Wiltshire Council

Cabinet

17 June 2014

Subject: Wiltshire Dementia Strategy - Update on Public

Consultation Process

Cabinet member: Councillor Keith Humphries – Public Health, Protection

Services, Adult Care and Housing

Key Decision: No

Executive Summary

The purpose of this item is to present an update on the progress of the Wiltshire dementia strategy consultation process.

The draft Wiltshire Dementia Strategy (see Appendix 2) provides the strategic direction for Wiltshire Council and NHS Wiltshire Clinical Commissioning Group (CCG) in supporting people with dementia and their carers over the next 7 years.

The aim of the strategy is that all people with dementia 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 and can remain independent and living at home for as long as possible within supportive communities.

Following the development of the draft strategy, a consultation ran from 20 February to 19 May 2014. Wiltshire Council and Wiltshire Clinical Commissioning Group who led the development of the strategy invited the general public and interested stakeholders to participate and provide feedback on the draft document. Initial feedback and analysis of the responses (as at 15 May) from stakeholders and members of the public is presented within this paper.

Proposal

That Cabinet note the consultation process and initial draft responses on the basis that following formal analysis these will be used to review and amend the Wiltshire Dementia Strategy. The updated strategy and action plan will be presented in the near future to Cabinet for formal approval, as well as to the NHS Wiltshire Clinical Commissioning Group Governing Body.

Maggie Rae Corporate Director

Wiltshire Council

Cabinet

17 June 2014

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Consultation Process

Cabinet member: Councillor Keith Humphries – Public Health, Protection

Services, Adult Care and Housing

Key Decision: No

Purpose of Report

- This Cabinet report briefs members on the consultation process for the draft Wiltshire Dementia Strategy (see Appendix 2) which ran from 20 February to 19 May 2014. The strategy provides the strategic direction for Wiltshire Council and NHS Wiltshire Clinical Commissioning Group (CCG) in supporting people with dementia and their carers and families from the point that people notice concerns about their memory through to end of life care. It includes a commissioning action plan for 2014/2015 which details the commitments and actions that will be delivered in order to achieve the objectives and priorities identified.
- 2. Upon launching the consultation process, Wiltshire Council and NHS Wiltshire Clinical Commissioning Group invited people with an interest in dementia, whether through personal or professional experience, to contribute their comments and viewpoints. Initial feedback and analysis of the responses (as at 15 May) from stakeholders and members of the public is presented within this paper.
- 3. Cabinet is asked to note the consultation process and initial draft responses on the basis that following formal analysis these will be used to review and amend the Wiltshire Dementia Strategy. The updated strategy and action plan will be presented for formal approval at a future Cabinet meeting.

Relevance to the Council's Business Plan

- 4. The Wiltshire Dementia Strategy aims to ensure that people are able to live well with dementia through accessing the right care and support, at the right time. The strategy also meets the Business Plan outcomes of:
 - a. Wiltshire has inclusive communities where everyone can achieve their potential
 - b. People in Wiltshire have healthy, active and high quality lives

Main Considerations for the Council

Wiltshire Dementia Strategy

- 5. The draft Wiltshire Dementia Strategy (see Appendix 2) provides the strategic direction for Wiltshire Council and NHS Wiltshire Clinical Commissioning Group in supporting people with dementia and their carers over the next 7 years.
- 6. The aim of the strategy is that all people with dementia 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 and can remain independent and living at home for as long as possible within supportive communities.

Engagement and consultation

- 7. In developing the strategy, work took place to engage with people with dementia and their carers and families in Wiltshire. This involved attending various forums and talking to people about their experiences of living with dementia in Wiltshire to identify what is important to them in their life, the areas that are working well and where service improvements are required. This engagement work formed the basis of the strategy. The Wiltshire Dementia Delivery Board has overseen this engagement process and has been active in the development of the strategy.
- 8. Following the development of the strategy, a formal consultation process was held from 20 February to 19 May 2014 in order to seek feedback upon the proposed strategic direction from people who have experience of dementia, whether from personal or professional perspectives.
- 9. 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 accessible online, in hard copy by request and as reference copies in all public libraries. In addition to this, presentations have been made to the Trowbridge and Corsham Area Boards, the Westbury Memory Cafe and Healthwatch coordinated two consultation events. There has also been local press coverage in newspapers and on the radio.
- 10. Appendix 3 provides more detail on the engagement work that was undertaken in developing the strategy and throughout the consultation process.

Responses on the draft Wiltshire Dementia Strategy

- 11. Responses on the draft Wiltshire Dementia Strategy at the time of submitting this report 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. Survey responses at this point in time totalled 92 and answers to the closed survey questions may be found in Appendix 1. These responses will need to be seen alongside the interaction and responses received at a number of events including the Trowbridge and Corsham Area Boards, HealthWatch events in Chippenham and Salisbury and the Westbury Memory Café, as well as additional written feedback that was provided throughout the consultation period. People welcomed the opportunity to provide feedback through different mechanisms appropriate to their requirements.
- 12. In relation to the different elements of the strategy, there are some areas that respondents (as at 15 May) have highlighted as being of particular importance:
 - a. Within the different stages of dementia, 25% believe that 'living well' is one of the most important stages, which supports the current and future focus of services, i.e. supporting people to remain well, independent and living at home for as long as possible.
 - b. In terms of supporting groups of people who may not be as well served by current services as the wider population, responses indicate that the strategy should focus on people who live alone without family support (44%) and those people who live in rural areas and / or who do not have access to transport (27%). This is a challenge for all services, particularly given the rural nature of Wiltshire and further work is required to look at how improvements can be delivered innovatively within existing budgets.
 - c. 18% of respondents felt that one of the most important priorities for health and social care was to ensure that health services have in place standard processes that allow for early identification, diagnosis and treatment of people with memory problems. This supports the work that has been taking place locally and nationally to raise awareness about dementia, encouraging people to seek a diagnosis and treatment if appropriate, as well as investment in primary care and hospitals to incentivise services to identify, diagnose, treat and review people with dementia.
 - d. 14% of respondents felt that one of the most important priorities for health and social care was to review and modernise dementia related specialist services to ensure timely access to specialist memory assessments and treatment as required, as well as specialist support to other care services. This supports the clearing of the backlog of patients waiting to access specialist services and the referral to specialist assessment which is now 2 weeks (target is 4 weeks) and the referral to treatment which has a target of 13 weeks.

- 13. Respondents also highlighted as priorities the importance of ensuring that all public services are able to support people with dementia and their carers and families (23%) and ensuring that all staff supporting people with dementia have the training, skills and qualities to do so to a high standard (28%). This echoes the strategic direction being taken which highlights that dementia is everyone's business and not just that of specialist care services. Whilst this is already being addressed within health and social care services, there is significant work to ensure that it is embedded across all public services. Dementia friendly communities will go some way in supporting the delivery of this priority.
- 14. Whilst the survey has been used to identify which elements of the strategy people believe to be of most importance to them, it should be noted that the survey results will not be used to discount certain elements from being implemented. It is also acknowledged that the areas of importance that people reported on will often reflect their personal experiences. This was reflected in written feedback that was provided by respondents, as well as throughout discussions at the various events that focused upon the strategy. A range of comments have been submitted as part of the consultation and the list below indicates themes that people felt were of importance and should be strengthened within the strategy:
 - a. Easy and timely access to information
 - b. Early decision making whilst people have the capacity to contribute to the process
 - c. Supporting people during times of crisis, including the role of specialist dementia inpatient services
 - d. Supporting people who fund their own care
 - e. Supporting people with health conditions in addition to their dementia e.g. learning disability, Parkinson's, hearing and sight impairments
 - f. Reducing the stigma associated with dementia
 - g. Improving the quality of care, particularly within health services and primary care
 - h. Staff training
 - i. Safeguarding
 - Communication and joint working between services so that people do not fall in to gaps
 - k. Listening to and involving family carers
 - I. Supporting people with dementia who do not recognise their needs and do not wish to accept support
 - m. Equitable services across the county
 - n. A broader range of services that are able to meet the needs of all people with dementia, irrelevant of the dementia an individual may have.

15. Whilst respondents welcomed the strategy and were supportive of the strategic direction set out in the document, an initial analysis of the responses to the consultation identified that many people also had concerns about how it will be implemented and the costs associated with doing so. As detailed under the Financial Implications section, the implementation of the strategy will be undertaken within existing health and social care budgets. Work will be required to prioritise key work streams.

Review of the strategy

- 16. Following the end of the consultation process (19 May), all responses will be formally analysed and the draft strategy will be reviewed and amended as required. It will then proceed through the relevant governance channels in order to be formally agreed by Wiltshire Council and NHS Wiltshire Clinical Commissioning Group. The Wiltshire Dementia Delivery Board will be responsible for overseeing the implementation and review of the strategy.
- 17. Discussions are taking place with HealthWatch Wiltshire to plan an ongoing programme of engagement and consultation on the Wiltshire Dementia Strategy. It is anticipated that this will provide a mechanism by which Wiltshire Council and NHS Wiltshire Clinical Commissioning Group can engage with the general public and other stakeholders on a regular basis to discuss the implementation of the strategy and ongoing programme of service improvements.

Safeguarding Implications

- 18. Safeguarding is a key priority for Wiltshire Council and NHS Wiltshire CCG, both in terms of the services that they deliver and commission and this applies equally to the Wiltshire Dementia Strategy and its implementation. It is acknowledged that people with dementia are at greater risk of being victims of abuse, self neglect and poor and undignified care, given that they often lack capacity and their situations can give rise to increased risk of exploitation, e.g. financial, and stress within care givers, if they are not in receipt of appropriate support and training.
- 19. The prime aim of the strategy is to support people to live well and be as independent as possible whilst ensuring that they remain safe and that they and their families have confidence in the quality of care delivered. An important element of implementation will be to address underlying factors that contribute to abuse and to enable people with dementia to be better protected from harm. In addition to this, Wiltshire Council and NHS Wiltshire CCG and the organisations that they commission have in place safeguarding policies, procedures and workforce development plans to ensure that safeguarding is and continues to be a key priority.

Public Health Implications

- 20. The public consultation on the Wiltshire Dementia Strategy helps to ensure that the population continues to be included in decision-making processes regarding their health and well being.
- 21. Dementia is a national priority area for action. Public Health staff are working closely with Adult Social Care and NHS staff to develop and deliver this strategy, with a number of healthy living schemes already in place to assist in reducing the risk of dementia.
- 22. The outcomes of this strategy should help to reduce health inequalities and improve healthy life expectancy for people with dementia and their carers, and also may help to reduce the future prevalence. The Dementia Strategy for Wiltshire is thus consistent and coherent with the aims of the Wiltshire Health and Well Being Strategy.
- 23. In addition, it is envisioned there will be an increase in social capital regarding dementia within specific local areas and across Wiltshire as a whole.

Environmental and Climate Change Considerations

24. There are no environmental or climate implications in relation to this cabinet paper.

Equalities Impact of the Proposal

- 25. The strategy aims to ensure services will be delivered with due regard to equality legislation and that people with dementia will have equitable access to services. An equality analysis has been undertaken and can be found in the appendices of the strategy document. This has identified that the main equality issues that will require further attention through the implementation of the strategy include:
 - a. People with early onset dementia (are aged under 65 years old)
 - b. People with learning disabilities and dementia
 - c. People with dementia from black and minority ethnic communities
 - d. People with dementia who live alone without family support
 - e. People with rarer forms of dementia
 - f. People who live in rural areas and those who lack transport
- 26. The equality analysis will be reviewed following the end of the formal consultation process.

Risk Assessment

- 27. The main risks associated with the Dementia Strategy are:
 - 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:

- 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:
 - a. Identification of strategic priorities with investment allocated accordingly.
 - b. Consideration of alternative ways of delivering care and support which can meet demand within the budgets available.
 - c. 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 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.
- 28. The significant risks associated with <u>not</u> implementing this strategy would include:
 - 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.

Financial Implications

- 29. In 2013/14 NHS Wiltshire Clinical Commissioning Group estimated that they would 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 estimated that they would invest £14.8 million into 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.
- 30. In addition to the amounts identified, 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.
- 31. Although there are no immediate financial implications arising from the consultation on the Dementia Strategy, it is acknowledged that the number of people living in Wiltshire with dementia is highly likely to increase by circa 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. 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. 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.

Legal Implications

32. The current relevant national policy, legislation and guidance are set out in the Strategy Appendix B, which will be reviewed in light of the introduction of the Care Act 2014.

Proposal

33. Cabinet is asked to note the consultation process and initial draft responses on the basis that following formal analysis these will be used to review and amend the Wiltshire Dementia Strategy. The updated strategy and action plan will be presented for formal approval at a future Cabinet meeting.

Maggie Rae Corporate Director

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16th May 2014

Background Papers

None

Appendices

Appendix 1 – Snap shot of responses to closed questions in the Dementia Strategy Consultation Survey (15th May 2014)

Appendix 2 – Draft Wiltshire Dementia Strategy

Appendix 3 – Engagement work in developing the strategy and throughout the consultation process

Appendix 1 – Snap shot of responses to closed questions in the Dementia Strategy Consultation Survey (15 May 2014)

Q1 fol de	% of responses	
a.	Reducing the risk of developing dementia	7
b.	Recognising memory problems	14
C.	Learning it's dementia	17
d.	Planning for the future	17
e.	Living well with dementia	25
f.	Managing at more difficult times	17
g.	Care at end of life	3

Q2. stat	% of responses	
a.	Promote the inclusion of people living with dementia in the community so dementia becomes everybody's business.	11
b.	Work together with partners to develop and deliver reliable, high quality and sustainable services that put the individual at the centre of delivery.	13
C.	Recognise and understand individuals, their identities, wishes and abilities.	9
d.	Promote health and wellbeing and support people to remain independent for as long as possible.	11
e.	Provide support and services to people with dementia and their carers in a compassionate, honest and equitable manner.	10
f.	Take a proactive approach to supporting people with dementia to live their lives to the full and to continue undertaking activities they enjoy.	10
g.	Listen to people and involve them in decision making so that they have control and influence over the care and support they receive.	12
h.	Treat people with respect and dignity.	10
i.	Improve services by listening to what people with dementia and their carers tell them about their experiences of receiving care and support.	16

sta	8. Making a difference. Which FOUR of the following tements do you think is most important when dealing with mentia in Wiltshire?	% of responses
a.	I am encouraged and supported to have a healthy and active lifestyle.	6
b.	I was diagnosed early and with the correct medication and treatment package.	14
C.	I understand the implications of my diagnosis in order for me to make good decisions and provide for future decision making.	9
d.	I get the care and support which are best for my dementia and my life.	19
e.	I am treated with dignity and respect.	13
f.	I know what I can do to help myself and who else can help me, especially in times of crisis.	8
g.	Those around me and looking after me are well supported.	15
h.	I can enjoy life.	7
i.	I feel part of a community and I'm inspired to give something back	4
j.	I am confident my end of life wishes will be respected.	5

fol	Q4. Groups of people living with dementia. Which TWO of the following groups do you think is most important when dealing with dementia in Wiltshire?		
a.	People with early onset dementia (aged under 65 years old)	20	
b.	People with learning disabilities and dementia	7	
C.	People with dementia from black and minority ethnic communities	0	
d.	People with dementia who live alone without family support	44	
e.	People with rarer forms of dementia	2	
f.	People who live in rural areas and / or who do not have access to transport	27	

Q5. follo dea	% of responses	
a.	Make sure that health promotion activities are taking place to reduce the risk of people developing dementia.	4
b.	Make sure that health services have in place standard processes that allow for early identification, diagnosis and treat of people with memory problems.	18
C.	Monitor and review the dementia adviser service and make improvements as necessary.	6
d.	Promote and improve services for carers, including carers breaks	12
e.	Continue to improve and rollout care services so that people can be supported to remain independent and living at home.	15
f.	Develop new care homes and extra care schemes designed to meet the needs of people with dementia to meet future demand.	9
g.	Improve the quality of care in different settings including care homes.	11
h.	Review and modernise dementia related specialist mental health services to ensure timely access to specialist assessments and treatment as required, as well as specialist support to other care services.	14
i.	Improve dementia care in acute hospitals.	7
j.	Improve end of life care for people with dementia.	4

ca	t. Priorities for all public services (including health and social re) and communities. Which THREE of the following attements do you think is most important when dealing with mentia in Wiltshire?	% of responses
a.	Raise awareness about dementia within the general public and mainstream services e.g. leisure and libraries.	10
b.	Undertake projects to better understand the needs of people with a dementia for whom services are less accessible so that improvements can be made e.g. learning disabilities, black and minority ethnic communities.	9
C.	Establish dementia friendly communities across Wiltshire.	16
d.	Make sure that all services are able to support people with dementia and their carers and family.	23
e.	Develop additional community therapeutic activities for people with dementia and their carers.	14
f.	Ensure that all staff supporting people with dementia have the training, skills and qualities to do so to a high standard.	28





DRAFT 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 that 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.

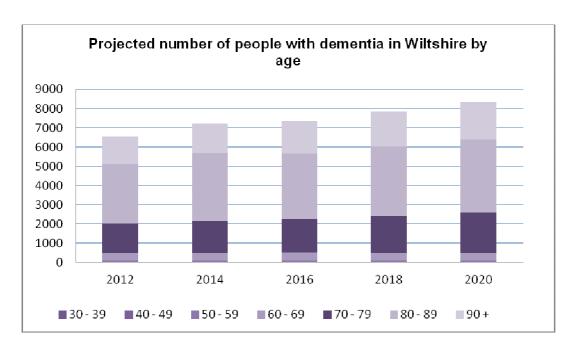
It has also been found that keeping one's mind active and also being socially active can also help reduce the risk of dementia. There is concern that due to the rural geography of Wiltshire, people are more likely to be socially isolated.

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)

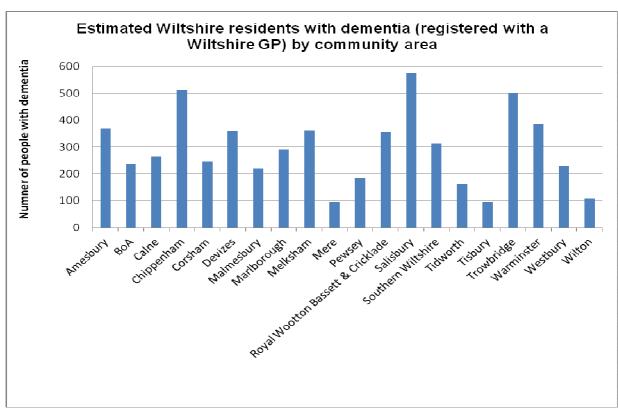
The NHS Commissioning Board and NHS South of England (2013) have also produced information about the population of Wiltshire with dementia through a tool called the Dementia Prevalence Calculator. This tells us that in 2013/14 there are an estimated 6,512 people with dementia in Wiltshire. Looking at 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 in 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

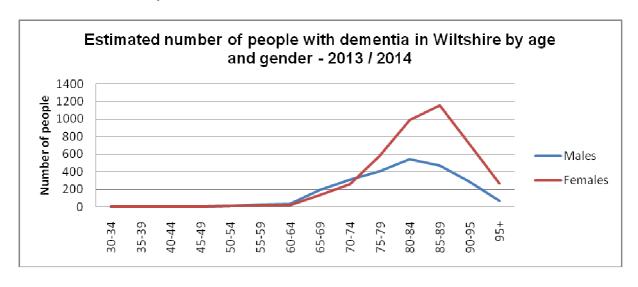
The following graph provides a picture of where Wiltshire residents who are registered with a Wiltshire GP surgery and have dementia live.



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)

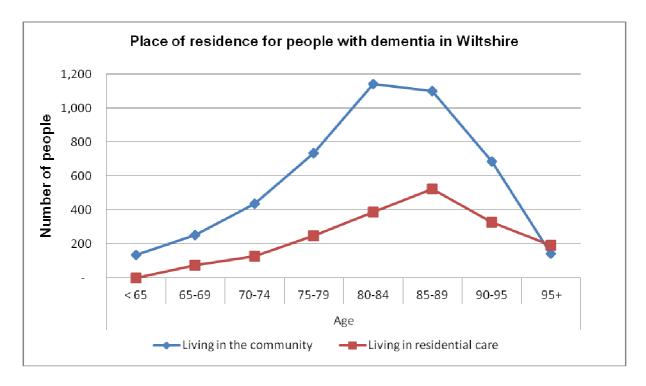
Severity of dementia

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 important to remember that there are certain groups of people with dementia in Wiltshire that services may not be as well placed to meet the needs of when compared to the general population. However, it is equally as important to do so and 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 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	Memory Service - Dementia asse		sessment, diagnosis and treatment		GP out of hours service ~	
Checks		- Dementia assessm			Complex Intervention & Therapy Team	
~		treatment	~			
Wiltshire	Dementia CQUI	N in acute hospitals	Life Story Groups	Specialist Home	Acute hospital liaison	My Home Life
Stop	Awareness	RUH Community	(Alz Support)	& Community	service	programme in
Smoking	raising	geriatrician	~	Support Service	~	care homes
Service	activities and		Home improvement	~	Acute hospitals	~
~	resources		agency – part of	Movement for	~	Continuing
Wiltshire			Help to live at Home	the Mind	Inpatient assessment	Health Care
Substance			service (Equipment	~ ~	service	~
Misuse			ICESS)	Singing for the	~	Hospices
Service				Brain	MH Care Home Liaison	
~ Λ αξίνια				~ ^	Service	
Active				Active Health	~ .	
Health				Programme	Emergency Duty Service	
~ Lift				Coupadling	CTADD cohomo	
Psychology				Counselling	STARR scheme	
Fsychology					~ Extra Cara Housing	
					Extra Care Housing	
					Care homes	
					care nomes	
					Respite	
				Social care ~	HTL@H ~ Telecare ~ DI	Ps ∼ 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 Mingehlla (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.

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 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

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.
- 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 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.

Planning for the future

- Monitor and review the effectiveness of the dementia adviser service and their interface 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.

Managing at more difficult times

- Work to shape and develop dementia related specialist mental health services to ensure timely access to specialist assessments and treatment as required, including the support they 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.

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.

Action plan, measuring success and governance

Supporting this strategy is an action plan that will be implemented (see Appendix H), 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. 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

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

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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/

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

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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 3 – Engagement work in developing the strategy and throughout the consultation process

Activity	Forum	Date	Detail
Engagement	Singing for the	10 September	Questions were
work with people	Brain	2013	asked to identify
with dementia	Memory Café,	16 September	a) What is
and carers to	Melksham	2013	important to people
inform strategy	Singing for the	September 2013	in their lives with
development.	Brain, Salisbury	_	dementia
	Movement for the	25 September	b) What is working
	Mind, Melksham	2013	well
	Carers Support	27 September	c) What could be
	Group, Devizes	2013	improved
	Carers Support	1 October 2013	
	Group	40.0-1-10040	
	Carers Reference	16 October 2013	
	Group, Melksham	04 October 2042	
	Carers Focus	21 October 2013	
	Group, Trowbridge	1 November 2013	
	3Ms memory group, Royal	I Novellibel 2013	
	Wootton Bassett		
Engagement with	Wiltshire Dementia	2 July 2013	Mapping and
stakeholder	Delivery Board	2 July 2013	gapping exercise of
organisations to	Belivery Board		all services with
inform the			strategic partners
strategy	Wiltshire Dementia	3 September	Discussion with
development and	Delivery Board	2013	strategic partners
to seek approval			to agree
to proceed to			engagement
consultation			mechanisms with
			people with
			dementia and
			carers
	Dementia Topic	30 October 2013	Discussion to
	Leads Meeting		identify key issues
			when supporting
			people living with
	Wiltshire Dementia	19 November	dementia. First draft of
	Delivery Board	2013	
	Delivery Doard	2013	strategy presented to the board
	Health Select	14 January 2014	Final draft
	Committee	Troundary 2014	presented
	Wiltshire Council	21 January 2014	Agreement
	Cabinet		obtained for draft
			strategy to proceed
			to consultation

	Wiltshire Dementia Delivery Board	21 January 2014	Final draft of strategy and consultation plans presented to Board
	CCG Governing Body	28 January 2014	Agreement obtained for draft strategy to proceed to consultation
Engagement during consultation period	Launch of consultation	20 February 2014	Communications to all stakeholders including VCS, health and social care providers, press, community groups, area boards, town and parish councils. Documents made available online, in paper format and in libraries. Posters displayed in various settings including hospitals, libraries and GP surgeries. Articles about the consultation have been placed in various forums including the local press, VCS and community area websites, VCS newsletters etc.
	Corsham Area Board	20 March 2014	Presentation on draft dementia strategy
	Wiltshire Dementia Delivery Board	20 March 2014	Update on consultation provided to the Board
	Trowbridge Area Board	27 March 2014	Presentation on draft dementia strategy
	Wiltshire Dementia Delivery Board	6 May 2014	Update on consultation provided to the Board

Westbury Memory Café	8 May 2014	Presentation and discussion on draft dementia strategy
Healthwatch consultation event, Chippenham	12 May 2014	Public meeting to discuss the strategy
Healthwatch consultation event, Salisbury	13 May 2014	Public meeting to discuss the strategy