Engagement Report for Dementia Services

Buckinghamshire County Council
in partnership with
Aylesbury Vale and Chiltern Clinical Commissioning Groups

September 2015
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Dementia Services
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1. Introduction

1.1 Seeking the views and experiences of people living with dementia or memory impairment and their carers is very important to Aylesbury Vale Clinical Commissioning Group, Buckinghamshire County Council and Chiltern Clinical Commissioning Group, to ensure the needs of people living in Buckinghamshire are identified and met.

1.2 A number of events took place across Buckinghamshire between September 2014 and July 2015 to encourage local people to have their say.

1.3 Aylesbury Vale Clinical Commissioning Group, Buckinghamshire County Council and Chiltern Clinical Commissioning Group, would like to take this opportunity to thank all those who gave their time and took part in this engagement process. It has ensured that the development of local strategies and service provision reflect current good practice and National Policy but also the views and experiences of local people.
2. Methodology

2.1 Engagement methods were chosen to appeal to a wide variety of audiences (both geographical and demographic).

2.2 The following engagement activity was undertaken:

- Two hundred questionnaires
- Four focus groups
- Three walking the patch sessions
- Two Dementia Partnership Board sessions
- Two Service Users and Carers Network sessions plus Carers Bucks Support Groups
- One Day Workshop

2.3 The different methods used for the engagement process were managed by officers in the Dementia Joint Care Commissioning team and supported by the Service User and Carers Organisation [SUCO], Carers Bucks, the Alzheimer’s Society and Age UK Buckinghamshire.

The purpose was to seek views regarding the following:

- Peoples experience of the dementia pathway
- Are there sufficient services available to meet people’s needs?
- Are there currently any gaps in service provision and the pathway?
- What are the priorities that Health and Social Care should focus on?
- What should the priorities of the Partnership Board and Service Users and Carers Network be?
- Prioritising the priorities for the enhanced Memory Support Service specification

2.4 Other forms of feedback included the views of people accessing current services through the contract monitoring process

2.5 The different methods of engagement were communicated through the following means:

- E mails, minutes and agendas
- Newsletters
- Partner organisations, 1:1 meetings and group sessions
- Press releases and radio news updates
3. Findings

3.1 The engagement methods proved to be effective on the whole, with the information and feedback gained being invaluable and contributed to the development of a number of pieces of work.

3.2 The findings informed the following:

- The priorities for the Dementia Partnership Board and the Service User and Carer Network
- The development of the Joint Commissioning Strategy for Dementia 2015 - 2018
- The service review and business case for the dementia pathway October 2014
- The Business case for Dementia Friendly Communities October 2014
- The Business case for the re-commissioning of the Memory Support Services May 2015

3.3 Questionnaires (see Appendix 2)

3.3.1 Two hundred questionnaires were sent out or 1:1 support provided to complete by the In Touch team, Age UK Buckinghamshire, Carers Bucks and the Alzheimer's Society. A 16% return rate was achieved.

3.3.2 Themes and issues can broadly be seen as:

- Communities need to understand the needs of people with dementia / memory concerns and their carers better
- Access to suitable and affordable transport especially in rural communities is a problem
- Services and local recreational groups to understand the needs for people with dementia, memory concerns and their carers to ensure they are not precluded from accessing these services.
- People often experience a loss in long term friendships following a diagnosis.

3.4 Focus groups

3.4.1 Four dedicated focus groups were organised by SUCO and facilitated by Officers of the Dementia Joint Care Commissioning Team. The focus groups took place in a number of different day opportunities across the county.

3.4.2 Themes and issues can broadly be seen as:

- Inconsistency in experience of support from GP practices
• Access to suitable and affordable leisure and recreation services who understand the needs of people with dementia or memory impairment and their carers. I.e. Art classes, photography groups, walking clubs etc.
• Support for people under 65 with dementia

3.5  Walking the patch

3.5.1  A ‘walking the patch’ session was held at each of the three launch events for Dementia-Friendly Community: Stokenchurch, Great Missenden, and Buckingham. The sessions were undertaken with a person with dementia and their carer to better understand their challenges in assessing services in their local communities.

3.5.2  Themes and issues can broadly be seen as:
  • Alternative methods of payment to chip and pin, money etc.
  • Environmental and physical barriers
  • Poor customer services can cause agitation leading to increased confusion leading to people withdrawing from the local communities.
  • Access to some shops can be difficult due to narrow isles, clutter, very loud music, entry switches for sliding glass doors not recognised etc.

3.6  Dementia Partnership Board

3.6.1  The Dementia Partnership Board meets bi-monthly and consists of nominated leads from all partner organisations, people with dementia or memory concerns and carers.

3.6.2  People with dementia or memory concerns and carers are supported on the board by SUCO.

3.6.3  Board members were asked in September 2014 to consider in preparation for the board meeting in December 2014 what they felt should be the 5 priorities for the board to focus on.

3.6.4  SUCO worked with individuals during October and November to identify their priorities, recording each one on separate post it notes. During the December 2014 partnership board the identified priorities were discussed and agreed.

3.6.5  The priorities can broadly be seen as:
  • Communication and Information
  • Services
  • Meaningful training and education, for professionals, for the community and for patients and carers
3.6.6 Carers Bucks have a number of carers support groups, the frequency of their meeting varies. Carers Bucks staff sought carers’ views regarding:

- Peoples experience of the diagnostic pathway
- Peoples experience of existing dementia support services
- Any gaps in service provision

3.6.7 The themes and issues can broadly be seen as:

- Better training should be provided to health and social care staff to understand the needs of people with dementia, memory concerns and their carers
- Better integration so people only have to tell their story once
- Information sharing agreement should be in place with professionals involved in a loved one’s care to ensure the carers knows what’s going on
- Support should be provided to the carer as this will then support the person with dementia or memory concerns and will help maintain relationships
- Opportunities should be given to carers by professionals to discuss their loved ones situation in private to ensure an accurate account is understood

3.7 Service Users & Carers Network sessions / Carers Bucks Support Groups

Two Service-User and Carers Network sessions plus Carers Bucks support group sessions were held.

3.7.1 The Service User and Carers Network roughly meet every 6 weeks. A similar process was followed as for the Dementia Partnership Board

3.7.2 The priorities can broadly be seen as

- Improved information, advice and training for different groups of people
- Better diverse mix of cost effective services including community interest groups who understand the needs of people with dementia, memory concerns and their carers.

3.8 One Day Workshop

3.8.1 A one day workshop was held in July 2015, the day was split into two halves. The morning session was for professionals and discussions were facilitated by carers. The afternoon session was for people with dementia or memory concerns and carers with the discussions being facilitated by professionals.

3.8.2 Memory Support service contracts are due to come to an end on 31st March 2016. Due to EU procurement law the services have to be re-tendered. The purpose of the conference was to seek people’s views regarding:

- What types of support the new enhanced service should provide.
- What do you think makes a helpful and accessible service
• Should the service be available to those living in long term care homes
• How can Health and Social Care work more closely together to deliver high
good dementia support
• What people thought about the proposed priority areas of spend as follows:
  o Crisis prevention support
  o Information, advice and signposting
  o Low level memory support

3.8.3 Themes and issues can broadly be seen as:
• Improved information in one place, which also makes best use of modern
technology and can be accessed when needed.
• Support to carers to avoid crisis situations resulting in inappropriate admission
  into hospital or a long term care setting
• Support to return home as quickly as possible if admitted into hospital
• Stop keep changing the name of services when they are re-commissioned
• Training for professionals and local communities to understand the needs of
  people with dementia, memory concerns and their carers
• Access to support outside of working office hours to avoid crisis
• One single point of contact for the whole county
• A named contact for each geographical area
• The facility to access the service as and when needed
• Although care homes are important, providers need to take some ownership
  of improving standards
• A service which is integrated with other services were possible
• Support planning to help people plan for the future and the progression of the
  condition
4. Outcomes and action taken

4.1 Questionnaires

The outcomes of the findings can broadly be seen as:

4.1.1 The enhanced Service Specification for the Memory Support Service includes quarterly training / awareness raising sessions for local communities.

4.1.2 Problems accessing suitable and affordable transport especially in rural communities have been fed into the Buckinghamshire Transport Review.

4.1.3 Information and guidance is being given to Community Links Officers to work with services in communities to ensure an inclusive approach is adopted for people with dementia, memory concerns and their carers. This also includes the use and roll out of the Dementia Friendly Communities DIY tool kit. [This also covers a number of other issues under other engagement methods]

4.1.4 Prescription books have been made available within libraries to support a wide number of issues; this includes books for children to understand dementia and how this can affect people through to useful information to enable carers to adopt coping strategies. The enhanced Service Specification for the Memory Support Service is designed to support people with dementia, memory concerns and their carers to maintain relationships.

4.2 Focus groups

The outcomes of the findings can broadly be seen as:

4.2.1 The Joint Commissioning Strategy for Dementia 2015 -2018 has a specific action to ensure consistency in experience from GP’s and the diagnostic pathway. This includes the development of a pathway tool kit for GP’s to use which also covers information and referral forms to support services in Buckinghamshire.

4.2.2 The Joint Commissioning Strategy for Dementia 2015 - 2018 has a specific action to work with providers to ensure a diverse mix of services are available, e.g. adult learning classes, community interest groups, etc.

4.2.3 The Joint Commissioning Strategy for Dementia 2015 -2018 has a specific action to work with providers to ensure a diverse mix of service is available for those under 65. This is also closely linked with 4.1.1, 4.1.3 and 4.2.2
4.3 Walking the patch

The outcomes of the findings can broadly be seen as:

4.3.1 The development of the Dementia Friendly Communities DIY tool kit has focused on addressing the issues identified to date both locally and at a National level.

4.3.2 The Joint Commissioning Strategy for Dementia 2015–2018 notes the importance of this initiative and has a specific action for the ongoing development of dementia friendly communities.

4.3.3 Buckinghamshire County Council and the Clinical Commissioning Groups have developed action plans ‘Working towards becoming dementia friendly’, which have been published on the National Dementia Alliance web page for Buckinghamshire.

4.4 Dementia Partnership Board

The outcomes of the findings can broadly be seen as:

4.4.1 The priorities identified by the Dementia Partnership Board have also been included within the action plan for the Joint Commissioning Strategy and the year 1 detailed action plan. Please see Appendix 1.

4.4.2 There are detailed requirements within the enhanced Service Specification for the Memory Support service for improved information, training and awareness raising sessions for professionals and local communities.

4.5 Service Users & Carers Network sessions / Carers Bucks Support Groups

The outcomes of the findings can broadly be seen as:

4.5.1 The priorities identified by the Service User and Carers Network and Carers Bucks Support Groups have also been included within the action plan for the Joint Commissioning Strategy and the year 1 detailed action plan.

4.5.2 There are detailed requirements within the enhanced Service Specification for the Memory Support service for improved information, training and awareness raising sessions for professionals and local communities.
4.5.3 The Joint Commissioning Strategy for Dementia 2015 -2018 has a specific action to work with providers to ensure a diverse mix of service is available for those under 65 and those over 65. This is also closely linked with 4.1.1, 4.1.3 and 4.2.2

4.6 One Day Workshop

The outcomes of the findings can broadly be seen as:

4.6.1 The name for the enhanced service for Memory Support has changed slightly to reflect the increased level of support. As Buckinghamshire currently has two similar services but both with different names the larger service supporting most of Buckinghamshire name was chosen for consistency.

4.6.2 The service will provide a single point of contact County wide with an answer machine for out of office hours and emergency coverage for evening and weekend as necessary.

4.6.3 The service will work with other services where interdependency has been identified.

4.6.4 The service will provide a named worker for each GP locality and for each person accessing the service.

4.6.5 The service will provide training / awareness raising sessions to professional and communities on a quarterly basis.

4.6.6 The service will work with commissioning partners, the Dementia Partnership Board, Service User and Carer Network to develop improved information.

4.6.7 The service will provide the following:

- Information, advice and signposting
- Dementia screening with GP Cog
- Training / awareness raising session to professional and local communities
- Crisis prevention support
Appendix 1

Buckinghamshire’s Joint Commissioning Strategy for Dementia
2015 – 2018

Action Plan for year 1: 2015 - 16

The Action Plan is for the first year of this commissioning strategy. The intention is that the Action Plan will be updated annually with new actions each year to continue the developments required to commission and provide quality dementia support services across Buckinghamshire.

The Action Plan supports the delivery of the five Themes:

1. Improve the diagnostic pathway and rate
2. Dementia awareness
3. Personalised support and independent living
4. Pre-crisis support
5. Young people with dementia i.e. those under 65

<table>
<thead>
<tr>
<th>Strategic Themes</th>
<th>Commissioning Outcomes</th>
<th>Actions</th>
<th>Lead responsibility</th>
<th>Time Frame</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Improve the diagnostic pathway and rate</td>
<td>Peoples mental health needs will receive the same level of attention as peoples physical health needs.</td>
<td>1.1 A report will be produced which will evaluate the effectiveness of the Memory Assessment Closer to Home [MACH] project</td>
<td>1.1 MACH project manager</td>
<td>1.1 August 2015</td>
</tr>
<tr>
<td></td>
<td>People with memory concerns and their carers will feel confident of the benefits of seeking an early diagnosis.</td>
<td>1.2 A dementia screening policy and tool kit will be developed for GP’s to access to support patients and carers.</td>
<td>1.2 MACH Project manager &amp; Joint Commissioning Manager – dementia Lead</td>
<td>1.2 Dec 2015</td>
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<td></td>
<td>People’s experience of the diagnostic pathway will enable them to feel supported</td>
<td>1.3 Locality Managers</td>
<td>1.3 April 2016 [review progress]</td>
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and have sufficient and appropriate information to enable them to plan for the future.

GP practices will see an increase in their diagnostic rate.

<table>
<thead>
<tr>
<th>1.3 Increase the number of GP practices working towards becoming “Dementia Friendly” with an agreed and published Action Plan</th>
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<tr>
<td>2. Dementia Awareness</td>
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<tr>
<td>Front line staff will feel confident in understanding the needs of people with dementia and their carers.</td>
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<td>People with dementia will be enabled to live well and as independently as possible within their local communities.</td>
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<tr>
<td>GP practices will see an increase in their diagnostic rate as dementia is de-stigmatised and the benefits of an early diagnosis is understood</td>
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<tr>
<td>2.1 Develop a communication plan and materials.</td>
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<td>2.2 Develop a training plan and resources across health, social care, and people with dementia, carers and businesses.</td>
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<tr>
<td>2.3 Continue to implement “Dementia Friendly Communities” embedding within the three pilot sites and roll out the DIY tool kit to a further three pilot sites</td>
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<tr>
<td>2.4 Partner Organisations on the “Dementia Partnership Board” to develop and</td>
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<td>2.1 June 2015</td>
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<td>2.2 Dec 2015</td>
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<td>2.3 April 2016 [Review progress ]</td>
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<td>2.4 April 2016 [Review progress ]</td>
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<td>2.5 April 2016 [Review progress ]</td>
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<tr>
<td>3. Personalised support and Independent Living</td>
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<td>Services</td>
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<tr>
<td>4. Pre-crisis Support</td>
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<tr>
<td>4.1 Work with providers of mental health services to maintain current services and the development of new approaches through a robust contract management framework</td>
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<tr>
<td>4.2 Ensure the existing pathway and service developments are effectively communicated to professionals, people with dementia and their carers.</td>
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<tr>
<td>5. Young people with dementia i.e. those under 65</td>
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</tbody>
</table>
| People under 65 will feel confident in accessing generic community based services | Identification and diagnosis of dementia and diagnosis of dementia and diagnosis of dementia. | * Dementia Friendly Communities
* Raising awareness – de-stigmatising the condition
* An enhanced "Memory Support Service"
* Improved information | 5.2 Joint Commissioning Manager – Dementia Lead | 5.2 April 2016 [review progress] |
Appendix 2

Memory Friendly Communities Questionnaire

Buckinghamshire County Council would like to better understand what the people in Buckinghamshire who are living with memory problems and dementia feel about their communities, what they like to do, what facilities and services they use and what helps and hinders them.

We want to find out what would make living in Buckinghamshire easier for people living with memory problems or dementia.

It would be very helpful if you could take the time to let us know what you think by answering the following questions and returning them in the pre-paid envelope by 30th September 2014.

August 2014

Buckinghamshire County Council
Adults & Family Wellbeing
Commissioning & Service Improvement
Walton Street
Aylesbury
HP20 1YU
Please tick the box that applies to you:

I am a person living with memory problems or dementia: ☐

I am a carer of a person living with memory problems or dementia: ☐

I am filling this form in on behalf of a person living with memory problems or dementia: ☐

I live in______________________________________________________

(Please indicate town or village only)

Age (person living with memory problems or dementia):

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<th>24 - 30</th>
<th>51 – 60</th>
<th>81 - 90</th>
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Gender (person living with memory problems or dementia):

Male ☐

Female ☐

Other ☐

Ethnicity (person living with memory problems or dementia):

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<th>Asian/Asian/British Other</th>
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<th>Black/Black/British Other</th>
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<th>Other ethnic Group</th>
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<tr>
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<tr>
<td>What does having memory problems or dementia mean to you?</td>
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| How does this make you feel? |
What support do you have? (Family, friends, carers etc.)

What things do you like to do in your local community?

What helps you to do these things?
What causes you problems or makes it more difficult for you to do these things?

Have you stopped doing things in your community – if so, what are they?

Why have you stopped doing them?
What would help you to start doing these things again?

What new things would you like to do in your community?

What is stopping you?
What would help you to do these things?