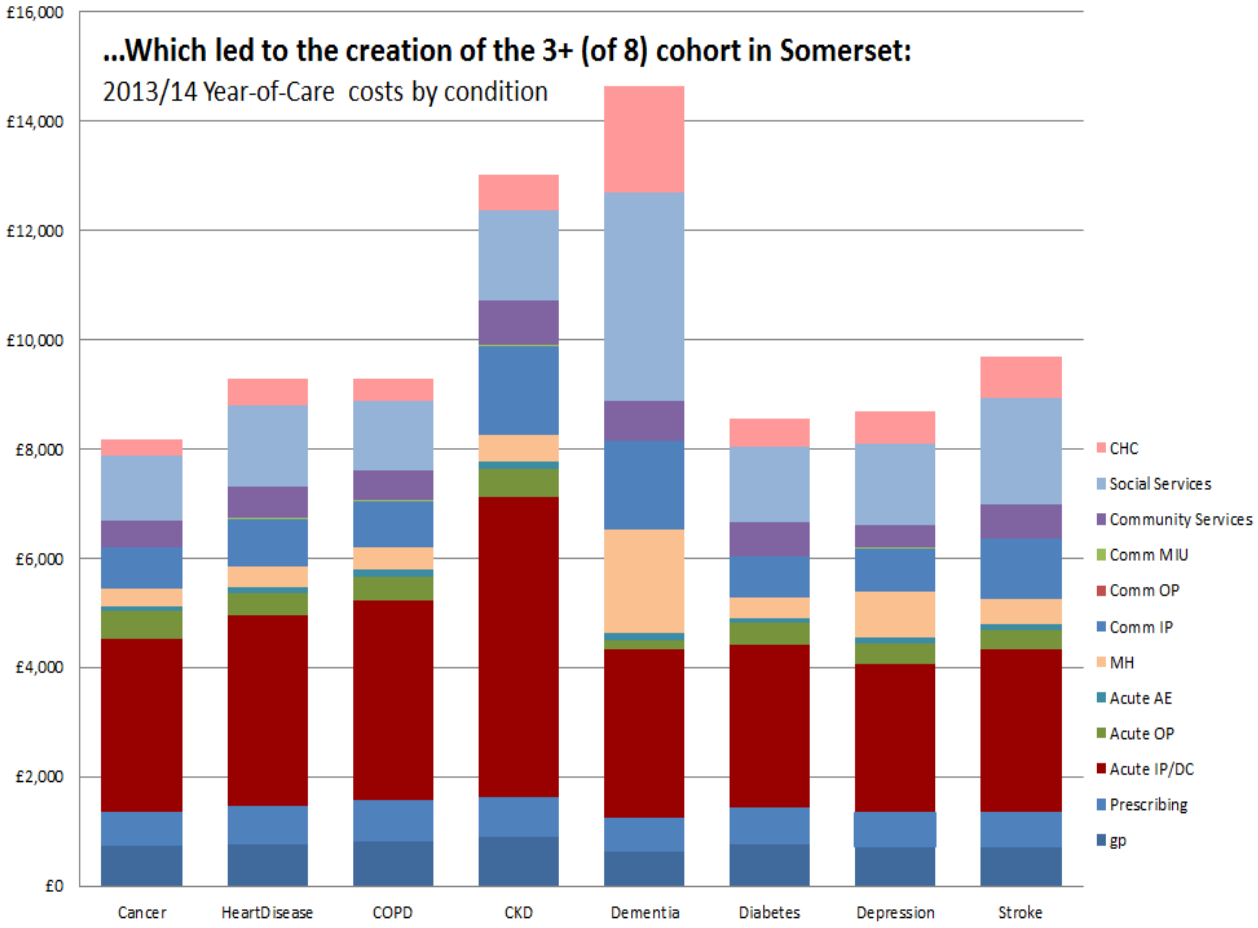


Figure 11 Comparative costs across the healthcare economy of dementia and other major disease conditions plus three or more other morbidities (Hudson, 2015)

It is worth noting that the number of conditions someone has is the main driver of costs rather than the age of the person. An increased number of morbidities will see much higher costs across the health and social care economy per individual.

3.1 Dementia prescribing

For some people with dementia pharmacological treatment will assist their symptoms, however care must be taken to ensure their wellbeing. For example there may be other factors which lead to agitation or aggression, including dehydration, pain or other medication, these require an in depth understanding of the person, their condition and appropriate training.

For Alzheimer's disease the aims of using medication as treatment are to;

- Promote independence, maintain function and treat symptoms including cognitive, non-cognitive (hallucinations, delusions, anxiety, marked agitation and associated aggressive behaviour), behavioural and psychological symptoms
- Treat cognitive, non-cognitive and behavioural symptoms. Acetylcholinesterase (AChE) inhibitors (donepezil, galantamine and rivastigmine) and memantine are the pharmacological treatments available specifically for Alzheimer's disease.

AChE drugs are not recommended for those who do not have Alzheimer's or who have a mild cognitive impairment as set out in the National Institute of Health and Social Care Excellence (NICE) dementia interventions pathway[vi].

NICE guidance states the importance of reducing the use of antipsychotic medications in patients with dementia. Use of these drugs should always be a treatment of last resort and should be reviewed regularly as the drugs are known to hasten cognitive decline and increase mortality and morbidity.

From Figure 12 below Somerset CCG is highlighted compared with other CCGs in the South of England using patient prescribing units which reflect prescribing practice and we can see Somerset is mid-range within the cohort.

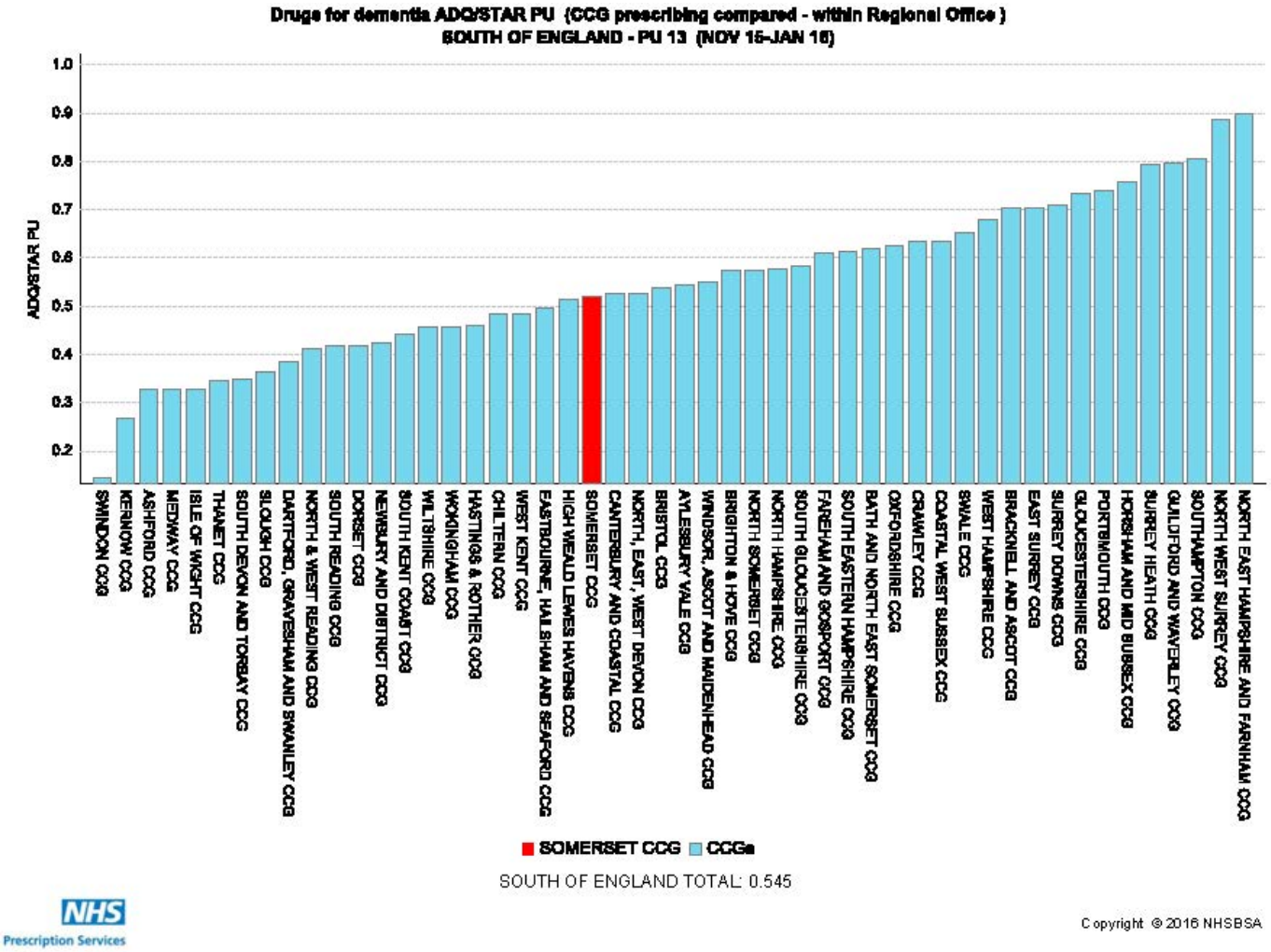


Figure 12 Somerset CCG compared to other South of England CCGs prescribing for dementia

In addition Figure 13 demonstrates that within Somerset there are wide variations in prescribing practice across the county, some of these may be accounted for by the presence of residential or nursing care homes within a practice area, as this is not evenly spread and would more likely be seen in the larger conurbations.

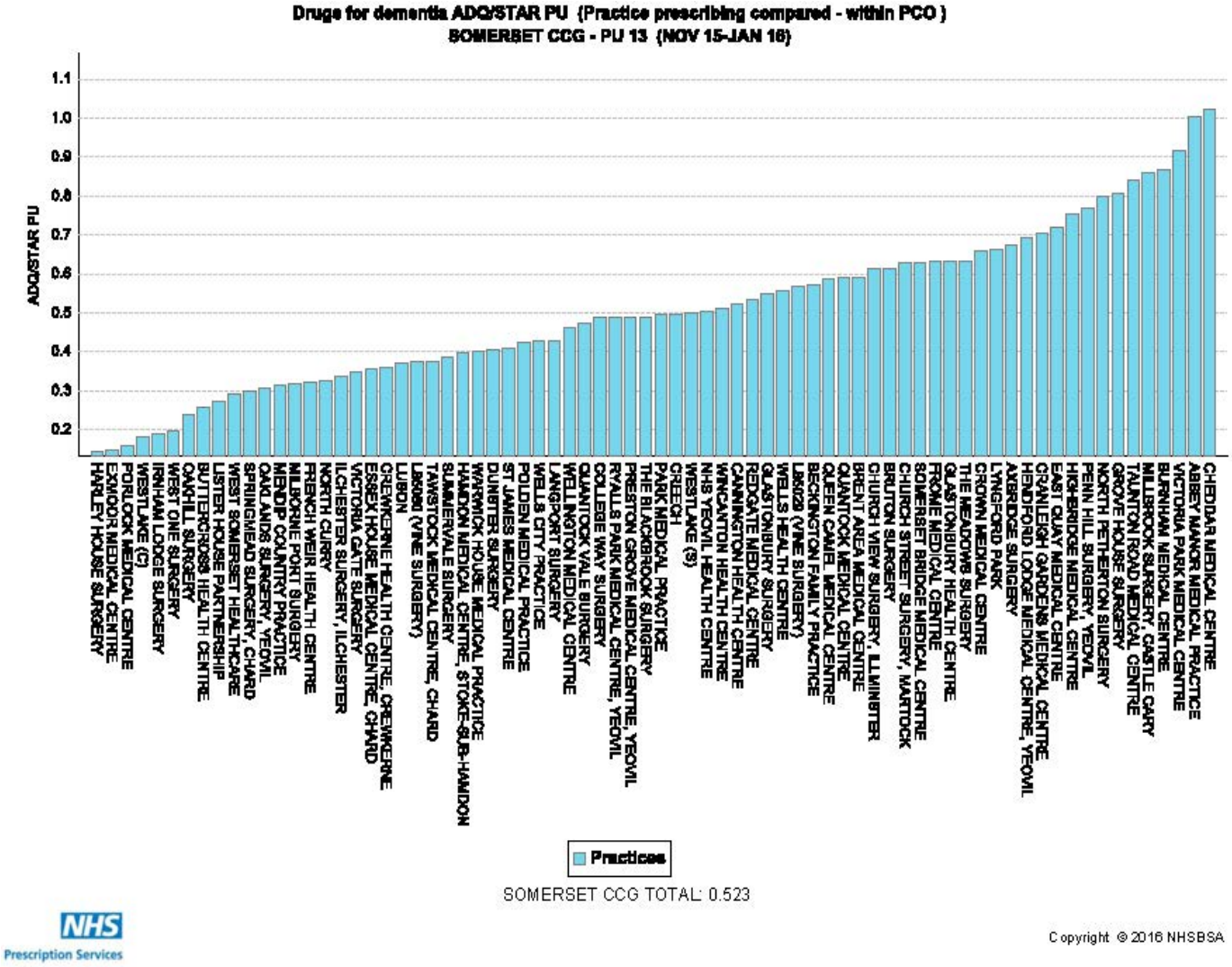


Figure 13 Somerset CCG practice prescribing for dementia

Some people without a formal diagnosis of dementia have been identified as taking dementia drugs in Somerset and the identification of those people is a priority for the CCG.

Research into comparing low practice prescribing rates alongside recorded dementia rates might be useful to help ensure equity of care across the county.

3.2 Hospital admissions

People with dementia are sometimes in hospital for conditions for which, were it not for the presence of dementia, they would not need to be admitted. It is estimated that 25% of hospital beds are occupied by people with dementia[vii]. In addition people admitted to hospital who also have dementia stay in hospital for longer, are more likely to be readmitted and are more likely to die than patients without dementia admitted for the same reason.

Figure 14 below, demonstrates that the standardised admission rate to hospital with a main diagnosis of dementia in 2015, which shows no evidence of a real difference in rate across commissioning localities in Somerset.

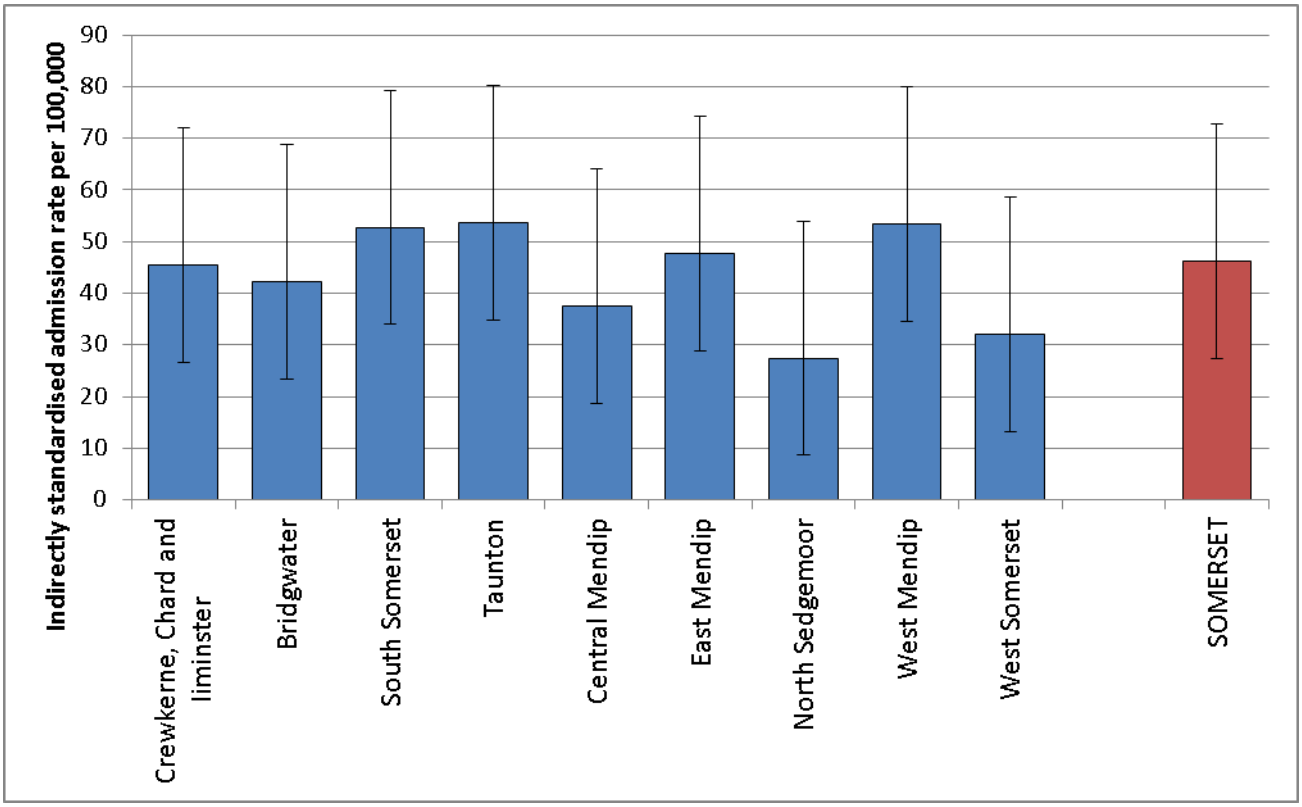


Figure 14 Admission rates by commissioning locality for dementia as a main diagnosis

There were much larger numbers of admissions which mentioned dementia as a secondary or subsidiary diagnosis ie admissions of people who had dementia but this was not the reason for the hospital admission, as demonstrated in Figure 15.

The standardised rates did show differences, with the highest admission rate from Crewkerne, Chard and Ilminster locality and the lowest from West Somerset – again this might reflect the lower diagnosis rate there. Further investigation on the three locality areas which had higher than Somerset average secondary diagnosis admission rates: Crewkerne, Chard and Ilminster; Bridgwater; South Somerset, would be beneficial to understand the impact on the local health and care systems and costs.

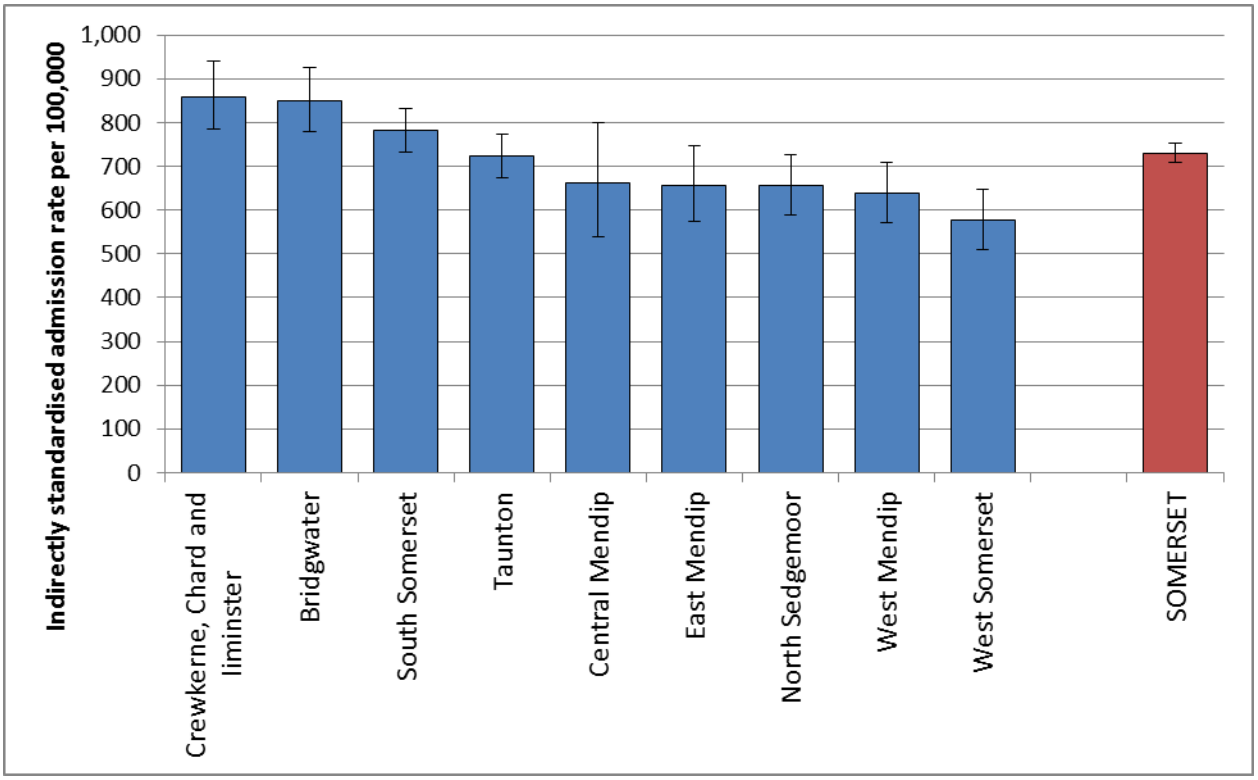


Figure 15 Admission rates by Commissioning Locality for dementia as a subsidiary diagnosis

In 2015 a National Dementia Intelligence Network briefing[viii] highlighted various factors for emergency hospital admission in particular:

- A 48% increase in emergency admissions involving people identified as having dementia between 2008/09 and 2012/13
- 20% of admissions were for potentially preventable acute conditions including disease of the urinary system, pneumonia and lower respiratory infections
- 26% of emergency admissions involving people with dementia were short stay admissions (one night or less)

  This indicates that more robust primary care and social care services and early identification of health conditions could reduce the need for hospital admission.

Figure 16 below, shows the rate per 1000 by age of those with dementia receiving an emergency hospital admission in Somerset and as would be expected the age specific proportion of emergency admissions increased strongly with age over the period. With nearly a fifth of emergency admissions being for people aged over 85 being of someone with dementia, equating to 4,948 out of 26,323 emergency admissions over this period, approximately 1,650 per year.

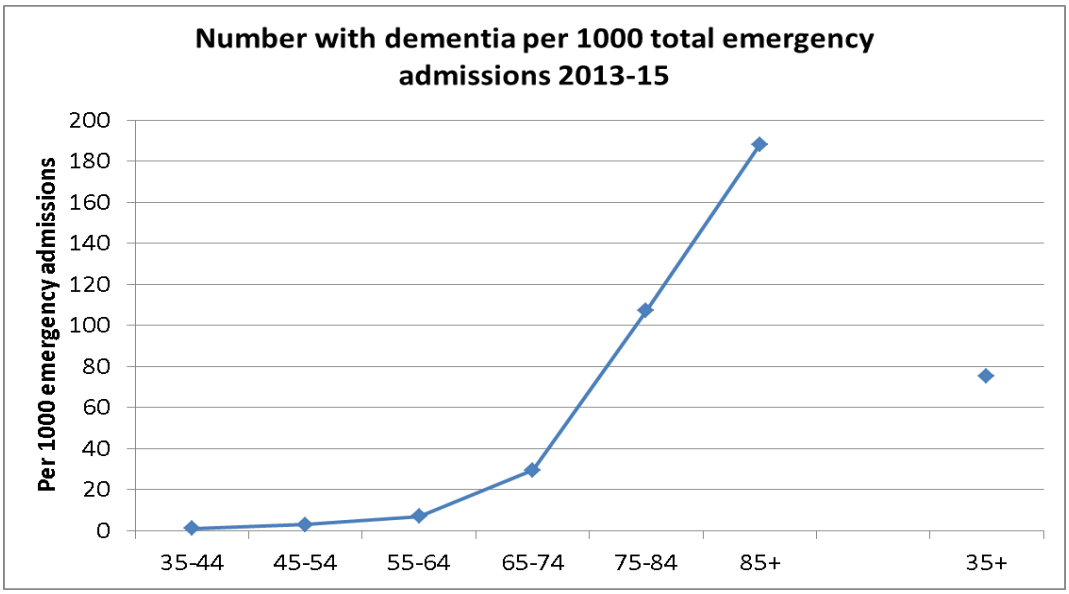


Figure 16 Increase in proportion of those with dementia amongst those receiving an emergency admission

Figure 17 gives the top eleven reasons of hospital admission in Somerset for people with dementia which accounted for almost half of the total, showing 8% had a urinary tract infection, 7% were for dementia itself, 6% for a fracture of the femur, 5.4% for pneumonia and between 3% and 3.5% for cerebrovascular diseases, a tendency to fall, syncope (brief loss of consciousness due to insufficient blood supply to the brain) and superficial injury. As defined above from national data the high rate of urinary tract infections as a reason for emergency admission is reflected nationally.

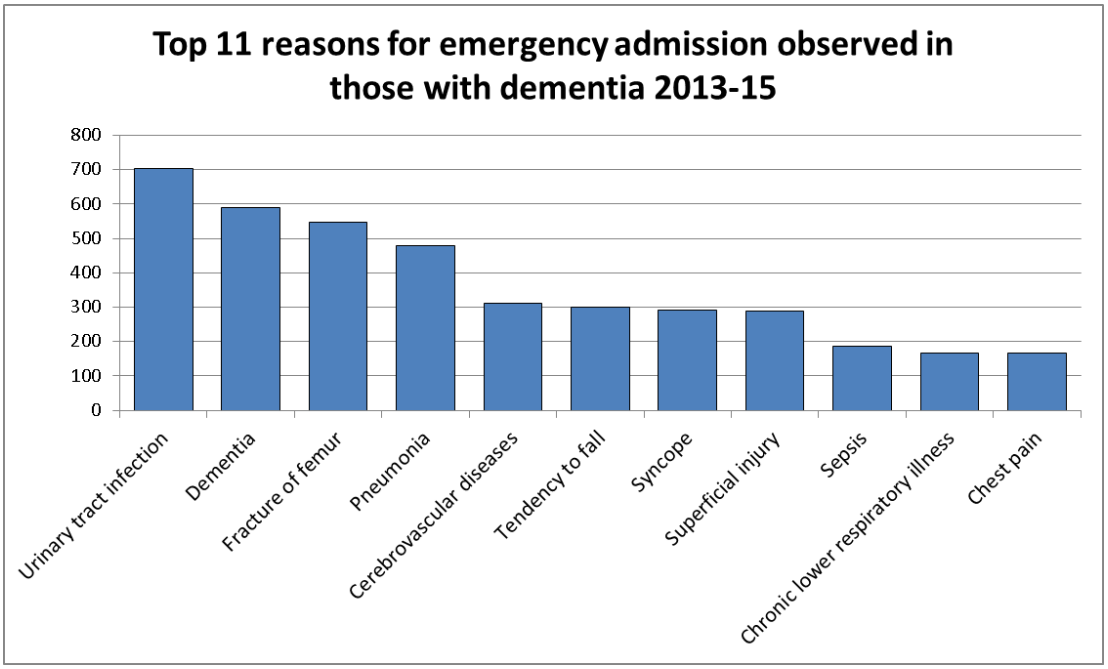


Figure 17 Top 11 reasons for emergency admission observed in those with dementia in Somerset

4. Estimated future impact and cost

4.1 Trends - Incidence

Using Alzheimer's Society estimates of age/sex specific incidence there were approximately 2,600 new cases of dementia in Somerset in 2015. This is expected to rise significantly to over 4,800 new cases each year in 2035, reflecting 86% more new cases than in 2015 as shown in Figure 18.

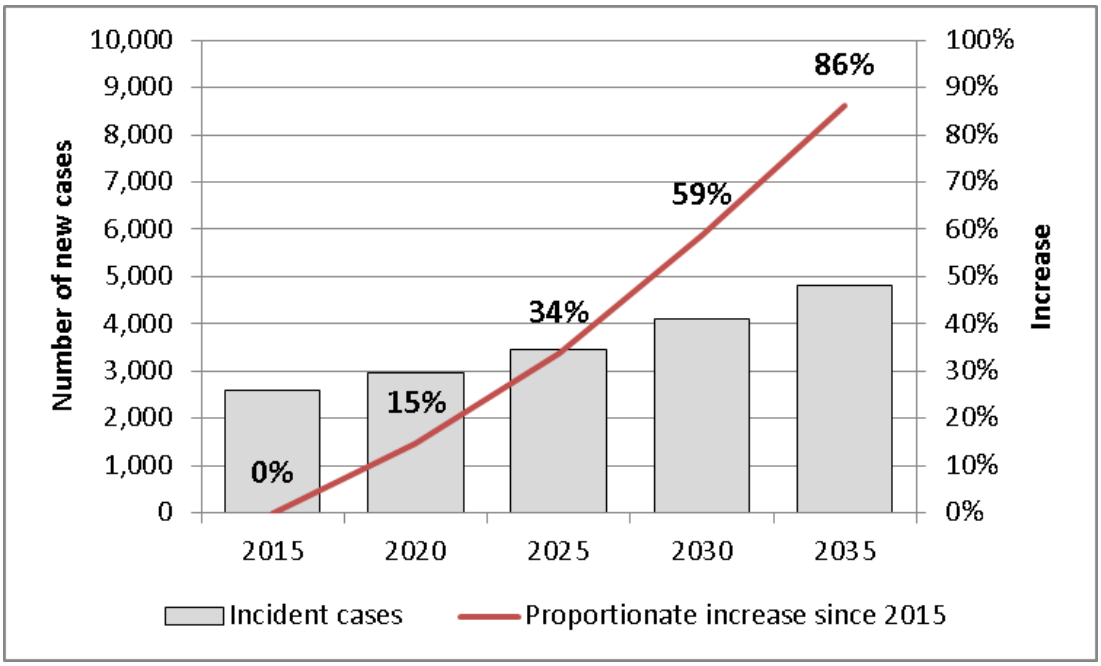


Figure 18 Modelled increases in new cases of dementia in Somerset 2015-2035

The graph below demonstrates the expected numbers of people aged 65 and over with dementia over the same time period as Figure 18 (using the Alzheimer's Society data modelling tool).

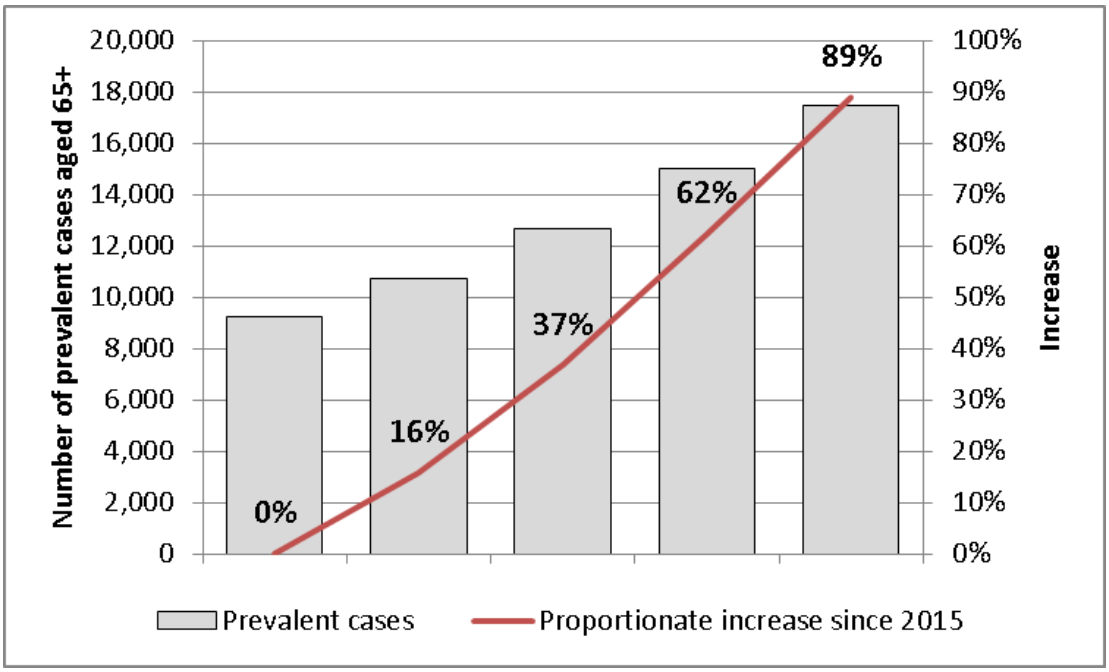


Figure 19 Modelled prevalence of dementia in Somerset 2015-2035 for those aged 65+

4.2 Trends - Prevalence

Somerset has an ageing population and is expecting its largest future population growth in the oldest age groups. As age is one of the strongest risk factors for developing dementia, this is a strong influence on future numbers of those who will develop dementia in Somerset. The following modelling is based on national prevalence models from the Alzheimer's Society updated report in 2014 and applying them to the Somerset population projections. As can be seen in Figure 20 and Table 3, the numbers of people with dementia in the younger age groups (30-59) and (60-69) does not show an appreciable change over the next 20 years. Those with dementia in the 70-79 age group show an increase which seems slight but reflects an almost 50% increase in numbers. The main increases are seen in the oldest age groups, reflecting growth in population numbers and an almost doubling of the numbers with dementia aged 80-89 over the next 20 years and an almost tripling of numbers with dementia in the 90+ age category.

Overall modelled numbers of those with dementia are predicted to almost double in the next 20 years. This will likely be reflected in a more than doubling of costs attributed to dementia if diagnosis rates continue to improve. It should be noted that with regard to the whole healthcare economy where patients may at present not be diagnosed and still not be receiving appropriate care, improvement in diagnosis may reduce costs per patient.

Table 3 Projected numbers of those with dementia in Somerset 2015-2035 (using Alzheimer's Society's rates and population change)

Age	2015	2020	2025	2030	2035
30-59	95	100	95	87	84
60-69	966	928	1,008	1,099	1,058
70-79	2,293	2,813	3,165	3,080	3,383
80-89	4,029	4,529	5,413	6,844	7,635
90+	2,279	2,768	3,439	4,377	5,730

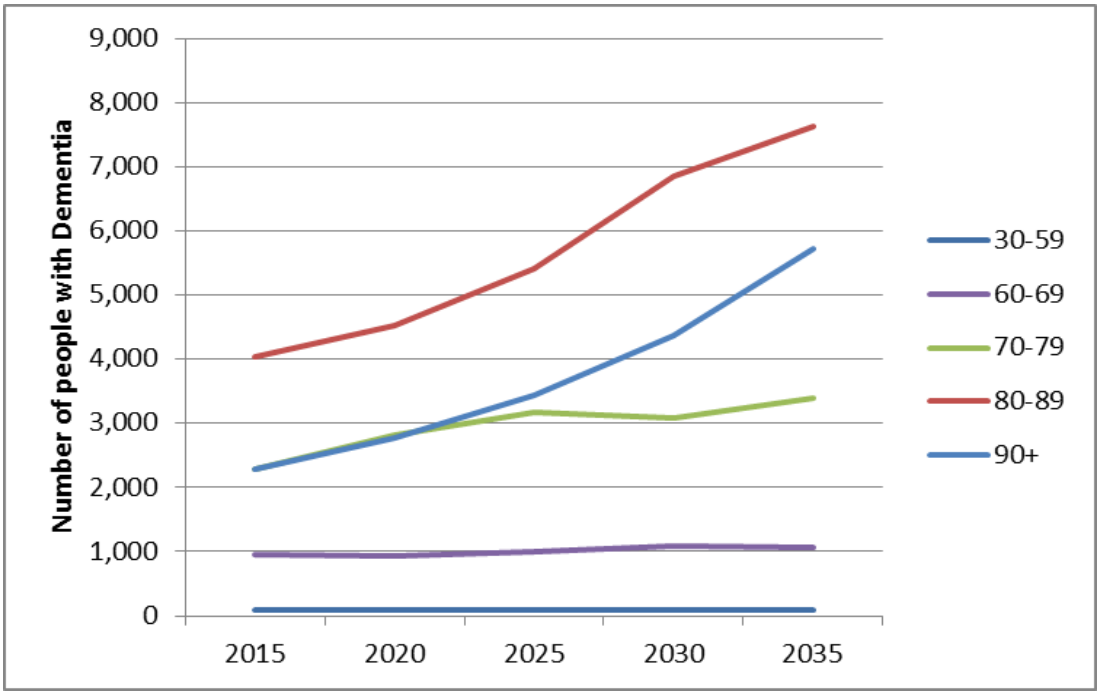


Figure 20 Modelled increase in numbers of those with dementia in each age group

From Figure 21 we can see the proportionate increase (in the combined early-onset dementia and dementia numbers) seems to vary by District, with the lowest expected increases in West Somerset and the highest in Mendip.

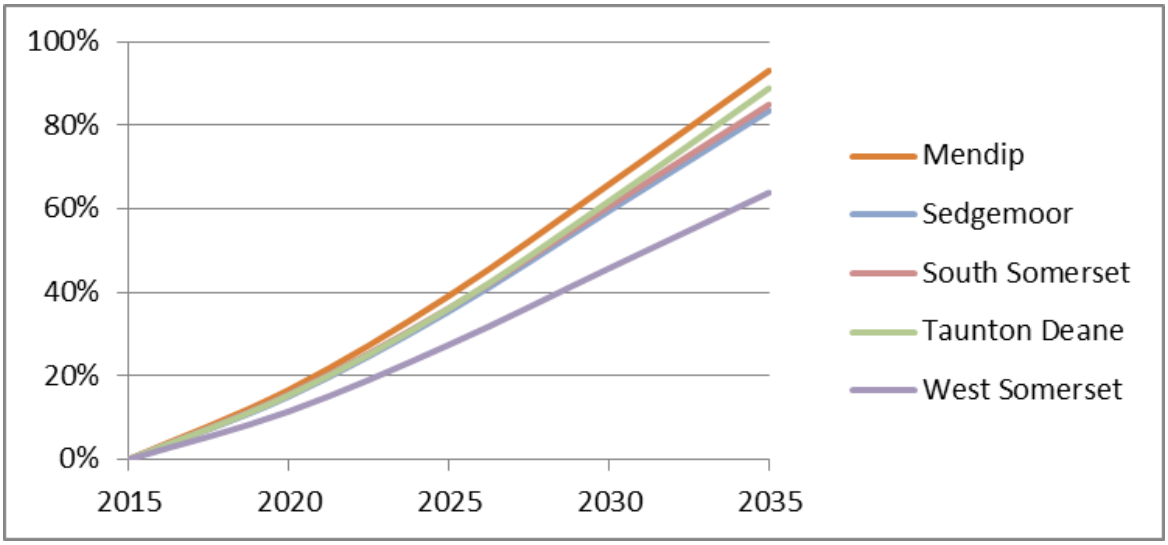


Figure 21 Modelled % increase of those with dementia by District

4.3 Contribution from family carers

The Prime Minister's challenge on dementia 2020[ix] records there are around 540,000 carers of people with dementia in England, and Alzheimer's Society[x] estimates that one in three people will care for a person with dementia in their lifetime. Half of them are employed and it is estimated that 66,000 people have already reduced their working hours to make time for caring, while 50,000 people have left work altogether.

The 2011 census showed that in Somerset one in nine people, or just over 58,000, said they provided unpaid care for a friend or relative, for a variety of reasons not solely caring

for someone with dementia. Nearly half of these carers are aged 65 or older, with 58% of carers being women. We also know that over one in five carers are aged between 55-64, and many will be younger, this potentially provides additional challenges for them if they are in employment.

Overall there were approximately 8,000 more carers identified in the 2011 census as compared to the 2001 census and these figures are in line with the national average.

Using a model produced by Alzheimer's Society which suggests that 11.2% of all carers look after someone with dementia, we can estimate that approximately 6,500 carers in Somerset currently care for someone with dementia.

A recent survey of adults caring for someone with dementia [xi] found that 1 in 4 carers had a longstanding illness, 1 in 5 had a physical impairment or disability and 65% of carers were retired. In addition 39% of carers spent 100 or more hours each week caring for the person with dementia and over half provide at least 50 hours of care a week. If we apply the Alzheimer's Society model to these figures we can conclude that over 2,500 carers support someone with dementia for at least 100 hours per week.

The demands of caring for someone with dementia cannot be underestimated, whether provided by a husband/wife/partner of a similar age who may have significant health issues of their own, or a family member or friend who is still in employment and may have other family commitments.

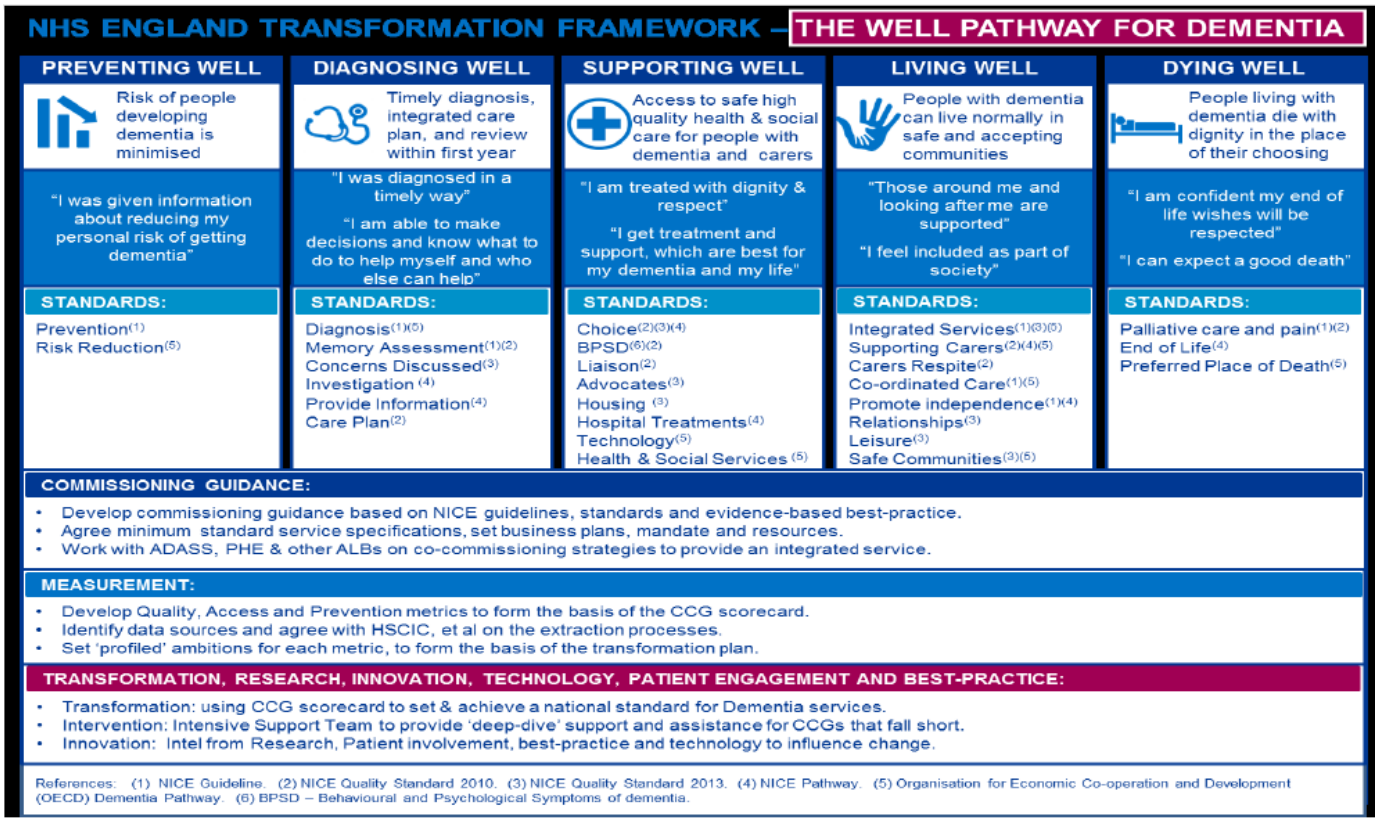
We will continue to see a rise in older carers as this age group is predicted to rise significantly in the coming years, for example from 2013 to 2021 it is estimated there will be a 46% increase in those aged 90 and over from 6,700 to 9,900, many of these carers will have significant health issues themselves and will require a high level of support to continue with their caring role.

5. The Well Pathway for Dementia

Over the past few years a range of policy and guidance has been produced to assist in the planning and development of dementia support pathways which put the needs of people with dementia at the centre of a network of care:

- NICE quality standard Dementia: support in health and social care (NICE, 2010)
- Commissioning framework for dementia (Department of Health, 2011)
- Dementia: A state of the nation report on dementia care and support in England (Department of Health, 2013)
- NICE commissioning guide on support for commissioning of dementia care (NICE, 2013)
- NICE quality standard Dementia: independence and wellbeing (NICE, 2013)
- NICE guidelines (CG42) Dementia: supporting people with dementia and their carers in health and social care (NICE, updated 2014)
- Prime Minister's challenge on dementia 2020 (Department of Health, 2015)
  Each has a clear emphasis on provision of support for the person with dementia and their carer following diagnosis as part of a cohesive, strategic pathway as outlined in the diagram below.

An Alzheimer's Society report *Dementia 2014: Opportunity for change*[4] details increasing evidence that appropriate support for people with dementia enables a better quality of life and that people achieve better outcomes. A Department of Health evaluation of peer support networks and dementia advisers in 2013[7] found that these services helped people affected by dementia to live better and feel more in control of their lives. Similarly, an independent evaluation of the Alzheimer's Society Carer Information and Support Programme found that support and access to information for carers improved care for themselves and for the person with dementia. The evidence on improvements in quality of life through investment in support services is strong.



There are helpful guiding statements as to what a person with dementia and their carers, should expect to support them to live well with their condition which come from the Dementia Action Alliance (DAA) statements[xii]. The DAA consists of organisations and groups from across health and social care that have come together to provide collective leadership and commitment to act to improve the quality of life for people affected by dementia.

DAA statements:

- I was diagnosed early
- I understand, so I make good decisions and provide for future decision-making
- I get the treatment and support that are best for my dementia and my life
- Those around me, and looking after me, are well supported
- I am treated with dignity and respect
- I know what I can do to help myself, and who else can help me
- I can enjoy life
- I feel part of the community and I'm inspired to give something back
- I am confident my end of life wishes will be respected
- I can expect a good death
- I had the opportunity to take part in research

6. Preventing Well

As well as supporting people who already have dementia, it is important that we take action to reduce the numbers of people developing dementia, postpone the onset of dementia or mitigate its impact. The Blackfriars Consensus on promoting brain health published in 2014[xiii] makes the case for concerted action to reduce people's risk of dementia by supporting them to live healthier lives and manage pre-existing conditions that increase their risk of dementia.

Although age and genetics are some of the most influential risk factors for developing dementia, there are a large number of people who have modifiable risk factors for dementia who can be targeted. Avoiding or delaying the onset of dementia for people within ten years of retirement age will mean more people can enjoy a healthy and independent life for longer.

As we might expect the risk factors associated with vascular dementia include type 2 diabetes, high blood pressure, obesity and high blood cholesterol. The effects of vascular dementia can be minimised through a healthy lifestyle, smoking and obesity for example affect many types of dementia in particular vascular dementia, and physical activity has many benefits which can help to reduce dementia risk.

There is growing evidence that the incidence of Alzheimer's disease might also be reduced through improved access to education and use of effective methods targeted at reducing the prevalence of vascular risk factors (e.g. physical inactivity, smoking, midlife hypertension, midlife obesity and diabetes) and also depression and that up to one third of Alzheimer's disease may be attributable to lifestyle factors[3]).

Further information and guidance is required to enable people (particularly those in mid-life) understand the impact of their lifestyle, to help them make better, more informed choices to reduce their risk of developing dementia. The recent launch of a *Health Matters: Midlife approaches to reduce dementia risk*[1] resource to support professionals consolidates evidence and raises the profile of the importance of prevention and that dementia is not an inevitable part of ageing.

NICE guidance 'Dementia, frailty and disability in later life – mid-life approaches to delay or prevent onset'[xiv] highlights the importance of promoting healthy lifestyles during mid-life (identified as ages 50-64). Cohort studies looking at successful ageing have demonstrated links to healthy lifestyle behaviours, that lead to more quality-adjusted life years (a measure of the state of health of a person or group in which the benefits, in terms of length of life reflect the quality of life).

Suggested opportunities for raising awareness include:

• Use routine appointments and contacts to identify people at risk of dementia, disability and frailty (for example, appointments with a GP or practice nurse, when attending leisure centre classes, or visiting a community pharmacy)

• Take advantage of times in people's lives when substantial change occurs. (Examples include: retirement, when children leave home, when starting to care for older relatives or grandchildren, or for women at the menopause). These are times when people may consider adopting new healthy behaviours, or may be at risk of adopting unhealthy ones

• Whenever the opportunity arises give people advice on how to reduce the risk factors for dementia, disability and frailty or refer them to specialist services when necessary

In addition the NHS Health Check programme, introduced in April 2009, offers advice and support to help people aged 40-74 make changes that can reduce the risk of ill health, including dementia. It also offers an opportunity to identify those at risk of certain diseases or who have undiagnosed conditions such as diabetes or high blood pressure.

Since April 2013, people in England aged 65-74, which accounts for more than 3 million people, were to be given information about dementia and the availability of memory services through the Health Check programme. In Somerset those aged 65 and over are given information about the risk of dementia following an NHS Health Check.

	Bridgwater	Central Mendip	Crewkerne, Chard and Ilminster	East Mendip	North Sedgemoor	South Somerset	Taunton	West Mendip	West Somerset	Somerset (County)	South West	England
Smoking prevalence in adults - current smokers (IHS)	22.0%	19.4%	16.8%	18.2%	16.2%	17.6%	17.7%	17.0%	16.9%	17.8%	16.9%	18.0%
Percentage of physically active and inactive adults - inactive adults										26.8%	26.3%	27.7%
Excess weight in adults										65.5%	62.7%	63.8%
Admission episodes for alcohol-related conditions (Narrow)										626	625	645
People receiving an NHS Health Check										16.5%	19.5%	22.9%
Hypertension: recorded prevalence (all ages)	14.7%	14.7%	19.0%	16.2%	16.9%	16.2%	14.7%	16.2%	19.3%	16.1%	14.5%	13.7%
Stroke: recorded prevalence (all ages)	2.1%	1.8%	2.5%	2.1%	2.6%	2.0%	2.2%	2.2%	3.3%	2.2%	2.0%	1.7%
Diabetes: recorded prevalence (aged 17+)	6.8%	5.5%	7.3%	6.0%	7.0%	6.4%	6.3%	6.2%	7.1%	6.3%	5.9%	6.2%
CHD: recorded prevalence (all ages)	3.7%	3.4%	4.2%	3.1%	4.5%	3.7%	3.6%	3.6%	5.3%	3.9%	3.5%	3.3%
Depression: recorded prevalence (aged 18+)	6.4%	9.5%	8.1%	7.0%	5.5%	8.6%	8.4%	7.6%	7.4%	7.0%	6.7%	6.5%

Table 4 Preventing Well, PHE Dementia Profile

The Public Health England Dementia Profile enables access to data to show how Somerset compares to other areas on key modifiable risk factors for dementia. Table 4 demonstrates Somerset's position against various risk factors mainly associated with lifestyle, and although some figures may appear slightly higher than the South West or England prevalence, these are affected by Somerset having an older population (as using crude rates), and generally Somerset has a lower than average for England risk.

7 Diagnosing Well

7.1 Dementia diagnosis rate

Comparison between the actual numbers of those with dementia and the modelled numbers with dementia gives an indication of the completeness of diagnosis. The Primary Care Web Tool (using Quality Outcomes Framework data) includes modelled estimates of the true prevalence of dementia and compares it with the actual recorded prevalence to give the dementia diagnosis rate.

As noted, Somerset is estimated to have a prevalence of just over 1.5%. However the number recorded on GP registers is 59% of the total modelled number of cases. Somerset has a slightly lower diagnosis rate than the national rate (59.1% compared to 60.8% at March 2015), see Figure 22 below.

In comparison with the CCG cluster Somerset is one of the CCGs towards the higher end, however there are still a considerable number of people without a diagnosis. Research highlights the complexities of receiving a dementia diagnosis, not everyone seeks this early on, they may be unaware of their symptoms, or it may take time for a diagnosis to be made.

Although initially discussing the diagnosis may be distressing, evidence suggests most people prefer to know if they have dementia in order to access appropriate support and treatment and to plan for the future[xv]. We know that people without a diagnosis and their families have less access to services, support, the ability to plan ahead, and in some cases appropriate medication.

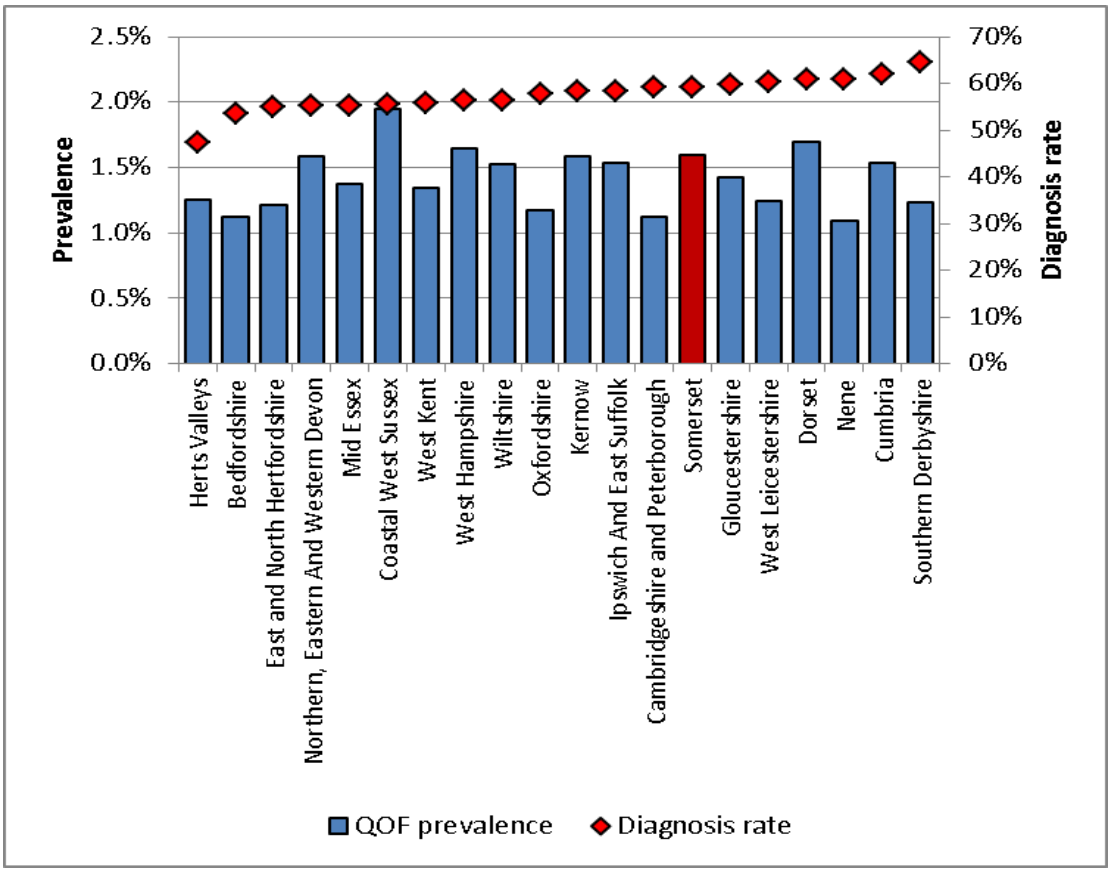


Figure 22 QOF prevalence and diagnosis rate for dementia across CCG areas

Within Somerset the diagnosis range is between 44.8% in West Somerset to 67.5% in East Mendip as shown in Figure 23.

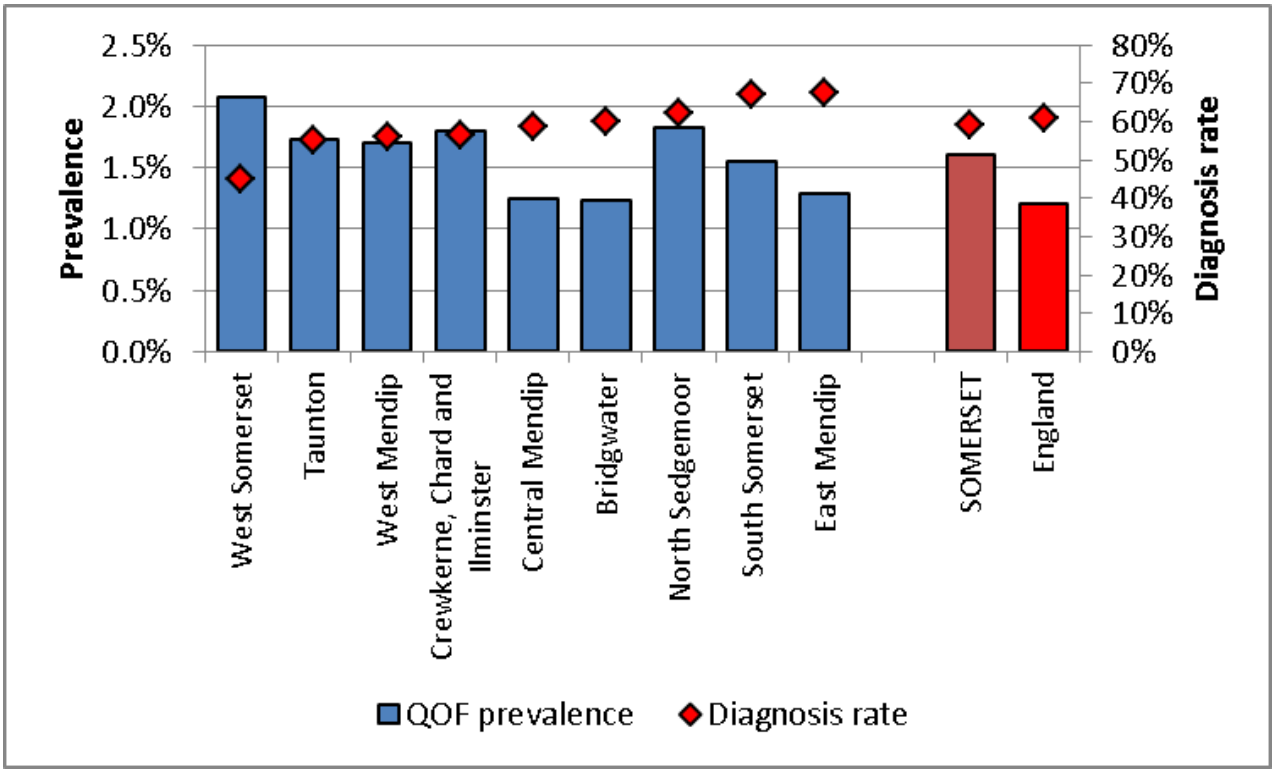


Figure 23 QOF prevalence and diagnosis rate for dementia across Somerset commissioning localities

The diagnosis rate by practice within Somerset is shown in the graph below. The practice diagnosis rates are between 13% and 122% of the modelled numbers.

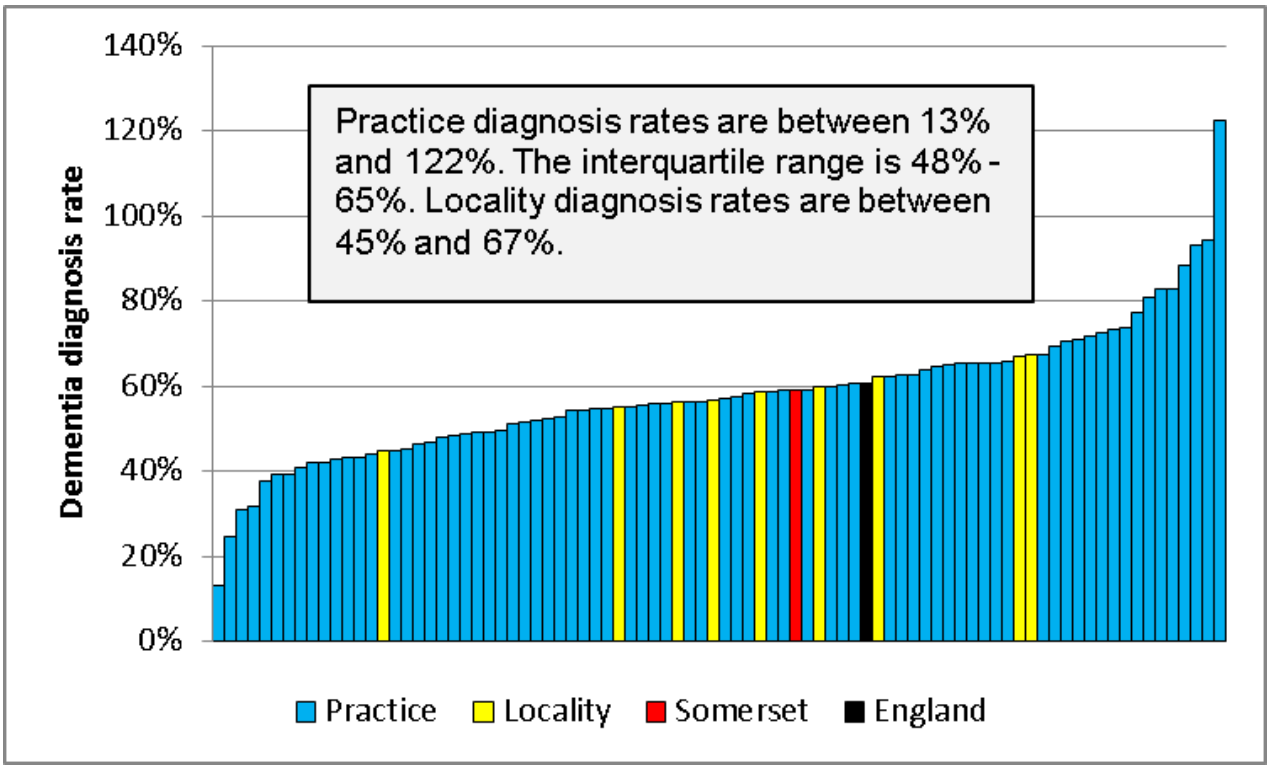


Figure 24 Practice dementia diagnosis rates

To identify any practices that had an outlying dementia diagnosis rate, a funnel chart was drawn of the rate against the expected true number. Four practices were below the lower limit and three above the upper limit.

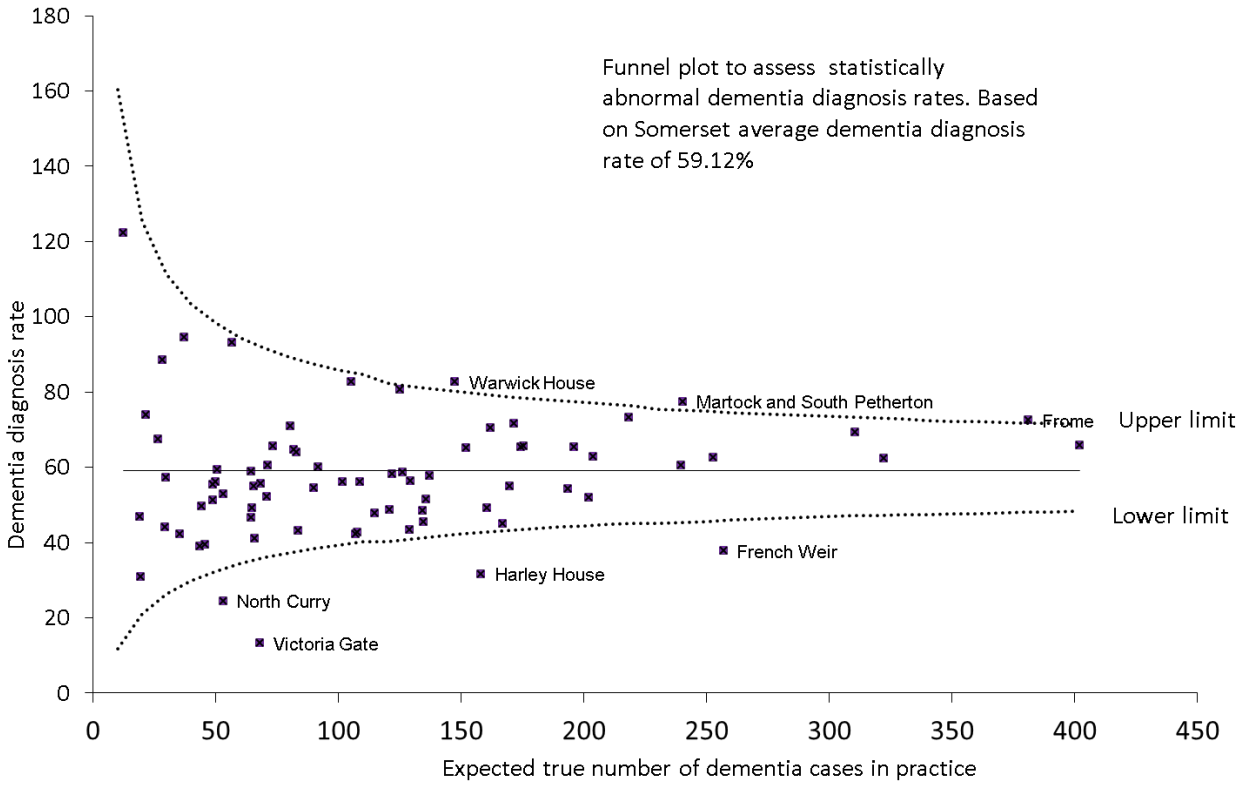


Figure 25 Funnel chart of expected true number of dementia cases by practice, Somerset, March 2015

8. Supporting Well

8.1 Data on quality of care

Data on quality of care indicators is provided in the Public Health England released Dementia Profiles – this is a summary of how Somerset compares with the other CCGs in the cluster of 'Larger CCGs, rural with more older people' and also, where possible for the commissioning localities within Somerset.

The indicators show that Somerset is much worse at recording initial blood tests which can exclude potentially reversible or modifying cause for dementia and to help exclude other diagnoses such as delirium. Reversible or modifying causes include metabolic and endocrine abnormalities (e.g. vitamin B12 and folate deficiency, hypothyroidism, diabetes and disorders of calcium metabolism). Somerset also scored lower on reviewing care than the other CCGs and England overall. Whether this could be due to not recording the activity, as most of Somerset is no longer part of the national Quality Outcomes Framework (QOF) reporting system is not clear.

The "Supporting Well" indicators show Somerset to have better (lower) levels of admission to hospital and better (more) short stay admissions than the national average.

The "Dying Well" indicators show better (lower) mortality from dementia and a better (greater) proportion dying in their usual place of residence than the national average.

Within Somerset comparisons are affected with the same issue of using crude prevalence rates as England as a whole. However blood test recording and dementia reviews should not be affected by the differing age ranges in the commissioning localities, but rates vary from 46.5% in Taunton to 85.3% in Bridgwater for blood tests (Figure 26).

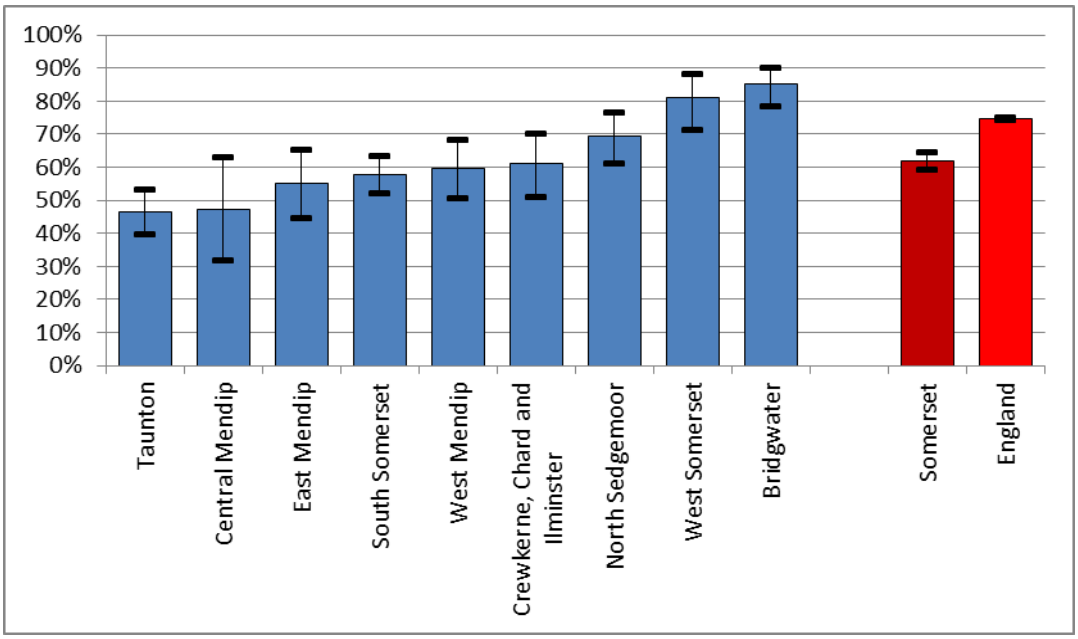


Figure 26 The proportion of new cases with a blood test within 6 months of entering dementia register

Dementia reviews come under another indicator and vary from 38.2% in South Somerset to 78.1% in West Somerset and overall, as stated above, Somerset has a lower level of reviews than England (Figure 27).

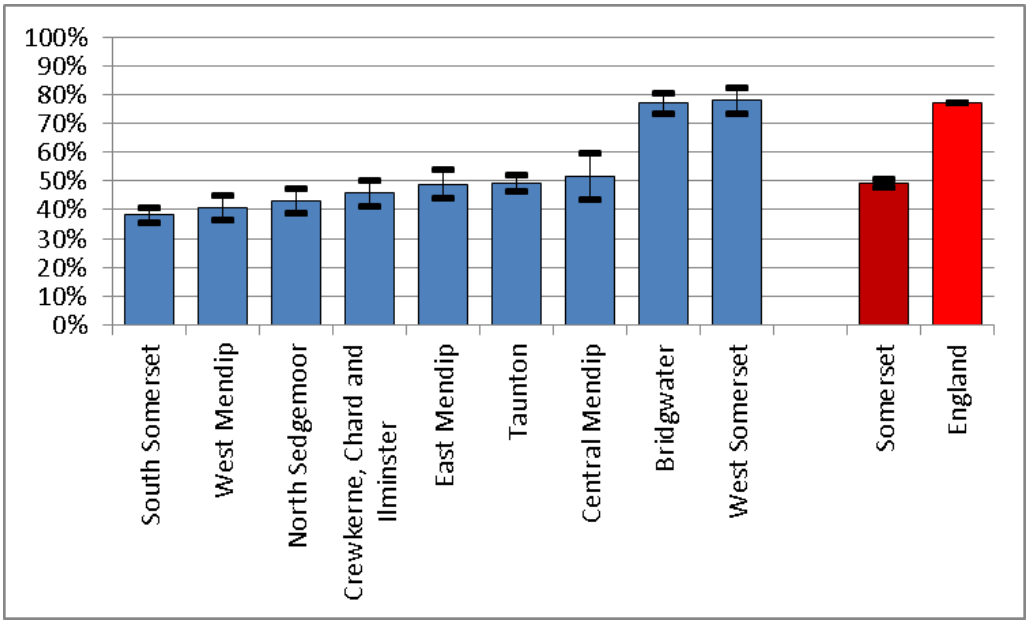


Figure 27, The proportion of people who have had their care reviewed in last 12 months

There are no particular trends in the QOF prevalence or the diagnosis rates across the deprivation quintiles in Somerset, but the most deprived quintile has the highest rate in both, which is a reason known to be a risk factor for dementia, as shown in Figure 28.

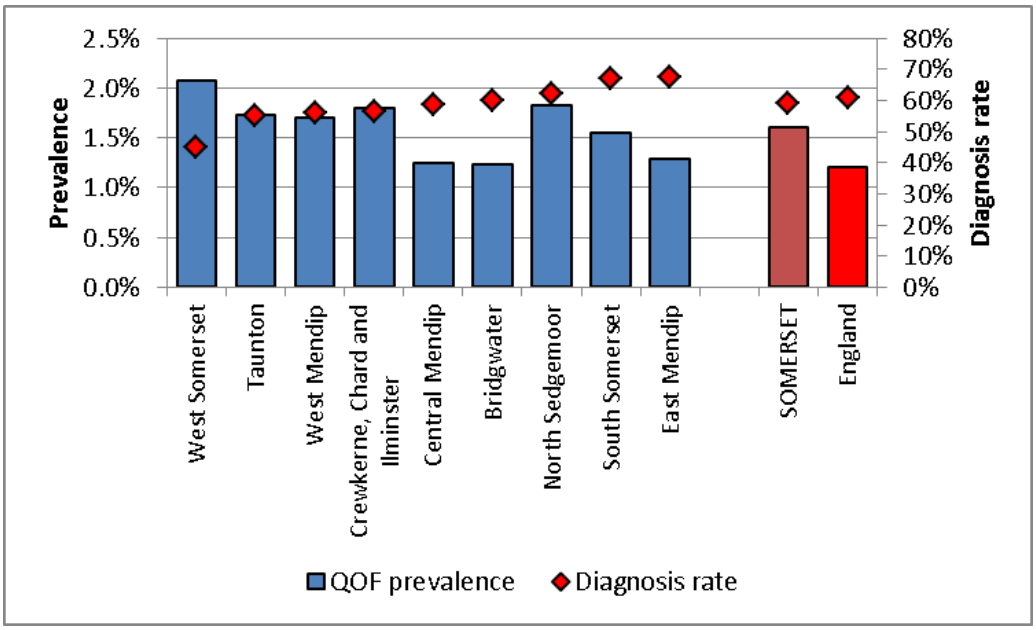


Figure 28 QOF prevalence and diagnosis rate for dementia across Somerset commissioning localities

9. Living Well

9.1 Alzheimer's Society Somerset Living Well with Dementia Programme

The programme was part of a pilot run by Alzheimer's Society in Somerset, which consisted of sessions over a period of seven weeks where people with dementia came together without their families or carers.

Each week a topic was discussed by the group and support, information and advice was available. But the focus was that the group had the opportunity to share experiences, feelings and knowledge of what it means to have a diagnosis of dementia.

Some of the modules covered included; health and wellbeing, support, communication, feelings, as well as activities, music, song, reminiscence and sharing of previous lives and experience.

Each week the group were given the opportunity to provide feedback and at the end of the course the opinions of the group and of the experience of being part of the programme was captured.

Some of the feedback included:

- 'We want things that are planned for us to be done with us not to us'
- 'Actually I am very angry at having a diagnosis of dementia and I feel I have been able to share that now'
- 'This is the first time I have been able to discuss my true feelings in a group situation with other people who understand'
- 'I am not always able to talk like this without my wife talking for me'
- 'What shall we do now that the group has ended?'
- 'You have all helped to give me back my confidence, and know it is not just me'
- 'Everyone with dementia should be given the chance to do something like this if they want'
- 'I never thought I would be able to be part of a group like this'

9.2 Place of Care

It is estimated approximately two thirds of people with dementia live at home and a YouGov poll for Alzheimer's Society in 2014 found that 85% of people would want to stay at home as long as possible following a diagnosis of dementia. Evidence shows that changes of environment can be particularly unsettling for people living with dementia, so maintaining familiar settings is very important. The Prime Minister's Challenge on Dementia sets a goal that by 2020 there should be a greater focus on independent living, with more people being able to live in their homes for as long as it is in their best interests to do so.

As up to one third of people with dementia live in residential care, it is essential care homes are able to meet their needs and provide high quality, personalised care to enable someone to live as full a life as possible. Ensuring staff have appropriate training is crucial and an important element to understand behavioural aspects of dementia where communication may be difficult. In addition approximately 69% of all people who live in care homes are estimated to have dementia and this increases with age, which again emphasises the need for competent, well trained staff and dementia friendly environments[4].

It is worth considering that care in people's own homes may have a positive impact on costs. It is known that people with dementia living in a care home are more likely to go into hospital with avoidable conditions (such as urinary infections, dehydration and pressure sores) than those without dementia.

Another aspect linked to the economic impact of dementia is the working age profile in Somerset over the coming 20 years, as this declines markedly especially in rural areas such as West Somerset. This is likely to have an impact on the numbers of staff available to support an ageing population including people with dementia, in provision of both domiciliary (home care) staff and staff in residential settings.

Although a relatively small number of younger people (those with onset before the age of 65) are identified in Somerset, evidence shows they often struggle to access appropriate care and support as dementia services are often designed to meet the needs of older people. As a result, dementia services may not be appropriate to the needs of younger people who are more likely to work, have family and financial commitments and rarer forms of dementia.

The proportion living in residential care was obtained from practice records and should be an actual recorded proportion. From graphs below we can see Somerset had slightly greater proportion in care than the national average and slightly higher in comparison with the CCG cluster.

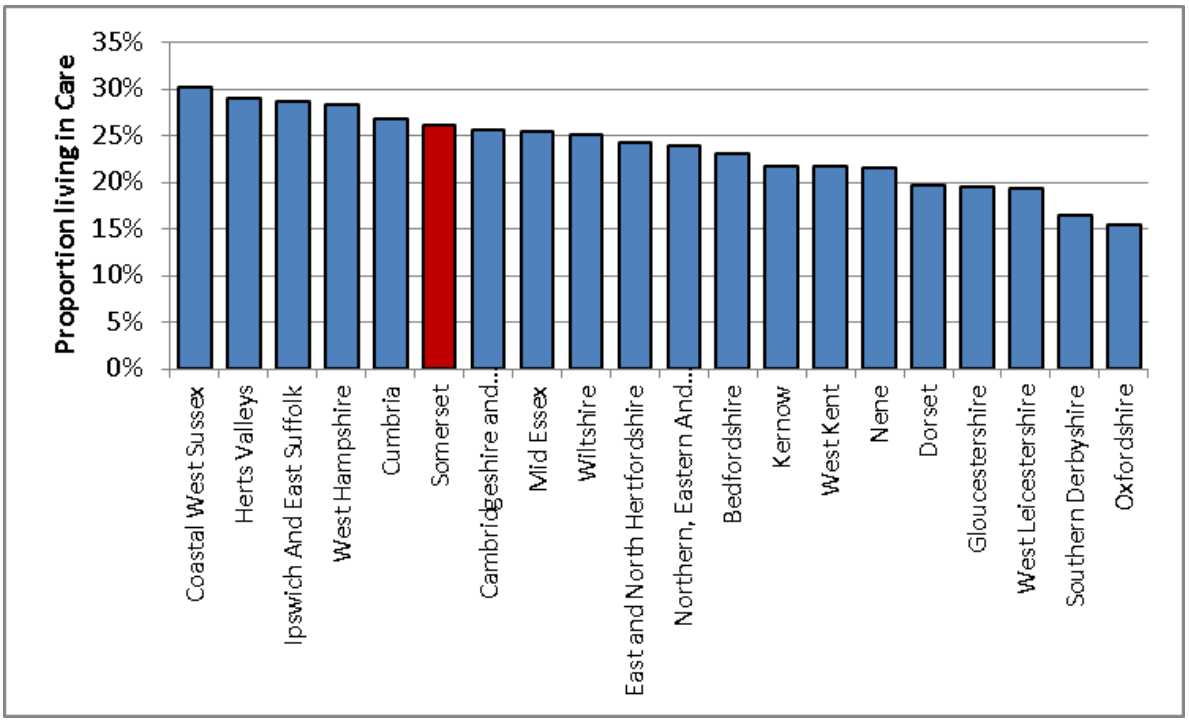


Figure 29 Proportion of people with dementia living in residential care by CCG cluster

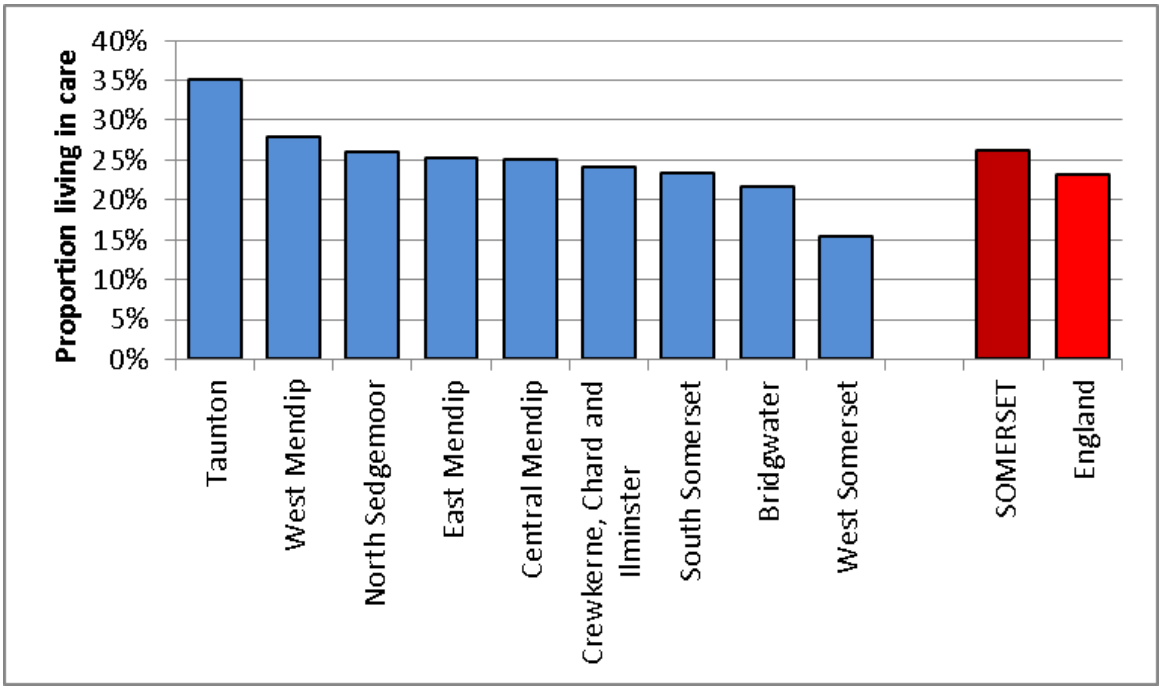


Figure 30 Proportion of people living in residential care by Somerset commissioning locality

Figure 30 also shows a wide variation between commissioning localities with values of 35.1% in Taunton down to 15.4% in West Somerset. This may be due to the lower population in West Somerset and a higher density of residential and nursing care homes within larger conurbations.

10. Dying Well

There was a change in the way the underlying cause of death was coded in 2011, and this affected dementia as can be seen from the graph below. The pattern for dementia as the underlying cause of death suddenly rose. However there was no such step change in the death rate for those with any mention of dementia and that has been used in the following analysis (Figure 31).

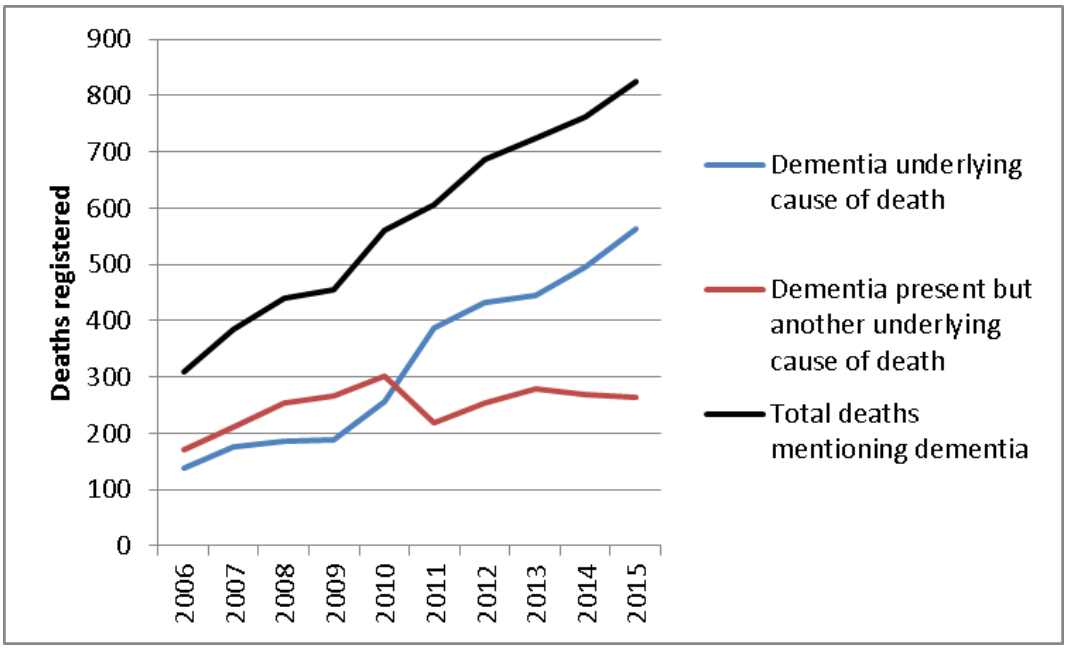


Figure 31 Deaths registered 2006 – 2015 for dementia

From Figure 32 the standardised mortality ratio (compared to Somerset over the whole time period) shows a constant upward trend. Standardisation takes out the effect of the distribution of age and gender in the populations compared, so this shows a real increase in people dying with dementia.

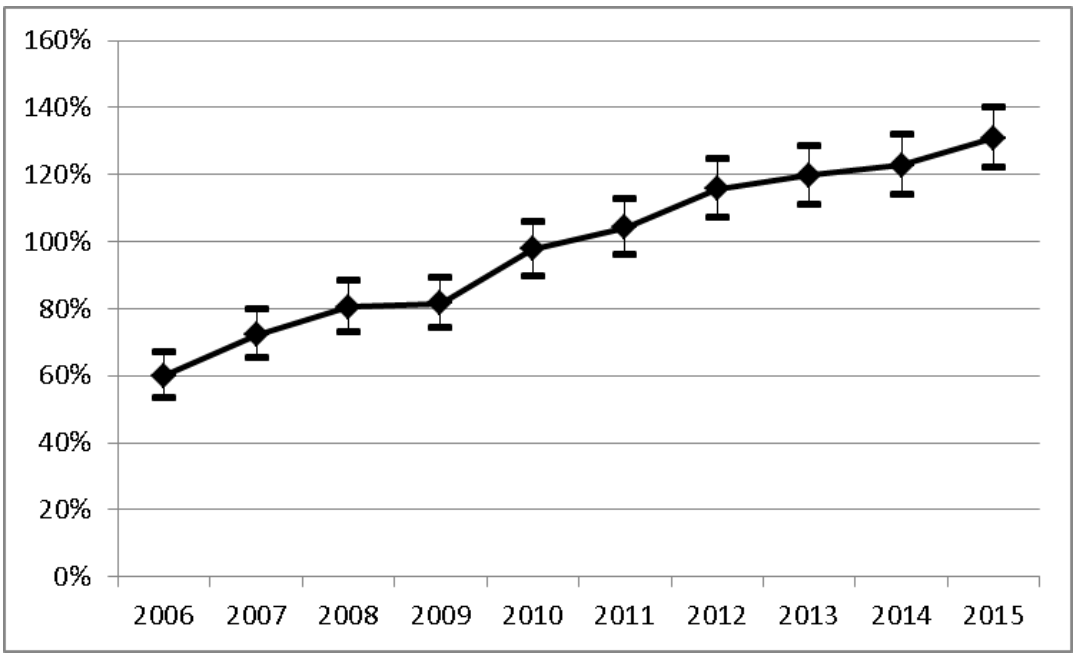


Figure 32 Dementia standardised mortality ratio 2006-2015

The age-gender specific death rates are as expected most high in the older age groups – with the rates being higher for women than men as shown in Figure 33.

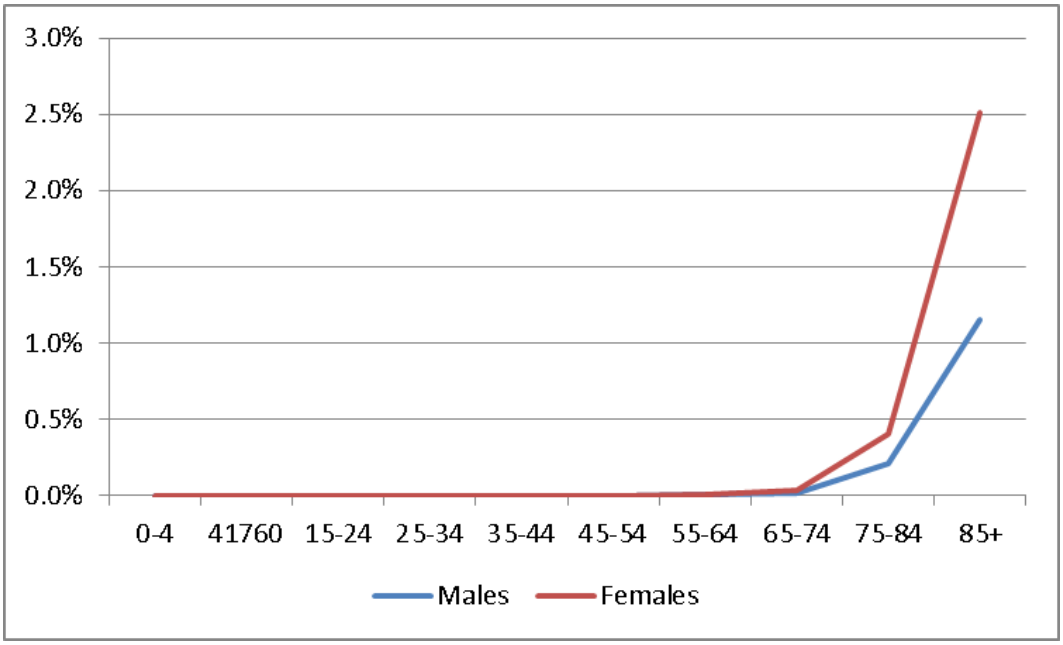


Figure 33 Age-gender specific death rates

The dementia standardised mortality ratios were very different across the commissioning localities, with Taunton having by far the highest ratio and West Somerset the lowest which is demonstrated in Figure 34. This could be related to the degree of diagnosis in West Somerset, it was noted above that their dementia diagnosis rate was the lowest of the commissioning localities and it is conceivable that the diagnosis would also not be made at the time of death, and hence not appear on the death certificate. The higher ratio areas may be influenced by the percentage of care homes found in larger towns.

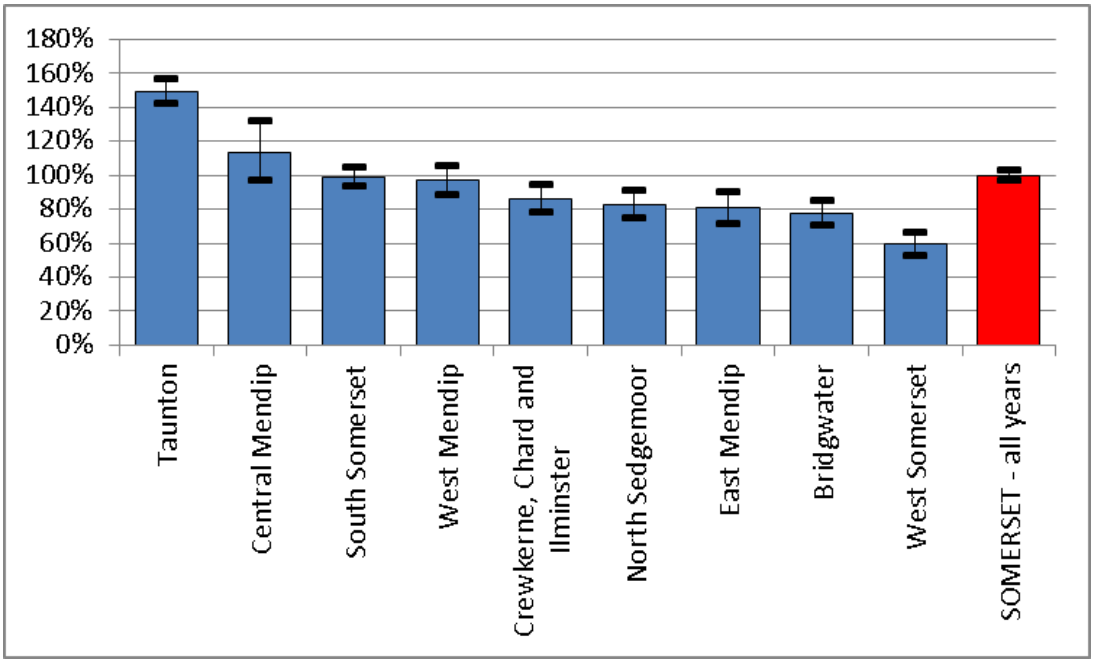


Figure 34 Dementia standardised mortality ratios by commissioning locality

There was no evidence of a correlation of standardised mortality ratio with deprivation (Figure 35).

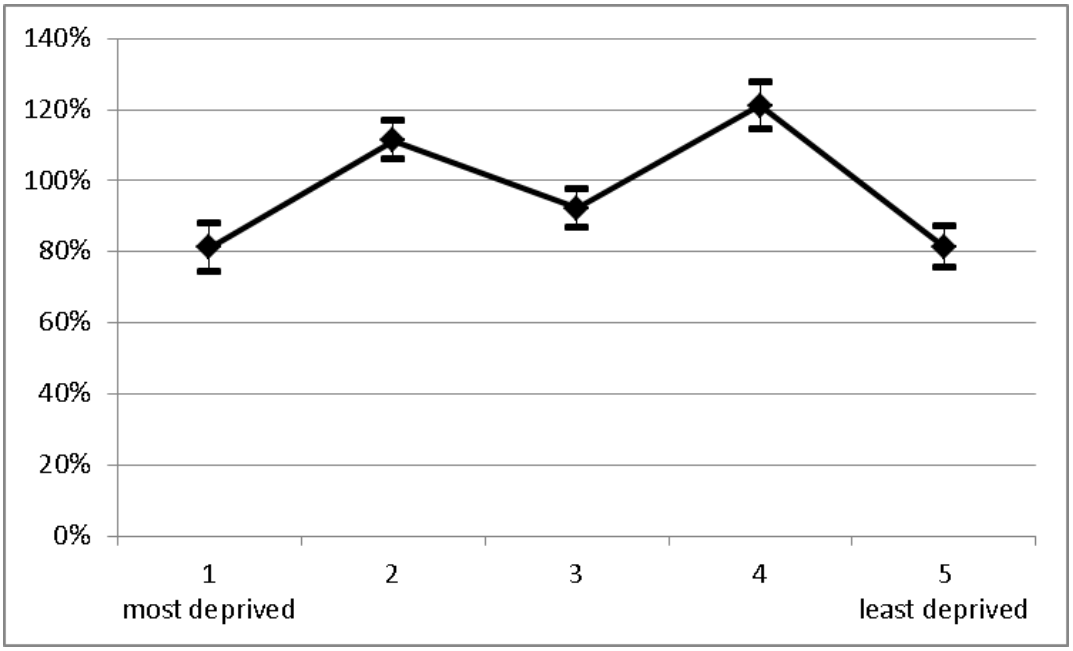


Figure 35 Dementia standardised mortality ratio by deprivation

From Figure 36 below, in order to avoid the change in the coding, the pattern of other conditions mentioned on the death certificates for those who died from dementia was restricted to 2013-15.

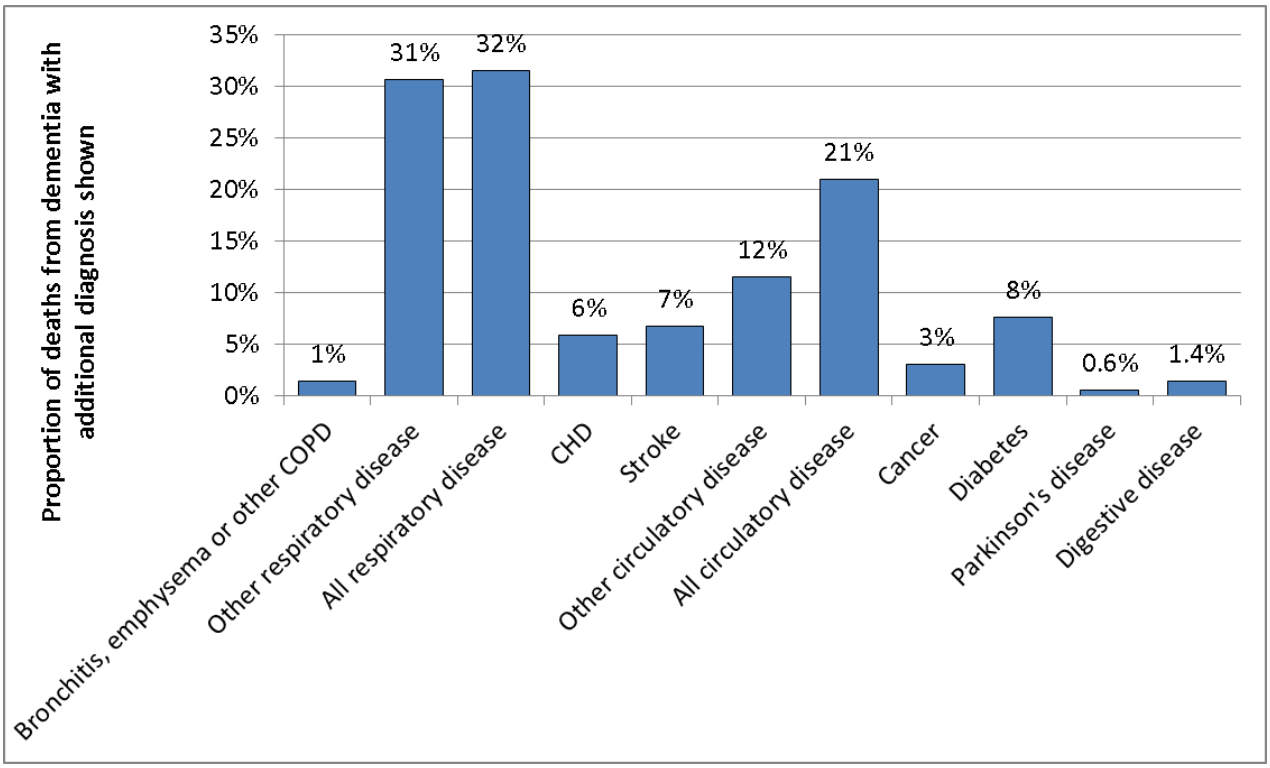


Figure 36 Proportion of deaths from dementia with additional diagnosis 2013-15

We can see that almost a third (32%) of those that died had a respiratory disease, mostly not COPD (chronic obstructive pulmonary disease), just over a fifth, 21% had a circulatory disease, 8% had diabetes and 3% had cancer.

11. Dementia Needs and Protected Characteristics

11.1 Black, Asian and Minority Ethnic groups (BAME)

An All-Party Parliamentary Group on Dementia report[xvi] recognised that dementia is more common among Asian and black-Caribbean communities, as this group are more prone to risk factors for vascular dementia such as cardiovascular disease, hypertension and diabetes. Recently larger numbers of people from BAME communities in the UK are reaching ages where dementia becomes common so numbers are rising. Overall, vascular dementia is thought to affect around 20% of people with dementia, but we do not know how many people with vascular dementia are from BAME groups. Even among people with Alzheimer's disease, signs of damage to the blood supply in the brain can sometimes be observed alongside other changes caused by the disease (mixed dementia).

In addition lower levels of awareness about dementia and the existence of stigma within some BAME communities help explain why this group are currently under represented in dementia services, that they are less likely to receive a diagnosis, or are diagnosed at a more advanced stage of illness than white-British people[xvii].

Although there are relatively few people from BAME backgrounds in Somerset it is worth considering how an increase in the number of older black and minority ethnic people (given the national prediction) is likely to lead to an increased need for dementia services. The BAME population of Somerset was estimated at 10,717 in 2011, equal to 2% of the population, an increase of around 5,000 people since the 2001 Census.

11.2 Rurality

Rurality is an additional, rarely reported factor that would interact with socio-economic position. Rural living, especially in early life is associated with increased risk of dementia[xviii]; this may be particularly relevant to some of our Somerset population.

A meta-analysis[17] concluded there is evidence of geographical variation in rates of dementia in affluent countries at a variety of geographical scales. Rural living was associated with an increased risk of Alzheimer disease, and there is a suggestion that early life rural living further increases this risk. There may be links to geographical distributions of related conditions such as cardiovascular disease and further research is recommended. This research is relevant to Somerset, especially to some areas which are more isolated.

People living in rural areas may also find it more difficult to access their GP, specialist dementia support, or live further away from support services, and their family carers may find it more difficult to access support. A lack of transport links can present more challenges in rural areas and the distance or time a journey takes may be unacceptable for some people with dementia and their carers.

Another aspect is for providers of dementia services in rural and remote areas who have identified a range of challenges including distance, lack of transport and shortages of skilled staff, leading to increased costs and a more limited choice of services than in urban areas[xix].

11.3 Socio-economic position

Socio-economic position has long been seen as an independent predictor of dementia. Those with a low socio-economic position have an increased prevalence of Alzheimer's disease, the reason for this is not clear, as it appears to be, in part, independent of educational status. However it is also known that education remains protective against developing dementia[xx] .

11.4 Religion, belief and culture

A recent Public Health England literature review showed that some ethnic groups may receive delayed health care services for dementia, this needs to be seen in context of cultural beliefs (as highlighted above) and how this influences willingness to seek support. Some culturally specific ideas about dementia, perhaps of it having a spiritual, psychological, or social cause may prevent people from seeking support.

11.5 Learning disability

People with a learning disability, primarily Down's syndrome as previously mentioned are at a greater risk of early onset dementia. Data drawn from the PANSI/POPPI (Projecting Adult Needs and Service Information /Projecting Older People Population Information) websites provide estimates of the number of people with Down's syndrome in Somerset and for 2015 this suggests there are 191 people under 65 years and 5 people 65 years old or older – it is further estimated that these numbers will remain stable over the next 10 years. From this we can conclude there will not be a higher level of demand for services to meet needs, however consideration is required as people with Down's syndrome may require specialist assessments, services, and support to ensure they live well with dementia.

Research suggests the assessment of cognitive impairment for someone with a learning disability needs special care, paying attention particularly to co-morbid physical and mental health disorders and less reliance of standard tests of cognition[xxi].

A recent report from the Royal College of Psychiatrists[xxii] states staff involved in assessment, diagnosis, interventions and support need to be trained in dementia care and able to offer both holistic and specialist assessments and a range of interventions to meet the needs of people with intellectual disabilities and dementia. A literature review indicated that people with Down's syndrome required multiple services including social care services[xxiii].

To best meet someone's needs following a dementia diagnosis they should be supported to remain in their familiar home environment with additional input provided in a timely manner, wherever possible.

11.6 Lesbian, gay, bisexual and transgender people (LGBT)

People from LGBT communities are often marginalised, this impacts further if someone receives a diagnosis of dementia, as this group are underrepresented in general dementia groups and charities. This is especially relevant in a rural county such as Somerset. In addition LGBT family carers may have negative experiences with health and social care professionals – often receiving heterosexist responses and assumptions.

Another aspect concerns people living in care homes as assuming heterosexuality can be the part of the home culture leading to adverse impacts on social, cognitive and communicative functioning for an older person with dementia. Research also shows there may be occasions where people were unwilling to declare their sexuality when moving into residential care, perhaps due to previous experiences of discrimination, which may impact on the ability of staff to support them[xxiv].

12. Conclusion

The challenge to Somerset to meet the needs of people with dementia over the coming years is considerable. This is reflected nationally, however with our higher ageing population it will require astute and joined up partnership working across health, social care and the voluntary sector to ensure people with dementia are diagnosed in a timely way, their families are involved and supported, and the person with dementia is able to live well at home for as long as possible, and that their end of life care wishes are taken into account.

As we expect to see the numbers of people with dementia to almost double in the next 20 years, this will be reflected in the corresponding costs to provide care and support across health and social care. There will also be challenges in supporting people's needs particularly in rural areas where the health and social care workforce will be lower due to the decline in the number of working age population.

Another area of focus needs to be on prevention of dementia, as evidence shows a proportion of dementias including Alzheimer's are influenced by lifestyle factors. For our population especially those in mid-life, it is essential this message is communicated we know that what is good for the heart is good for the brain.

The recent Prime Minister's Challenge on Dementia 2020 implementation plan and Commitments, and the National Dementia Intelligence Network Dementia Data Catalogue can be used to assist with monitoring and improving outcomes for people with dementia and their families.

13. Recommendations

Preventing Well

- Raise the profile of prevention of dementia – through local campaigns and promotion across communities and through organisations.

Diagnosing Well

- Maintain focus on diagnosing dementia, especially in GP practices with low diagnosis rates.
- Research into comparing low practice prescribing rates alongside recorded dementia rates might be beneficial, to help ensure equity of care across the county.

Supporting Well

- Improve the numbers of people that have received a diagnosis of dementia that have appropriate follow up, such as blood testing, and a review of care.
- Ensure dementia medications are prescribed only where meet NICE and pharmalogical guidance and criteria to benefit the patient, and that antipsychotics are used as a treatment of last resort.
- Ensure a robust primary, secondary and social care services model exists to promote early identification of health conditions for people who have dementia, especially urinary tract infections, which could reduce the need for hospital admission.
- Ensure people with early-onset dementia have appropriate services to meet their needs as their dementia develops, this also applies to some protected characteristic groups such as those from Black, Asian and minority ethnic communities and people with a learning disability.

Living Well

- Ensure people with dementia and their families are consulted and involved in changes or development of services to meet their needs.
- Continued focus on supporting people with dementia to live in their own homes.
- Ensure care homes are able to meet the needs of someone with dementia and provide high quality, personalised care, including staff that are well trained.
- Ensure carers (particularly older carers) receive information and support to maintain their own health and wellbeing to enable them to continue with their caring role.

Appendix A Dementia Profile Somerset and CLOCS

Section	Indicator	Period	England	Larger CCGs with older population*	Somerset	Commissioning Localities in Somerset: Bridgwater	Central Mendip	Crewkerne, Chard and Ilminster	East Mendip	North Sedgemoor	South Somerset	Taunton	West Mendip	West Somerset	Deprivation quintiles of practices within Somerset: 1 most deprived	2	3	4	5 least deprived
Prevalence	Dementia: Recorded prevalence (all ages)	2014/15	0.7	0.8	1.0	0.7	0.7	1.0	0.9	1.1	1.0	1.0	1.0	0.9	0.7	1.1	0.8	1.1	1.1
	Dementia: Recorded prevalence (aged 65+)	Sep 2015	4.27	4.07	4.09	3.99	3.85	3.58	4.14	4.02	4.39	4.31	4.34	2.75	3.88	4.29	3.80	4.18	3.89
Preventing well	Smoking: Recorded prevalence (aged 15+)	2014/15	18.4	17.0	18.0	22.0	19.4	16.8	18.2	16.2	17.6	17.7	17.0	16.9	23.8	19.0	18.0	15.5	13.5
	Obesity: Recorded prevalence (aged 16+)	2014/15	9.0	8.8	7.9	9.8	7.1	8.6	6.8	8.8	7.7	6.5	7.6	9.3	10.1	8.0	7.7	7.2	6.7
	Hypertension: Recorded prevalence (all ages)	2014/15	13.8	14.3	16.1	14.7	14.7	19.0	16.2	16.9	16.2	14.7	16.2	19.3	14.3	16.5	15.7	17.4	16.6
	Stroke: Recorded prevalence (all ages)	2014/15	1.7	1.9	2.3	2.1	1.8	2.5	2.1	2.6	2.0	2.2	2.2	3.3	2.0	2.3	2.2	2.3	2.5
	Diabetes: Recorded prevalence (aged 17+)	2014/15	6.4	6.0	6.5	6.8	5.5	7.3	6.0	7.0	6.4	6.3	6.2	7.1	6.5	6.9	6.3	6.5	6.4
	CHD: Recorded prevalence (all ages)	2014/15	3.2	3.4	3.8	3.7	3.4	4.2	3.1	4.5	3.7	3.6	3.6	5.3	3.7	4.1	3.5	3.8	3.9
	Depression: Recorded prevalence (aged 18+)	2014/15	7.3	7.6	7.7	6.4	9.5	8.1	7.0	5.5	8.6	8.4	7.6	7.4	6.4	8.2	8.5	7.7	6.9
Diagnosing well	DEM003: Blood tests recorded (den.incl.exc.)	2014/15	74.7	72.9	62.0	85.3	47.2	61.1	55.3	69.4	57.8	46.5	59.8	81.3	79.1	65.1	58.4	50.5	60.0
Living well	DEM002: Dementia care has been reviewed last 12 months (den.incl.exc.)	2014/15	77.0	75.5	49.3	77.2	51.4	45.7	48.8	43.0	38.2	49.2	40.6	78.1	76.4	41.2	50.8	41.4	51.5
Supporting well	Dementia: Ratio of inpatient service use to recorded diagnoses	2013/14	65.1		54.5														
	Dementia: DSR of emergency admissions (aged 20+)	2013/14	779		595														
	Dementia: DSR of emergency admissions (aged 65+)	2013/14	3046		2348														
	Dementia: Short stay emergency admissions (aged 20+)	2013/14	25.5	25.5	28.7														
	Dementia: Short stay emergency admissions (aged 65+)	2013/14	25.4	25.4	28.6														
	Alzheimer's disease: DSR of inpatient admissions (aged 20+)	2013/14	146		109														
	Alzheimer's disease: DSR of inpatient admissions (aged 65+)	2013/14	574		423														
	Vascular dementia: DSR of inpatient admissions (aged 20+)	2013/14	128		91														
	Vascular dementia: DSR of inpatient admissions (aged 65+)	2013/14	505		361														
	Unspecified dementia: DSR of inpatient admissions (aged 20+)	2013/14	336		298														
	Unspecified dementia: DSR of inpatient admissions (aged 65+)	2013/14	1327		1180														
Dying well	Directly Age-Standardised Rate of Mortality: People with dementia aged 20+	2013	187		171														
	Directly Age Standardised Rate of Mortality: People with dementia aged 65+	2013	746		681														
	Deaths in Usual Place of Residence: People with dementia aged 65+	2013	66.6	72.0	74.6	60.6	77.3	62.0	62.8	84.4	71.4	83.9	71.7	70.2	69.0	78.1	73.1	73.0	73.6
	Place of death - care home: People with dementia aged 65+	2013	58.6	63.5	67.9	51.4	77.3	54.0	55.8	76.6	65.4	79.2	62.8	63.8	59.8	73.2	65.4	67.0	68.5
	Place of death - hospital: People with dementia aged 65+	2013	32.6	27.3	24.7	40.3	22.7	36.0	32.6	15.6	27.2	16.5	27.7	27.7	30.4	20.7	27.4	26.7	23.6
	Place of death - home: People with dementia aged 65+	2013	7.4	7.8	6.0	8.3	0.0	8.0	7.0	7.8	5.3	3.5	7.4	6.4	8.8	4.6	6.7	4.5	5.5

Lower than Somerset
Similar to Somerset
Higher than Somerset

* aggregated from all known lower geography values

References

[i] Health Matters: Midlife approaches to reduce dementia risk, Public Health England (2016) https://www.gov.uk/government/publications/health-matters-midlife-approaches-to-reduce-dementia-risk/health-matters-midlife-approaches-to-reduce-dementia-risk

[ii] Knapp M, Prince M, Albanese E, Banerjee S, Dhanasiri S, Fernandez J-L, Ferri C, McCrone P, Snell T & Stewart R (2007) Dementia UK. A report to the Alzheimer's Society on the prevalence and economic cost of dementia in the UK, produced by King's College London and the London School of Economics, London: Alzheimer's Society, accessed 10/2/16 www.alzheimers.org.uk/News_and_Campaigns/Campaigning/PDF/Dementia_UK_Full_Report.pdf

[iii] Norton S, Matthew FE, Barnes DE, Yaffe K, Brayne C. Potential for primary prevention of Alzheimer's disease: an analysis of population-based data. The Lancet Neurology 2014; 13(8): 788–794

[iv] Alzheimer's Society (1) (2014) Opportunity for Change https://www.alzheimers.org.uk/dementia2014 (accessed 29/2/16)

[v] Centre for Economics and Business Research (2014) http://www.cebr.com/reports/cost-of-dementia-to-business/ (accessed 29/2/16)

[vi] NICE quality standard Dementia: independence and wellbeing (QS30) 2013 www.nice.org.uk/guidance/qs30

[vii] Department of Health. Dementia A state of the nation report on dementia care and support in England. 2013 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/262139/Dementia.pdf (accessed 29/2/16)

[viii] National Dementia Intelligence Network briefing: Reasons why people with dementia are admitted to a general hospital in an emergency (2015) http://www.yhpho.org.uk/default.aspx?RID=207311

[ix] Policy Paper: Prime Minister's challenge on dementia 2020 (2015) https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020#fnref:14 (accessed 29/2/16)

[x] Alzheimer's Society (2) (2014) Local dementia prevalence data by local authority, clinical commissioning group and parliamentary constituency https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2496 (accessed 29/2/16)

[xi] HSCIC Personal Social Services Survey of Adult Carers in England, 2014-2015. www.hscic.gov.uk/pubs/psscarersurvey1415

[xii] National Dementia Action Alliance www.dementiaaction.org.uk/

[xiii] Blackfriars Consensus on promoting brain health (2014) Public Health England & UK Health Forum http://nhfshare.heartforum.org.uk/RMAssets/Dementia/Blackfriars%20consensus%20%20_V19c.pdf

[xiv] NICE guideline Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset, (NG16) 2015 http://www.nice.org.uk/guidance/ng16 (accessed 17/2/16)

[xv] Robinson L, Gemski A, Abley C, et al. The transition to dementia: individual and family experiences of receiving a diagnosis: a review. International Psychogeriatrics 2011;23:1026-43

[xvi] Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities. All-Party Parliamentary Group on Dementia (July 2013) https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1857 (accessed 15/2/16)

[xvii] Moriarty J, Sharif N and Robinson J. Black and minority ethnic people with dementia and their access to support and services (2011) http://www.scie.org.uk/publications/briefings/files/briefing35.pdf (accessed 10/2/16)

[xviii] Russ T, Batty GD, Hearnshaw GF, Fenton C and Starr JM. Geographical variation in dementia: systematic review with meta-analysis. International Journal of Epidemiology. 2012;1–21 (10):1093

[xix] Clark A, Bradford L and Robertson J (2010) Dementia care at home in rural and remote areas: Summary findings of literature review. Centre for Rural Health Research and Policy, University of Aberdeen www.abdn.ac.uk/crh

[xx] Public Health England (2015). Prevalence of dementia in population groups by protected characteristics: A systematic review of the literature

[xxi] Emerson E, Baines S, Allerton L & Welch V. Health Inequalities & People with Learning Disabilities in the UK: 2011 Improving Health and Lives Learning Disability Observatory

[xxii] Dementia and People with Intellectual Disabilities: Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia. 2015. Royal College of Psychiatrists http://www.bps.org.uk/system/files/Public%20files/rep77_dementia_and_id.pdf (accessed 25/2/16)

[xxiii] Llewellyn P. The needs of people with learning disabilities who develop dementia: a literature review. Dementia: the International Journal of Social Research and Practice 2011; 10(2): 235-247

[xxiv] Peel E & McDaid S 'Over the Rainbow' Lesbian, Gay, Bisexual and Trans People and Dementia Project http://dementiavoices.org.uk/wp-content/uploads/2015/03/Over-the-Rainbow-LGBTDementia-Report.pdf (accessed 10/2/16)

Dementia Wellbeing: Crosswalks

	Preventing Well	Diagnosing Well	Supporting Well ⟷	Living Well	Dying Well
"i" Statements	I was given information about reducing my personal risk of dementia	I was diagnosed in a timely way and told about research	Those around me and looking after me are supported	I feel included and I am treated with dignity and respect	I am confident my end of life wishes will be respected
NICE Guideline	Prevention	Diagnosis and assessment	Integration	Promote independence	Palliative care and pain
NICE Quality Standard 2010 (1)		Memory Assessment	Carers, Respite, Care Plan, Information	Choice BPSD(3) Liaison	Palliative Care
NICE Quality Standard 2013 (2)		Concerns Discussed	Needs	Advocates, Housing, Choice, Relationships, Leisure, Community	
Prime Minister's Challenges (1) (5)	Prevention	Diagnosis, Treatment by 2025	Meaningful Care, Continuity	Dementia Friendly Settings, Awareness	End of Life Care
NICE risk reduction	Guidance for prevention				
NICE Pathway (1)		Services Investigation Information	Supporting Carers Intergrated Services	Choice, Independence Living, Hospitals Treatments	End of Life
OECD (4)	Risk Reduction	Diagnosis	Supporting Carers Social Care Co-ordinated Care	Safe Communities Environments Technology Health Services	Preferred Place of Death

(1) Training - common to all areas.
(2) Includes wellbeing and choice evaluation
(3) BPSD – Behavioural and Psychological Symptoms of dementia
(4) Organisation for Economic Co-operation and Development
(5) 2012, 2015

SOMERSET ENGAGEMENT ON DEMENTIA 2015-16

1. During the year running up to the new Somerset Dementia Strategy local organisations have engaged with service users, staff and the public in a a number of ways. This has included:

- A large public event in January 2016 hosted by Somerset CCG for all health and care professionals, commissioners, providers, service users, carers, voluntary and charitable organisations. The event had a focus on Diagnosing Dementia but also covered the whole pathway with guest speaker Professor Alastair Burns, National Clinical Lead for Dementia and presentations from a range of local organisations.
- A stakeholder workshop which included members of the Somerset Dementia Strategy Group and interested others from the January event. This workshop looked at the structure and content of the new Somerset Dementia Strategy
- A public event hosted by Somerset County Council in a community setting to gather views on mental health and dementia
- Annual service level formal engagement as required within contractual arrangements
- Informal engagement and feedback in a number of settings and agencies

2. The Dementia Action Alliance (DAA) has developed 'I' statements in its national Dementia Declaration as shown below, and these provide excellent reference points for all organisations considering the development of new services or during service reviews.

The National Dementia Declaration is based on 7 'I' Statements:

1. I have personal choice and control or influence over decisions about me.
2. I know that services are designed around me and my needs.
3. I have support that helps me live my life.
4. I have the knowledge and know-how to get what I need.
5. I live in an enabling and supportive environment where I feel valued and understood.
6. I have a sense of belonging and of being a valued part of family, community and civic life.
7. I know there is research going on which delivers a better life for me now and hope for the future.

http://www.dementiaaction.org.uk/nationaldementiadeclaration

3. When discussing the reasons why a diagnosis of dementia might be delayed, the most common views were:

- Stigma of being 'demented'
- Fear
- Lack of understanding of:
  - Risk factors
  - Different types of dementia, e.g. early onset
- Perception there is nothing that can be done – 'no cure'
- Impact on relationships; work; driving
- Isolation – no one there to notice
- Confusion:
  - Whose responsibility is it to make diagnosis?
  - GP or consultant?
  - Where is diagnosis data extracted from?
  - Which codes?

4. People attending events have been asked what they felt priorities should be over and above striving to meet national guidance. Below are some specific responses from a range of individuals/agencies.

Response 1: *Age UK Somerset*
• Recognition and understanding at the point of diagnosis. • More education and information given to patients – clear and concise information needs to be given so that patients and carers are able to understand each step that needs to be taken and what support is available • More involvement in everyday social activities that help keep the patient stimulated and not necessarily within a 'dementia focussed' setting • Education of the general public on how and what to expect with dementia patients, information on why certain behaviours are linked to certain types of dementia • Local health services working in partnership with the voluntary sector that can provide outlets for patients and carers
Response 2: *Reminiscence Learning*
Regarding the plan to refresh the Somerset Dementia Strategy – I would like to propose that our regional and national award winning intergenerational dementia awareness Archie Project is introduced to primary schools across Somerset (see file link below).

The Archie Project

We are delivering this successful project across Somerset linking approximately 20 schools and care homes and we know from the testimonials the difference that is making to improve dementia awareness across the generations. As these children are the workforce of our future we feel this is a priority group to target for dementia awareness to reduce the fear and stigma often associated.

As this project has grown and evolved throughout the years, there are many benefits for all generations, please see links to videos below which as you will see are endorsed by Angela Rippon.

https://www.youtube.com/watch?v=U8BiInbYH0M

http://youtu.be/6eATnjPVeK8

Suggestion 3: *Associate Specialist in Old Age Psychiatry*

As part of the refresh of the Somerset dementia strategy, I feel that the dementia pathway should be reviewed.

My suggestions would be:

1. Some of the straight forward dementia diagnoses could be undertaken in primary care, and those which are complex or uncertain would need to be seen in secondary care. There could be a stepped approach to care, so that secondary care focuses on the patients who are the most complex, challenging, or where the diagnosis is unclear. I think there are benefits to patients if they are seen locally, by a doctor they know. GP's would need to be able to request a CT head scan to undertake a full assessment and there may be training needs. The risks would be possibly missing a diagnosis of dementia or diagnosing dementia when there is no evidence. The risk could be reduced by close links between primary and secondary care, and easy access to specialist opinion when there are any doubts about diagnosis.

2. Memory medications could also be started and stopped in primary care, as well as in secondary care. The benefits are that it is easier for patients to be seen by their GP and memory medication started locally and reviewed if there are side-effects. Evidence now indicates that patients may deteriorate if memory medications are discontinued.

Routine follow-up of patients on memory medication is therefore not necessary and is not targeting those patients most in need.

3. Follow-up should be targeted to those most in need and be easily accessible.

4. Focus on prevention strategies, post diagnostic support and psychosocial interventions.

Suggestion 4: *GP and carer for wife (also doctor) who has early onset*

My suggestion is that thought needs to be given to the capabilities and continuing participation in working life. For instance, on many days, my wife not only retains great knowledge from her medical experience but also gives the benefit of her insight and understanding of many conditions.

I am sure that many who suffer from this condition are written off, discounted and discouraged from work and that our society is poorer.

Suggestion 5: *Health Promotion Manager – Public Health*

Carolyn Arscott

Prevention - Increase focus on dementia prevention, getting messages out to people in mid-life that a healthy lifestyle can reduce their risk of developing dementia, especially vascular dementia is very important. This could have a beneficial outcome for individuals and potentially reduce the need for funding services.

Suggestion 6: *Somerset GP*

The Dementia Event in Bridgwater (January 2016) really looked at dementia from a very different perspective and was hugely helpful.

I am a GP, but I am so glad I attended. It totally changed my view of dementia. I learnt so much.

My mum died of Alzheimers at the age of 89 last year and my sister and I were her main carers. I wish I had as full an understanding as I do now.

I would like to suggest an educational day for GPs just on Dementia like the

SGPET Dillington days which are already running very successfully: maybe just collaborating with them and using their template. I really think that GPs are not that knowledgeable about dementia. Combining the more clinical type information highlighted on the Cambridge Course with the information from the Bridgwater dementia day would really help raise awareness and interest and hopefully improve care.

5. ORGANISATIONAL FEEDBACK

5.1 Below are some extracts of feedback received by dementia related service providers from their service users.

Alzheimer's Society

5.1 The Alzheimer's Society have shared a thank you letter which indicated how helpful its services were to this particular family and the following extract from it indicates the importance of 'going out':

'We joined the Memory Cafe at Street, then Singing for the Brain at Wells and Ansford all three of which I enjoy very much because it gets us out and mixing with people in a similar position as ourselves. We always get a lovely cup of tea from the Volunteers who are vital help to us all, and cake and biscuits, have a lot of laughs with everyone and a good sing!'

5.2 Below are some messages from 2015 responders to the Society's regular surveys:

- Service Users
  - 30 were aged over 65; and 6 under 65
  - 25 responses required assistance
  - One respondent said they were unable to use phone support as they are deaf
  - One suggested having easy to find support/emergency contact if carer was ill
- Carers:
  - Community understanding of dementia could be better
  - Independence of carer could be supported more
  - In the responding group there were four times the number of female carers compared male
  - 23 aged 45-79; and 9 over 80
  - One person commented on lots of paperwork from various agencies but difficult to put your hand on the telephone number you need
  - One commented on needing someone to sit with their person with dementia for an hour or so if a neighbour wasn't available
  - Evening activities suggested so that carers who work can take the service user
  - It was suggested that 'ex-carers' could become coaches to new ones

Somerset Partnership NHS Foundation Trust

5.3 The Quarter three 2015-16 Friends and Family Test for Somerset Partnership NHS Foundation Trust's Mental Health Inpatient Wards (dementia) shows that 85% of responders were likely to recommend the service.

Somerset Dementia Gap Analysis

AWARENESS AND WORKFORCE

The national picture

- The public and professionals should be well informed about dementia
- Health checks to undertake risk assessment
- Importance of timely diagnosis and the benefits this brings in terms of long term outcomes

The Somerset picture

- Awareness raising sessions (Dementia Friends) are held/provided in, by, and for all commissioners and providers and in association with the voluntary and not-for-profit for staff and the public
- Dementia Friendly Communities (DFCs) in place in Chard, Crewkerne, Ilminster, Wells, Bridgwater, Watchet and Minehead
- Taunton, Yeovil, Wellington and Langport are developing as DFCs
- Archie Project – intergenerational awareness raising
- Health Checks countywide
- Practice engagement and support to increase diagnosis rates

The Somerset ambition:
The public and care professionals are well informed about dementia; and Dementia Friendly communities/organisations are 'the norm'

What's working well in Somerset

- Collaborative working between public, private and voluntary/not for profit organisations
- Archie Project courses within schools
- Dementia Awareness week activities
- Volunteers supporting people with dementia across a range of locations
- Dementia Friends and Dementia Friend Champions in GP practices and some are Dementia Friendly Communities

What do we need to improve?

- Increased and maintained DFCs
- DFC gaps identified in Burnham on Sea, Williton and Exmoor
- Public sector staff should all receive dementia awareness training
- Public sector organisations should lead the way as Dementia Friendly Communities and as Dementia Friendly Employers
- Somerset organisations' sharing of awareness sessions with each other
- destigmatising interactions such as Archie Project within available funding
- Raise awareness of the vascular/lifestyle related dementia risk factors
- Raise awareness of conditions which can develop e.g. mood disorders
- Engagement of all types of social landlords

PREVENTING WELL

The national picture

- Increasing evidence around prevention of dementia, especially around lifestyle factors leading to vascular dementia and some evidence around Alzheimer's
- Information about risk reduction to be given to people at optimum times (especially during mid-life)
- Health Matters document
- The Prime Minister's Challenge on Dementia (PMCD) recommends improved public awareness and understanding about risk factors, living healthily, and campaigns around healthy ageing
- NHS Health Check programme provides information on dementia to those aged 65 – 74

The Somerset picture

- Information on dementia risk reduction given to those aged 65-74 following an NHS Health Check
- Somerset has a similar position to other areas on smoking prevalence, percentage of active and inactive adults, those who are very overweight, diabetes, high blood pressure, coronary heart disease and depression
- There are some variations across Somerset commissioning localities for the above
- Preventative strategies in primary care for cardiovascular disease

The Somerset ambition:
Raise awareness of how lifestyle factors can contribute to dementia

What's working well in Somerset

- NHS Health Check programme
- Smoking cessation programme
- Drug and alcohol programmes
- Promotion of physical activity across the life course
- Public Health promotion of risk factors for dementia
- Primary care preventative strategies for cardiovascular disease

What do we need to improve?

- Increase awareness of public importance of a healthy lifestyle to reduce risk of developing dementia and signpost to support
- Awareness of all health and social care providers of modifiable risk factors that can reduce risk of people developing dementia and other health conditions that place someone more at risk of developing dementia – stroke, type 2 diabetes, high blood pressure, Parkinson's disease
- Awareness of the greater prevalence of dementia among certain ethnic groups

DIAGNOSING WELL

The national picture

- Getting a diagnosis is important as it can help people to understand and manage their condition, make informed decisions about their life, plan for the future and ensure that their carers and families can access the information and support that they may need
- The Prime Minister's Challenge on Dementia has set a target that two thirds of people with dementia should have a formal diagnosis
- People should have access to a good quality and timely assessment in a supportive environment

The Somerset picture

- 1 in 24 adults over the age of 65 are diagnosed with dementia
- In 2015, there were an estimated 9000 people with dementia in Somerset. Of these, 5300 have a diagnosis.
- The overall diagnosis rate in Somerset is 62.1% (31.3.16
- Diagnosis rates vary across areas of Somerset
- The 65+ prevalence rate of in Somerset is slightly lower than the England average but slightly higher than the average rate in the South West of
-

The Somerset ambition:
Timely diagnosis and treatment is the rule rather than the exception

What's working well in Somerset

- There has been a slow but steady increase in diagnosis rates over recent years
- Memory Assessment Clinics
- County-wide Dementia Advisor Service is in place to offer people support following their diagnosis, as well as carers?
- A range of dementia awareness initiatives to encourage people to talk about dementia and seek advice if they have concerns about their memory.
- There is a dedicated website called Dementia Somerset offering information and advice

What do we need to improve?

- To increase the diagnosis rate so that by March 2017, 69% of people have a diagnosis
- We need to improve the equity of diagnosis rates across Somerset or validate the variation;
- Provide education to improve GP and public understanding of living positively with dementia
- Dementia diagnostic pathway should be reviewed
- Annual GP and staff training and education including the benefits of timely diagnosis
- Ensure that diagnosis is accurately recorded
- Increased recording of initial blood tests that can rule out other potential causes of symptoms e.g. vitamin B12 deficiency
- Increase dementia reviews undertaken by GPs following dementia diagnosis
- Training for social workers to spot the early signs of dementia

LIVING WELL

The national picture

- The PMCD and the Care Act 2014 provides an expectation that people with dementia and their carers are supported in a personalised way to optimise wellbeing
- Personal budgets can be considered for people living with dementia
- Aim for all tiers of local government to be part of a local Dementia Action Alliance
- Expectation of increase in personal budgets
- Medicines management initiative to reduce use of anti-psychotic medicines

The Somerset picture

- Somerset Choices website provides signposting to services, information and resources www.somersetchoices.org.uk
- Memory Clinics across the county
- Singing for the Brain in some parts of Somerset
- Memory Cafes in some parts of Somerset
- Several Dementia Friendly Communities and more developing
- Archie Project – intergenerational activities to aid understanding and remove stigma of dementia
- People with dementia who have Continuing Health Care are offered a personal health budget
- Rural county with limited public transport

The Somerset ambition:
People have access to personalised and appropriate care and support to optimise their wellbeing

What's working well in Somerset

- Reducing social isolation projects across Somerset such as Forget me Not Club
- Somerset Choices website provides signposting to services, information and resources www.somersetchoices.org.uk
- Memory Clinics across the county
- Singing for the Brain in some parts of Somerset
- Memory Cafes in some parts of Somerset
- Several Dementia Friendly Communities
- Collaborative training opportunities for health and care professionals including care home staff
- Monitoring of use of anti-psychotic medicines

What do we need to improve?

- reducing loneliness, stress, and risk of depression in people with dementia and their carers
- Widely accessible group and individual activities
- Number of dementia friendly communities, organisations, employers, and friends – with the public sector leading by example
- Resources available online to support communities, organisations and employers to become dementia friendly
- Dementia friendly access/transport to the natural world
- Intergenerational activities
- Use of assistive technology
- Strategic planning by all agencies to meet the forecast increase in people living with dementia by 2035

SUPPORTING (CARERS) WELL

The national picture

- PMCD commitment to 'a right to stay' for relatives when a person is nearing the end of their life in hospital or a care home
- Employers encouraged to have carer friendly policies
- Aims to support people to live at home longer
- Expectations of the Care Act 2014 for all care agencies to focus on 'Wellbeing'

The Somerset picture

- Many GP practices have staff who are Carers' Champions and some have Dementia Friend Champions – these staff are able to provide information, signposting and advice to carers
- GP practices have registers of carers
- Alzheimers Society and Compass Carers are commissioned to support Somerset Carers
- Somerset Carers Network for mental health
- Age UK and Alzheimers Society provide training for volunteers who support people with dementia (including early onset)
- Somerset Dementia Website www.dementiasomerset.org.uk
- www.somersetchoices.org.uk

The Somerset ambition:
Carers are supported to have a life of their own during and after caring for a person with dementia

What's working well in Somerset

- Visiting hours have been widely extended and overnight chair/facilities are also widely available for carers to stay with their loved ones
- Information and Advice sessions provide signposting; support advocacy; and offer support with paperwork
- Training for family carers (Somerset Partnership)
- Online resources and support from networks, websites, etc.
- Peer support

What do we need to improve?

- Access to peer support and carer networks
- Carers' willingness to acknowledge they are a carer and to be registered as a carer
- Increase numbers of organisations/employers with carer friendly policies – with the public sector leading by example and sharing good practice
- Access to individual and group activities including the local natural environment
- Support to carers own health needs
- Dementia friendly communities

DYING WELL

The national picture

- Advance care planning should be undertaken early in the course of the illness, including plans for end of life
- People with dementia and their carers should receive co-ordinated, compassionate and person-centred care towards and at end of life including access to high quality palliative care from health and social care staff trained in dementia; end of life; and bereavement support for carers
- Prescribing of antipsychotic medication for people with dementia should be reduced with less variation in prescribing levels
- Skilled assessment should ensure the person with dementia is not disabled or harmed by inappropriate care or medication

The Somerset picture

- Somerset End of Life Website providing information and signposting
- Reminiscence Learning provide training; bespoke activity cushions and books with activities for late stage dementia; sessions on 'behaviour we find difficult' and end of life
- Open visiting hours and overnight chairs
- Increasing levels of personalised advance care planning
- Volunteers supporting patients in hospitals
- 22% of patients supported to die at home (2015)

The Somerset ambition:
People with dementia and carers have choice and access to personalised, appropriate, advance care planning and support

What's working well in Somerset

- Visiting hours have been widely extended and overnight chair/facilities are also widely available for carers to stay with their loved ones
- Medicines management initiatives to reduce antipsychotic prescribing
- End of Life Co-ordination and Fast Track to continuing health care (personal health budget)

What do we need to improve?

- All people with dementia have a personalised advance care plan in place well before end of life phase and a personal budget has been considered
- % of people dying in the place of choice
- Advance care plans available to urgent and emergency services
- Reduction in prescribing and in variation of prescribing of antipsychotics
- Increase numbers of Advance Care Plans and for these to include thoughts of how a personal health or integrated budget might be used

NHS
Somerset
Clinical Commissioning Group

EQUALITY IMPACT ASSESSMENT FORM

INITIAL INFORMATION

Name of policy/service: Somerset Dementia Strategy Version number (if relevant): 14	Directorate/Service: Clinical Commissioning and Somerset County Council
Assessor's Name and Job Title: Lydia Woodward, Service Development and Clinical Engagement Telephone: 01935 385026	Date: 24 May 2016
Sponsoring Director: Ann Anderson	Date:

Please refer to the Equality Impact Assessment Guidance to complete this form.

OUTCOMES
Briefly describe the aim of the policy / service and state the intended outcomes for patients and / or staff?
The Somerset Dementia Strategy is aligned to national ambitions and guidance. It aims to improve all sections of the Dementia Action Alliance 'Well Pathway for Dementia': • **Preventing well** • **Diagnosing well** • **Living well** • **Supporting (carers) well** • **Dying well** **It also aims to deliver against the Prime Minister's Challenge on Dementia 2020 and its commitments.** **Somerset is striving to improve rates of diagnosis of dementia and to remove variation in the rates of diagnosis between areas of Somerset or validate these.** **Somerset providers and commissioners will continue to work together to share learning and deliver the ambitions of the new strategy:**

- **Raise awareness of how lifestyle factors can contribute to dementia**
- **Timely diagnosis and treatment is the rule rather than the exception**
- **People have access to personalised, appropriate care and support to optimise wellbeing**
- **Carers are supported to have a life of their own during and after caring for a person with dementia**
- **People with dementia at end of life and their carers have choice and access to personalised, appropriate, advance care planning and support.**

EVIDENCE

What data / information have you used to assess how this policy / service might impact on protected groups?

Somerset Public Health has undertaken a Somerset Health Needs Analysis for Dementia in 2016 (Appendix 1 of the Strategy)

Engagement has taken place at various levels and will continue and have a central role in the implementation of the strategy (Appendix 3 of the Strategy).

Who have you consulted with to assess possible impact on protected groups?
If you have not consulted other people, please explain why?

Protected groups have been considered within the Health Needs Analysis; for example it identifies risk factors for dementia:

- **Ageing**
- **Gender**
- **Learning disabilities**
- **Ethnicity**

No changes to services are currently planned therefore no impact expected, appropriate groups will be consulted with during the delivery of the strategy.

ANALYSIS OF IMPACT ON EQUALITY

The Public Sector Equality Duty requires us to **eliminate** discrimination, **advance** equality of opportunity and **foster** good relations with protected groups. Consider how this policy / service will achieve these aims.

Please read 'Questions to Ask' in the EIA guidance.
Note: in some cases it is legal to treat people differently (objective justification).[1]

- ***Positive outcome*** *– the policy/service eliminates discrimination, advances equality of opportunity and fosters good relations with protected groups*

[1] See definition of 'objective justification' in guidance

- ***Negative outcome*** *– protected group(s) could be disadvantaged or discriminated against*

- ***Neutral outcome*** *– there is no effect currently on protected groups*

Please tick to show if outcome is likely to be positive, negative or neutral. Consider direct and indirect discrimination, harassment and victimisation.

Protected Group	Positive outcome	Negative outcome	Neutral outcome	Reason(s) for outcome
Age	yes			Older people are more likely to be assessed and if appropriate receive diagnosis and support for dementia
Disability[2]	yes			Risks associated with Learning Disability highlighted and dementia care in general will improve for people with dementia
Religion and belief			yes	No service changes planned at this stage but any proposed will be mindful of religion and belief
Sex	yes			58% of unpaid carers are women and the strategy aims to increase support to carers
Sexual Orientation			yes	There is no proposed change that would affect this group and no increased risk of dementia
Gender Reassignment			Yes	There is no proposed change that would affect this group and no increased risk of dementia
Race	Yes			Ethnicity is an increased risk for dementia and the strategy notes that some groups associate dementia with negative thoughts/stigma. Increased awareness and education will help with all this.

[2] Includes mental impairment, learning difficulty (dyslexia). Full definition in guidance.

Protected Group	Positive outcome	Negative outcome	Neutral outcome	Reason(s) for outcome
Pregnancy and maternity	possibly			It is rare for a person to develop dementia in reproductive years but it is possible to have early onset dementia.
Other Disadvantaged Groups (for example carers, veterans and military staff, homeless)	yes			Carers of people with dementia are identified in the Strategy as a specific group which Somerset wishes to improve support for

MONITORING OUTCOMES Monitoring is an ongoing process to check outcomes. It is different from a formal review which takes place at pre-agreed intervals.
What methods will you use to monitor outcomes on protected groups?
The Prime Minister's Challenge on Dementia 2020 provides a list of commitments which Somerset will aim to achieve. The Somerset Dementia Strategy Group will oversee delivery of the strategy and develop an action plan which will be reviewed and reported on annually. An EIA will be completed with each report.
REVIEW
How often will you review this policy / service? (Minimum every three years)
Progress against the Strategy will be reported annually and the Strategy as a whole will be reviewed in 2020 at the latest.
If a review process is not in place, what plans do you have to establish one?

n/a

IMPLEMENTING THE POLICY / SERVICE

Negative outcomes – action plan

An Equality Impact Assessment **cannot be signed off** until negative outcomes are addressed. What actions you have taken / plan to take to remove / reduce negative outcomes?

N/A

Action taken / Action to be taken	Date	Person responsible
N/A		

NEGATIVE OUTCOMES cont.
If a negative outcome(s) remain explain why you think implementation is justified.