

**Clinical Commissioning Group Governing Body
Paper Summary Sheet
Date of Meeting: 22 July 2014**

For: PUBLIC session PRIVATE Session

For: Decision Discussion Noting

Agenda Item and title:	GOV/14/07/09 Wiltshire Dementia Strategy
Authors:	Rhian Bennett (Commissioning & Contracts Lead, Wiltshire Council) Victoria Hamilton (Associate Director of Commissioning (Mental Health), NHS Wiltshire Clinical Commissioning Group)
Lead Director/GP from CCG:	Ted Wilson - Group Director - N&E Wiltshire Group, Wiltshire Clinical Commissioning Group Dr Celia Grummitt, Wiltshire Dementia GP Lead, Wiltshire Clinical Commissioning Group
Executive summary:	This paper provides an update to the Governing Body on the Wiltshire Dementia Strategy 2014 – 2021 with a recommendation to formally approve the strategy for implementation. In addition, it is noted that the final strategy is also being presented to the Wiltshire Health and Wellbeing Board on 31 st July for formal approval and that it has been shared with the Health Select Committee for their meeting on 15 th July.
Evidence in support of arguments:	The focus on dementia has been increasing in recent years, both at a national and local level. It is now considered as a priority area for action, largely due to the increasing population with dementia, the cost of this to services, communities and families and the variable quality of care that many people with dementia receive from health and care services. The Wiltshire JSA supports this identifying that the number of people with dementia will nearly double by 2030 in Wiltshire, whilst the Health and Wellbeing Strategy acknowledges the increasing population living with dementia and identifies it as an area for action. The key national policies include the Living well with dementia: a National Dementia Strategy (Department of Health, 2009) and Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015 (Department of Health, 2012). These place a focus on improving health and care services and dementia friendly communities, as well as improving people's awareness and understanding of dementia, the importance of early diagnosis and ongoing support and the role of services in ensuring that people can live well with dementia. Wiltshire Council and NHS Wiltshire Clinical Commissioning (CCG)

developed the draft Wiltshire Dementia Strategy 2014 – 2021 and held a public consultation from February to May 2014 during which time individuals and organisations with an interest or experience of dementia were invited to participate.

Following the consultation, an evaluation of the responses was undertaken. Responses indicate that people are supportive of the strategic direction that is being set and agree with the intentions of Wiltshire Council and NHS Wiltshire Clinical Commissioning Group. However, there were a range of comments received that highlight a number of themes that people felt were of importance and should be strengthened further within the strategy.

Work has taken place to identify the responses of a strategic nature and the strategy has been amended accordingly to reflect these (see Appendix 1). These include work on the following:

- The role of commissioned services in the delivery and implementation of the strategy
- The support available to people who fund their own care
- A pathway within primary care through to community services.
- The role of primary care and need for it be dementia friendly
- The role and importance of safeguarding across all activity
- Improved discharge planning from hospital
- The role and provision of advocacy services
- The support options available for people with dementia when carers become unwell and unable to provide care
- The role and model of advanced dementia care
- The importance of ensuring that services are developed upon an equitable basis across Wiltshire
- The role of staff training in ensuring that carers are involved, listened to and supported
- The need to ensure that services are joined up and have good communication routes so that people are provided with coordinated care and do not fall in to gaps.

As well as the responses of a strategic nature, there were a number of responses to the consultation that require further work to understand the issues being presented, that focus upon specific service areas or that are concerned with implementation, operational and monitoring issues. These responses will be reflected in the commissioning action plan which will be presented to the Joint Commissioning Board, following agreement of the strategy.

In addition to the comments received upon the content of the strategy, consultation responses also highlighted the importance of ensuring that progress on the strategy and its implementation is provided to all interested individuals, organisations and groups at regular intervals in to the future. Work is now commencing on developing an engagement plan that will sit alongside the strategy and which will outline how this will be undertaken.

The updated strategy will shortly be presented to the Health and Wellbeing Board on 31st July for formal approval and has been shared with the Health Select Committee which is meeting on 15th July.

<p>Who has been involved/ contributed:</p>	<p>In developing the strategy, work has taken place to engage with people with dementia and their carers and families in Wiltshire. The Wiltshire Dementia Delivery Board has overseen this engagement process and has been active in the development of the strategy.</p> <p>The consultation process was open to the general public, groups and organisations in Wiltshire who had an interest in dementia and wished to participate by providing feedback on the draft strategy.</p> <p>All relevant stakeholders were informed and invited to participate with communications being circulated to the general public, people with dementia and their carers, health and social care organisations, area boards, councillors, voluntary and community organisations, Healthwatch and town and parish councils. Consultation packs were available online, in hard copy by request and as reference copies in all public libraries. In addition to this, presentations were made to the Trowbridge and Corsham Area Boards and HealthWatch coordinated two consultation events.</p> <p>In total over 100 responses were received by individuals, groups of people with dementia and their carers and organisations that support and care for people living with dementia. Wiltshire Council and NHS Wiltshire Clinical Commissioning Group would like to thank all those who participated.</p>
<p>Cross Reference to Strategic Objectives:</p>	<p>This draft strategy supports the four main outcomes of the Health and Wellbeing Strategy, including the dementia-themed ambitions set out in the action plan. It does this through placing an emphasis on the following:</p> <ul style="list-style-type: none"> • Making dementia everyone’s business so that people can live well in supportive and inclusive communities. • Providing care and support to promote people’s independence, health and wellbeing and quality of life. • Delivering improvements to care and health services so that they are able to deliver quality services that meet the needs of people with dementia. • Wherever possible, supporting people within their own homes, with care and support being delivered as close as possible.
<p>Communication Issues:</p>	<p>Communications are being led by NHS Wiltshire Clinical Commissioning Group and Wiltshire Council in partnership. There are no issues to report.</p>
<p>Engagement and Involvement:</p>	<p>Please see “Who has been involved/contributed” section.</p>
<p>Financial Implications:</p>	<p>Although there are no immediate financial implications arising from the consultation on the Dementia Strategy, it is expected that the number of people living in Wiltshire with dementia is highly likely to increase by about 28% by 2020. It is anticipated that unless additional ‘new’ funding is made available within the future, the delivery of the strategy will be achieved through using existing health and social care spend in an efficient and effective manner in order to meet the anticipated increase in demand.</p> <p>As such the implementation plans will need to have a cost / benefit analysis of actions to ensure that the Council and CCG remain within their current funding, and proposed changes approved within this envelope, or alternative savings / funding found to cover investments.</p>

	<p>The implementation of the strategy and the associated investment will also be aligned with the implementation of other health and social care priorities which will deliver services to people living with dementia including the Older People's Accommodation Strategy, Care Act and Better Care Plan. This investment and related savings will need to be analysed in detail as the strategy is implemented through the Action Plan at Appendix H and service plans, and then built into the future financial planning of both commissioning organisations.</p>
<p>Review arrangements:</p>	<p>The Wiltshire Dementia Delivery Board will be responsible for overseeing the implementation and review of the strategy.</p>
<p>Risk Management:</p>	<p>The main risks associated with the Dementia Strategy are:</p> <ul style="list-style-type: none"> a) The increasing number of people living with dementia in Wiltshire and increased demand being placed upon services. The strategy addresses this through a number of measures which include: <ul style="list-style-type: none"> i. Developing dementia friendly communities so that people are supported by their local community and informal networks to live well with dementia and maintain their independence and wellbeing. ii. Working with non-specialist services to ensure that they are trained and supported to meet the needs of people with dementia, so that they can support people who require their services, with specialist services only being required at critical points in time. iii. To monitor, review and implement improvements in existing services, including those that have seen recent investment including the dementia adviser service, primary care and the memory service. iv. To look at alternative ways of delivering care and support, which can meet demand within the budgets available. b) That due to the financial pressures on all public sector organisations the additional funding required to meet increasing demand is not available. This will be managed through: <ul style="list-style-type: none"> i. Identification of strategic priorities with investment allocated accordingly. ii. Consideration of alternative ways of delivering care and support which can meet demand within the budgets available. iii. Engagement with the general public, customers and partner organisations to communicate risks, agree priorities and consider innovative solutions. c) Raised expectations of what the dementia strategy will deliver amongst the general public, customers and partner organisations as a result of the strategy development and consultation. This will be managed through ensuring that priorities identified from the consultation are balanced within the overall resources available to deliver the strategy. This will be

	<p>clearly communicated within the final strategy and through a continuing programme of engagement with the general public, customers and partner organisations which will allow for priorities and progress to be communicated.</p> <p>The significant risks associated with <u>not</u> implementing this strategy would include:</p> <ul style="list-style-type: none"> a) Placing the wellbeing, independence and safety of people with dementia and their carers and families at significant risk through a lack of suitable provision of care and support services. b) An increased demand on health and social care services and budgets when people reach crisis due to a lack of preventative, skilled and responsive services. c) A failure of the statutory bodies within Wiltshire to respond to national guidance, policy and legislative duties.
National Policy / Legislation:	The key national policies include the Living well with dementia: a National Dementia Strategy (Department of Health, 2009) and Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015 (Department of Health, 2012).
Equality & Diversity:	An equality analysis has been undertaken (see Appendix 2) and this will be reviewed shortly now that the draft strategy has been through the formal consultation process.
Other External Assessment:	Prior to entering formal consultation, the draft strategy was agreed by Wiltshire Council Cabinet and NHS Wiltshire Clinical Commissioning Group Governing Body. It was also presented to the Health Select Committee on 14 th January 2014 and has been the subject of attention of the AWP / Dementia Task Group over recent months. A wide range of partners and stakeholders have been invited to review the strategy as part of the consultation process and submit responses on the document. In addition, an update on the consultation was presented to the Health and Wellbeing Board on 22 nd May.
What specific action re. the paper do you wish the Governing Body to take at the meeting?	The Governing Body is asked to formally approve the Wiltshire Dementia Strategy.



Wiltshire Dementia Strategy

2014 – 2021

Introduction

This strategy has been developed by Wiltshire Council and NHS Wiltshire Clinical Commissioning Group (CCG) in conjunction with various local partners from the statutory and voluntary sector, as well as through talking to people with dementia and their carers and families about their experiences in Wiltshire (see appendix A).

The main purpose of the strategy is to ensure that people with dementia and their carers and families are able to live well and are supported to do so through being able to access the right services and support at the right time, whether that be from organisations or their local community.

However, it is recognised that minimising people's risk of developing dementia is also an important aspect of care for the population as a whole. Thus this strategy also highlights the links to other relevant strategies and health promotion activities and services that target the risk factors.

We want the message of this strategy to be that it is everybody's business to support people with dementia and their carers and families in Wiltshire and not just the reserve of specialist care services.

For this to happen we need to understand:

- where we are now
- where we want to be by 2021
- how we get there and what success will look like

This document will address each of the above points so that people can understand the commitments and priorities of Wiltshire Council, NHS Wiltshire Clinical Commissioning Group and other organisations that support people with dementia and their carers and families in Wiltshire.

The focus of this strategy is all people with dementia and their carers and families, right from the point that they have concerns about their memory through to the end of their lives. For clarity, several different phrases will be used within the document to describe different groups of people:

- People with dementia – People who have dementia (whether diagnosed or undiagnosed)
- Carers – People who provide unpaid support to people with dementia – they are normally family members, partners, friends or neighbours.
- Care workers - Care workers – Paid staff who support the person with dementia and their carer(s).

The word 'dementia' describes a group of symptoms that occur when the brain is affected by specific diseases and conditions, such as Alzheimer's disease and vascular dementia, amongst others. Symptoms of dementia vary but often include loss of memory, confusion and problems with speech and understanding.

Dementia is progressive and as it advances so do the symptoms, up to the point that people will have difficulty in undertaking everyday tasks and will need increasing support and assistance from others.

In Wiltshire dementia is seen as a long term condition, although it is acknowledged that many specialist dementia services are provided by a mental health organisation (Avon and Wiltshire Mental Health Partnership) and that people with dementia may also have needs relating to their mental health.

Whilst there is currently no cure for dementia, there are a number of types of support that can help someone to live well with dementia. Support and treatment can also often help to alleviate symptoms or to slow the progression of the dementia for many people.

Section 1: Where we are now

National and local policy, legislation and guidance

Within recent years there has been an increased focus on dementia at a national level due to a number of factors, including a rising older population and therefore increasing number of people with dementia coupled with a lack of awareness and understanding of dementia leading to stigmatisation and poor quality care.

As a result of this, there is now a substantial body of national policy, legislation and guidance that advises and directs organisations on how to best support people with dementia and their carers and families (see Appendix B for more detail). Amongst this there are two pieces of policy which are most relevant to this strategy:

Living well with dementia: a National Dementia Strategy (Department of Health, 2009)

The strategy focuses on driving improvements for people with dementia and their carers and families in three main areas:

- Awareness and understanding – Improved public and professional awareness and understanding of dementia and the stigma associated with it.
- Early diagnosis and ongoing support – Good quality early diagnosis and intervention; good quality information for those with diagnosed dementia and their carers; and easy access to care, support and advice following diagnosis and follow on medication management.
- Living well with dementia – High quality health and social care services so that people can live well with dementia until the end of their lives.

Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015, (Department of Health, 2012)

This aims to deliver a number of actions that focus on three main areas:

- Driving improvements in health and care
- Creating dementia friendly communities that understand how to help
- Better research

Locally, the previous Wiltshire Dementia Strategy developed in 2009 has provided the context and direction for health and social care provision for people with dementia and their carers and families. However, many people with dementia and their carers will have needs that can be met by non-specialist services and/or have other needs that do not relate to their dementia e.g. housing, other long term conditions etc. There are a number of other local strategies (listed in Appendix B) which cover these areas and so this document should be read in conjunction with them.

People at risk of developing dementia

Age is considered the highest risk factor for dementia, and the percentage and numbers of older people in the population is increasing. However, there are a high number of people who have modifiable risk factors for dementia who can be targeted.

In addition to age, risk factors for developing dementia include vascular disease such as cardio-vascular disease and stroke plus smoking, excessive alcohol use, obesity, diabetes, hypertension and raised cholesterol levels (NICE, 2013). Those who have depression are also at higher risk of developing dementia. There are also those who have a genetic risk for dementia, though this area is not yet fully understood. There are people who will have more than one of these risk factors.

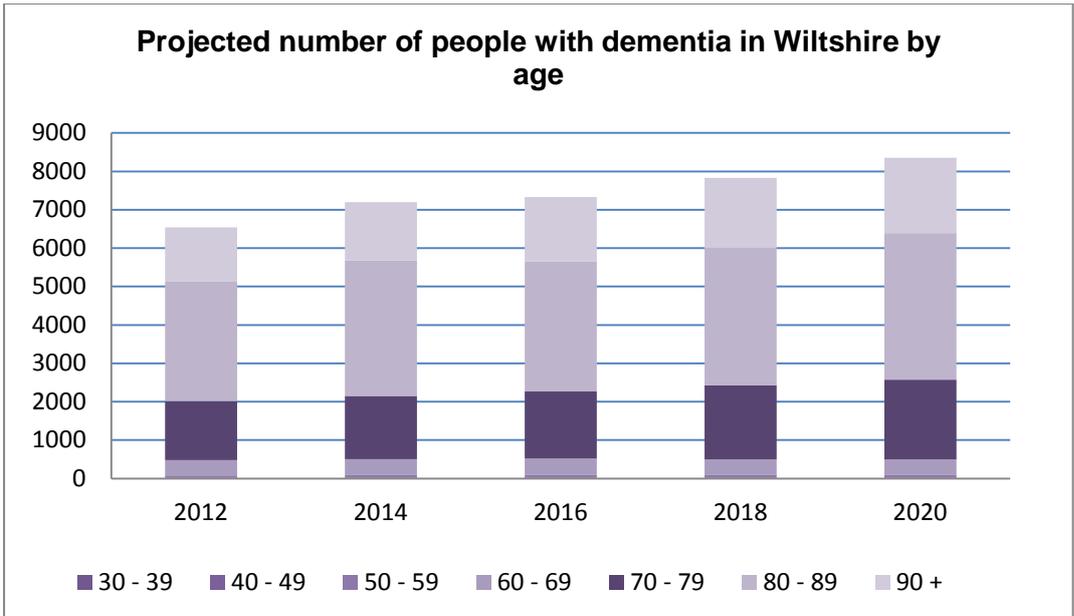
It has also been found that keeping one's mind active and also being socially active can also help reduce the risk of dementia. There is concern that due to the rural geography of Wiltshire, people are more likely to be socially isolated.

People with dementia and their carers and families in Wiltshire

Wiltshire is a predominantly rural county and in 2011 had a total population of 470,981, 21.5% of whom were at retirement age (65+ years for men and 60+ years for women). This compares to 19.4% for the whole of England. This is significant because dementia is most common in the older population as its prevalence rises significantly with increasing age. One in three people over 65 will develop dementia, whilst a much smaller proportion of the population (about 1 in 1400) will be affected by early onset dementia which occurs in younger age groups.

It is difficult to give exact figures for the number of people with dementia within the population as reported rates differ widely depending on the criteria and study methods used.

According to figures produced by Oxford Brookes University and the Institute of Public Care (2013), the population of Wiltshire with dementia in 2012 was 6,538 and they estimate that this will increase by 27.8% in 2020 – this equates to an additional 1800 people with dementia. The age groups that will see the largest increases are 90 + years old (40% increase) and 70 – 79 years old (36% increase), whilst there will be a decrease of 12% in people aged 40 – 49 years old.



Information source: Projecting Older People Population Information System and Projecting Adult Needs and Service Information (Oxford Brookes University and Institute of Public Care, 2013)

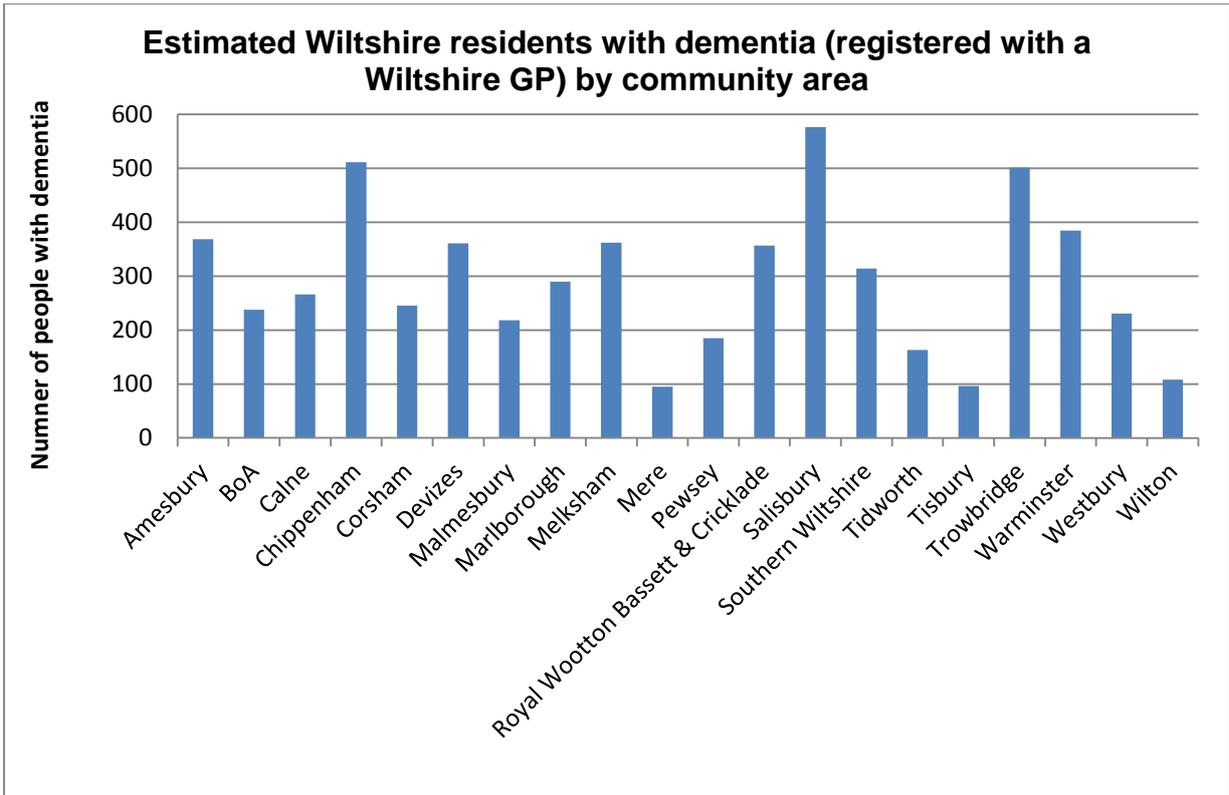
The NHS Commissioning Board and NHS South of England (2013) have also produced information about the population of Wiltshire with dementia through a tool called the Dementia Prevalence Calculator. This tells us that in 2013/14 there are an estimated 6,512 people with dementia in Wiltshire. Looking at the information in more detail we can get a better understanding of our local population (more detailed information can be found in Appendix C):

Diagnosis

According to the Dementia Prevalence Calculator, the current diagnosis rate in Wiltshire is 37.4%. This is the number of people with dementia who have received a formal diagnosis which has been recorded by their GP. This means that 62.6% of the population who have a dementia do not have a diagnosis i.e. this is an unmet need. Nationally there is a drive to promote early and timely diagnosis to ensure that people can access the care and support they require, as well as being able to plan for their futures.

Community areas

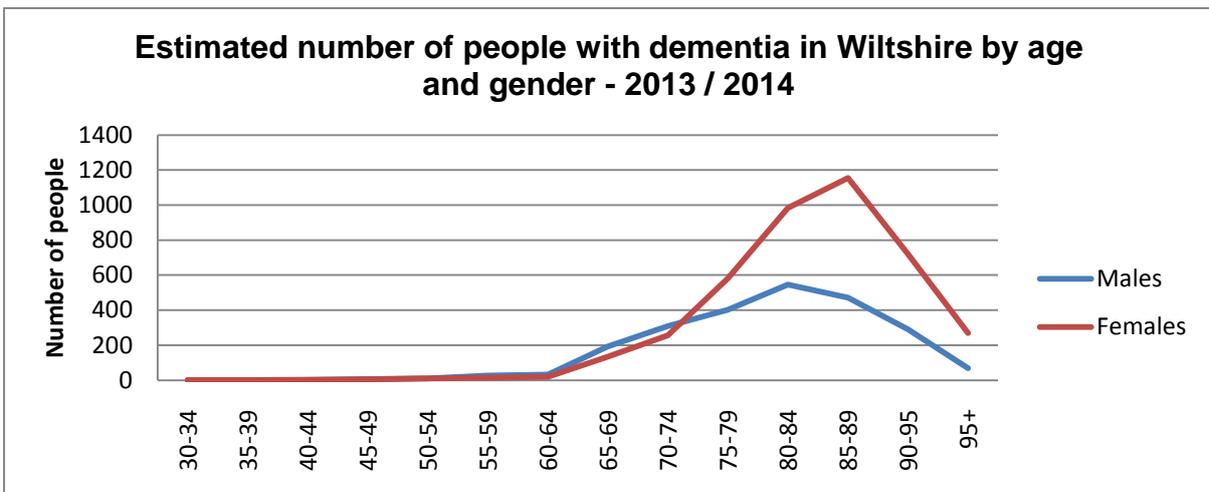
The following graph provides a picture of where Wiltshire residents who are registered with a Wiltshire GP surgery and have dementia live.



Information source: Dementia Prevalence Calculator (NHS Commissioning Board and NHS South of England, 2012)

Age and gender

In line with national figures the majority of people with dementia in Wiltshire are women (64%) whilst only 36% are men. However it is worth noting that of the 135 people who have early onset dementia (this is when the individual is under the age of 65 years old) 59% are male and 41% are female. This again reflects the national trend. Over 4,500 of people with dementia are aged 80 years of age or older, and of these 1,348 are 90 years or older.



Information source: Dementia Prevalence Calculator (NHS Commissioning Board and NHS South of England, 2013)

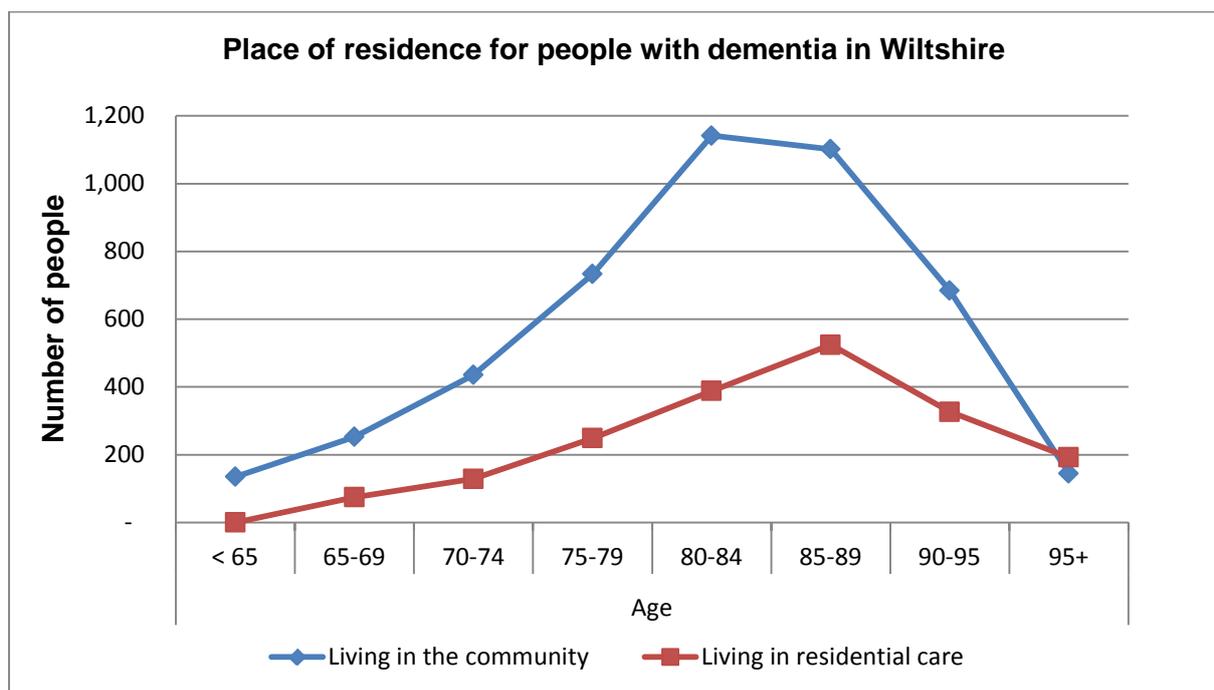
Severity of dementia

Dementia is progressive, meaning that as time passes people's symptoms will increase and they will require more help and support to live well. It is recognised that there are three broad levels of dementia, which reflect the impact that the dementia has on the individual and their ability to care for themselves. In 2013, the Dementia Prevalence Calculator identified that of the population with dementia in Wiltshire:

- 55% have mild dementia
- 32% have moderate dementia
- 13% have severe dementia

Place of residence

According to national statistics, 71% of people with dementia live within the community, whilst 29% in residential care. If applied to the Wiltshire population this equates to 4,629 people living in their own homes, whilst 1,899 live in residential care settings (residential and nursing care homes). Of those people who live in the community in their own home, Alzheimer's Society (2012) estimate that one third live alone.



Information source: Dementia Prevalence Calculator (NHS Commissioning Board and NHS South of England, 2013)

End of Life

The National End of Life Care Programme (2012) highlighted that in 2008 - 2010 in 18.3% of deaths in Wiltshire, the cause of death on the death certificate mentioned Alzheimer's, dementia and senility. This compared to the England average of 17.3%.

In Wiltshire this represented an average of 766 deaths per year and of these the place of death was as follows: 11% at home, 62% in a care home, 26% in a hospital and 0% in a hospice.

Carers

In relation to the support provided by carers, according to figures produced by Alzheimer's Society (2012) it has been estimated that there are approximately 5,454 family members and friends acting as carers to people living with dementia in Wiltshire.

Other aspects of the Wiltshire population

In relation to ethnicity and religion, there is no specific data about the population of Wiltshire who have dementia. However, we do have information from the 2011 Census which relates to the whole population. Whilst we need to take in to consideration that this may not be truly reflective of people with dementia, it would indicate that:

- The majority of people are White British (93%) followed by Other White (which mainly consists of European Accession countries, including Poland) and then Other Asian (which includes the Filipino and Polynesian communities).
- The majority of people are Christian, followed by having no religion or not wishing to state their religion.

It is vital to remember that there are certain groups of people with dementia in Wiltshire who may be small in number, but whose needs are as equally as important to meet as the wider population of people with dementia and . further work is needed to look at how this is best achieved. These groups include, but are not limited to:

- People with early onset dementia (are aged under 65 years old)
- People with learning disabilities and dementia
- People with dementia from black and minority ethnic communities
- People with dementia who live alone without family support
- People with rarer forms of dementia
- People with dementia and other health conditions e.g. Parkinson's, sight or hearing impairments
- People who live in rural areas and / or lack transport

An equality analysis (Appendix H) provides more information.

Investment in services

Using estimates from Knapp and Prince (2007) and the Dementia Prevalence Calculator, the annual financial cost of dementia in Wiltshire in 2013/14 is approximately £152 million. This includes accommodation, care provided by formal care agencies, as well as approximately £55 million from informal care by family and friends.

In 2013/14 NHS Wiltshire Clinical Commissioning Group project they will invest £7.5 million into supporting people with dementia, their carers and families. This sum includes memory services, the dementia Local Enhanced Service (LES), voluntary sector services, inpatient accommodation, community support and acute hospital liaison services.

During the same period, Wiltshire Council project they will spend £14.8 million supporting people with dementia and their carers and families. This sum includes commissioning specialist voluntary sector services and individual social care packages and placements where people have a recorded dementia that has been diagnosed.

There is also approximately £0.1million invested through a budget that contains pooled funding from Wiltshire Council and NHS Wiltshire Clinical Commissioning Group that is targeted at supporting carers of people with dementia.

In addition to the amounts identified above, it should be noted that many services funded by Wiltshire Council and NHS Wiltshire Clinical Commissioning Group which people with dementia and their carers and families access are not specialist and so it has not been possible to include the associated costs within these figures. Examples include non-specialist carer support services, hospital care and community services for older people. In addition many people who have dementia do not have a formal diagnosis and so have not been included in the figures above.

In addition to this, there is a notable contribution from the voluntary sector with specialist dementia organisations bringing approximately £395,000 of fundraising in to the county in 2012/13. Alzheimer's Support also estimates that their unpaid volunteers give an average of 101 hours support each week. According to the formula recommended by Volunteering England, this volunteering activity is worth £1,324 per week or approximately £69,000 annually.

Current service provision in Wiltshire

The services currently available to people with dementia and their carers and families have been delivered to date under the direction of the previous Wiltshire Dementia Strategy which was developed in 2009 and the Prime Minister's Challenge on Dementia (2012). Successes that have been delivered during this time can be found in Appendix E.

The Wiltshire Dementia Delivery Board has been responsible for mapping current service provision for people with dementia and their carers and families in Wiltshire. This exercise was undertaken in 2013 and the model of care developed by Dr Edana Minghella (2012) was used as the framework (see Appendix D). This model of care identifies the following six phases that people are likely to experience when living with dementia:

- Recognising memory problems
- Learning it's dementia
- Planning for the future
- Living well with dementia
- Managing at more difficult times
- Care at end of life

Minghella identifies a range of proposed services within each of the above phases that should be in place if people are to receive the care that they may need when living with dementia. It was agreed that this was the desired model of care in Wiltshire and so was used as the basis for looking at the services that already exist in the county and where there were gaps or further improvements were required. A further phase of 'Reducing Risk' has also been added to cover the work taking place to promote health and wellbeing, and therefore reduce the risk factors within the general population associated with the development of dementia.

It was identified that many of the current services accessed by people with dementia and their carers and families are non-specialist services i.e. they support people with a range of needs. These services include support for carers, hospital care, Help to Live at Home etc.

There were also a number of current specialist services identified that are designed to specifically work with people with dementia and their carers and families and these include dementia community activities, the dementia adviser service, specialist mental health service etc.

In addition there are a number of services that support people to reduce their risk of developing dementia. These focus on reducing the risk of cardiovascular disease, stroke and diabetes and aim to reduce the levels of obesity, smoking, excessive alcohol use, cholesterol and mental health conditions such as depression.

These current services can be seen in the table below on page 12.

The Wiltshire Delivery Board also looked at where the gaps were in provision for people with dementia and their carers and families and where there could be improvements made to existing services in order to deliver better care and support. These gaps and improvements included support for specific groups of people with dementia (including people who live alone, people with early onset dementia and people with learning disabilities), advanced care planning and out of hours support during a crisis.

Appendix E provides more information about the services and gaps that were identified, as well as describing what current services look like.

Reducing risk	Recognising concerns	Learning it's dementia	Planning for the future	Living well with dementia	Managing at more difficult times	Care at end of life
NHS Health Checks ~ Wiltshire Stop Smoking Service ~ Wiltshire Substance Misuse Service ~ Active Health ~ Lift Psychology	Memory Service - Dementia assessment, diagnosis and treatment				GP out of hours service ~ Complex Intervention & Therapy Team	
	Primary care - Dementia assessment, diagnosis and treatment			Day services ~		
	Dementia CQUIN in acute hospitals		Life Story Groups (Alz Support) ~	Specialist Home & Community Support Service ~	Acute hospital liaison service ~	My Home Life programme in care homes ~
	Awareness raising activities and resources	RUH Community geriatrician	Home improvement agency – part of Help to live at Home service (Equipment ICESS)	Movement for the Mind ~	Acute hospitals ~	Continuing Health Care ~
				Singing for the Brain ~	Inpatient assessment service ~	Hospices
				Active Health Programme ~	MH Care Home Liaison Service ~	
				Counselling	Emergency Duty Service ~	
					STARR scheme ~	
					Extra Care Housing ~	
					Care homes ~	
				Respite		
				Social care ~ HTL@H ~ Telecare ~ DPs ~ Health community teams ~ Court of Protection		
			Support for people who fund their own care			
	Safeguarding ~ Primary care liaison service ~ Dementia Adviser Service ~ Memory cafes ~ Library resources ~ Support for carers (groups, training, assessments, breaks) ~ Advocacy ~ Good Neighbour Scheme ~ Wiltshire Citizens' Advice Bureau ~ Health Matters sessions					

What do people with dementia and their carers and families tell us?

There is a large amount of research that has taken place at a national level that shares the experiences of people with dementia and their carers and families and much of this can be applied to Wiltshire.

However, in developing this strategy, work has taken place to meet with people with dementia and their carers and families in Wiltshire to find out what is important to them in relation to their lives with dementia and what their experiences of care and support services have been locally.

The things that people with dementia and their carers and families said are important to them and are going well include:

- Community activities such as memory cafes and Singing for the Brain
- Support from the voluntary sector
- Being able to meet and socialise with other people living with dementia
- Day care
- Telecare

The things that people told us are important to them and need improving include:

- Support for people living alone
- Support to plan for the future
- Direct payments
- Transport
- Support for carers
- Understanding of professionals of the challenges of living with dementia
- Processes, paperwork and the language used
- More time
- The general public's understanding of dementia
- Support from businesses
- Person centred care

There were some things that people with dementia and their carers and families told us are important to them, but people have had mixed experiences:

- Support from GPs
- Specialist mental health services
- Knowing where to go for information and help
- Carer involvement
- Acute hospitals
- Care in care homes

More detailed information about the experiences of people with dementia and their carers and families can be found in Appendix F.

Section 2: Where we want to be by 2021

Ambition

It is our ambition that all people with dementia and their carers and families in Wiltshire are treated as individuals and are able to access the right care and support, at the right time so that they can live well with dementia within supportive and understanding communities. This will be supported by providing care and support to promote people's independence, health and wellbeing and quality of life

It is recognised that people will experience different phases of living with dementia, all of which are important, but which can differ vastly. In the model of care developed by Mingejlla (2012) these phases are as follows:

- Recognising memory problems
- Learning it's dementia
- Planning for the future
- Living well with dementia
- Managing at more difficult times
- Care at end of life

The strategy's ambition is equally applicable across all of these stages, as is the aim to minimise the number of times that people need to move within their life with dementia in order to receive the care they need, whether that be to a hospital, residential or nursing care home setting. It is also the intention of this strategy to ensure that services are joined up so that it is easy for people to access the care and support that they need without falling in to gaps between services.

The ambition will be achieved by taking a proactive approach to supporting people to stay within their home and community wherever possible through the provision of care and support so that they can live well on a daily basis. At difficult times, such as crisis or illness, if people do need to travel to health or care services that cannot be delivered within their community, e.g. acute hospitals and/or specialist inpatient hospitals, this will be for as short a time as possible, with the aim to get the person back to their home as soon as possible.

Whilst it is acknowledged that there will be periods of time when people will require specialist dementia care services, it is the aim that people will be supported by generic, non-specialist care services for as long as possible and that these will be skilled and knowledgeable to appropriately support people with dementia and their carers and families.

In addition to this, it is the aim of this strategy to ensure that local communities are supportive, understanding and inclusive of people with dementia so that people can live well as active and valued members of our society. This will be achieved through implementing the concept of dementia friendly communities across Wiltshire.



This ambition and the following objectives, outcomes and principles will contribute to the service model that this strategy will deliver. In terms of delivery these elements will be structured across the phases of care identified by Minghella (2012) to form an action plan that organisations will sign up to (see Section 3 for more information).

With regard to reducing people’s risk of developing dementia, we will ensure that this strategy is linked in to the various other relevant strategies for risk factor reduction.

Objectives

The objectives of the strategy are to:

- Keep up to date with the latest knowledge and research regarding dementia prevention, services and care and ensure these are integrated as appropriate into the initiatives and services provided
- Ensure that there are awareness raising resources within all sectors and generations of the community to support and encourage people to seek advice when they have concerns about their memory
- Ensure that there are processes in place across services to identify people who may have concerns about their memory

- Work with primary care and specialist health services to ensure that people are able to obtain a timely and quality assessment and diagnosis
- Ensure that following diagnosis, people (including those who fund their own care) are able to access good quality information and advice so that they can make informed and timely decisions and plan for their future
- Ensure that people have access to dementia community based services and activities that support them in their local communities
- Ensure people with dementia have access to appropriate specialist therapeutic services
- Ensure that people have access to peer support opportunities so that they can share their experiences and socialise with people in similar circumstances
- Support people to remain in their own home (whether that be a family home, extra care or residential care setting) for as long as possible through the provision of a range of care and support services
- Support people to remain independent for as long as possible through the use of telecare (assistive technology) and dementia friendly environments
- Ensure that there are a range of appropriate housing options for people with dementia, where their care needs can be met appropriately
- Ensure that carers are recognised and supported to care for as long as they are able and willing to do so through providing appropriate care and support.
- Work with local communities so that they are inclusive and supportive of people with dementia and their carers and families
- Ensure that there are good quality services in place that are able to appropriately support people with dementia and their carers at more difficult times in their lives e.g. access to specialist hospitals for assessment and treatment
- Ensure that people have access to support so that they are able to plan for end of life and have a good death
- Ensure that staff who work with people with dementia and their carers and families have the skills, knowledge and support to do so
- Ensure that people with dementia are encouraged and supported to make decisions and remain in control of their lives for as long as possible
- Ensure that people with dementia and their carers and families are kept safe, whilst a proactive approach to risk enablement is maintained.
- Ensure that services are joined up and have good communication routes so that people are provided with coordinated care and do not fall in to gaps.

Outcomes

Wherever organisations, services and support may be involved in a person's life, by becoming signatories to this strategy, they are committing to improving services so that people with dementia and their carers and families in Wiltshire are able to agree with the following outcomes:

- I am encouraged and given the opportunity to have a healthy, active lifestyle.
- I was diagnosed early and with the correct medication and treatment package.
- I understand the implications of my diagnosis in order for me to make good decisions and provide for future decision making.
- I get the treatment and support which are best for my dementia and my life.
- I am treated with dignity and respect.
- I know what I can do to help myself and who else can help me, especially in times of crisis.
- Those around me and looking after me are well supported.
- I can enjoy life.
- I feel part of a 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.

These outcomes were developed by the Department of Health (2010) for use by local areas to ensure that they are working to the standards in the National Dementia Strategy.

Principles

All organisations are committed to ensuring that in the delivery of the services and support to people with dementia and their carers and families they will:

- Promote health, wellbeing and social inclusion.
- Work together with partners to develop and deliver reliable, high quality and sustainable services that put the individual at the centre of delivery.
- Be person centred and recognise and understand the individual and their identity, wishes and abilities.
- Enable people to maintain their independence and have freedom to live as they wish to do so for as long as possible and appropriate.
- Provide support and services to people with dementia and their carers and families that are compassionate, honest, accessible and equitable.
- Help to keep people safe from harm, whilst also taking a positive approach to risk.
- Listen to people with dementia and their carers and families and communicate with them effectively.
- Involve people with dementia and their carers in service delivery and recognise that involvement will look different for different people.
- Treat people with respect and dignity.
- Learn from their experiences of supporting people with dementia to inform future service improvements.
- Be flexible to the changing needs of people with dementia and their carers and families, whilst promoting continuity of care.

Section 3: How we get there and what success look like

Priorities

A number of areas have been identified as priorities for the initial period of this strategy. These include, but are not limited to:

Reducing risk

- To ensure that the strategy is linked to other relevant strategies involved in minimising people's risk of developing dementia, emphasise the dementia prevention aspect of their activities and that their outcomes are being achieved with any support that dementia services are able to provide.

Recognising memory problems

- Awareness raising within the general public and across mainstream services e.g. leisure and libraries to tackle the stigma about dementia and ensure that there is improved understanding of dementia and the impact that it has on people's lives
- Ensure that health services, e.g. GPs and hospitals, have in place standard processes to identify, diagnose and treat people when they may have problems with their memory.

Learning it's dementia

- Monitor and review the delivery of timely and quality assessments and reviews by GPs and the memory service and make improvements as necessary.
- Undertake a research project to identify the understanding of dementia within black and minority ethnic communities and access to services in order to inform future service delivery.
- Work to make primary care dementia friendly.
- Develop a pathway within primary care through to community services.

Planning for the future

- Monitor and review the effectiveness of the dementia adviser service in supporting people to access good quality and timely information
- Monitor and review the interface between the dementia adviser service with other GP based services and make improvements as necessary.
- Commission a generic information portal linked to the Council's website and which will also be available in GP practices and libraries. Information included on the portal will include community services, universal services as well as registered services.

Living well with dementia

- Continue to work to promote and improve services for carers, including carers breaks
- Continued oversight and maintenance of treatment packages by general practitioners.
- Establish dementia friendly communities across Wiltshire.
- Work with mainstream care and health services, including Help to Live at Home, Neighbourhood Teams and GPs to ensure that they are able to appropriately support people with dementia and their carers and families.
- Work with public services, e.g. libraries and leisure, to ensure that they are able to appropriately support people with dementia and their carers and families to access their services.
- Further implement Help to Live at Home and its principles, including the delivery of initial support and outcome based care planning and delivery.
- Implement personal budgets and develop a personalisation policy.
- Develop links with the Community Campus programme.
- Develop community therapeutic activities.
- Develop new care homes delivering specialist dementia and nursing care.
- Support to improve the quality of care in different settings including care homes.
- Develop new extra care schemes, designed to meet the needs of people with dementia.
- Explore the use of Staying Well plans and Crisis plans

Managing at more difficult times

- Work to shape and develop dementia related specialist mental health services, including the role and model of advanced dementia care, to ensure timely access to specialist assessments and treatment as required, including the support specialist services provide to other services e.g. care homes and hospitals.
- Ensure that all emergency / response / intermediate care services are skilled and knowledgeable about working with people with dementia
- Monitor and review progress within hospitals to deliver high quality dementia care in all relevant departments and disciplines.
- Analysis of triggers for people reaching crisis / requiring a move of home to receive appropriate care in order to inform future commissioning.
- Further develop and implement care options to support people with dementia when carers become unwell and unable to provide care

Care at end of life

- Implementation of the End of Life Strategy, which will include people with dementia as a target group.

Overarching

- Development of a needs assessment for people with learning disabilities and dementia to inform future service developments and commissioning.
- Development of a needs assessment for people with early onset dementia to inform future service developments and commissioning.
- Ensure that all staff supporting people with dementia have the training, skills and qualities to do so to a high standard both in relation to how they support people with dementia, but also how they involve and support carers and family members.
- Ensure that there is good quality information and support to people who fund their own care
- Work to ensure that whilst people are supported to maintain their independence, safeguarding is a key consideration in all activity, including identifying and addressing underlying factors that contribute to abuse and to increasing people's awareness of abuse and the steps to take when someone has concerns
- Ensure that there is provision of good quality advocacy services in Wiltshire.
- Ensure that services are developed upon an equitable basis across Wiltshire.

Action plan, measuring success and governance

Supporting this strategy is an action plan that will be implemented (see Appendix A), which not only looks to address the priorities listed, but also the gaps identified within the mapping exercise and improvements required by people with dementia and their carers.

The action plan will be led by Wiltshire Council and NHS Wiltshire Clinical Commissioning Group and will be delivered in partnership with the organisations from which they commission services through commissioning and contract management processes and partnership working. It is also acknowledged that a number of organisations bring in to Wiltshire a significant income through fundraising activities. Wherever possible, Wiltshire Council and NHS Wiltshire Clinical Commissioning Group will work with these organisations to ensure that any new service developments complement existing service provision and strategic approaches.

This action plan will be accompanied by a set of success measures, which will be updated on an annual basis and overseen by the Wiltshire Dementia Delivery Board. The success measures will provide the Board with information to identify whether the implementation of the action plan has made a difference to people with dementia and their carers and families. In addition, there will be an engagement plan that will sit alongside the strategy to ensure that there are processes in place for the general public and all interested parties to receive progress updates on the strategy and to provide feedback on services. The Wiltshire Dementia Delivery Board is a multi-agency board that is chaired by NHS Wiltshire Clinical Commissioning Group and consists of representatives from Wiltshire Council, health and social care organisations and the voluntary sector. It meets bi-monthly and is accountable to the Joint Commissioning Board.

Also in existence and with a role in delivering this strategy are the following groups:

- Carers Reference Group
- Wiltshire Alzheimer's Partnership Group
- Salisbury Foundation Trust Dementia Steering Group
- Transforming community services

References

The following documents and information have been used in the development of this strategy:

Alzheimer's Society (2012) Dementia 2012: A National Challenge

Department of Health (2009) Living well with dementia: a National Dementia Strategy

Department of Health (2010) Quality outcomes for people with dementia: building on the work of the National Dementia Strategy

Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015

Knapp, Martin and Prince, Martin (2007) Dementia UK. Published by Alzheimer's Society

Minghella, Dr Edana (2012) Transforming models of care for people living with dementia: Improving experiences and outcomes for people with dementia and their carers and families

National End of Life Care Programme (2012) National End of Life Care Profiles for Local Authorities: Wiltshire. Published by National End of Life Care Intelligence Network

NHS Commissioning Board and NHS South of England (2013) Dementia Prevalence Calculator - www.dementiaprevalencecalculator.org.uk/

NICE (2013), Dementia Pathway Overview, <http://pathways.nice.org.uk/pathways/dementia#content=view-node%3Anodes-risk-factors-and-prevention>

Our Health South West (2013) Dementia Care www.ourhealth.southwest.nhs.uk/service-data/indicator/diagnosis-rate.html?id=12253

Oxford Brookes University and Institute of Public Care (2013) Projecting Older People Population Information System - www.poppi.org.uk/

Oxford Brookes University and Institute of Public Care (2013) Projecting Adult Needs and Service Information - www.pansi.org.uk

Wiltshire Council (2012) Wiltshire's diverse communities: Results from the Census 2011

Wiltshire Council (2013) Wiltshire Census 2011- Selected Statistics Profile Tool: Wiltshire Unitary Authority

APPENDIX 2 - EQUALITY ANALYSIS

Name of Service/Policy/Project/Decision to undergo Equality Analysis:
Wiltshire Dementia Strategy
Key contact person & others involved: Key contacts: Rhian Bennett (Commissioning & Contract Lead – Dementia, Wiltshire Council) & Susan Dark (Dementia Lead, Wiltshire Clinical Commissioning Group) Partners involved: Wiltshire Dementia Delivery Board
Date Completed: 19 th November 2013
Review date (at least annually): May 2014 – following the formal consultation process of the draft dementia strategy
Identify aims:
<p>The aim of the strategy is to ensure that all people with dementia and their carers and families in Wiltshire are treated as individuals and are able to access the right care and support, at the right time so that they can live well with dementia within supportive and understanding communities. This will be supported by providing care and support to promote people's independence, health and wellbeing and quality of life.</p> <p>It is recognised that people will experience different phases of living with dementia, all of which are important, but which can differ vastly. These are as follows:</p> <ul style="list-style-type: none"> • Recognising memory problems • Learning it's dementia • Planning for the future • Living well with dementia • Managing at more difficult times • Care at end of life <p>The strategy's ambition is equally applicable across all of these stages, as is the aim to minimise the number of times that people need to move within their life with dementia in order to receive the care they need, whether that be to a hospital, residential or nursing care home setting.</p> <p>Whilst it is acknowledged that there will be periods of time when people will require specialist care dementia services, it is the aim that people will be supported by generic, non-specialist care services for as long as possible and that these will be skilled and knowledgeable to appropriately support people with dementia and their carers and families.</p> <p>In addition to this, it is the aim of this strategy to ensure that local communities are supportive, understanding and inclusive of people with dementia so that people can live well as active and valued members of our society. This will be achieved through implementing the concept of dementia friendly communities across Wiltshire.</p>
Collect and use evidence:
<p>The strategy includes a range of information about the population of Wiltshire living with dementia. The majority of this has been developed by applying national statistics to the Wiltshire population and includes:</p> <ul style="list-style-type: none"> • Prevalence and diagnosis rates • Severity of dementia • Place of residence • End of life • Age and sex • Distribution of the population by community area • Ethnicity • Religion / faith

- Carers

In relation to gaps in the knowledge, these include:

- Disability
- Sexual orientation
- Marriage and civil partnership

Further work is required to look at these gaps in more depth although it is likely that in many cases national statistics would be applied to the Wiltshire population. In relation to disabilities it is acknowledged that certain conditions and illnesses increase people's risk of developing dementia. This is to be addressed through the action plan of the dementia strategy, which will include the commitment to undertake a needs assessment for people with learning disabilities and dementia. This will be overseen by the Wiltshire Dementia Delivery Board which will ensure that all relevant partners and stakeholders are involved as appropriate.

Further work is also required to look at whether the people accessing services are representative of the population with dementia. This will need to be addressed through commissioning and contract monitoring arrangements.

Assess the impact:

It is the intention that the individuals that will benefit from the dementia strategy include all people who have dementia and their carers (people who provide unpaid care and support) and family members.

However there are certain groups of people with dementia for whom services have been less successful in reaching. These include:

- People with early onset dementia (are aged under 65 years old) – Due to age being a determining factor in the onset of dementia, it is noted that the majority of services for people with dementia are accessed by people who are in their 70s, 80s and 90s. It has therefore been identified that the small number of people (approx. 135 people) with early onset dementia may not feel that these services are appropriate for them. In addition the challenges that someone with early onset dementia may face are likely to be different to an older person, including employment, children and the misconception that dementia only affects older people. At present there are no services commissioned specifically for this group of individuals.
- People with learning disabilities and dementia – It has been identified that people with a learning disability, and particularly Down's Syndrome, are at higher risk than the general population of developing a dementia. In addition the assessment and diagnosis process can often be more difficult and so people may not receive a timely diagnosis and without this may not be supported appropriately to live well. However in Wiltshire little work has been undertaken to raise awareness of this or to better understand the needs of this group of people.
- People with dementia from black and minority ethnic communities – Studies at a national level have identified that further work is required across the country to better support people from BAME communities who have dementia. Within different BAME communities and cultures there are varying degrees of understanding and awareness of dementia, as well as attitudes towards caring and family duties. These can often prevent people from accessing advice and support in a timely manner. In addition health and care services are often not proactive in engaging with BAME communities or supporting people with dementia in a way that is appropriate.
- People with dementia who live alone without family support – It has been acknowledged by all stakeholders in Wiltshire that supporting people who live alone can be particularly difficult and often results in people not accessing services until they reach crisis. This can be exacerbated when people with dementia may not be aware that they are unwell and require care and support. At present no work has been undertaken to target this

specific issue.

- Couples where both individuals have dementia – On a similar note to people who live alone without support, it can also be difficult to support couples who live in their own home and both of whom have dementia.
- People who live in rural areas and those who lack transport – With Wiltshire being a predominantly rural county, people with dementia and their carers have raised concerns about transport and the difficulty in accessing services. These difficulties can often result in people not being able to access services that people who live in towns or who have access to transport can.

It has been acknowledged that from a commissioning perspective there is work to be done to better understand the needs of the above groups and how they could best be met. This work is being addressed through a number of actions within the strategy action plan which will include:

- Undertaking a number of needs assessments, including for people living alone, people with learning disabilities and people with early onset dementia.
- Developing a working group focusing upon transport issues and possible solutions
- Undertaking a project that will engage with the BAME population to identify their awareness and understanding of dementia, as well as the services that they access.

In addition to identifying areas for improvement, it is widely considered that if you get services right for people with dementia then they will be right for most people i.e. others will benefit from the improvements implemented specifically for people with dementia. In relation to the dementia strategy actions delivering these wider benefits include the following:

- The development of dementia friendly communities
- Improving the workforces understanding of dementia
- Dementia friendly environments

Ensure fairness:

The implementation of the dementia strategy is a priority as it has been identified that there is an increasing number of people with dementia in Wiltshire – by 2020 there will be a 28% increase. Not only is this affecting individuals, families and communities, but is also placing an increasing pressure upon health and care services. It is also acknowledged that people with dementia and their carers often receive care that is of variable quality and / or does not meet their needs appropriately. This is often because of a lack of understanding about dementia, systems not being flexible to making the adjustments that people with dementia require, and dementia still being a stigma for many people.

At a national level quality of life outcomes for people with dementia are often lower than for the general population. For example:

- Isolation caused by loss of social networks ability to access community activities etc
- Reduced life expectancy
- Stigmatisation of dementia and lack of public understanding

The strategy aims to improve the equity between people with dementia and the general population. This will ensure that people with dementia have an improved quality of life and are able to achieve the same outcomes in life as those without dementia. It has not been identified as excluding any particular groups, although work is required to ensure that all groups can equally benefit.

Finalise your decision:

The draft strategy has been developed through engaging with stakeholders and people living with dementia in Wiltshire.

Wiltshire Council and Wiltshire Clinical Commissioning Group have been engaging with people with dementia and their carers and family a various forums across Wiltshire. Discussions focused around identifying what is important to people in terms of living with dementia, what is working well and what could be improved.

The Wiltshire Dementia Delivery Board has overseen this engagement process and has been active in the development of the strategy. This includes representatives from the Wiltshire Council, NHS Wiltshire Clinical Commissioning Group, the Avon and Wiltshire Mental Health Partnership, Alzheimer's organisations, Carer Support Wiltshire, Wiltshire and Swindon Users Network, SWAN Advocacy, the three acute hospitals, hospices and GWH community services. They agreed the draft strategy on 19th November 2013.

In addition the draft strategy is being presented to the CCG Executive on 2nd December, CCG Clinical Executive on 10th December and Joint Commissioning Board (JCB) on 12th December for approval. The JCB will approve the draft strategy before it goes to formal consultation.

This formal consultation process will last for three months and give people the opportunity to comment of the draft strategy. It will be placed upon the Wiltshire Council website, will be sent to partners for distribution amongst their customers, staff and partners and a press release will also be developed to ensure that people who may not be contact with services can contribute.

Communicate what has happened:

People with dementia and their carers and families have been informed of the development of the strategy through the engagement sessions, as well as inclusion of an article in the Alzheimer's Support summer newsletter. Organisational partners have been informed through the Wiltshire Dementia Delivery Board.

When the draft strategy goes to formal consultation, various methods will be used to inform people and provide them with the opportunity to contribute.

Review your decision:

The draft strategy will be reviewed following the end of the formal consultation process, which will last three months, as will this equality analysis.