

Talking to people about  
dementia:  
a focus on support for  
people with the most  
complex needs

Local health  
and care  
shaped by you

# Notes:

## Carers

Where we talk about carers in this report we are referring to unpaid carers:

“A carer is anyone who cares unpaid for a family member or friend who cannot always manage without their support. They might look after someone with a physical disability, long term health condition, mental health issue or a problem with substance misuse.” (Carers Support Wiltshire<sup>1</sup>)

Where the report refers to paid care workers, we will make this clear, for example by stating “agency care worker.”

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### Reference:

<sup>(1)</sup> <https://carersinwiltshire.co.uk/are-you-a-carer/#amiacarer>

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# What this report is about

This report will tell what the public said when Healthwatch Wiltshire asked them about dementia between 25 July and 25 August 2017. During this time, we asked local people what they thought about some proposals for caring for people with dementia with the most complex needs that had been put forward by NHS Wiltshire Clinical Commissioning Group and Wiltshire Council. This report illustrates what people thought about the proposals. During this engagement people also shared their views about dementia services in general in Wiltshire and these are also included in this report.



## Background

Wiltshire's Dementia Strategy was approved by Wiltshire Health and Wellbeing Board in July 2014 with its purpose to provide the direction for commissioning bodies to support people with dementia and their unpaid carers. Its implementation is coordinated and monitored by the Dementia Delivery Board which is a group of agencies including Wiltshire Council and NHS Wiltshire Clinical Commissioning Group (CCG). You can read the strategy on the Healthwatch Wiltshire website here - [healthwatchwiltshire.co.uk/wp-content/uploads/2017/10/WILTSHIRE-DEMENTIA-STRATEGY.pdf](http://healthwatchwiltshire.co.uk/wp-content/uploads/2017/10/WILTSHIRE-DEMENTIA-STRATEGY.pdf)

Healthwatch Wiltshire formed a partnership with voluntary and community sector groups in Wiltshire, committed to making sure that this strategy is delivering in practice what it promises on paper.

From December 2014 to March 2015, Healthwatch Wiltshire facilitated a consultation about the location of specialist dementia hospital beds. This resulted in the decision to permanently locate the beds in Fountain Way, Salisbury and to close Charter House in Trowbridge. Since then we have been monitoring what people told us they thought was important during the consultation.

During the consultation, it was said that if the beds were permanently located at Fountain Way, Salisbury, this would result in an annual saving of around £440,000 that would be available to invest in community services. We have been informed by Wiltshire CCG that this has been invested in the expansion of the Care Home Liaison Service, which is managed by Avon and Wiltshire Mental Health Partnership (AWP). This is a specialist service that supports people living with dementia who live in care homes. It aims to improve care, help maintain residents in their current setting and reduce hospital admissions enabling people to remain in their own care homes.

It was also said that there would be additional specialist dementia beds in care homes for people with dementia with the most complex needs. This has not happened, and Wiltshire Clinical Commissioning Group and Wiltshire Council have acknowledged that there are still areas of the dementia strategy that need to be looked at. These areas relate to caring for people with dementia with the most complex needs. They asked Healthwatch Wiltshire to facilitate some public engagement about this.

The aim of this engagement was to enable the public to:

- hear about how the dementia strategy is being put into practice
- find out what has happened since the consultation on specialist dementia hospital beds
- have their say on new proposals for dementia care in Wiltshire

## What we did

From 25 July to 25 August 2017 we engaged with people in a number of different ways.

We prepared information for local people. This included a document, prepared by NHS Wiltshire CCG and Wiltshire Council outlining the background to this engagement, the progress of the dementia strategy and the proposals that they wanted the public's view about. Healthwatch Wiltshire produced leaflets and posters advertising the engagement opportunities and these were distributed by our volunteers and through our partner organisations.

The engagement was promoted in several ways including through social media. We used press releases to get the message out through local media. There was information available on websites including a dedicated page on Healthwatch Wiltshire's website. We made local voluntary sector organisations, Area Boards and Community Engagement Managers aware of the consultation and invited them to help promote it.

We held three public meetings in Trowbridge, Salisbury and Devizes. On reflection and following some comments that people from North Wiltshire would find these locations difficult to access, we held a further focus group in Malmesbury.

We visited two groups, a memory café for people living with dementia and a support group for carers of people living with dementia. We told people about the engagement and gathered their views.

A public survey was prepared which was available online and in hard copy with a freepost envelope. A survey for care homes was also prepared and sent to targeted care homes that care for people living with dementia.

We visited four care homes across Wiltshire that cared for people living with dementia to talk to staff about caring for people with dementia with complex needs. We also talked to some of the residents and their relatives about their experiences.

The surveys, with results, are attached at the back of this report as appendices 1 and 2. 'Free text' comments from the survey have been analysed and the key themes from them included in this report.





# How we engaged with people



- 55 people attended our public meetings and focus group
- 51 people completed our survey for members of the public
- 40 people were spoken to at 2 community groups
- 10 care home managers or senior care workers took part in face-to-face interviews
- 6 further care homes completed our care home survey
- 6 interviews were completed with residents and/or relatives at care homes
- 2 phone interviews took place with paid advocates of people living with dementia
- 2 people shared their views during a home visit
- 3 people shared their views with us in written comments

## Our volunteers

Healthwatch Wiltshire has a team of trained volunteers. Sixteen of our volunteers were involved contributing a total of 45 hours of their time.

They supported the engagement by:

- helping to promote and distributing posters
- supporting the public meetings
- promoting the online survey
- typing up the focus group notes and inputting surveys
- visiting care homes and groups, and
- sharing their own personal experiences.



# What did people tell us?

Our survey and focus group questions were designed to get people's views about two proposals put forward by Wiltshire CCG and Wiltshire Council to support people with dementia who have the most complex needs and their carers.

In particular about two proposals:

- (i) to provide a clear consistent pathway for people living with dementia to be supported from initial diagnosis onwards, and
- (ii) to enhance specialist care home support for people living with dementia with complex needs.

Our engagement with care homes aimed to get their views about caring for people with dementia with the most complex needs.

We also recorded anything else that people wanted to talk about regarding dementia services in Wiltshire. We have analysed the results and below are the key messages, followed by a more detailed analysis of what people told us.

## The key messages

Most people told us that they thought both proposals were needed, but that they felt more resources should be allocated to support people in their own homes (proposal one).
People emphasised that proposal one must include provision for support in a crisis if it is to be effective in enabling people living with dementia to stay at home for longer.
People were concerned about the impact that proposal one may have on carers and felt that adequate support for carers must be in place for it to be successful.
Most people felt that residential care for people with dementia with the most complex needs should be provided in a small number of homes to enable resources to be focussed on this group. Most of the care homes we spoke to also thought this.
People said that they thought dementia training for care workers was the most important factor in enabling care homes to provide good quality care for people with complex needs.
Care homes told us that they thought the Care Home Liaison Service was useful and suggested ways in which it could be further developed.
Some people said that they had noticed improvements in dementia services over the last few years and mentioned diagnosis rates, community services and dementia friends and dementia action alliance initiatives.
People said that there were still gaps in dementia services across Wiltshire. This was emphasised particularly in North Wiltshire where people felt that there was a lack of community services and specialist residential care there.
Some people said they had difficulty finding information about dementia support and services when they needed it.

# What did people say about proposal one?

## Summary of proposal one

Proposal one would involve designing a clear consistent pathway for people living with dementia to be supported from initial diagnosis onwards. The proposal would involve a team of dementia specialists from different areas coming together to work alongside each other in one team. The focus of this team would be around the local GP practice. The redesigned pathway will ensure that everyone has the same level of service across the county. This proposal would involve investing in more specialist nurses linked to the local GP practice.

Further details about this proposal can be found in the information sheet as Appendix 3.

Both during this engagement and in previous engagement people have told Healthwatch Wiltshire that they think it's important for people living with dementia to be able to stay at home for as long as possible. During this engagement, the majority of people we spoke to said that proposal one would enable people living with dementia to be cared for at home for longer. Of our survey respondents, 74% either strongly agreed or agreed with this, compared to 8% who disagreed or strongly disagreed and 18% neither agreed or disagreed.

“As a dementia champion, I have spoken to a lot of people with dementia who would rather stay in their own home for as long as possible. This proposal appears to offer that.”

“...A proper infrastructure for carer breakdown will need to be put in place if you proceed with this proposal...”

We asked people what they thought was important to enable those living with dementia to live at home for longer. They highlighted availability of support in a crisis as being a key feature of this. It was rated very important by 90% of our survey respondents and important by the remaining 10%. Other things that people thought were very important were advice about available dementia services, training for carers and respite care to give carers a break.

There was support for a clear dementia pathway which could be used by professionals, voluntary organisations and the public. In general people were positive about the idea of focussing this service around GP practices. They told us it was important that this team was multidisciplinary and integrated with other health and social care services. They said that they thought the team would be valuable if they were able to offer knowledge and understanding about caring for people with dementia in a home environment, liaison with other services and to be responsive in crisis situations.

“This will only work when focus is also placed on non-paid carers and that they also receive specialist support and respite to enable them to manage and cope with caring for the person with dementia.”





We asked people if they had any concerns about focussing support in people's homes and a number of concerns were mentioned. Concerns about out of hours support and the impact on carers were the ones most selected in our survey responses. The impact on carers was also a key issue raised at our public meeting and groups. Many people said that they felt that proposal one would not be successful if the right support for carers was not put in place.

Other concerns that people mentioned about proposal one were: how it would work for people with dementia who lived alone; whether the resources available would provide adequate resource and staffing for the team; difficulties with some home environments not being suitable; and worries that some people would 'slip through the net' and not get the support they needed.

"I think focussing around GP practices is essential as people trust the services provided by their own GP and feel safe and comfortable in their own surgeries environment. They may not want to access the same service if they had to go somewhere different and new to them."

# What did people say about proposal two?

## Summary of proposal two

Proposal two would involve undertaking a review with care home providers and managers to outline the support they need. It would aim to identify a number of homes across the county who, with strong links and support, can support people with the most complex needs. The intention is to improve the skills and expertise of staff in caring for people living with dementia in Care Homes. This proposal may mean that there is more good quality care available for people living with dementia with the most complex needs across Wiltshire. However, it could potentially reduce the capacity of Care Home Liaison Service to support a broad range of Care Homes. The proposal may involve investing in GP's to provide 'dedicated' support to care homes dependent on capacity.

Further details about this proposal can be found in the information sheet as Appendix 3.

The people we spoke to told us that they thought there was a shortage of care home places for people with the most complex needs in Wiltshire and the majority agreed that something should be put in place to address this issue.

“Very good teamwork would ensure communication, less duplication and the person with the right skills to address each specific issue in care homes.”

Most people we spoke to said that they agreed that highly specialist dementia care should be provided in a small number of care homes so that support could be focussed on providing good quality care for people with dementia with the most complex needs. 78% of our survey responses either strongly agreed or agreed with this, compared to 16% who disagreed and 6% who neither agreed or disagreed. There was also widespread agreement that strong links and support from a team of dementia specialists could enable care homes to provide good quality care to this group of people.

We asked people what they thought was important for care homes to be able to provide good quality care for people with dementia with complex needs. Dementia training for care workers was said to be most important with the next two important things being availability of specialist support in a crisis and a dementia friendly environment. Other things that people thought were important was strong, values-based leadership, and a stable, consistent staff team.

“Training and ongoing specialist support will enable care homes to meet the needs of those with the more complex needs.”

“There is little public transport. Travelling is difficult for people without access to their own transport.”

“I would have concerns about a dementia client being moved away from families.”

We asked people if they had any concerns about specialist support being focused in a small number of care homes. The main concern expressed was the location of these homes and the travelling times for people friends and relatives to visit them.

Other concerns included the limited availability of specialist places and whether there would be enough places available to meet the demand. People also said that the proposal could limit people’s choice of homes that were able to care for them. Another concern that was talked about was the potential impact on other care homes and their ability to care for people living with dementia.

“This limits choice and control and does not take into account carer and family’s needs and for people to live in their local community.”

“In non-specialist homes, dementia care skills will wither.”

A small number of concerns were expressed about the financial implications of this proposal for self-funders. Some people said that they thought that this proposal would mean that people would be paying for a service that would have previously been funded through the NHS in a specialist dementia unit. Others were concerned that these specialist places would have higher rates than other care home places.

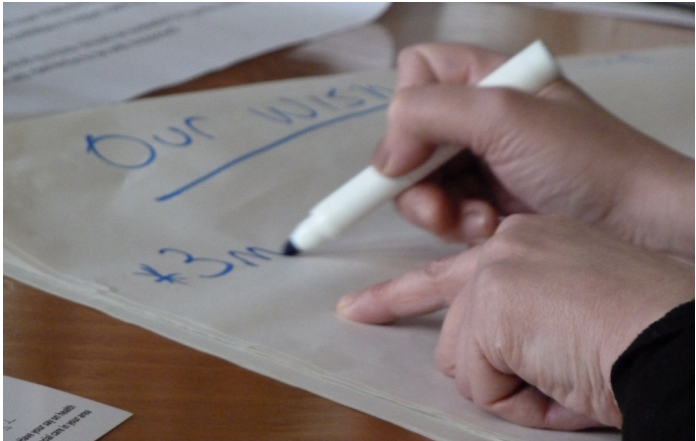
“People with dementia with the most complex needs should be cared for by the NHS. Medical expertise is necessary. I think this is just an outrageous idea to shift care costs on to self-funders.”





# What did people say about dividing available resources between proposals one and two?

Most people we spoke to at our public meetings and at groups said that they thought both proposals were important, but that they felt more resources should be allocated to support people in their own homes (proposal one). Generally our survey respondents also indicated in more support for proposal one, although a significant number of people felt that resources should be spread equally between the two proposals.



The chart below shows how our survey respondents thought available resources should be divided.

Most for proposal one but some for proposal two	<div></div>	43.5%
Resources equally split between proposals one and two	<div></div>	43.5%
Most for proposal two but some for proposal one	<div></div>	11%
All resources for proposal two	<div></div>	2%
All resources for proposal one	<div></div>	-

## What did care homes tell us?

It is acknowledged by Wiltshire CCG and Wiltshire Council that there are times when people living with dementia with the most complex needs stay in hospital for longer than they need while they wait for a placement in a care home. Not all care homes in Wiltshire can offer support to people with dementia with very complex needs.

We wanted to find out more about care homes' experience of caring for people with dementia with the most complex needs. We interviewed and surveyed a small number of homes that had been identified as caring for people living with dementia. We received 13 responses from 10 different care homes. The results of this survey are shown at the end of this report as **appendix 2**. Of the responses we received, 50% of care homes strongly agreed that they could provide care for people with dementia with complex needs at their home and 50% agreed that they could provide this to some extent.

We asked care homes if there were any particular behaviours or needs that they were unable to support or found difficult to manage. Most homes that responded said that they felt able to support complex behaviours. However, physical aggression particularly when this involved other residents was mentioned by several homes. Some homes also said that families' expectations were something they found difficult to manage at times.

We asked care homes about the organisations and agencies they had asked for support in caring for people with dementia with complex needs. All the homes who responded mentioned their GP practice and said their support was either very good or good. All homes said that they had requested support from social workers or customer coordinators with 46% saying the support was good or very good and 54% saying it was neither bad nor good. Other agencies that were mentioned were the Wiltshire Quality Team, the Wiltshire Care Partnership, the Care Quality Commission, the Mental Health Team, occupational therapists, physiotherapists and the Continence Service.

“We are able to support complex behaviours here in the home; my main concern is the interactions between complex residents which can cause ill-being to escalate.”

“Sometimes social workers give (residents) false promises.”

“The Care Home Liaison Team are invaluable”

All but one home mentioned the Care Home Liaison Service with 42% rating the support as very good, 25 % saying it was good, 25% as neither bad nor good and 8% (one home) rating it as poor. Many of the homes we visited said they valued this service and that they thought it had an important role to play in supporting care homes to care for people with dementia with complex needs. The team were viewed as being responsive and visiting regularly to review the people they were involved with. Some feedback was received that more-nurse qualified members of the team should be assigned to homes caring for a lot of people with very complex needs and that the team could have more direct contact with residents and provide more hands-on support. It was also mentioned that, on some occasions, there had been confusion over who was supporting a resident between the Care Home Liaison Team and the Mental Health Team. However overall, the feedback was that this was a useful service with potential for further development.

We asked care homes what were important concerns that might prevent them from agreeing to care for people with dementia with complex needs. Most frequently highlighted was the homes capacity to manage a number of people with complex needs at once. Care homes emphasised the need for careful assessment including considering how a new resident may get on with existing residents. This was seen as easier to manage in homes with a number of smaller units. Safeguarding was also frequently mentioned as a concern and some homes said they worried that reporting safeguarding incidents would lead to a negative perception of the home.

“I believe we need to provide this in the county and that we could definitely do this with the right resources support and training.”

We talked to care homes about the proposal to work with a small number of care homes to improve the skill and expertise of staff caring for people with the most complex needs. Of those care homes who responded 72% either strongly agreed or agreed that this would enable more good quality care for people with dementia with the most complex needs. Care homes said that they felt that this proposal would enable more concentrated expertise focussing on people with dementia with the most complex needs. They added that they felt that limited resources should be targeted towards homes that were prepared to take on this remit.

We asked care homes if they had any concerns about concentrating resources on a small number of care homes. A number of homes said they had no concerns about this. The concern that was mentioned was that they would not want other homes to not be able to access support and training for people living with dementia as and when they needed it, as people's needs changed. Another concern was that other homes might struggle to fill their beds as preference would be given to homes involved in this project.

“I am firstly concerned about where people with complex needs will be cared for as we always used to support people like this. However, with CQC / safeguarding expecting that we both ‘predict’ and therefore ‘prevent’ these ‘behaviours’ it is becoming increasingly more difficult to accept people that will pose a risk to our compliance with the CQC. We have always been open and honest with CQC but we are also judged by the number of safeguardings that the home has over a certain period of time and the number of statutory notifications that we make. With complex dementia care, these are always going to be higher than a standard residential or nursing home.”



Talking to people about dementia



# What else did people tell us about dementia care in Wiltshire?



Many people, especially at the public meetings, wanted to talk about other aspects of dementia care and support in Wiltshire. We asked people in our surveys if there was anything else they wanted to tell us. People shared a variety of wide ranging views with us.

Lots of people wanted to talk about local community services for people living with dementia. They said that if there were good quality community services things would work from the 'bottom up' and crises requiring hospital admissions could be avoided in many

cases. It was recognised that there were many good quality community services in Wiltshire for people living with dementia. However, some said that these were not always consistent across Wiltshire or easy to find out about.

Some people said that they still had difficulty getting accurate information about the range of services and benefits that were available to them. For example, at one public meeting we met someone who had not seen a dementia adviser until a number of years after diagnosis. They told us that their GP had never mentioned this service to them despite being aware that they were the main carer of someone with dementia. As a result they had not claiming allowances that they were entitled to, until they recently came across the service.



"Information for carers needs to be given in a way they can receive it - 'drip fed' bit by bit."

The importance of getting information to people in a way that they can take in was emphasised. In general, it was felt that information needed to be targeted to what the individual wanted at that time. People felt that the internet should not be the only source of information as many older people don't use it. There was agreement that information needs to be provided in a variety of formats to ensure that it reaches as many people as possible.

"I have been extremely disappointed since coming to North Wiltshire to find that very few courses, meetings etc. actually take place here. It is often not possible to travel to other areas and difficulty getting someone in for 4 hrs approx to look after the person we care for. Also need to be considered, the staff in North Wiltshire must be continually fighting disillusionment making their job twice as difficult."

People from North Wiltshire said that they felt that there were still gaps in services North Wiltshire as compared to the rest of the county. In particular, community groups for people living with dementia and dementia specialist residential care were mentioned.

Other gaps mentioned included a lack of services for younger people with dementia and inconsistent provision of specialist day care across Wiltshire.

People valued voluntary organisations and volunteers and felt that there was potential to use more volunteers if there was a way of coordinating them into providing what was needed. It seemed clear that in some areas of Wiltshire, organisations were working more closely together than in other areas and that this was having a positive impact on local people.

It was noted that many people living with dementia are remaining in their own homes for longer. Whilst this was thought to be good, it was emphasised that the right support must be in place for them and their carers. Carers of people living with dementia told us that they would like more training in a number of areas, these included dementia, personal care and cookery.

The need to work with and support home care providers as well as care homes was talked about, particularly to make sure that care workers received the right training to enable them to care for people with dementia who have more complex needs.

Several people mentioned that they thought dementia services in Wiltshire had got better over the past few years. Improvements in diagnosis rates, community services and the dementia friends and dementia action alliances initiatives were mentioned.

It was suggested that carers, and dementia action alliances have a clear way of feeding into the dementia delivery board and that information also flows back to them. Some people said that the dementia delivery board seemed 'distant' and suggested that there should be a 'lay' representative on the board.



## Limitations and what we learnt

We had a relatively short time frame for this engagement and it is possible that some people who might have wanted to take part were not able to. However, we do feel that we spoke to enough people to gain a consensus of views about the options.

We initially planned our public meeting around the locations used for our previous consultation about specialist dementia hospital care. However, we had some comments that these would be difficult for people from North Wiltshire to attend. On reflection, we agreed that this was the case and put on an extra focus group in Malmesbury. In future, we will ensure that our public meetings are evenly spread across Wiltshire in the planning stage.

# Next steps



This report has been shared with Wiltshire NHS Clinical Commissioning Board and Wiltshire Council, so that they can use what people have told us to inform their decisions about planning and providing dementia services in Wiltshire.

- We will publish and share this report with our partners, providers and the public.
- We will produce a report - You Said, We Did - about what has happened as a result of this engagement. This will be published and shared with those who took part.
- We will monitor the issues raised in this report.
- We will continue to engage with people living with dementia and their carers and report their views and experiences of dementia services in Wiltshire.

## Finally, thank you!

Healthwatch Wiltshire would like to thank everyone who took the time to contribute their views and experience through the many engagement activities.

Thanks also to our dedicated volunteers and voluntary and community sector organisations who helped to support the engagement activity. Without their help to recruit people with dementia and their unpaid carers we would not have been able to reach the numbers of people which we did.

One in fourteen people over 65 have dementia at any one time and that's why 'dementia is everyone's business'. Healthwatch Wiltshire is always interested in finding out about your experiences and views on health and social care services. Please get in touch with us.

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# Commissioners' Response



This report and its findings has been shared with Wiltshire Council and NHS Wiltshire Clinical Commissioning Group who have acknowledged the report and its findings and made the following points:

- It is acknowledged that crisis prevention and support for carers is an area of great importance.
- The aim is that the appropriate support is provided at the right time, whether it be support at home, in a care home or in specialist dementia hospital care.
- Opportunities for more joint working with carer support services are going to be considered. A new tender for the county wide service has just been awarded and more joint work with the carers commissioner is proposed to explore areas where improvements can be made to improve dementia carer support.
- Training for carers and the provision of respite care are two areas that it is proposed are further developed.
- A Task and Finish Group is being organised to look at communication between the Dementia Delivery Board and Dementia Action Alliances across the county.
- Consideration is being given as to how representation from people living with dementia and carers can be included in the dementia delivery board structure.
- Work is being done to focus on how we can encourage and support existing care homes across the county to enhance their dementia care. The aim is that a small number of care homes who support people with more complex needs have specialist support which enables them to provide quality care for this group of people.
- It is the aim that all staff who are caring for people living with dementia should have training in the support of a person with dementia as standard. Some additional funding has recently been secured to provide dementia training to care home managers. Those homes who choose to support people with higher and more complex needs will be supported to increase their training for staff so that they can provide more specialist complex dementia care.
- The proposals are not intended to disadvantage any one client group, for example self-funders. Everyone irrespective of funds is entitled to be assessed for their eligibility for NHS funding for nursing care costs and continuing health care, although not everyone with dementia will be eligible for this funding.
- It is recognised that it is vital that providers and managers feel safe in accepting people with complex needs. There should be close communication between the CQC, Wiltshire Council, Wiltshire CCG and providers in order to achieve this.

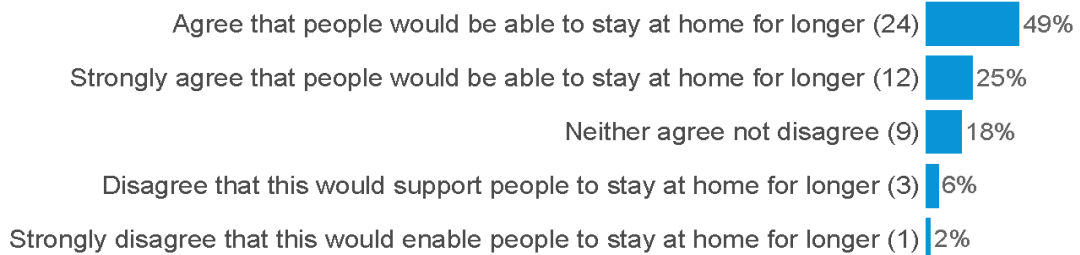
# Appendix 1

Dementia Proposals Survey Results

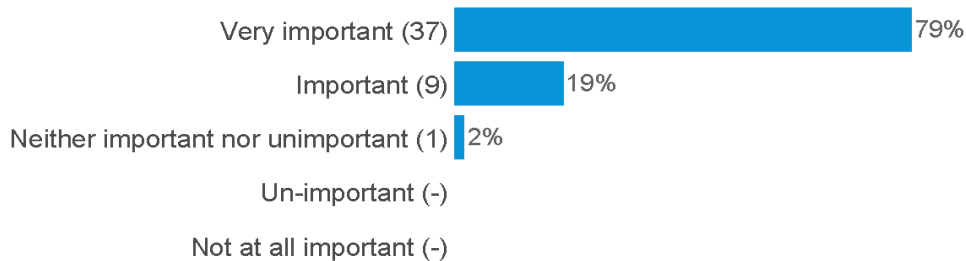


## Have your say on dementia care in Wiltshire

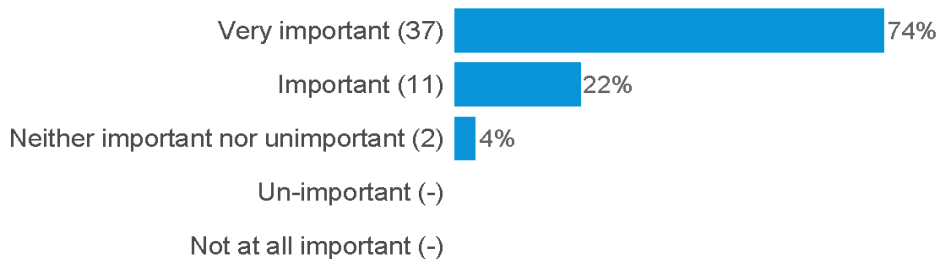
**To what extent do you think this proposal would enable people living with dementia to be cared for at home for longer:**



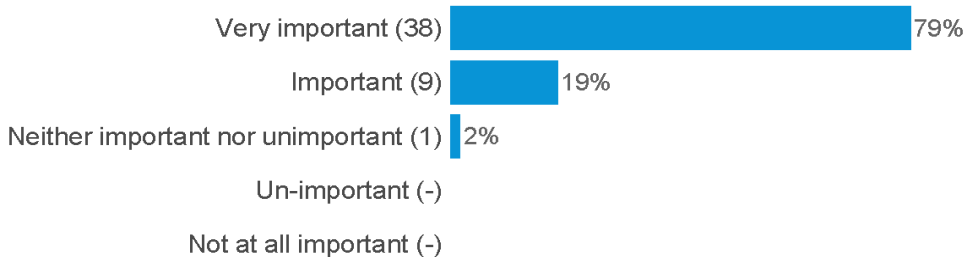
**What do you think is important to enable people living with dementia to stay at home for longer? Please rate how important you think these are: (Advice about available dementia services)**



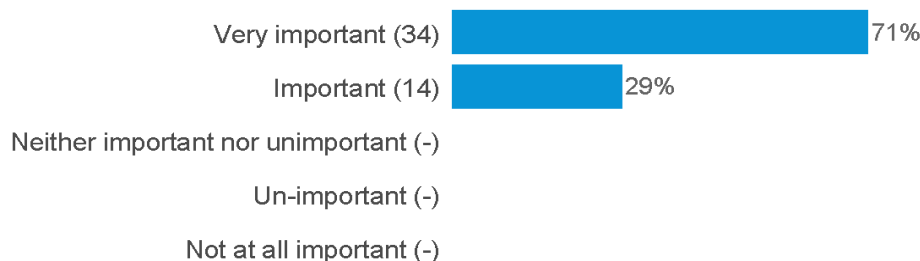
**What do you think is important to enable people living with dementia to stay at home for longer? Please rate how important you think these are: (Support from specialist dementia nurses)**



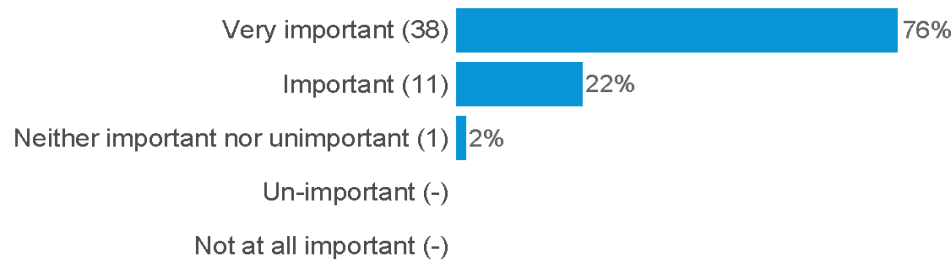
**What do you think is important to enable people living with dementia to stay at home for longer? Please rate how important you think these are: (Training for carers)**



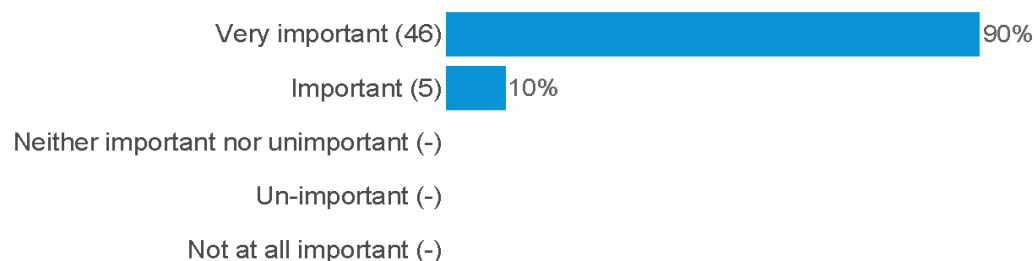
**What do you think is important to enable people living with dementia to stay at home for longer? Please rate how important you think these are: (Domiciliary care at home)**



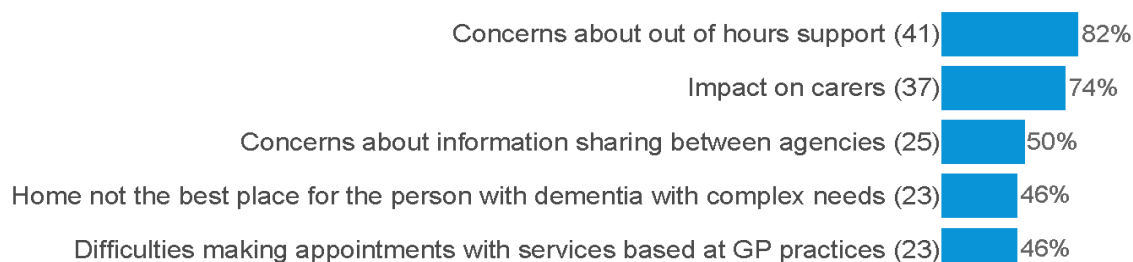
**What do you think is important to enable people living with dementia to stay at home for longer? Please rate how important you think these are: (Respite care to give the carer a break)**



**What do you think is important to enable people living with dementia to stay at home for longer? Please rate how important you think these are: (Availability of support in a crisis)**

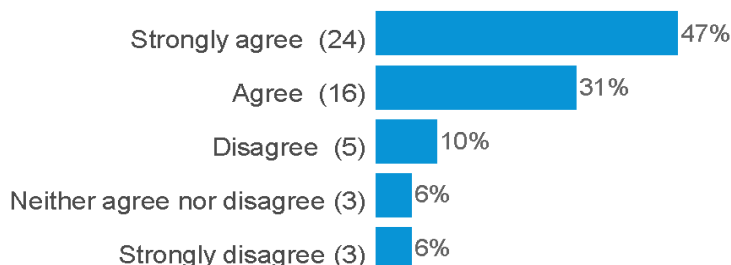


**What concerns would you have about focussing support in people's homes? (select as many as you think relevant)**

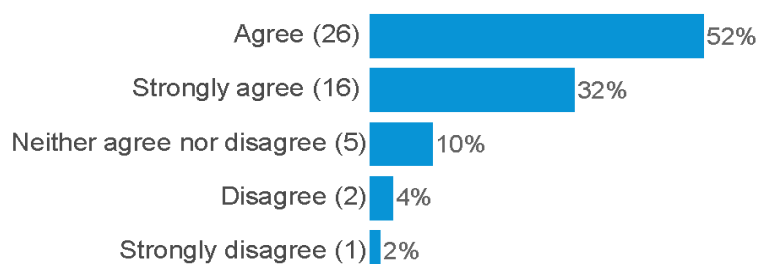




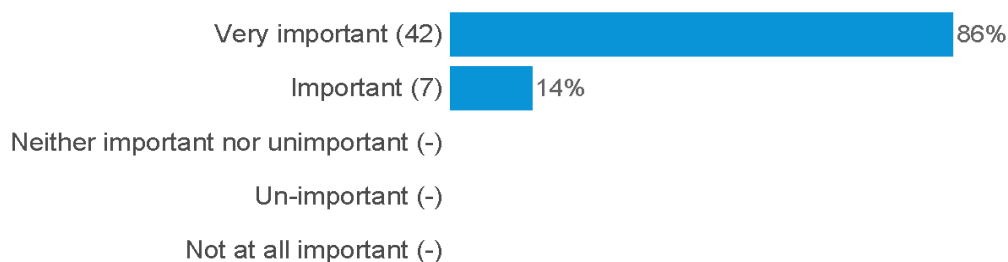
**Do you think highly specialist dementia care should be provided in a small number of homes to focus support on providing good quality care for people with dementia with the most complex needs?**



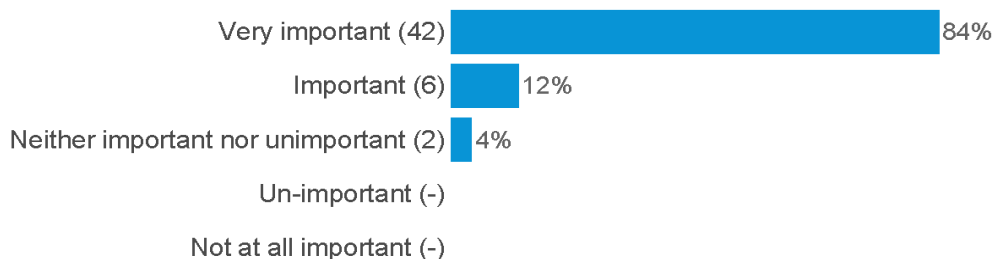
**Do you think that strong links and support from a team of dementia specialists (such as the care home liaison services, Community Mental Health Teams and “dedicated” GPs) could enable care homes to provide good quality care for people with dementia with the most complex needs?**



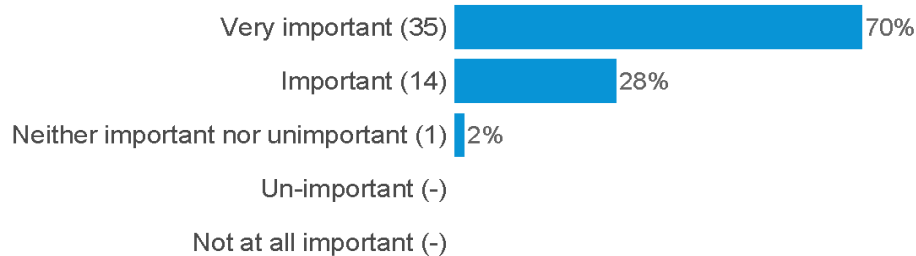
**What do you think is important for care homes to be able to provide good quality care for people with dementia with the most complex needs? Please rate: (Dementia training for carers)**



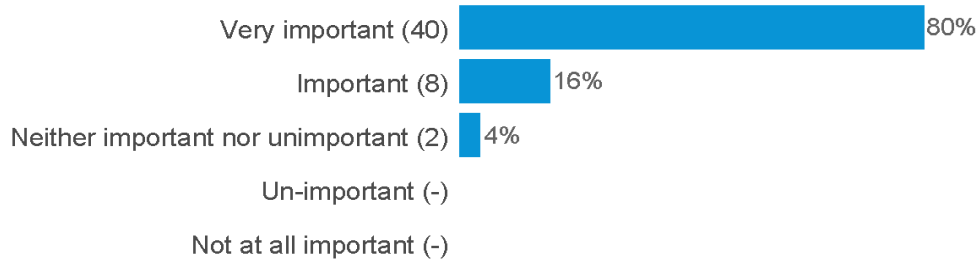
**What do you think is important for care homes to be able to provide good quality care for people with dementia with the most complex needs? Please rate: (Dementia friendly environment )**



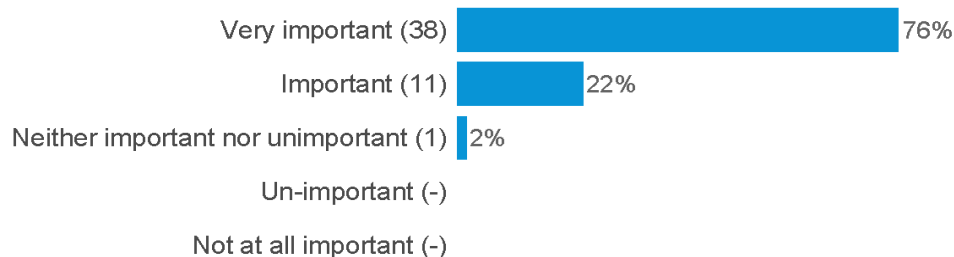
**What do you think is important for care homes to be able to provide good quality care for people with dementia with the most complex needs? Please rate: (High staffing levels)**



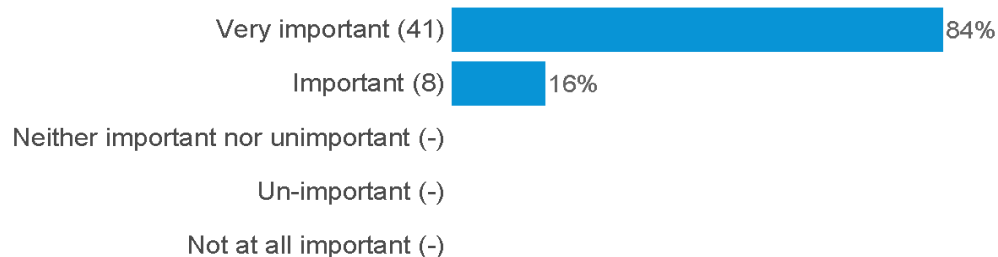
**What do you think is important for care homes to be able to provide good quality care for people with dementia with the most complex needs? Please rate: (Supportive management)**



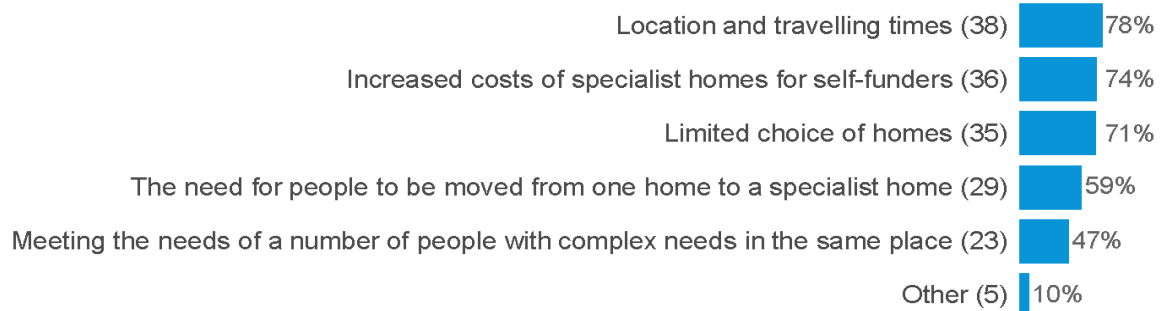
**What do you think is important for care homes to be able to provide good quality care for people with dementia with the most complex needs? Please rate: (Regular specialist support)**



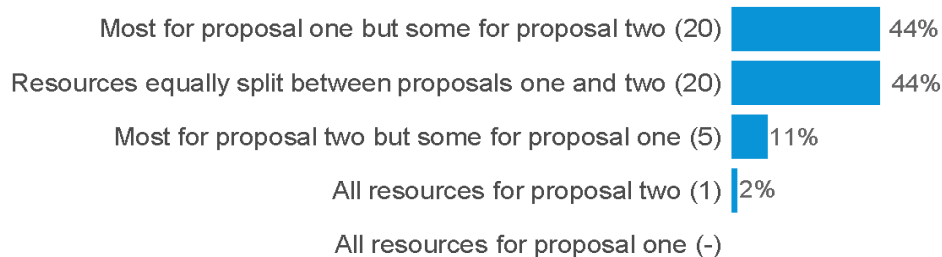
**What do you think is important for care homes to be able to provide good quality care for people with dementia with the most complex needs? Please rate: (Specialist support available in a crisis)**



**Would you have any concerns about specialist care being focussed in a small number of homes?**



**Do you have a view on how available resources should be divided between proposal one and proposal two?**



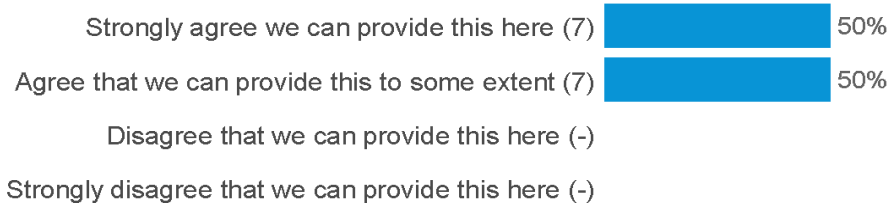
# Appendix 2

Dementia Care Home staff survey Results

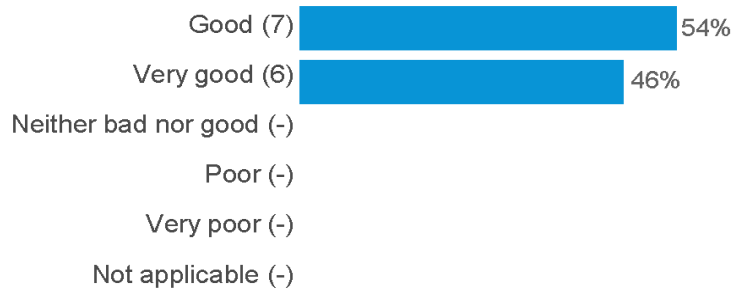


## Dementia Care in Care Homes Survey for Staff

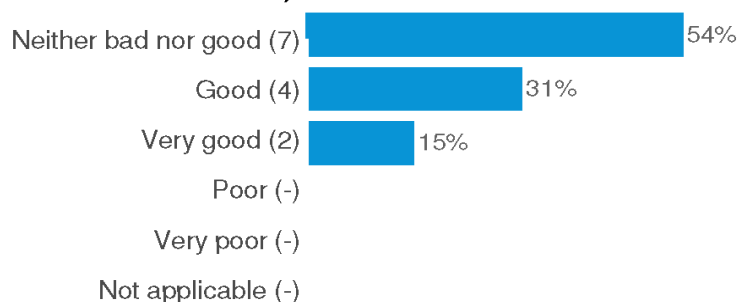
**To what extent do you feel able to give good quality care to people living with dementia with complex needs in your care home?**



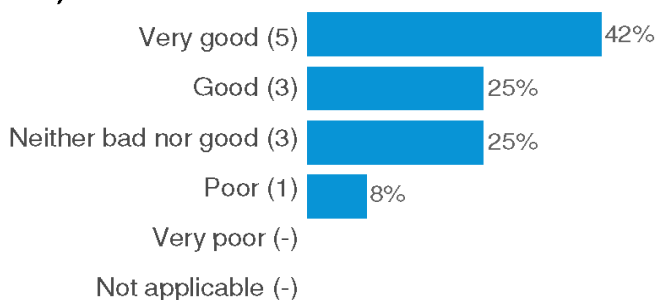
**What organisations/agencies have you requested support from in caring for people with dementia with complex needs? Please rate the quality of support you received? (GP Practice)**



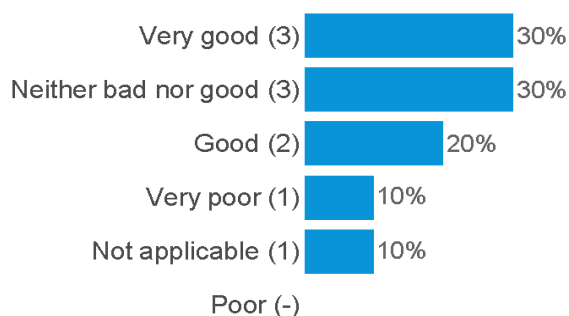
**What organisations/agencies have you requested support from in caring for people with dementia with complex needs? Please rate the quality of support you received? (Social worker/customer coordinator)**



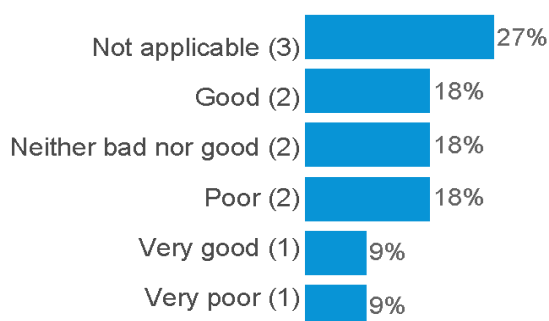
**What organisations/agencies have you requested support from in caring for people with dementia with complex needs? Please rate the quality of support you received? (Care home liaison team)**



**What organisations/agencies have you requested support from in caring for people with dementia with complex needs? Please rate the quality of support you received? (Wiltshire Quality Team)**



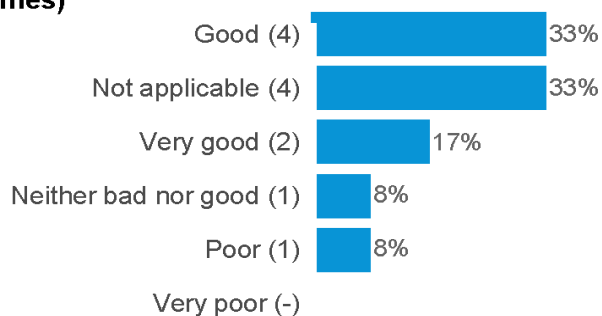
**What organisations/agencies have you requested support from in caring for people with dementia with complex needs? Please rate the quality of support you received? (Care Quality Commission)**



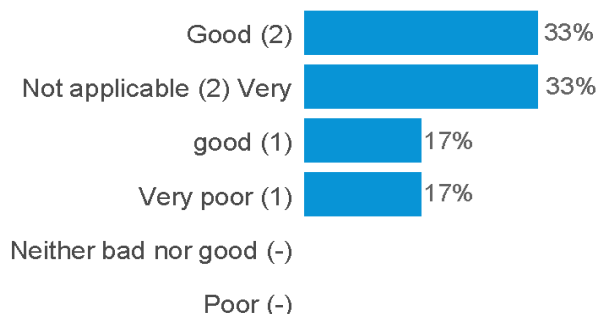
**What organisations/agencies have you requested support from in caring for people with dementia with complex needs? Please rate the quality of support you received? (Wiltshire Care Partnership)**



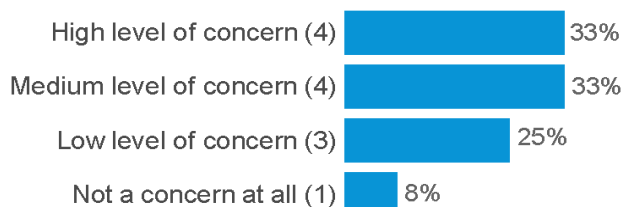
**What organisations/agencies have you requested support from in caring for people with dementia with complex needs? Please rate the quality of support you received? (Other care homes)**



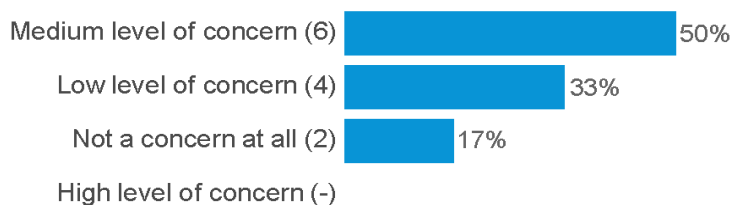
**What organisations/agencies have you requested support from in caring for people with dementia with complex needs? Please rate the quality of support you received? (Other)**



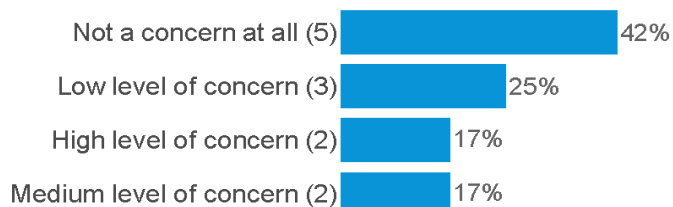
**What do you feel are the important concerns that could prevent you from agreeing to care for people with dementia with complex needs? (Lack of sufficient staff)**



**What do you feel are the important concerns that could prevent you from agreeing to care for people with dementia with complex needs? (Lack of staff training)**

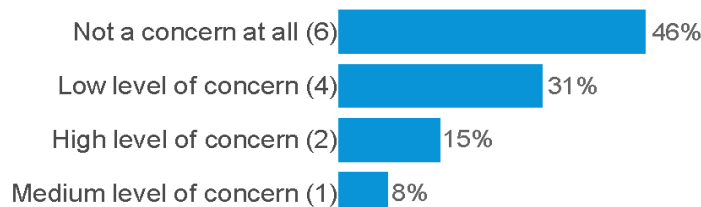


**What do you feel are the important concerns that could prevent you from agreeing to care for people with dementia with complex needs? (Unsuitable environment)**

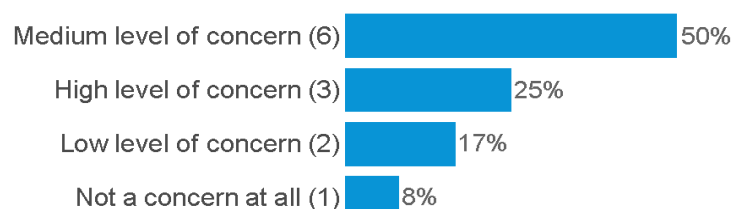




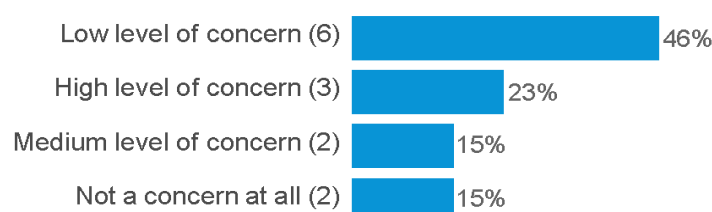
**What do you feel are the important concerns that could prevent you from agreeing to care for people with dementia with complex needs? (Lack of equipment)**



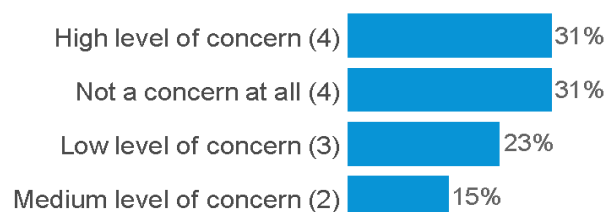
**What do you feel are the important concerns that could prevent you from agreeing to care for people with dementia with complex needs? (Concerns about reactions of other residents)**



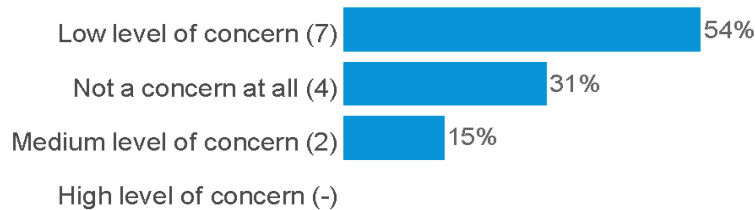
**What do you feel are the important concerns that could prevent you from agreeing to care for people with dementia with complex needs? (Concerns about reactions of relatives)**



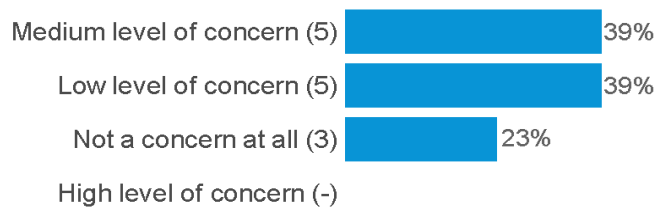
**What do you feel are the important concerns that could prevent you from agreeing to care for people with dementia with complex needs? (Concerns about managing difficult behaviours)**



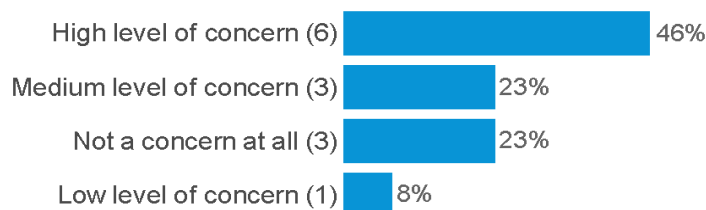
**What do you feel are the important concerns that could prevent you from agreeing to care for people with dementia with complex needs? (Concerns about caring for physical symptoms)**



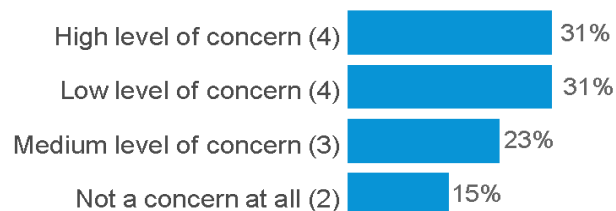
**What do you feel are the important concerns that could prevent you from agreeing to care for people with dementia with complex needs? (Concerns about managing psychological symptoms)**



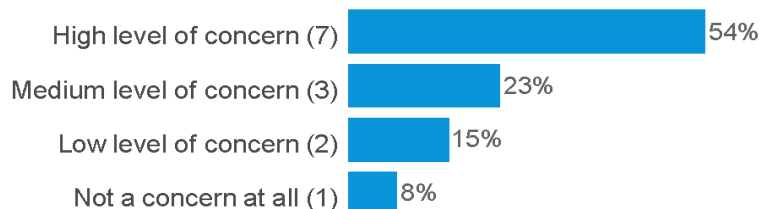
**What do you feel are the important concerns that could prevent you from agreeing to care for people with dementia with complex needs? (Concerns about safeguarding issues)**



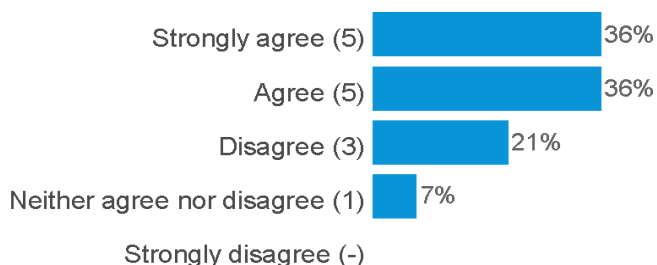
**What do you feel are the important concerns that could prevent you from agreeing to care for people with dementia with complex needs? (Lack of external support)**



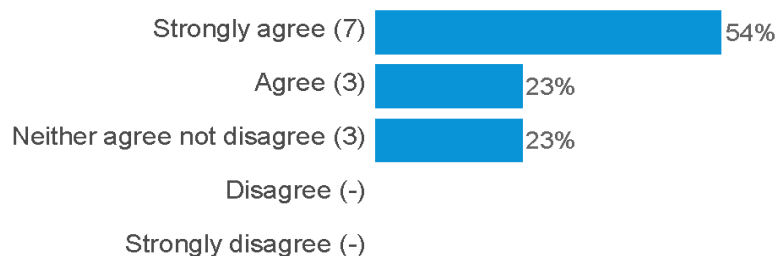
**What do you feel are the important concerns that could prevent you from agreeing to care for people with dementia with complex needs? (Capacity to manage a number of people with complex needs at once)**



**Do you think that resources should be concentrated on a small number of homes to enable more good quality care for people with dementia with the most complex needs?**



**Do you think that strong links and support through the care home liaison services, Community Mental Health Teams and “dedicated” GPs will enable care homes to provide good quality care for people with dementia with the most complex needs?**



# Appendix 3



## Have your say on dementia care in Wiltshire



### Information sheet about dementia engagement 25 July – 25 August 2017

#### Background

The Wiltshire Dementia Strategy was launched in late 2014. It is the responsibility of the Wiltshire Dementia Delivery Board to co-ordinate and monitor its implementation. This is a group of agencies which includes Wiltshire Council and NHS Wiltshire Clinical Commissioning Group (CCG), and other voluntary and community sector groups who are involved with people living with dementia and their carers in Wiltshire.

Healthwatch Wiltshire formed a partnership with voluntary and community sector groups in Wiltshire, committed to making sure that this strategy is delivering in practice what it promises on paper.

From December 2014 until March 2015 Healthwatch Wiltshire facilitated the public engagement to consult on the location of specialist dementia hospital beds. This resulted in a decision to permanently locate the beds in Fountain Way, Salisbury and to close Charter House in Trowbridge; with beds re-provided at Fountain Way.

At the CCG Governing Body meeting on the 24th March 2015, the CCG agreed to:

“Ringfence the resources released from the permanent closure of Charter House (£440,000) for the improvement of specialist dementia services in the community”.

The specialist services in the community referred to in the paper to the Governing Body, were support to care homes through the expanded Care Home Liaison Service and the joint commissioning of specialist care home beds.

#### What has happened since then?

##### 1. Work to implement the Wiltshire Dementia Strategy

The dementia delivery board has been working to implement the dementia strategy and reports that this has moved forward considerably.

Below are further details of the progress that has been made over the past two years in a number of areas:

##### Improving information

- A Dementia Roadmap that is under development, will be a resource to finding what services are provided by the Council, the NHS and local voluntary organisations.

##### Training for health and social care to improve quality

- Partnership working with Wiltshire Care Partnership & Managers Network.
- Care Home Training, developed by Sterling University (40 Home Managers on 1st cohort).
- Dementia services, environment and staff training in acute trusts (hospitals) across the county.

##### Consistency and equity across Wiltshire

- Full Wiltshire analysis of community support services completed by Healthwatch, commissioned by Alzheimer's Support to ensure equity across the county. Used to identify areas to further develop services.
- Audit and analysis of the number of people living with dementia admitted to hospital beds in Amblescroft, the reasons for admission, where they had been admitted from, the time they spent in hospital and their place of discharge.

##### Access to specific dementia support

- New Community & Dementia Advisor Contract - commenced 1st April 2017 - one provider, increases consistency and number of services across the county and increased resources for front line services.

- Dementia Advisers keep in regular touch with families and they provide confidential advice and up-to-date information that can help people to understand more about dementia and what might happen in the future, and to make informed decisions about care, treatment and support.
- Services also include award-winning day clubs and the much-valued one-to-one home support. Community activities include Singing for the Brain, Movement for the Mind, memory cafés, art groups, a discussion group, wildlife club and many more - all designed to keep minds and bodies active and reduce isolation.
- Healthwatch Dementia Reports - used to shape future services such as community groups, and the Dementia Advisor service within GP practices.

### **Raising awareness and involvement in decision making**

- Wiltshire Dementia Action Alliances (Dementia Friendly Communities) with 18 Area Boards across Wiltshire.
- Dementia Aware Project - raising awareness across the county, including schools, leisure and libraries.
- Improvements in End of Life management, now part of the Dementia Strategy with involvement in developing advanced care plans for people living with dementia in care homes.

### **Improving specialist support in the community**

- Expansion and redesign of Care Home Liaison Service - launched April 2016 (service review currently in progress). The service aims to support care homes in caring with people with dementia to prevent hospital admission, sustain people in care homes if things become difficult and to facilitate people being discharged from hospitals (both acute & mental health).

## **2. Changes that have happened since the consultation**

In 2016 Wiltshire Council and the CCG undertook an audit of the use of Avon & Wiltshire Mental Health Partnership specialist dementia hospital beds. This showed that the need for these beds was not as high as originally expected. It also found that a significant number of admissions in to these beds were from home, rather than care homes. This indicates that more support may be needed for people living with dementia in their own homes. It also highlighted whether the original plan to commission a block of specialist dementia beds in one care home in Wiltshire would be the best way to meet the needs of people with the most complex needs, both in terms of the best way to use our scarce resources and providing local services.

There are still areas that need further work and the public engagement will provide valuable intelligence and direction in the forward planning of services for people with dementia.

## **The proposed new plans**

There are two proposals that Wiltshire Council and the CCG would like to hear the public's views about.

It is not necessarily a choice between one or the other. There are options that one or the other could go ahead, or that both could. However, if both proposals went ahead each one would have less funding.

### **Proposal One - redesign an Integrated Dementia Pathway in Wiltshire to improve support at home**

This proposal would involve designing a clear consistent pathway for people living with dementia to be supported from initial diagnosis onwards.

The proposal would involve a team of dementia specialists from different areas coming together to work alongside each other in one team.

The focus of this team would be around the local GP practice. This would mean that Dementia Advisors, Care Coordinators, Memory Nurses and other specialists will be together in one area making it easier and more practical for the person who needs services. The redesigned pathway will ensure that everyone has the same level of service across the county.

This proposal would involve investing in more specialist nurses linked to the local GP practice.

## **Proposal Two - Increase the support to care homes for people living with dementia with the most complex needs**

There are times when people living with dementia with the most complex needs stay in hospital for longer than they need while they wait for a placement in a care home. Not all care homes can offer support to people with very complex needs and the number of people living with dementia who have their discharge from hospital delayed has been unpredictable.

There are care homes within Wiltshire, particularly smaller independent local homes, who, with the appropriate and timely extra level of support could offer the level of care and support required for people living with dementia with the most complex needs. We would intend to find out if care homes are interested in this approach.

It is proposed that Wiltshire Council and CCG undertake a detailed review with care home providers and managers to outline the precise support they need. The aim will be to identify a number of homes across the county with strong links and support through the Care Home Liaison Service, and working with Community Mental Health teams and primary care, to support people with the most complex needs. Our aim is to increase the opportunities for people to live in a care home.

Our intention is to improve the skills and expertise of staff in caring for people living with dementia in care homes.

This proposal may mean that there is more good quality care available for people living with dementia with the most complex needs across Wiltshire. However, it could potentially reduce the capacity of Care Home Liaison Service to support a broad range of care homes.

The proposal may involve investing in GP's to provide 'dedicated' support to care homes dependant on capacity.

## **What will the impact be on people?**

These proposals aim to:

- Focus on supporting people in the community
- Enable people to live at home for longer
- Provide care home places more locally for people who do need specialist care

## **Have your say about these proposals**

Wiltshire Council and CCG want to know what the public thinks about these proposals. They have asked Healthwatch Wiltshire to independently facilitate this public engagement.

This engagement will involve:

- 3 public meetings across Wiltshire with focused discussions
- Outreach visits to care homes and dementia groups
- An online and paper based survey
- Opportunities for people to give their views by email, post and phone

Healthwatch Wiltshire will gather all the feedback from Wiltshire people and write a report. This report will be given to the CCG and Wiltshire Council to help them with their plans.



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## Why not get involved?



[healthwatchwiltshire.co.uk](http://healthwatchwiltshire.co.uk)



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