



# **Consultation Report:**

## **Early Diagnosis in Dementia**

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### 1. About NHS Oxfordshire

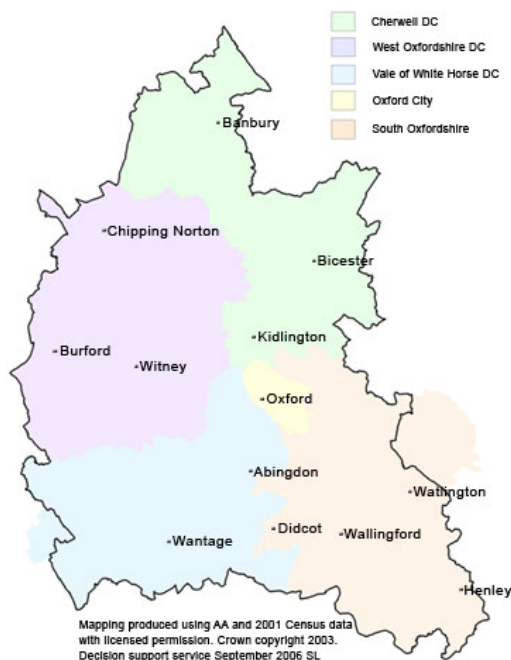
NHS Oxfordshire is a Primary Care Trust (PCT) and serves a population of around 600,000.

We are ambitious about improving the health and wellbeing of local people. NHS Oxfordshire intends that, by 2013, the people of Oxfordshire will:

- be healthier, particularly if they are vulnerable or live in our most deprived communities
- be working with NHS Oxfordshire to promote physical and mental wellbeing and prevent ill health
- be actively supported to manage their health and care needs at home when this is appropriate
- have access to high quality, personalised, safe and appropriate health services
- get excellent value from their local health services
- have a PCT which is a high performing organisation.

Oxfordshire is the most rural county in south east England and has a large geographical area to cover as well as a diverse population to serve. The population of Oxfordshire ranges from a predominantly older, white population in the rural areas to very ethnically diverse populations in Banbury and Oxford city where one third of the population are students.

NHS Oxfordshire works with our communities and our partners to improve health in the area and to make sure that local people's needs are being met. We also work with organisations from the voluntary, private and community sectors so that we can make sure that the organisations providing health and social care services are working effectively.



**Area covered by NHS Oxfordshire**  
Oxfordshire PCT serves a population of approximately 630,000 and covers the areas of Cherwell Vale District Council, Oxford City, South Oxfordshire, Vale of White Horse District Council and West Oxfordshire District Council.

## **2. Executive summary**

### **2.1 Purpose of the public engagement**

The Communications and Engagement directorate at NHS Oxfordshire, in partnership with Oxfordshire County Council embarked on a period of engagement from May-June 2010, to engage and involve all those patients, carers and families with experience of dementia<sup>1</sup>, and those organisations interested in helping to ensure more people receive a good early diagnosis of dementia. The feedback gathered and results from this report will then be used to inform and determine the shape of the care pathway for early diagnosis in dementia in Oxfordshire.

### **2.2 Process & Methodology**

A number of consultation and engagement methods were used simultaneously to enable maximum feedback from a wide variety of stakeholders in the time available. This included a public consultation workshop at County Hall, Oxford; gathering feedback at the Dementia Awareness Day and online engagement methods on the 'Talking Health' website, a questionnaire and feedback via email or by phone.

### **2.3 Key Findings**

Analysis of the consultation findings from the public consultation workshop, written responses, email and online responses interestingly resulted in very similar response themes. These included:

- The need for clearer access points at which patients, their families and carers can get the information and help that they need
- The need for better quality information and support for dementia
- The need for more specialist knowledge about dementia in GP surgeries and therefore more training on dementia to be provided.
- Follow up appointments to be carried out by a dementia specialist – this could be a GPSI, a specialist nurse or a specialist at a memory clinic. The important thing is that they are a specialist in dementia.
- A more person-centred approach to services and care – including the need for home visits and (younger) age related services where appropriate
- A more integrated and coordinated approach to dementia diagnosis, care and support, with systems and processes to support this.

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<sup>1</sup> An explanation of dementia is included in Appendix 3.

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- More awareness raising to help understanding of dementia and prevent negative attitudes/stigma.

### 2.4 Conclusion

The report recommends that the participants' concerns from this consultation are fully considered and as many of their comments and suggestions regarding dementia diagnosis, support and care are incorporated wherever possible into the design of the new care pathway for early diagnosis in dementia in Oxfordshire.

### **3. Background**

#### **3.1 Why do we need a care pathway for early diagnosis in dementia?**

A strategic, cross-cutting approach is vital if we are to deal with the challenges and consequences of dementia as a society. The National Dementia Strategy for England, 2009 outlines 17 key objectives to transform services for people with dementia and their carers, making dementia a key national priority. The national strategy is outcome-focused and the objectives have been grouped into three broad themes:

1. Raising awareness
2. Early diagnosis
3. Living well with dementia

The project will deliver objective two of the National Dementia Strategy 2009 - Good-quality early diagnosis and intervention for all.

#### **3.2 The local context**

NHS Oxfordshire and Oxfordshire County Council ("the Commissioners") have a joint strategy for the development of dementia services across the county. Oxfordshire already has in place a number of well established memory clinics, however there are at present two providers with different service models and lack of equity to capacity of population needs. This consultation on early diagnosis in dementia is part of a project to build and develop the current services to meet the project aims and objectives.

#### **3.3 The Vision for Dementia Services**

To develop the current Memory Clinic provision within Oxfordshire with an agreed pathway of care for early diagnosis and intervention in dementia across all healthcare sectors, which has the capacity to assess all new cases occurring in Oxfordshire. This service will offer assessment, treatment initiation and support following diagnosis and will significantly increase the number of people receiving a diagnosis of dementia, also providing a diagnosis earlier in the course of the illness.

#### **3.4 What was the purpose of this consultation?**

NHS Oxfordshire and Oxfordshire County Council were seeking views and feedback from the public to enable the development of an agreed pathway of care for early diagnosis and intervention in dementia for patients in Oxfordshire. The purpose of the consultation was to:

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- Provide an opportunity for the public to tell us about their experiences of dementia diagnosis – what works and what doesn't
- Examine the proposed care pathway for diagnosis of dementia and allow the public to give their views on what changes need to be made
- Give the public a chance to tell us what their vision of a care pathway for early diagnosis in dementia looks like

### **3.5 How will the feedback be used?**

The opinions gathered from all of the consultation methods - including the workshop, the online consultation, and the questionnaire responses - are being used to help shape the design of the care pathway for services and care to support early diagnosis in dementia and to feed into the strategic and operational plans for the development of dementia services in Oxfordshire.



## **4. Stakeholders**

The stakeholders for the early diagnosis in dementia consultation are patients, their families and carers of people that have dementia as well as organisations or groups with an interest in supporting people with dementia.

### **4.1 Stakeholders**

The key stakeholders identified for this consultation were:

#### Patients with dementia, their families and carers

This is the primary target group and provides an opportunity for those who have experience of diagnosis as carers, dementia patients or supporting organisations to identify the key issues which may be preventing or mitigating against early diagnosis

#### Current Service Providers (including the voluntary sector where appropriate)

Engaging with these groups when and where appropriate and encouraging dissemination of information of the consultation to further interested individuals, groups and organisations.

E.g. Memory clinic staff, GPs

#### Other Organisations and groups with an interest in dementia

It was important to ensure that other voluntary organisations with an interest in this work are kept informed and provided with appropriate opportunities to engage, including attending and participating in the consultation workshop.

#### NHS Oxfordshire staff

NHS Oxfordshire staff may have experience of working with those patients with dementia, their families or carers or may have personal experiences that they would like to share. It was important to therefore include and engage with staff in this consultation.

#### Those generally interested in dementia, older people and general mental health issues

There may also be people in Oxfordshire who, whilst not having any personal experience, may have a particular interest in dementia or related issues. It was important that the consultation was therefore communicated in a way that enabled as many people as possible to participate.

#### Media

Throughout the project media activity was developed when and where appropriate published to ensure communication is open and helpful and that were providing and supporting positive messages to enable maximum stakeholder involvement.

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### Other

When communicating this consultation with the key stakeholders listed above, encouragement was also given to share this information with any individual or organisation that may be interested in issues regarding dementia in Oxfordshire.

## **5. Engagement process**

Due to the limits placed on the consultation duration due to election activities, efforts were made to engage with and facilitate feedback from the public, families, carers of dementia and staff of dementia related services using as many different methods as possible.

The consultation was communicated to over 200 organisations and individuals with an interest in dementia. In total 62 people actively engaged with NHS Oxfordshire regarding the dementia consultation:

- 26 attended the workshop
- 19 commented during the dementia awareness day
- 17 engaged with the consultation online

### **5.1 'Early Diagnosis in Dementia' – Online engagement**

#### NHS Oxfordshire Talking Health website

##### **The care pathway diagram**

The early diagnosis in dementia care pathway diagram was set up on the *Talking Health* website to enable stakeholders to have a visual picture of the care pathway and to enter their own comments, views and feedback. The care pathway diagram can be seen in Appendix 1.



##### **Early Diagnosis in Dementia Questionnaire**

A questionnaire on early diagnosis in dementia was set up on *Talking Health* to ask key questions about the proposed care pathway and to gather further feedback and ideas. This questionnaire was also shared in hard copy format among key organisations and the attendees of the consultation workshop. A copy of the questionnaire can be seen in Appendix 2.

#### NHS Oxfordshire Intranet

NHS Oxfordshire's intranet was used to communicate the consultation and available response methods to all staff, encouraging further dissemination of information to organisations and interested individuals.

#### All Staff email

The consultation was communicated widely to all NHS Oxfordshire staff in the weekly staff bulletin via the everyone@... email facility.

#### Twitter and Facebook

A number of announcements and 'tweets' were made on the Twitter and Facebook websites for NHS Oxfordshire about this consultation and the associated public consultation workshop.



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### Email

An email campaign promoting the 'Early Diagnosis in Dementia' consultation workshop and other response methods was communicated to a large target audience of over 200 individuals, community and voluntary groups across the county.

## 5.2 'Early Diagnosis in Dementia' consultation workshop

The consultation workshop for early diagnosis in dementia was held at County Hall, Oxford on the 18<sup>th</sup> May 2010.

It included an introductory talk by Meg Barbour, giving a brief insight into her own personal experience as the wife and carer of someone with dementia, and the importance for her and her family of receiving an early diagnosis.

Duncan Saunders then gave a further explanation of why NHS Oxfordshire is doing this consultation and how the views and feedback that people give will be used to shape the care pathway.

The attendees then split into three groups of approximately 8 people for the workshops. Three key questions were discussed:

1. In your experience, what currently works well with dementia diagnosis?
2. In your experience, what currently does not work well with dementia diagnosis?
3. (Blue sky thinking) – What things would need to be included for a really good dementia diagnosis?

The questions were answered in a progressive manner which meant that each group started with a different topic. In the next group, they then built on what the previous group has already said, and then finally the attendees were asked to discuss and prioritise the final topic.

At the end of the workshop, discussion comments were shared with all attendees at the event both by verbally summarising key themes discussed in each group and by putting flipchart posters of notes up around the room for all to view.

Time was also allowed at the end of workshop to raise any specific questions that stakeholders had about 'Early Diagnosis in Dementia' and for attendees to add any personal comments or ideas to the flipcharts using post-its.

## 5.4 Other methods of engagement

### Dementia Awareness Day

A Dementia Awareness Day, hosted by Oxfordshire County Council and other partner organisations, was held on the 23<sup>rd</sup> May at the Ashmolean museum, Oxford to raise awareness of the condition and also to gather views on the proposed care pathway for early diagnosis. The event was promoted throughout NHS Oxfordshire, Oxfordshire County Council, key partners and interested organisations.



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A tabletop display, manned by NHS Oxfordshire, was set up at this event to invite people to give their views on diagnosis of dementia and to comment on the care pathway.

### **Parish Magazines**

The early diagnosis in dementia consultation was circulated by email to all parishes in Oxfordshire and then published in a number of parish magazines on online newsletters such as the Benson Bulletin, Hook Norton Newsletter and Kennington Chronicle.

## **6. Engagement Findings – Consultation workshop**

### **6.1 Number of responses**

In total 26 people attended the consultation workshop at County Hall, Oxford. These consisted mostly of an even split between carers/family members of people with dementia and individuals from interested organisations.

### **6.2 Discussion questions**

The comments from each of the three discussion questions at the consultation workshop were gathered into response themes so that trends could be identified.

The results for the discussion questions are shown below:

#### **Discussion question 1: In your experience, what currently works well with dementia diagnosis?**

The key themes for this discussion question are shown below.

Resources and support were the main themes for this discussion question and respondents highlighted some of the existing sources of good information, support and advice for dementia patients, their families and carers.

<b>Key Theme</b>	<b>Resources</b>
<b>Comments</b>	<ul style="list-style-type: none"> <li>• Wonderful staff in the system</li> <li>• Learning very helpful – books recommendations</li> <li>• Age Concern – useful advice</li> <li>• Oxford carers centre – run courses with experts – offer other support i.e. transport</li> <li>• Information and advice from the consultant – (breathing clinic)</li> </ul>
<b>Key Theme</b>	<b>Support Groups</b>
<b>Comments</b>	<ul style="list-style-type: none"> <li>• Carers groups and being part of group – knowledge – was a constant when other care is very fragmented. Offer practical advice</li> <li>• Care Management (SS) support is very good, reduces pressure on family (process took about 1 year)</li> <li>• Family support groups</li> </ul>

Another key theme of what works well was the current activities taking place – particularly in the media - related to raising awareness of dementia and some people’s positive attitudes towards dementia.

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<b>Key Theme</b>	<b>Attitudes</b>
<b>Comments</b>	<ul style="list-style-type: none"> <li>• Always looking for positives – concentrating on what people can do</li> <li>• Becoming less scared to seek help – less stigma</li> </ul>
<b>Key Theme</b>	<b>Raising Awareness</b>
<b>Comments</b>	<ul style="list-style-type: none"> <li>• Terry Pratchett! Talking about it – other celebrities publicising. Public awareness through drama – ‘The Archers’</li> <li>• General public – raising awareness</li> <li>• Increased awareness of the disease – more media coverage (although people still afraid)</li> </ul>

Other themes of things that are currently working well with dementia diagnosis were related to some of the good training and research that is currently taking place.

<b>Key Theme</b>	<b>Training</b>
<b>Comments</b>	<ul style="list-style-type: none"> <li>• Best GP referrals come from GPs who have had specialist training</li> <li>• Carers training in dementia/workshops. E.g. “Dignity champions”, “Caring with confidence”</li> </ul>
<b>Key Theme</b>	<b>Research into Dementia</b>
	<ul style="list-style-type: none"> <li>• Donating Brains for research. Positively/actively taking part in research</li> <li>• If can get early diagnosis – can get accurate understanding – could be another memory problem that can be cured</li> </ul>
<b>Key Theme</b>	<b>Others</b>
<b>Comments</b>	<ul style="list-style-type: none"> <li>• Works well when services follow similar route to cancer – “hidden disease”</li> </ul>

### Discussion question 2: In your experience, what currently does not work well with dementia diagnosis?

There were quite a number of comments made about what currently does not work well in dementia diagnosis.

The three main themes that were highlighted that needed attention were: the need for GPs to have more time, specialist knowledge, and understanding of dementia; problems with communication/delays within the system; and the need for both better and more information and support for patients, families and carers of those with dementia.

<b>Key Theme</b>	<b>GPs</b>
<b>Comments</b>	<ul style="list-style-type: none"> <li>• GP’s feel disempowered/lack of confidence and therefore gate keep using ‘confidentiality’</li> <li>• GPs need to allow time with carer on his/her own to understand the problem</li> </ul>



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	<ul style="list-style-type: none"> <li>• Had to fight to get a referral</li> <li>• There is a reluctance to refer to diagnosis by GPs</li> <li>• Some GPs not trained or don't use what they have learned. SO don't identify or know where to send for support</li> </ul>
<b>Key Theme</b>	<b>Information/Support</b>
<b>Comments</b>	<ul style="list-style-type: none"> <li>• Need to increase knowledge in all areas i.e. benefits</li> <li>• Information in Surgeries – little available</li> <li>• Don't know who to talk to</li> <li>• More support at end stages i.e. Vale House</li> <li>• Info not passed around the family</li> </ul>
<b>Key Theme</b>	<b>Communication/delays</b>
<b>Comments</b>	<ul style="list-style-type: none"> <li>• Systems e.g. at memory clinic do not allow advance booking so carer has to be responsible for remembering repeat booking</li> <li>• Delays in getting diagnosis – (even this pathway doesn't look like a one-stop-shop.)</li> <li>• Time delay if referral to community team and then a memory clinic</li> <li>• Referral for C.T. Scans can delay the diagnosis because of medical focus on another illness can mean dementia is not properly addressed</li> <li>• Once in system sometimes takes a while to get into service. "Missed opportunities"</li> </ul>

Other comments about what was not working well in dementia diagnosis related to transport problems when patients/families wanted to access support services and also the negative attitudes surrounding dementia. These negative attitudes appeared to be apparent across all areas – in the general public, relatives, in local communities and even in some health care staff.

<b>Key Theme</b>	<b>Access/Transport</b>
<b>Comments</b>	<ul style="list-style-type: none"> <li>• Access issues often run during the day</li> <li>• Really difficult if family carer is living at a distance even harder to get the system to support</li> </ul>
<b>Key Theme</b>	<b>Attitudes</b>
<b>Comments</b>	<ul style="list-style-type: none"> <li>• Fear of dementia in public causes issues</li> <li>• Like a 'cloudy' room for the relatives – can be in denial</li> <li>• Ageist attitudes – ignored in A&amp;E because with an elderly patient.</li> <li>• Attitudes in community – fear, ageism, breaking bad news</li> </ul>

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### Discussion question 3: (Blue sky thinking) – What things would need to be included for a really good dementia diagnosis?

The participants of the consultation workshop came up with a lot of suggestions on what a really good dementia diagnosis would need to include.

<b>Key Theme</b>	<b>Patient/carer focused</b>
<b>Comments</b>	<ul style="list-style-type: none"> <li>• Take into account different people's needs. Carers versus patients' needs</li> <li>• Carer involvement in diagnosis</li> <li>• Carer Involvement facilitated in TVE way</li> </ul>
<b>Key Theme</b>	<b>Good support for patients and carers</b>
<b>Comments</b>	<ul style="list-style-type: none"> <li>• Support in the clinic when diagnosis made – someone to give information and answer questions</li> <li>• Effective social service to support person with dementia in community</li> <li>• Carer support and information sign posting</li> <li>• Practical support to get people to GP initially</li> <li>• Support to adjustment - emotional and practical</li> </ul>
<b>Key Theme</b>	<b>Consistency</b>
<b>Comments</b>	<ul style="list-style-type: none"> <li>• Consistent point of contact to go back to if information needed later</li> <li>• Continuity of care needed</li> </ul>
<b>Key Theme</b>	<b>Good communication of information</b>
<b>Comments</b>	<ul style="list-style-type: none"> <li>• Copy of report sent to referrer, (consultant – GP) and carer.</li> <li>• Effective systems integrated and joined up</li> <li>• Transparency with diagnostic process – Patient information to help them understand and be reassured that symptoms taken seriously</li> <li>• Central repository of information – help translating this into framework</li> </ul>
<b>Key Theme</b>	<b>Attitudes</b>
<b>Comments</b>	<ul style="list-style-type: none"> <li>• Knowledge, awareness raising to drop stigma with both professionals and public.</li> <li>• Confusion about labels 'Dementia' and 'Alzheimers'.</li> <li>• Demystifying needed.</li> </ul>
<b>Key Theme</b>	<b>Holistic and proactive approach</b>
<b>Comments</b>	<ul style="list-style-type: none"> <li>• Holistic/Relationship based model of care where all area addressed</li> <li>• Good co-ordination between providers and families – care navigation and proactive management.</li> <li>• System needs to have a more pro-active approach to supporting, assisting and informing the carer.</li> </ul>
<b>Key Theme</b>	<b>Location of care</b>
<b>Comments</b>	<ul style="list-style-type: none"> <li>• Memory clinics in the community.</li> <li>• First point of contact – GP – does this need to be the GP? More important to have the appropriate understanding, knowledge and communication</li> </ul>

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Key Theme	Others
Comments	<ul style="list-style-type: none"><li>• Quicker diagnosis</li><li>• General strategies are needed to support even if <u>no</u> diagnosis is made</li></ul>

### Good Ideas

Attendees were also asked to add any comments or good ideas towards the end of the workshop.

Some of the key themes included the need for a clear, central place for patients, families and carers to go to whenever they need more information on dementia – whether this is at before, at, or after diagnosis.

"Need a one stop shop with easy access to information and support for patient and family."

"It needs Primary Care services to see themselves as THE hub for dementia services - proactive and relationship building."

The majority of suggestions were made around the whole approach to dementia diagnosis and the need for care to be more integrated and joined up.

"We need systems which are fully integrated and supportive of carers/family members and recognise the holistic nature of the condition."

"We need proper care - co-ordination and care. Navigation from the earliest possible identification. Current state is a rag-bag, no-one "holding" the issue."

"The solution is not with health care alone, a comprehensive health and social care system needs to be established, which removes the block of the means test."

A number of comments and suggestions were also made around the patient – with a focus on both diagnosis and care being person-centred and tailored to the individual.

"Thorough medical assessment of an individual's physical and mental health is needed to reach accurate diagnosis."

"Person Centred Care training should be offered to all who work with people with dementia, including in generic services."

Other ideas included:

"Memory clinic administration needs/must be supported by bespoke software (database) as currently relies on completely inadequate systems"

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"GPs should have useful strategies to help carer get the 'patient' to go to the GP to start the assessment process. It can be very difficult to get patient to go to GP for that first appointment."

### **6.3 Prioritising responses**

After working through the discussion questions, the final activity for the consultation workshop participants was to prioritise the suggestions and comments that had been made, identifying three key areas for each.

#### **Discussion question 1: In your experience, what currently works well with dementia diagnosis?**

The priorities that the workshop participants identified for this discussion question were:

- Resources – wonderful staff in system
- Awareness raising and the use of key public figures
- Some good sources of support out there (if you know where to look)

#### **Discussion question 2: In your experience, what currently does not work well with dementia diagnosis?**

The priorities that the workshop participants identified for this discussion question were:

- Some GPs not trained or don't use what they have learned. So don't identify or know where to send for support
- Attitudes in community – fear, ageism, breaking bad news
- Delays in getting diagnosis – even the pathway doesn't look like a one-stop-shop

#### **Discussion question 3: (Blue sky thinking) – What things would need to be included for a really good dementia diagnosis?**

The priorities that the workshop participants identified for this discussion question were:

- A quality of first point of contact – knowledgeable, compassionate, understanding
- Information for the carer and sufferer needs to be in formats appropriate to needs, at key stages
- Awareness raising needs to take place for the public and professionals – memory clinics widely available.

## **7. Engagement Findings – Other methods**

### **7.1 Comments on the care pathway**

The following are key themes and examples of comments on the care pathway diagram for early diagnosis in dementia (as shown in appendix A) that were taken both from the 'Talking Health' website and from the Dementia Awareness Day on the 23rd May at the Ashmolean museum, Oxford.

Two main themes came out of the comments made. These were around support for patients and carers and also comments regarding the point at which a diagnosis is made.

It was clear from comments made that respondents felt that the support - not just for patients - but also for families and carers, needed to be improved:

"Support and follow up; ideal to have groups in the same location as medical appointments."

"Need to consider support for carers."

"Very little support and no counselling was given to my father."

There were also many comments related to importance of a good, early diagnosis and the need for the knowledge, skills and training to be there to enable GPs to give an accurate, early diagnosis.

"Need an earlier diagnosis to help them to plan: sometimes there is a reluctance to diagnose, or to refer among GPs. Also a reluctance from the person to allow diagnosis."

"DLB hard to diagnose; clinic struggled, diagnosis came late."

"When GP refers quickly, system works well."

Other comments related to things such as the need to improve attitudes to dementia, transport and for good sources of supporting information:

"Attitudes vary among GPs; there is need to ensure GP buy in, and make sure they are on board with the pathway."

"Ensure other information services are tied in; examples of good practice from other agencies, statutory and voluntary"

"Consider where people obtain information before they see GP."

"Car parking needs to be good."

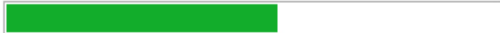


## 7.1 Questionnaire responses

The online and hard copy questionnaire asked key questions about the proposed care pathway and gathered further feedback and ideas. The responses are detailed below:

### Question 1 – About You

There were just 11 responses to this questionnaire. 4 of which were from carers, 3 from organisations with an interest in dementia and 4 from people who had some experience of working with those with dementia e.g. nurse

### Question 2 - Should the entry point into memory services be via a referral from the patient's GP?

Option	Results
Yes	 55% (6)
No	 9% (1)
I don't know	 36% (4)

The majority of responses felt that the referral should come from the GP, however when asked to comment on their response a number of concerns were also expressed about GP's needing the time, training, specialist knowledge and awareness of dementia.

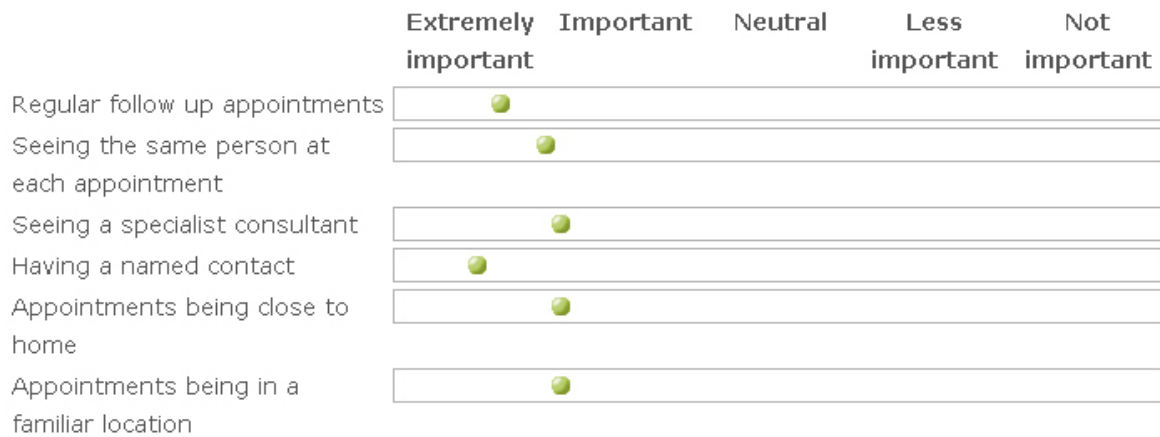
"Gps often too busy to spend enough time to develop awareness"

Suggestions were also made in the comments section that the referral could come from another specialist at a GP surgery:

"Use trained persons in surgeries who can be more caring about dementia and the fear for families"

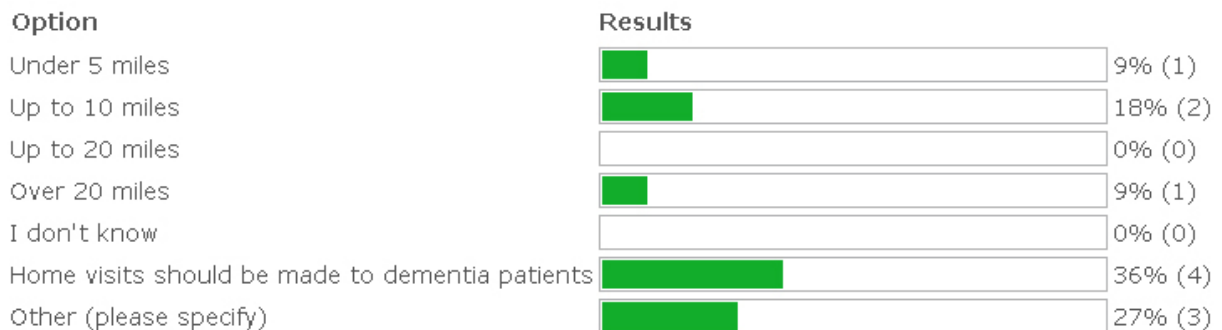
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**Question 3 – Please rank the following in order of importance for the patient:**



All of the above factors were felt to be of fairly high importance for a person with dementia and the most important factor, which was ranked 'extremely important' by 90% of respondents, was the need to have a named contact. This was closely followed by the need to have regular follow up appointments.

**Question 4 - How far do you think it is acceptable to travel for a Memory Clinic appointment for a patient with dementia?**



When asked about how far people thought it would be acceptable to travel to a Memory Clinic appointment, the response was mixed. However the majority of responses (36%) indicated that it was important that home visits should be made to dementia patients.

Only one person felt it was acceptable to travel over 20 miles to a memory clinic appointment.




When asked to comment on their responses to this question it became clear that the acceptable distance to travel depended very much on the needs of the individual patient:

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"I think the distance depends on the individual. Someone with an existing disability or long term condition who then goes on to develop dementia will tolerate travelling less well."

"I think it depends on what people are used to e.g. in a rural area, longer distances are the norm."

### Question 5 - Should younger people with dementia follow the same care pathway as older people with dementia?







Option	Results
Yes	 45% (5)
No	 27% (3)
I don't know	 27% (3)

The majority of respondents (45%) indicated that younger people with dementia should follow the same care pathway as older people with dementia. However, when asked to comment on their responses it was clear that people felt that although the care should be more or less the same, the services that people visit should be more tailored to younger people:

"They should follow the same generic process/pathway, but be in clinics not full of very old/frail demented patients (at late stage!)"

"Make care applicable to younger people somehow."

### Question 6 - Who should conduct the patient's ongoing follow-up appointments once a dementia assessment and diagnosis have been given?

Option	Results
The patient's GP	 0% (0)
A GP with Special Interest (GPSI)	 18% (2)
A specialist nurse	 27% (3)
A specialist at the Memory Clinic	 18% (2)
I don't know	 0% (0)
Other (please specify)	 36% (4)

The response to who should conduct the follow-up appointments was fairly evenly spread across the GP with Special Interest (GPSI), a specialist nurse, and a specialist at the Memory Clinic.

The majority of responses however came back as 'Other' (36%). When asked to indicate what people meant by 'Other' respondents again indicated that it should








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be any of the GPSI, specialist nurse or a specialist at the Memory Clinic and that specialist training and knowledge were the most important factors.

"The GPSI, specialist nurse or specialist at the memory clinic are all acceptable."

"Any of above - training & knowledge of dementia are more important than professional qualifications."

### Question 7 - When should supporting information on dementia be given to the patient?

Option	Results
At the same time as diagnosis	 27% (3)
Shortly after diagnosis	 27% (3)
When the patient asks for it	 0% (0)
Don't know	 0% (0)
Other (please specify)	 45% (5)

Responses to when supporting information should be given to the patient/their family, were equally split between 'at the same time as diagnosis' and 'shortly after diagnosis'.

The majority of responses made were 'other' (45%). When asked to indicate what they meant by 'Other' respondents indicated that supporting information should be given whenever a patient, their family or their carer needs or asks for it:

"Both at the same time as diagnosis and then whenever the patient/family asks for it."

"Information needs to be continuously available so that people can keep coming back to it as they need to."

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The survey also gave respondents the opportunity to feedback on the same discussion questions that were asked in the consultation workshop:

### **Question 8 - Are there any areas of the current dementia care pathway that are working well?**

There were only a few responses related to things that are currently working well with the dementia care pathway, indicating that the current care pathway for early diagnosis in Oxfordshire is not consistent in the existing care, support and services that are being provided.

"Medication"

"The GPs who have a good understanding and work in a holistic way who know where to find support."

"Not too many."

"Yes. Some people receive some very timely and effective intervention and good support for their carers."

### **Question 9 - Are there any areas of the current dementia care pathway that are not working well?**

There was quite a large response to this question. Comments were varied, but as in the rest of the questionnaire and consultation workshop, common themes became apparent.

Inconsistencies in existing dementia services were one of the main themes:

"Fragmented, inconsistent services"

"The care pathway is not consistent and people's experience is mixed."

"It's fragmented and not always accessible. Services have little to offer after diagnosis - resources are poor."

Support for dementia patients and their carers was also another strong theme for things that are not currently working so well:

"The lack of an effective social care system to enable someone to be properly cared for in their own home"

"Information and advice to family/relatives/carers - and GP practices not having funds/interest or specialism."

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"From a carers perspective, it is continuously like "pulling teeth" getting any real input, support or access to appropriate services (health or social care) for my mother."

Other comments related to attitudes and the need for a more coordinated, person-centred approach:

"Attitude of GP services is not helpful"

"People of her age with dementia have multiple complex needs...requiring a combined and coordinated approach."

### **Question 10 - any other comments or feedback that you would like to add regarding early diagnosis in dementia**

When asked to make any further comments, respondent to the questionnaire made a number of suggestions on how they would like to see services and the care pathway for early diagnosis in dementia to be developed. This included the need for services to be more integrated, with systems to support an integrated approach to working; having information available for patients in an Easy Read format; the need for quicker diagnosis and to increase the level of knowledge of the condition so that there are more specialists available for patients.

"Services need to be developed in a fully integrated relationship-based way, with systems that are supportive, inclusive and pro-active."

"Diagnosis should be the sooner the better - to enable medium and longer term planning and support for and to families."

"Those that make the diagnosis **MUST** really know about the disease and real markers of disease progression, and know how to access help and support."

## **8. Limitations**

### **8.1 The Election**

The election posed a number of restrictions on the dementia consultation due to a period known as 'purdah'. This lasts from the moment a forthcoming election is announced, until the moment the new government is announced. The purdah period means that all public sector organisations are restricted in making any proactive communications.

NHS Oxfordshire was therefore unable to promote the early diagnosis in dementia consultation as much as it could have done in normal circumstances. We did however ensure that as much awareness was raised as possible within the purdah guidelines. Interested organisations were informed of the forthcoming consultation workshop date and a 'future consultation' announcement was made on the *Talking Health* website. The start date of the consultation was delayed by a few days due to purdah whilst the coalition government arrangements were agreed. However as soon as the restrictions were lifted, full promotion and communication of the consultation could begin.

### **8.1 Other Limitations**

Due to the nature of the symptoms of dementia, such as memory loss and the ability to reason, the early diagnosis in dementia consultation did not receive many known responses from those patients with the illness. The majority of responses were therefore from carers/family members of those that have/have suffered from dementia and those that work with patients with dementia or for organisations with an interest in this area.

## **9. Key recommendations**

The findings from the consultation on 'Early Diagnosis in Dementia' has highlighted the need for:

### **Clearer points at which patients, their families and carers can access supporting information**

- Throughout the consultation, respondents regularly raised the need for better supporting information and the need for a central 'hub' or clear point at which they should go to get this information.

### **The need for more specialist knowledge about dementia in GP surgeries**

- Whilst it was felt that the GP surgery is the main place from which referrals to Memory Clinics should be made. General concerns were raised around the in-depth knowledge of the condition and that more specialist knowledge and/or training in dementia is needed.

### **Follow up appointments to be carried out by a dementia specialist**

- Respondents were less concerned with the job title/role of the person conducting the follow up appointments, and felt it was much more important that the person had specialist knowledge of dementia.

### **A more person-centred approach to services and care**

- In many responses to survey questions and in the workshop, it was highlighted that the services and care needs to be more person-centred. A more holistic consideration needs to be given to an individuals health needs, transport needs and communication needs.

### **A more integrated and coordinated approach to dementia diagnosis, care and support**

- Inconsistencies was a common theme in current services for dementia and so to enable both more and earlier diagnosis of dementia to be made, there clearly needs to be a more integrated and coordinated approach.

### **More awareness raising to help understanding of dementia and prevent negative attitudes/stigma**

- It was highlighted that one of the main positive things currently happening relating to dementia diagnosis was the recent awareness raising activities and adverts in the media. In addition it was highlighted that negative attitudes are one of the main problems related to dementia and so it is recommended that more activities and communication takes place to help reduce the stigma associated with dementia.

## **10. Next steps**

A copy of this consultation report will be made available to all those that participated in the early diagnosis in dementia consultation workshop and questionnaire and will also be available for download on NHS Oxfordshire's website: [www.oxfordshirepct.nhs.uk](http://www.oxfordshirepct.nhs.uk)

The report will be used by NHS Oxfordshire and Oxfordshire County Council (the commissioners) to develop a care pathway for early diagnosis in dementia that appropriately meets the needs, concerns and expectations of dementia patients, their families and carers.

## **11. Thanks**

Thanks to all those who responded to this consultation and particularly to both patients, their families and carers of dementia who shared their personal experiences of receiving a dementia diagnosis.

### **13. Supporting information**

#### Definitions

##### Stakeholders

- A person or group with a direct interest, involvement, or investment in something.
- Stakeholders are individuals or organisations that have a direct interest in a service being provided.

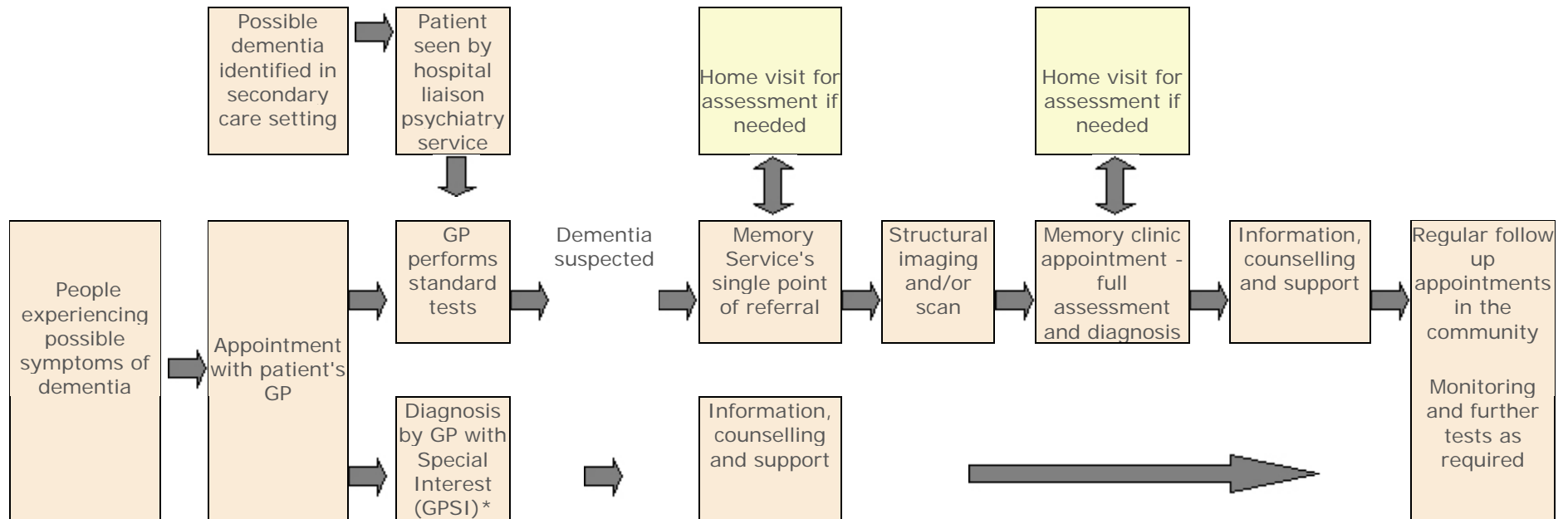
#### Glossary

NHS	National Health Service
PCT	Primary Care Trust
Facebook	Social networking website
Twitter	Twitter is a social networking tool aimed at enabling its users to exchange up-to-the-minute news and opinions on specific topics.
Intranet	A private computer network open to users working within an organisation to share information, news and documents
Talking Health	NHS Oxfordshire's consultation and engagement area on our public website

## 14. Appendices

### Appendix 1: Early Diagnosis in Dementia Questionnaire

The diagram below illustrates the proposed care pathway for early diagnosis in dementia:



\*There are currently no GPSI's in Oxfordshire to support dementia at the moment.



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### The Early Diagnosis in Dementia care pathway - explained

The table below further explains certain sections of the dementia care pathway diagram:

Section of dementia care pathway	Further details
GP performs standard tests	These tests may include a memory assessment and blood tests. If dementia is then suspected a referral is sent on to the Memory Service.
Diagnosis by GP with Special Interest (GPSI)	A patient's GP could refer the patient to a GP with Special Interest (GPSI). GPSIs could provide a diagnosis to a patient with dementia in the future (there are currently none in Oxfordshire at present).
Memory Service single point of referral	Referrals are assessed and assigned at the Memory Service according to clear criteria.
Memory Clinic appointment - full assessment and diagnosis	Memory Clinics operate throughout Oxfordshire at main community locations and offer assessment, support, information and advice to those with memory problems and their carers. A full assessment and diagnosis is given at the Memory Clinic in line with National Institute of Clinical Excellence (NICE) guidance. The decision to start medication for dementia is also made.
Home visit for assessment if needed	If the patient with dementia has mobility or travelling difficulties then an assessment at home can be arranged.
Information, counselling and support	After a dementia diagnosis is given, information is provided for the person with dementia and their family/carer as necessary. Post diagnosis services are offered (such as counselling) and a letter is sent to the patient's GP confirming the diagnosis. It is important that equal access to information and support is provided regardless of whether a diagnosis is given through a GPSI or a Memory Clinic.
Regular follow up appointments in the community Monitoring and further tests as required	Follow up appointments could take place in the community by a specialist nurse or GP. This may include monitoring of medication and tests for the progression of dementia, including other related problems such as depression.

## Appendix 2: Early Diagnosis in Dementia Questionnaire

### Early Diagnosis in Dementia – Questionnaire

We would like to hear about your views on dementia diagnosis in Oxfordshire. This survey will take no more than 5 minutes to complete.

#### 1 - About You

Are you...

- A patient with dementia
  - A carer of someone with dementia
  - A family member of someone with dementia
  - Representing an organisation with an interest in dementia
  - Other (please specify)
- 

#### 2 - About the early diagnosis in dementia care pathway

Should the entry point into memory services be via a referral from the patient's GP?

- Yes
- No
- I don't know

Please give any reasons below:

#### 3 - Please rank the following in order of importance for the patient:

	Extremely important	Important	Neutral	Less important	Not important
Regular follow up appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Seeing the same person at each appointment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Seeing a specialist consultant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having a named contact	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Appointments being close to home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Appointments being in a familiar location	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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**4 - How far do you think it is acceptable to travel for a Memory Clinic appointment for a patient with dementia?**

- Under 5 miles
  - Up to 10 miles
  - Up to 20 miles
  - Over 20 miles
  - I don't know
  - Home visits should be made to dementia patients
  - Other (please specify)
- 

**5 - Should younger people with dementia follow the same care pathway as older people with dementia?**

- Yes
- No
- I don't know

Please give any reasons below:

**6 - Who should conduct the patient's ongoing follow-up appointments once a dementia assessment and diagnosis have been given?**

- The patient's GP
  - A GP with Special Interest (GPSI)
  - A specialist nurse
  - A specialist at the Memory Clinic
  - I don't know
  - Other (please specify)
-

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**7 - When should supporting information on dementia be given to the patient?**

- At the same time as diagnosis
- Shortly after diagnosis
- When the patient asks for it
- Don't know
- Other (please specify)

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**Your Experiences**

**8 - Are there any areas of the current dementia care pathway that are working well?**

**9 - Are there any areas of the current dementia care pathway that are not working well?**

**10 If you have any other comments or feedback that you would like to add regarding early diagnosis in dementia, please give them below:**

**11 Please add your contact details below if you would like to receive a copy of the consultation report:**

Name:	Email:
Address:	Phone:

**Thank you for taking the time to answer this questionnaire**

## Appendix 3: What is dementia?

### What is dementia?

Dementia is the term used to describe a range of symptoms that occur when the brain is affected by certain diseases or conditions. Dementia can affect anyone in society – irrespective of gender, ethnicity or class. Symptoms of dementia may include memory problems mood changes and communication difficulties.

Dementia is actually quite common. Around 750,000 people in the UK have dementia, which becomes more common with increasing age. Younger people can also be affected by dementia; about 18,000 people under the age of 65 in the UK have dementia.

### Other sources of information

For more information see the Alzheimer's Society factsheet: What is Dementia?

<http://www.alzheimers.org.uk>

DementiaWeb - Dementia information sources for Oxfordshire

<http://www.dementiaweb.org.uk>

Alzheimers society helpline – Tel: 0845 300 0336