



Insight

Patient experiences of information
provision and support at dementia
diagnosis

November 2016

Table of contents

1	Summary of Evidence	3
1.1	Introduction	3
1.2	Main findings	3
2	Conclusions and recommendations	7
3	Introduction	10
3.1	Dementia diagnosis services in Nottinghamshire	10
3.2	Our Approach	11
3.3	Our Team	12
4	Findings from patient surveys	13
4.1	Introduction	13
4.2	Profile of respondents	13
4.3	Accessing appointments for diagnosis	14
4.4	Overall experience	15
4.5	Information provision and support	16
4.6	Improving the experience for people faced with a dementia diagnosis	18
5	Findings from interviews with people with dementia and/or their carers	20
5.1	Introduction	20
5.2	Accessing appointments for diagnosis	20
5.3	Overall experience	21
5.4	Information provision and support	22
5.5	Support after diagnosis	22
5.6	Improvements to be made	23
6	Findings from our database	24
6.1	Introduction	24
6.2	Services talked about and overall sentiment	24
6.3	Accessing appointments for diagnosis	24
6.4	Overall experience	25
6.5	Information provision and support at diagnosis	25
6.6	Support after diagnosis	26
7	What next?	28
7.1	Official responses	28
8	Appendix 1	29
8.1	Alzheimer's Society services in Nottinghamshire	29
9	Appendix 2	31
9.1	Experiences of the Memory Assessment Service	31
10	Appendix 3	34
10.1	Experiences of the other services where a dementia diagnosis was given.	34

1 Summary of Evidence

1.1 Introduction

We wanted to understand people's experiences of the information provision and support at dementia diagnosis. To do this we undertook a focussed project, where we collected data through a survey and interviews. In addition, we also gathered experiences from people with dementia and/or their carers about their experiences of health and social care. The questions included in the survey and interview guide were developed having reviewed the National Institute for Health and Care Excellence (NICE) guidelines¹. Therefore we were able to find out how people's experiences related to what is considered to be best practice.

In total, we collected 133 responses. This can be broken down in the following way:

- 52 completed surveys from people with dementia and/or their carers who had been diagnosed in the last twelve months;
- 26 completed surveys from people with dementia and/or their carers who had been diagnosed more than twelve months ago;
- 9 people interviewed about their experiences of dementia diagnosis; and
- 46 experiences gathered (since January 2015) of health and social care services from people with dementia and/or their carers.

These activities were conducted and supported by a group of Healthwatch Nottingham and Healthwatch Nottinghamshire staff and trained volunteers. Every effort was made to access local dementia support groups and engage with as many people with dementia and/or their carers as possible. We acknowledge that as participation was voluntary and that some people who chose not to engage with us may have different experiences to those presented in this report.

This section details the main findings across all of these sources of evidence.

1.2 Main findings

The waiting time after being referred for a diagnosis is much longer than guidelines state. Just over half (51%) of people who completed our survey told us that they were waiting longer than 6 weeks to see a specialist for diagnosis, rather than the 4-6 weeks. Our findings also show that there is a difference in waiting times for Nottingham City residents and Nottinghamshire residents, with a higher proportion of City residents having to wait more than 6 weeks from the point of diagnosis to being seen compared to County residents.

People we spoke to gave examples of delays in primary and secondary care. We were told of patients being hospitalised and found to have suspected dementia, who were then discharged back to their GP to seek a referral to see a specialist. In some instances, patients report that they were inappropriately prescribed medication which further delayed a diagnosis:

¹ Dementia support in health and social care. NICE quality standard [QS1]. Quality statements (2010) <https://www.nice.org.uk/guidance/qs1/chapter/Quality-statement-3-Written-and-verbal-information>

My father had been hospitalised for surgery due to a heart condition and he had experienced an unexpectedly slow and difficult recovery - he remained extremely disoriented. He remained in the hospital at my insistence. We were brushed off initially when we discussed that his recovery difficulties could be attributable to dementia. However he was not sent for a scan despite our requests...he was discharged and inappropriately offered treatment for depression.

My father is in a high dependency ward and I am worried that they aren't doing any tests for dementia despite everything we have told them.

My husband started having problems with his memory back in December 2009. He saw several GPs who each reacted differently.

Experiences of carers

These examples are not only significant in themselves, particularly with inconsistencies in reactions to patients presenting with memory loss, but some people that we spoke to felt that doctors are resistant to diagnosing people with dementia.

There are differences between carers and people with dementia with regards to how easy they feel it is to access an appointment for diagnosis. We asked people to rate how easy it was to get an appointment, where one is the worst and five is the best. People with dementia rated "how easy was it to get an appointment" most frequently as 1. This experience was rated much worse for someone with dementia compared to a carer completing our survey (who most frequently rated 4).

Overall experience of the dementia diagnosis was variable. We asked people to rate their overall experience of the dementia diagnosis in terms of treatment and care using a five point scale, where one is poor and five is excellent. We found that the people who had experience of a diagnosis within the last twelve months gave an average rating of 3.35 and people who had a more historical experience gave an average rating of 3.38. This difference is not statistically significant but may suggest that services haven't improved over time. Ratings were also given on two additional domains: whether everything was clearly explained about the diagnosis/condition; and whether they felt cared about. The average score for the former was 3.2 (for people with dementia) and 3.5 (for carers) who rated whether everything was clearly explained to them but the most frequently reported score was 4 or 5. However, there was a difference between how carers and people with dementia rated whether they felt cared for. Carers rated "I felt like they cared about me" most frequently as 3. Again in contrast, people with dementia most frequently rated this as 4.

Overall experience of the diagnosis was often dependent on the attitude of the member of staff that was present. Many people spoke highly of the staff that were present at the diagnosis, using words like "lovely", "great" and "terrific". However there were also some rather concerning comments made about some staff:

The consultant was very abrupt in how he delivered the news of a diagnosis of dementia in a rather parrot-like fashion as if by rote. My husband (person with dementia) was asked to leave the room by the consultant whilst he delivered the news of the dementia diagnosis to me. My husband was never called back into the consulting room... I was left to break the news to my husband that he had dementia - this was difficult for me.

Accounts about staff where there is an issue with communication and a perceived lack of sensitivity can have a negative impact on the person with dementia and/or their carer, as indicated by our evidence.

A diagnosis of dementia is a cause of distress for patients and carers. These are some of the words used to describe emotional feelings from all sources of evidence.



"Traumatic" *"Shocked"* *"Downhearted"* *"Worried"* *"Upset"*
"Lost" *"Frustrated"* *"Confused"* *"Disappointed"*
"Isolated" *"Sad"* *"Devastated"* *"Unsure"*

Individuals who experience dementia diagnosis are not always being given information about the condition, treatment, support options locally, a personalised care plan and carer's assessment (for carers). The NICE Quality Standard for Dementia states that information about these five areas should be given both verbally and in written format. The findings from our survey show that:

- 29% (15 people) were given both written and verbal information about the condition;
- 17% (8 people) were given both written and verbal information about treatment;
- 23% (11 people) were given both written and verbal information about support options locally;
- 5% (2 people) were given both written and verbal information about a personalised care plan and;
- 7% (2 people) were given both written and verbal information about a carer's assessment respectively.

Five experiences in our database told us that no information or support was provided at diagnosis, with the expectation that the patient/carers would look up information themselves.

Despite not always being given all the required information verbally and in writing, we heard varying views about whether the amount of information provided at diagnosis was the amount that best suited the needs to the patient and/or carer. Our survey data show that 45% of people felt that they had been given the right amount of information at diagnosis, 45% stating they were not given enough and 10% reporting that they received too much. On interviewing people, no-one who we spoke to felt as though they were given the right amount of information:

I was not given much information at diagnosis and if that, this information was not easy to assimilate as I was very upset.

I was given tonnes of information, both verbal and written, but I wasn't able to take it in as I was quite shocked with the diagnosis.

All but one of the nine people that we interviewed felt that the amount of information provided to them, as well as the format that this information was presented, was not helpful to them. We were told that there was not enough information or that too much was given, but the overall consensus was that the feelings evoked by the diagnosed made what was offered difficult to assimilate.

The input of voluntary sector services after the diagnosis was praised by the majority. Specific services that were mentioned were those which provided information and support for carers. These were praised because of the provision of ongoing emotional and practical support post-diagnosis. In particular, the Carer Information and Support Programme (Alzheimer's Society) and Carers' Information Session (St Francis Unit) were highly regarded by the people who completed our survey.

Carers often feel unsupported. Our survey found that 61% of carers were not offered a carer's assessment and many rated 3 out of 5 in terms of how much they felt cared about at the point of diagnosis. More long term experiences shared with us suggested a lack of adequate specific support for carers and social care services (such as care homes, home care and specific support provided by Nottinghamshire County Council). We were also told by carers that often health and social care services are not joined up, and that this is not only detrimental to the carer, but also the person with dementia.

It is difficult navigating through the system. There is no-one to co-ordinate things. There is no facility to follow up anything. No-one asks "How's it going?" or "What next?" Very often what we think happens isn't in place. It's crisis management - we go from one crisis to the next.

People faced with a diagnosis of dementia felt that there is room for improvement in terms of information and support both at diagnosis and long-term. We wanted to find out what people who had experienced a dementia diagnosis thought could improve their experience and the experiences of others:

More information at diagnosis and an opportunity for follow-up discussion. 57% of people who completed our survey told us that they would have liked to have been given more information (both verbal and written) at the point of diagnosis, and been given more time to discuss this with a health professional shortly after.

More emotional support after diagnosis. 13% specifically told us that they would welcome more emotional support after diagnosis through face-to-face contact with someone so that they could talk about their experience.

2 Conclusions and recommendations

Conclusion 1:

The waiting times from presenting with symptoms of memory loss to being referred to a specialist vary significantly.

Current guidance stipulates that the waiting time from being referred by a GP to being seen by a specialist should be no longer than 6 weeks^{2,3}. However our data shows variation in how long people are waiting to be diagnosed, with some individuals having to wait several months. There is an indication that City residents are waiting longer than County residents. We know that this can be frustrating for those who are affected. We would expect that everyone would be seen within a six week period and there would not be a difference between City and County residents.

Our data has also highlighted the perception that some GPs are not making timely referrals for diagnosis. However we do not know the circumstances of the alleged delays. This may warrant further exploration. We know that benefits of a timely diagnosis can allow people to plan their care in advance, to access support and information, review physical health and co-morbidities and allow access to peer and carer support. This ultimately maximises the chances that people with dementia and their carers can live well with the disease.

Recommendation 1:

Improve waiting times from the point of referral to diagnosis to comply with current guidance with a particular focus on reducing inequality between City and County residents. We recommend that actions are put in place to reduce the waiting times for individuals with suspected dementia. We would anticipate that there would not be any variations for individuals based on where they live and that timely access to the service should be consistent.

² Best practice in Memory Services: Learning across from across England. (2014)
<https://www.england.nhs.uk/wp-content/uploads/2014/12/memory-clinics-final.pdf>

³ Assessment and diagnosis (Factsheet 426), Alzheimer's Society. (2014)
https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=260

Conclusion 2:

There are inconsistencies in the information given to people experiencing a diagnosis of dementia.

The standards set out in the NICE guidelines state that all people who attend for a diagnosis of dementia should be given information about their condition (e.g. type of dementia, symptoms and how the illness might develop), treatments, support options locally, a personalised care plan and a carer's assessment (for carers). We are aware that this has not been the experience of those who have had a recent experience of dementia diagnosis. Our data show that negative experiences can be attributed to a perceived lack of sensitivity shown by some staff, on occasions, who are involved in the diagnosis process. In addition, the amount of information and support given to people with dementia and/or their carers at diagnosis is not always to be perceived as the right amount or presented in a format that suits the needs of the individual.

Recommendation 2:

People with dementia and/or their carers attending the Memory Assessment Service must be given both written and verbal information as per the NICE guidelines.

The NICE guidelines state that people experiencing dementia diagnosis must be given both written and verbal information about their condition, treatment options, a personalised care plan, and a carer's assessment (for carers attending). Our data show that the services that deliver dementia diagnoses are not fulfilling these criteria on a regular basis.

Recommendation 3:

Ensure that all individuals attending services that deliver dementia diagnoses are contacted by telephone following their visit.

Our data show that being given a dementia diagnosis can cause feelings of shock, sadness, frustration and anger. This may affect people's ability to digest and comprehend the next steps. In implementing a telephone follow-up, individuals will have a chance to speak with someone about concerns that they have and will be given an opportunity ask questions that they may not have had the chance to ask at the diagnosis. We have been told that support following the diagnosis is non-existent in some cases and this step would address that and make individuals feel better supported, particularly carers.

Conclusion 3:

Where people with dementia and/or their carers are being supported post-diagnosis, whether this be through NHS or third-sector services, this can have a positive impact.

The Nottinghamshire Dementia Joint Strategic Needs Assessment states that “dementia is overwhelming for carers and they need adequate support” (Nottinghamshire Dementia JSNA, 2014). Therefore ongoing support is key in ensuring that both people with dementia and their carers are able to live well with the condition. Our data indicated that attending support and activity groups can provide an opportunity for carers to feel supported and for activity groups to help the cognitive issues that people with dementia may face. We were told that information programmes for carers, carer support groups and peer support groups can be beneficial. Unfortunately our data show that these may not have the capacity for additional attendees and that these groups may not operate as regularly as needed.

Recommendation 4:

Increase the number of support groups and the capacity of existing support groups to accommodate more users.

Our data show that support groups, whether statutory or voluntary, have benefits for people with dementia and their carers, and given the increasing diagnosis rates, demand will increase every year. Because there isn't the possibility to increase capacity in existing groups, we suggest that the frequency of these groups, and the number of these groups should be increased. In doing this, more people with dementia and/or their carers will be supported now and in the future.

3 Introduction

Dementia is a term used to describe a range of brain disorders that have in common a loss of brain function that is usually progressive. The most common types of dementia are Alzheimer's disease, vascular dementia and dementia with Lewy bodies.

Dementia is one of the main causes of disability in later life and the number of people with dementia is rising yearly as the population ages. Dementia can affect people of any age but is most common in older people, particularly those over 65 years. The number of people aged over 65 living with dementia in Nottinghamshire is predicted to rise from 11022 in 2015 to 13138 in 2021⁴ (a rise of 16% over five years).

Diagnosis rates have improved across the county, with all Nottinghamshire Clinical Commissioning Groups (CCGs) achieving above the average diagnosis rate for England. Benefits of a timely diagnosis include advanced care planning (medical, financial, social, driving, end of life care, etc.), access to information and support (dementia advisers, groups, assistive technology, home care, day care etc.), review of physical health and co-morbidities and access to peer and carer support. According to the Nottinghamshire Joint Strategic Needs Assessment for Dementia (2014), the benefits of early diagnosis may not be attained without adequate support and information provision, particularly at diagnosis.

We started this project because we had received some comments about a lack of information and support for people with dementia at the point of diagnosis. Healthwatch Nottinghamshire's Prioritisation Panel (a group of trained volunteers who help us make decisions about where we focus our work) scored these comments as a high priority and asked us to undertake a project so that we could understand more about patients' experiences of this service.

The overarching aim of this project is to evaluate patient and carer experiences of dementia diagnosis in terms of information provision and support. This can be broken down into the following objectives:

1. To understand what information is provided to individuals attending the Memory Assessment Service and other assessment services that can provide a dementia diagnosis.
2. To explore the impact that information provision and support at diagnosis can have immediately and longer-term on patient and carer quality of life.
3. To provide a series of conclusions and evidence-based recommendations detailing what changes could be made to improve the service and maintain positive experiences for both patient and carer.

In doing this we aim to understand what works, what doesn't and why so that the findings can be used to further develop these services across the City and County.

3.1 Dementia diagnosis services in Nottinghamshire

The Memory Assessment Service in Nottinghamshire is provided by Nottinghamshire Healthcare Trust. The Memory Assessment Services offer early diagnosis for people experiencing memory problems and dementia. According to information provided by Nottinghamshire Healthcare Trust, each service is nurse-led but works closely with doctors and other healthcare professionals⁵. Referral to this service must be made by a GP for patients who are over 65 years with no previous diagnosis of dementia.

⁴ Nottinghamshire Joint Strategic Needs Assessment (2014).
<http://jsna.nottinghamcity.gov.uk/insight/Strategic-Framework/Nottinghamshire-JSNA/Older-people-chapter/Dementia-2014.aspx>

⁵ Memory Assessment Services (Mental Health Services for Older People) (2015).

There are venues that provide a Memory Assessment Service across all districts of Nottingham and Nottinghamshire:

- 1) Bassetlaw
 - Retford Primary Care Centre
 - Harworth Primary Care Centre
- 2) City South
 - Greenfields Medical Centre
 - St Anns Medical Centre
 - Clifton Cornerstone
- 3) City North
 - Grange Farm Medical Centre
 - Wollaton Park Medical Centre
 - Bulwell Riverside Health Centre
- 4) Mansfield and Ashfield
 - Mansfield Community Hospital
 - Ashfield Health Village
- 5) Broxtowe
 - Sheila Gibson Unit
 - Church Street Medical Centre
- 6) Rushcliffe
 - Lings Bar Hospital
- 7) Newark and Sherwood
 - Ollerton Health Centre
 - Rainworth Health Centre
 - Byron House, Newark Hospital
- 8) Gedling
 - St Francis Unit, Nottingham City Hospital

However the Memory Assessment Service is not the only service that can provide a dementia diagnosis, with any trained professional able to do this. This may be in a primary or secondary care setting. Healthwatch Nottingham and Healthwatch Nottinghamshire believe that patient experiences should not differ between services. As such, the findings in this report reflect information provision and support for all services accessed, including but not limited to the Memory Assessment Service. A breakdown for experiences relating to the Memory Assessment Service in Nottinghamshire and for other services where a diagnosis can take place can be found in Appendices 2 and 3.

3.2 Our Approach

We collected data in the following ways over a six month period:

- **Experience survey.** We produced a survey for distribution, which contained questions about where the diagnosis was made, who was present and what information was provided. Individuals were asked to rate their overall experience of diagnosis, and provide some sub-ratings of specific aspects of their experience such as the communication, the compassion experienced and the ease with which they were able to access the service. The questions included in the survey were developed having reviewed the National Institute for Health and Care Excellence (NICE) guidelines⁶, so we were able to find out how people's experiences related to what is considered to be best practice. The survey was available in hard copy and electronic versions.

We collected experiences from people with a recent diagnosis of dementia (diagnosed in the last 12 months at the point that individuals completed the survey) and/or their carers who attended diagnosis with them and wanted to access this group through community based groups. We did the following to access these groups of people:

- We made contact with over 40 dementia support groups for people with dementia and/or their carers across the City and County.
- We approached the Alzheimer's Society and were given permission to attend the following groups during March and April 2016: Memory Cafes and Groups; Singing for

Retrieved from <http://www.nottinghamshirehealthcare.nhs.uk/memory-assessment-service-for-older-people> on 09/06/2016

⁶ Dementia support in health and social care. NICE quality standard [QS1]. Quality statements (2010) <https://www.nice.org.uk/guidance/qs1/chapter/Quality-statement-3-Written-and-verbal-information>

the Brain; Carer's Information and Support Programme; and Carer's Support Groups. We visited 21 Alzheimer's Society groups in total.

- The Alzheimer's Society also agreed to post copies of our survey to individuals who had been diagnosed within the specified timeframe. We included some supplementary questions specifically about the services provided by the Alzheimer's Society (see Appendix 1 for the results).
- Articles were published in at least seven media publications and newsletters including the Nottingham Evening Post and Age UK's Engage Magazine. Information has also been distributed through other established networks and organisations to inform people about the project and encourage participation.

In total, we collected 78 completed surveys:

- 52 completed surveys from people with dementia and/or their carers who had been diagnosed in the last twelve months;
- 26 completed surveys from people with dementia and/or their carers who had been diagnosed more than twelve months ago;
- **Face to face interviews.** Individuals who complete the survey and had, at that point, been diagnosed in the last 12 months, were asked whether they would like to share their experiences in more detail through a face-to-face interview or a telephone interview with a member of our project team. These detailed experiences complemented the findings from the survey to illustrate what information provision at dementia diagnosis is like for the patient and carer.
 - We interviewed 9 people about their experiences of dementia diagnosis.
- **General experiences.** We gathered additional experiences from visiting groups and speaking with people that did not a) fit into the specified timeframe or b) want to discuss what happened at the diagnosis, but revealed what happened at different points along the illness trajectory. This was valuable when trying to capture long-term impact of information provision and support at diagnosis, and was therefore included in our data analysis.

In addition to the focussed survey and interviews that we used to gather people's experiences, we searched our database of service experiences for anything shared by people with dementia or their carers, which specifically mentioned experiences of diagnosis or any experience relating to support after diagnosis. Through this we included 37 experiences that were collected since January 2015 through four main channels:

- Direct methods including Healthwatch engagement activities, our website, telephone and email.
- Through our online monitoring system which collects evidence from Twitter, blogs and news sites.
- Patient Opinion, although this data has only been collected since May 2015.
- Information sharing data includes experiences passed to us from neighbouring Healthwatch.

3.3 Our Team

The use of our staff and volunteer team was a key part in collecting experiences of dementia diagnosis, all of whom were trained Dementia Friends. All volunteers had received training developed by members of staff, which covered the Insight Project aims and objectives and review of the data collection tools (survey and interview schedule) and how to use these. Issues around confidentiality, safeguarding and equality and diversity were also discussed. We wanted to prepare our volunteers as much as possible when they attended any dementia

support groups. Our project team was made up of nine members of staff from Healthwatch Nottingham and Healthwatch Nottinghamshire, and six volunteers.

4 Findings from patient surveys

4.1 Introduction

We produced a survey for distribution, which we asked people with dementia and/or carers to complete when we visited dementia support groups. Individuals were able to complete the survey at that point, or they were provided with a freepost envelope if they wanted to complete this outside of the group. The Alzheimer’s Society also posted copies of our survey to individuals, at their home address, who had been diagnosed within the specified timeframe with a freepost envelope so that completed surveys came directly to us. The Alzheimer’s Society’s list comprised of individuals who had been in direct contact with them - this list did not include everybody with a recent experience of dementia in the County.

We also had an online version of the survey that was accessible via the Healthwatch Nottingham and Healthwatch Nottinghamshire websites.

4.2 Profile of respondents

We collected 52 completed surveys from people with dementia and/or their carers who had been diagnosed in the last twelve months and 26 completed surveys from people with dementia and/or their carers who had been diagnosed more than twelve months ago.

Figure 1. Characteristics of respondents. Diagnosis made more than 12 months: 26 people; diagnosis made in the last 12 months: 52 people. Total: 78 people

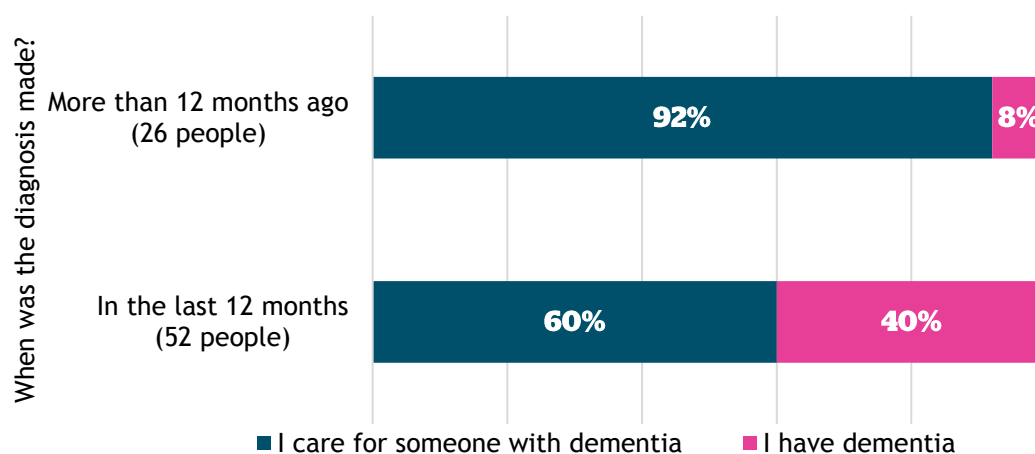
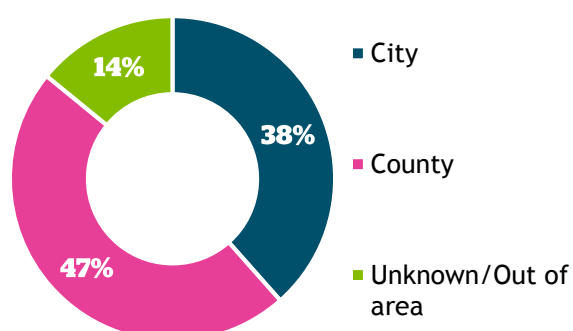
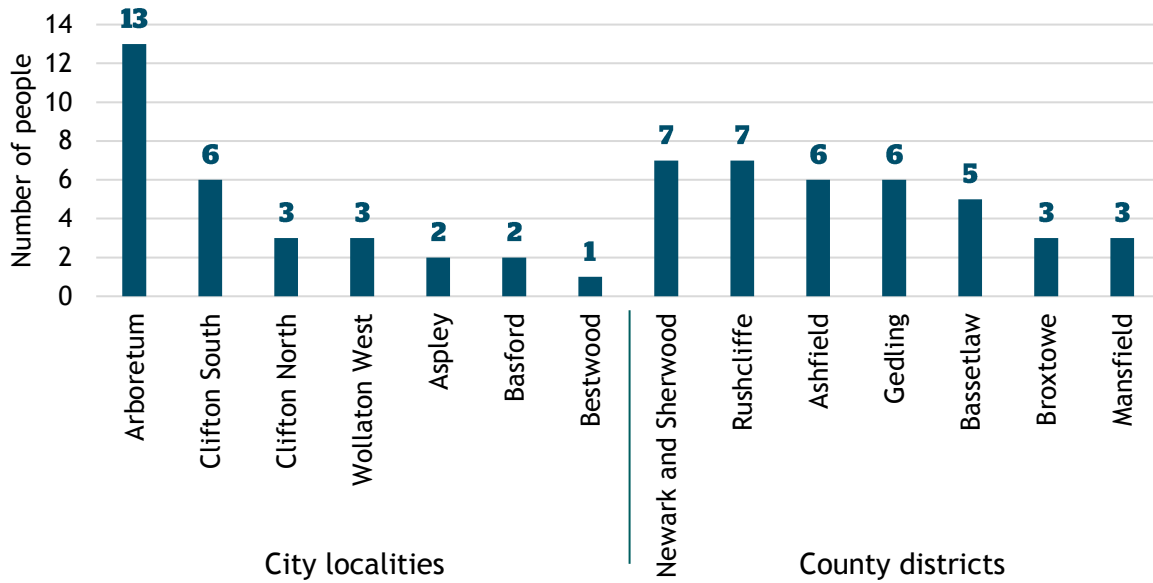


Figure 2. Respondents by location. Total: 78 people



Almost half of the respondents lived in the County (36 people) and 38% (30 people) lived in the City. 14% did not tell us their postcode (8 people), or provided one that was outside Nottinghamshire (3 people). However these survey responses were still included in the analysis as diagnosis services in Nottinghamshire were accessed.

Figure 3. Respondents by City localities/County districts. Total: 67. Note: not everyone answered this question.



4.3 Accessing appointments for diagnosis

We asked respondents how long they had to wait from the point of referral to being seen at for assessment. Our data show that 50% (n = 26) had to wait for longer than 6 weeks, and waiting periods ranged from two weeks to eight months. Figure 5 shows that 28% of City residents and 65% of County residents were seen within 6 week. 72% of City residents waited for more than 6 weeks to be seen for assessment, compared to 35% who waited for this length of time in the County.

Figure 4. Waiting time from referral to be seen for assessment. Total: 76 people. Note: "not applicable" describes people diagnosed whilst an inpatient, or in their own home.

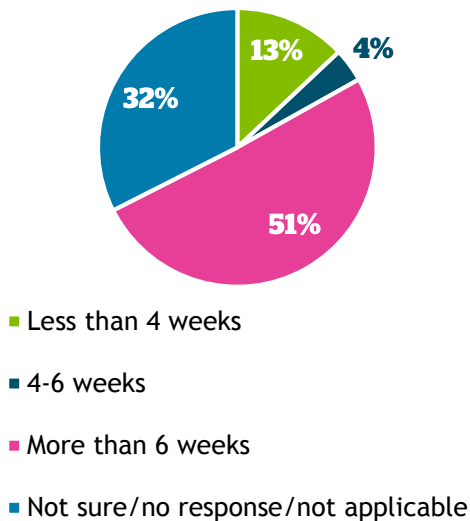
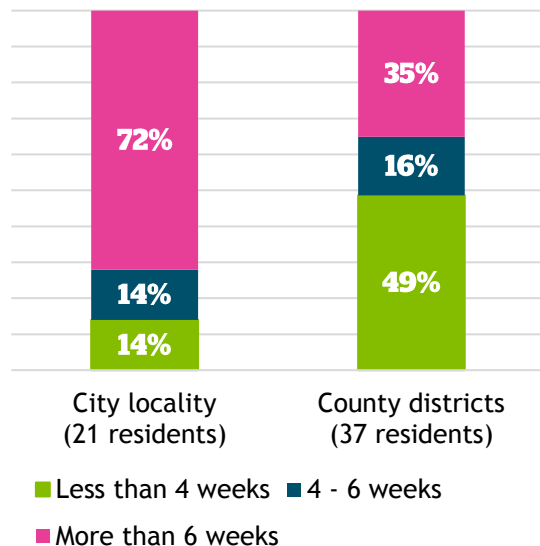


Figure 5. Waiting times by location. Total: 58 people. Note: not everyone answered this question.



We also asked people to rate how easy it was for them to get an appointment using a five star rating, where one is the worst and five is the best.

Table 1. Star ratings for making an appointment.

Responses from experiences in the last 12 months	Group	Count	Average	Most frequent
It was easy to get an appointment.	Person with dementia	20	3.1	1
	Carer	30	3.4	4
Responses from experiences more than 12 months ago				
It was easy to get an appointment.	Person with dementia	2	4	3/5
	Carer	24	3.6	5

People with dementia rated “how easy was it to get an appointment” most frequently as 1. This experience was rated much worse for someone with dementia compared to a carer completing our survey (who most frequently rated 4).

4.4 Overall experience

We asked people to rate the overall experience of the dementia diagnosis using a five star scale, where one is the worst and five is the best. We found that the average rating was 3.35 for people diagnosed in the last 12 months (48 people) and 3.38 for people diagnosed more than 12 months ago (26 people). Looking at the overall rating for people with dementia and people who are carers, there was not a significant difference in the rating given, for either time frame.

Figure 6. Average rating of experience by people diagnosed in the last 12 months



Source: Responses from 48 people

Figure 7. Average rating of experience by respondents diagnosed more than 12 months ago



Source: Responses from 26 people

We also asked people to rate how easy it was for them to get an appointment, how clearly everything was explained to them and how much they felt cared for by the service.

Table 2. Star ratings for communication and how caring the staff were.

Responses from experiences in the last 12 months	Group	Count	Average	Most frequent
Everything was clearly explained to me about the diagnosis/condition	Person with dementia	20	3.2	5
	Carer	30	3.5	4
I felt like they cared about me.	Person with dementia	21	3.6	4
	Carer	30	3.4	3
Responses from experiences more than 12 months ago				
Everything was clearly explained to me about the diagnosis/condition	Person with dementia	2	3	3
	Carer	24	3.7	4
I felt like they cared about me.	Person with dementia	2	3	3
	Carer	24	3.5	5

Carers and people with dementia who had experienced the diagnosis in the last 12 months, rated 5 and 4 most often when asked whether everything was clearly explained to them about the diagnosis/condition.

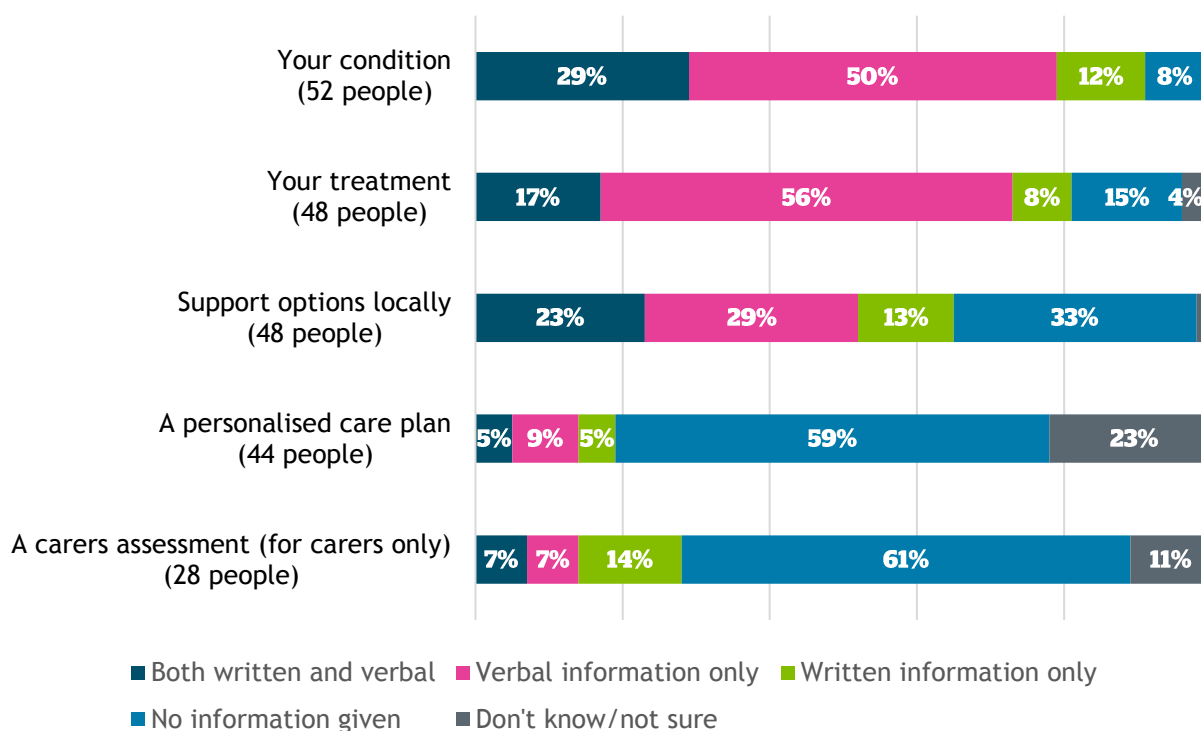
Carers rated “I felt like they cared about me” most frequently as 3. In contrast, people with dementia most frequently rated this as 4.

4.5 Information provision and support

The standards set out in the NICE guidelines state that all people who attend for a diagnosis of dementia should be given their condition (e.g. type of dementia, symptoms and how the illness might develop), treatments, support options locally⁷ and a personalised care plan⁸. In addition, any carers should be offered a carer’s assessment so that any emotional, psychological and social needs of carers are addressed⁹.

One of the primary objectives of this insight project was to understand more about people’s experience of the information and support that was given to them at diagnosis.

Figure 8. Experiences of the information and support received (from 52 people diagnosed in the last 12 months). Note: not all respondents answered each question.



⁷ Dementia support in health and social care. NICE quality standard [QS1]. Quality statement 3 (2010) <https://www.nice.org.uk/guidance/qs1/chapter/Quality-statement-3-Written-and-verbal-information>

⁸ Dementia support in health and social care. NICE quality standard [QS1]. Quality statement 4 (2010) <https://www.nice.org.uk/guidance/qs1/chapter/Quality-statement-4-Assessment-and-personalised-care-plan>

⁹ Dementia support in health and social care. NICE quality standard [QS1]. Quality statement 6. (2010) <https://www.nice.org.uk/guidance/qs1/chapter/Quality-statement-6-Emotional-psychological-and-social-needs-of-carers>

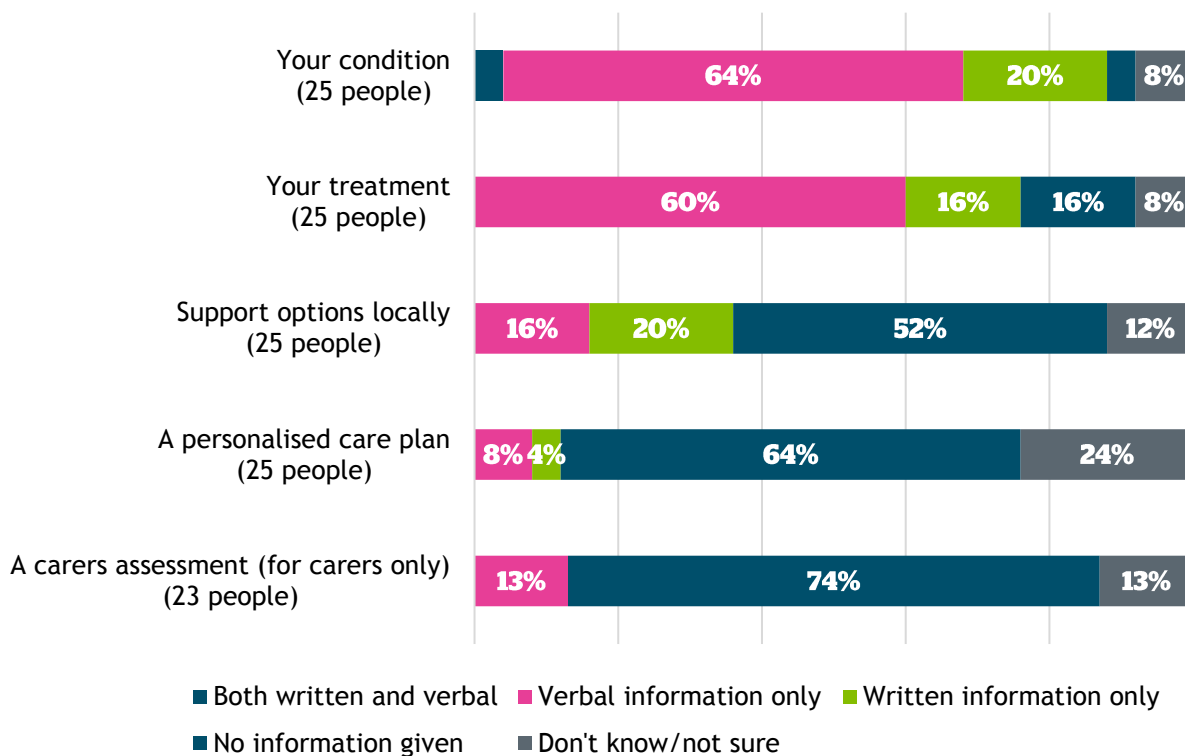
Figure 8 shows that:

- 29% (15 people) were given both written and verbal information about the condition;
- 17% (8 people) were given both written and verbal information about treatment;
- 23% (11 people) were given both written and verbal information about support options locally;
- 5% (2 people) were given both written and verbal information about a personalised care plan and;
- 7% (2 people) were given both written and verbal information about a carer’s assessment respectively

7% (2 people) were offered both written and verbal information about all of these subjects.

For respondents who had been diagnosed more than 12 months ago, verbal and written information was only provided to one person (see Figure 9).

Figure 9. Experiences of the information and support received (from 25 people diagnosed more than 12 months ago). Note: not all respondents answered each question.



We wanted to know where the information that was provided at diagnosis was too much, the right amount, or not enough. For those diagnosed in the last 12 months, 45% felt that the amount of information received was the correct amount, and 10% and 45% felt that they were given too much or too little information respectively. Figure 11 shows that for people diagnosed more than 12 months ago, 77% and 23% felt that they were given too little and too much information respectively. However we note that proportionately twice as many people with an experience in the last 12 months are getting the right amount of information compared to those with an experience more than 12 months ago.

Figure 10. Experiences about the amount of information received (more 56 people diagnosed in the last 12 months.)

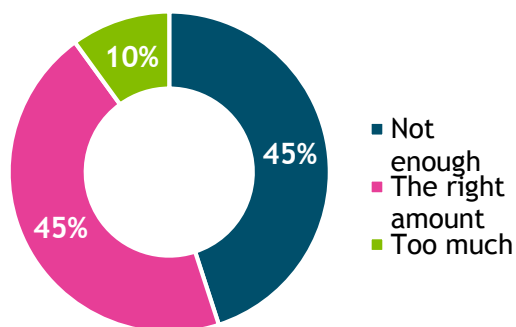
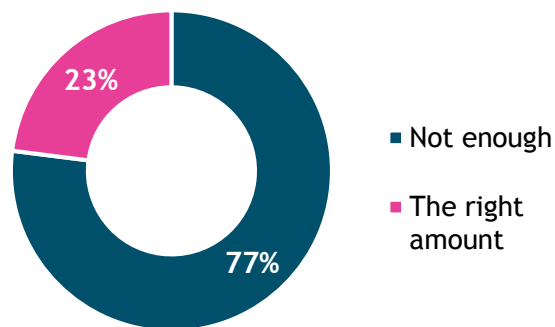


Figure 11. Experiences about the amount of information received (from 25 people diagnosed more than 12 months ago).



4.6 Improving the experience for people faced with a dementia diagnosis

The people who filled in our survey were asked about what could improve the experience of being diagnosed with dementia. 31 people felt that some improvements could be made.

4.6.1 Opportunities for more discussion at the diagnosis and after

The most frequently identified improvement was the provision of more information at the point of diagnosis, suggested by 57% (44 people). When people talked about this, they said that it was often the case that they or family members had to go and seek information independently, but also wanted the opportunity to discuss this with someone.

There should have been more information explained in person and not just been left to read leaflets.

Three of these respondents felt that information and support programmes, specifically Carer Information and Support Programme (CrISP provided by the Alzheimer’s Society) and the Carers’ Information Session (run by the St Francis Unit) were very helpful, but unfortunately it was felt that they were not run as regularly as desired. Again, having the opportunity to speak with someone about the diagnosis may be useful.

The session at St Francis for carers was good and informative. BUT could be given at more regular intervals- it was right for me but my brother in law was not ready to receive information.

We acknowledge that not everyone will want this opportunity, but our data suggests that this may be helpful for people to cope and live well with dementia.

4.6.2 More emotional support after diagnosis

Thirteen people (17%) felt that they needed more support after diagnosis, but reference was largely made to the provision of emotional support. One person highlighted the need to talk about the diagnosis, how they felt about it and welcomed the opportunity to share their experiences with us:

No one has ever sat with me (like Healthwatch did today) and talked to me about this diagnosis.

One respondent felt that many services should be offering emotional support to people affected by dementia:

Offer more than just leaflets - face to face contact or a phone call which is repeated at different intervals. Keep in touch with the family too. A support worker assigned to a family at diagnosis, so they can be there through the whole journey and help deal with the issues that arise. Ensure GP's are fully supporting carers and making their carer champion known.

4.6.3 More time for reflection

When talking about the diagnosis, four people told us that there was too much information provided to them at the diagnosis, and they felt overwhelmed with this. Despite this, the information (when given in a written format) would be taken away and digested at the pace that is desired by the person with dementia and/or their carer:

Overwhelmed as too much to take in. However, I was given plenty of material to take home and look through.

5 Findings from interviews with people with dementia and/or their carers

5.1 Introduction

This section details the findings from interviews with nine people with dementia and/or their carers who had an experience of dementia diagnosis made in the last 12 months. These individuals had initially completed the survey, and had provided their details so that we could speak with them about their experiences.

5.2 Accessing appointments for diagnosis

Out of the nine people we spoke to, two individuals spoke positively about the route and time taken to be diagnosed:

Patient attended an appointment with the Nurse for his normal Diabetes check. The nurse knew he was concerned about problems with his short term memory and asked him to see his GP. His GP referred him to the Memory Assessment Service and he was seen within 1 month of the nurse raising concerns.

Other experiences of the initial step of being referred for assessment were more difficult:

My father had been hospitalised for surgery due to a heart condition and he had experienced an unexpectedly slow and difficult recovery - he remained extremely disoriented. He remained in the hospital at my insistence. We were brushed off initially when we discussed that his recovery difficulties could be attributable to dementia. However he was not sent for a scan despite our requests...he was discharged and inappropriately offered treatment for depression.

(First presented in 2014, seen at the Working Age Dementia service in December 2015, diagnosis at the Memory Assessment Service in February 2016). We went to the GP and checked her thyroid. They upped the dose. We went back. They said no. They said she must be anaemic...went on some iron tablets. Made no difference. "Right you're deficient in B-12", so went on a course of injections. "No that's not it". I turned around and said "No, that's enough."

Experiences of carers

The examples above are implicit in revealing a long waiting time from initial presentation to referral for assessment. A more explicit example of waiting times follows:

I took her to the GP where they did some tests and told me nothing was wrong. I went back six months later - still nothing wrong, and again six months after that - still nothing wrong. I went back again and was finally referred to the Memory Assessment Service. From noticing something was wrong to getting a diagnosis took four years.

One carer we spoke to commented that they were referred in a timely manner to the Memory Assessment Service and had a diagnostic scan. However they did not receive the results and it was only when the person with suspected dementia collapsed and was

hospitalised that the family received the scan results which confirmed short-term memory loss and recall issues. On a similar vein, another carer told us that her husband had been admitted to A & E following a suspected stroke and on discharge, recommended that he be seen by his GP for referral to a Memory Assessment Service. Overall seven people we spoke to had been seen in less than 6 weeks from the point of referral.

5.3 Overall experience

Everyone who we spoke to talked about the staff that were present at the diagnosis. They included doctors, nurses and a few mentioned a representative from the Alzheimer's Society. In particular communication and compassion were key in whether the experience was overall positive or negative. Two people felt that the overall experience was good:

Despite the negative impact of diagnosis, one person with dementia felt the overall experiences at the Memory Assessment Service was positive:

My personal view is very positive of all aspects of care he received from the Memory Assessment.

I want to say that at the diagnosis the nurse was very kind and compassionate. She sat us down and prepared us for what she would be saying.

However we were also told some negative accounts about some staff, and the adverse impact that this had on people attending for a dementia diagnosis:

The consultant was very abrupt in how he delivered the news of a diagnosis of dementia in a rather parrot-like fashion as if by rote. My husband (person with dementia) was asked to leave the room by the consultant whilst he delivered the news of the dementia diagnosis to her. My husband was never called back into the consulting room... I was left to break the news to my husband that he had dementia - this was difficult for me.

The young girl [psychiatrist] that told us - she was quite excited because she'd just got engaged... and we're sitting there... It was inappropriate.

One carer that we spoke with felt strongly that a nurse imparted her father's diagnosis and she felt that this was inappropriate:

I phoned the memory clinic myself to clarify my father's diagnosis. I spoke to a nurse who liaised with the memory clinic team and called me back with the diagnosis and explained that whilst the diagnosis may be given by a specialist nurse - a doctor has always looked at test and scan results and made a proper formal diagnosis for the nurse to deliver. I feel this should be made clearer because otherwise I feel the gravity of dementia diagnosis and its seriousness is undermined by the memory clinics having a nurse and not a doctor deliver the diagnosis.

Where the people we interviewed spoke about the diagnosis, the negative impact that this had on themselves and the person being diagnosed was clear as illustrated:

She [my wife] went through a really dark time, she thought she was going to die tomorrow....shaking...it was awful. Absolutely awful....We went through a traumatic experience. It is a life-changing, life-shortening thing to tell us... It was a very dark time for us... It was not a good time... It was a dark period.

I felt deflated by the diagnosis. It was like a bomb going off.

5.4 Information provision and support

We asked patients and carers about the information and support received at diagnosis. Eight people we spoke to talked about this in a negative way. There was clear variations regarding what information is given, the method in which this is communicated (verbal or written) and the support provided by the medical professional present at the diagnosis

I was not given much information at diagnosis and if that, this information was not easy to assimilate as I was very upset.

I was given tonnes of information, both verbal and written, but I wasn't able to take it in as I was quite shocked with the diagnosis.

Another concern that was raised by carers was the lack of information and support that was carer-specific.

There was no information given on support for me [as a carer]. Nothing was said about the Carers Federation, nothing about what help I could get.

Whilst the consultant told me that there was "plenty of help out there" he was not specific about this. No particular information was offered to me regarding help or advice for my husband. I felt that I (as the carer) had to accept it and get on with it.

5.5 Support after diagnosis

All of the people that we spoke to praised the input of voluntary organisations in ongoing care and support for themselves or the person they care for:

They are amazing...I feel totally supported.

NHS organisations were mostly absent when discussing ongoing care and support, though the St Francis Unit was positively regarded by one carer, who had "nothing but praise for the staff and their support".

One carer felt as though neither she (nor her father who was diagnosed with dementia) was supported by any services. She particularly had concerns about the GP that her father is registered with:

The GP does home visits but doesn't tell the family what happened - and we can't rely on Dad to give an accurate report anymore. Despite being asked, professionals who visit don't pass on updates to the family every time.

5.6 Improvements to be made

We asked everyone that we spoke to what could be done to improve their experience from the point of referral to the present day.

One carer felt that people in her situation should be “offered more sympathy with more time provided to talk and ask questions”:

An improvement that was voiced by most of the people we spoke to was about the information and support offered at diagnosis and how this should be delivered:

Carer felt that information should be given in a verbal format so that one can clarify things whilst still at the hospital (or wherever the diagnosis is delivered).

There was no consensus about whether information should be discussed or provided in writing, suggesting that this is something that varies from person to person.

Finally one issue that a carer raised was the lack of continuity between the various health and social care services that were in place to support her and her father:

It is difficult navigating through the system. There is no-one to co-ordinate things. There is no facility to follow up anything. No-one asks “How’s it going?” or “What next?” Very often what we think happens isn’t in place. It’s crisis management - we go from one crisis to the next.

6 Findings from our database

6.1 Introduction

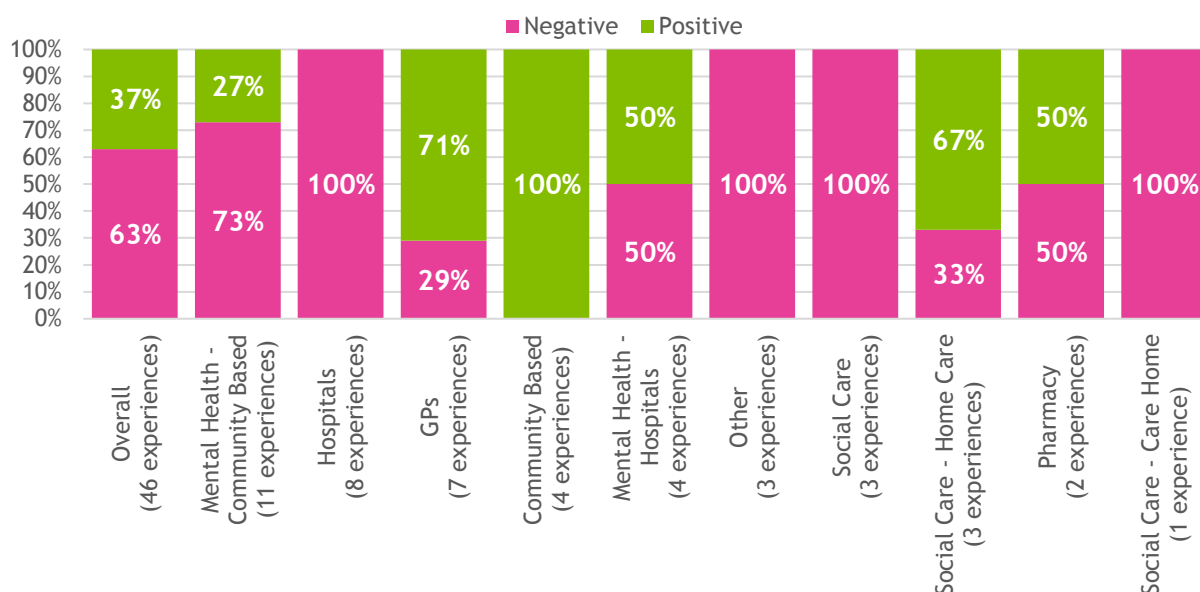
This section is based on the findings from 46 experiences gathered since January 2015 through general engagements that had previously been submitted and logged on our service experience database. These experiences were included if they referenced:

- Accessing the appointments for diagnosis
- Overall experience of the diagnosis
- Information provision and support at diagnosis
- Support after diagnosis

6.2 Services talked about and overall sentiment

Figure 12 show that the most talked about service was community based mental health services, accounting for just under a quarter (24%) of all referenced services. Services that were most likely to be talked about in a negative way were hospitals, social care and care homes. Community based services were most likely to be talked about in a positive way, with all experiences being positive (although only 4 experiences were made about this type of service).

Figure 12. Services and sentiment.



6.3 Accessing appointments for diagnosis

One experience described accessing the Memory Assessment Service, where this occurred more than 12 months ago. They told us that it took 14 months from first seeing the GP to being diagnosed:

About 6 years ago she realised that something was wrong and went to see the GP. He didn't want to recognise her condition as dementia and instead, gave her medication for depression and referred her to a CPN. After several sessions with the CPN, the CPN felt that the diagnosis was wrong. The lady went back to the GP, was taken off the medication (which wasn't having an effect) and was referred to the Memory Assessment Service.

6.4 Overall experience

Six experiences described the overall experience of diagnosis, of which 3 (50%) were positive and 3 (50%) were negative. The most commonly described feature of this service related to staff and communication: how much they felt members of staff listened to them and the extent to which reporters felt that the attitude of staff impacted on their experiences of the services. We had some very positive experiences shared with us, for example:

Excellent consultation. From her initial assessment visit to the diagnosis of Alzheimer's/Dementia [the doctor] was professional, caring and explained everything in clear language to my elderly mother.

I felt very happy to attend the MAS clinic, the staff were very helpful and I felt I got a lot from just talking to them. We (my husband also) were very satisfied with the service offered.

Experiences of two carers

Our data also showed that when people were talking about positive experiences with staff, words like “lovely”, “helpful”, “compassionate” and “excellent” were often used.

People also told us about negative experiences, and there were issues around communication, particularly around a lack of empathy:

The first thing she [consultant] said to patient was "Tell me about yourself, as I haven't had time to read your notes" He was rushed when taking the test and therefore given a low score as couldn't complete each task, needed more time. Also she wouldn't let me speak. I did not want to see that doctor again, she has no communication skills.

Consultant was very rude and not good at communicating and understanding.

Experiences of two carers

One experience referenced the facility itself, and how the environment was not pleasant and therefore had an impact on the overall experience:

I am sending this as I was appalled by the lack of concern for the waiting area and poor access to the clinic. The waiting room was completely without any thought being given to the needs of people who would have to sit waiting for an important interview having recently been diagnosed with a distressing condition, or to their carers. The room was bare, no pictures, not even leaflets let alone magazines and with chairs arranged facing the door.

Experience of a carer

6.5 Information provision and support at diagnosis

Five experiences talked about the information provision and support at diagnosis. All of these were negative. For example:

I was told “You have dementia” and no services were offered.
I was diagnosed with vascular dementia and told to go home and look it up on a computer.

The memory nurse did not say much other than not having tumours on the brain

Experiences of people with dementia

My wife was diagnosed with Working Age Dementia. She has a memory test done and then said “Goodbye”. There was no access to a nurse, or referral to the Alzheimer’s Society people.

The nurse just said “Goodbye”. Didn’t offer any information or support. I had to get my son to find out what we do.

Experiences of carers

6.6 Support after diagnosis

Our database held 34 experiences which talked about support after diagnosis. 19 experiences (56%) of these were negative and 15 experiences (44%) were positive.

The most common positive theme was about staff. People told us that having awareness of dementia, treating patients and carers with compassion and holistically made a difference to them, and made them feel supported. Community based mental health services, community based services, pharmacies and GPs were talked about in a positive way:

They were always prompt and displayed an admirable professional attitude towards my mother. The regular taking of her medication certainly helped her general health. Their social worker attached to their team could not have been more helpful in arranging on-going assistance

Experience of a community based mental health service

I cannot tell you how much better we both feel now that my husband is getting some help and support. It would not have happened so quickly without you!

Experiences of a community based service

She [pharmacist] wrote all the brands that match the colours to help us, and now we can ask the chemist for the brand that has the colour we are used to. This has helped us a lot and is helping with the confusion. She goes the extra mile, she’s great.

Experience of a pharmacy

They also call in on [person with dementia] once a year to see how she’s coping. It’s very straightforward to speak with some. The receptionists are helpful and show compassion and the nurses are lovely.

Receptionist is helpful, show compassion, nurses are lovely.

Experience of a GP surgery

Negative experiences regarding support after diagnosis were largely due to disappointment with the available services, or a lack of support with 13 experiences describing this. Of these, 5 experiences attributed this to a lack of continuity and communication between services, or to a lack of services:

My husband used to have follow up appointments, but we can't do that anymore. All you are allowed to do is get your diagnosis, there is no follow up. They have cut down on the number of CPN's. I don't know what we would have done without ours.

My husband had a lot of depression at the beginning, without the CPN I just don't know what we would have done. People need this support desperately, but don't get it now due to all the changes.

We NOW NEED HELP!! I feel sure that if we had a CPN it would be someone I could turn to for help/advice and someone who would visit on a regular basis.

I have seen the consultant and asked her who should be coordinating my wife's care, she had stated the GP. The GP states otherwise. I feel that I have organised and coordinated my wife's care completely and she is not getting the support she needs.

The CPN that visited my wife promised that I wouldn't be unsupported which he stated is the only way it's been.

Nottinghamshire County Council services are not good because they are not joined up.

Experiences of carers

Seven experiences described the lack of support specifically for carers, and the negative impact this can have. The experiences demonstrated that in some cases, being identified as a carer did not positively impact on support that they (and in some cases the person they care for) receive:

A paramedic wanted to take me to hospital. I said I have a County Carer's card, and she called them and was told they could not do anything unless I was in the hospital. We would either have to get someone to stay with my husband [person with dementia], or take him to the hospital as well.

Experience of social care services

I am registered as a carer but don't feel this makes any difference. Ideally I want to phone the surgery, and book an appointment for my husband with a Doctor who he knows, rather than seeing a different person each time.

Experience of a GP surgery

7 What next?

7.1 Official responses

This report has been sent to:

- Gill Oliver, Senior Public Health Manager, Nottinghamshire County Council
- Karen Hampson, Community Service Manager for Mental Health Services for Older People, Nottinghamshire Healthcare Trust
- Clare Hopewell, Head of Strategy, Rushcliffe Clinical Commissioning Group
- Kazia Foster, Mental Health Lead, Bassetlaw Clinical Commissioning Group
- Scott Smith, Service Manager, Alzheimer's Society Nottingham

8 Appendix 1

8.1 Alzheimer's Society services in Nottinghamshire

Background

Healthwatch Nottingham and Healthwatch Nottinghamshire are independent organisations that help local people get the best from their health and social care services. We listen to people's experiences of services in the city and county and use this evidence to bring about changes in how services are designed and delivered.

We recently undertook an Insight Project looking at information provision and support at dementia diagnosis. In exchange for them informing their contacts about this Insight Project and allowing us to attend some of their support groups, we offered to include some supplementary questions to evaluate the services provided by the Alzheimer's Society. These include countywide support and information services, including Singing for the Brain, Memory Cafes and Groups, Carer's Information and Support Programmes (CriSP), Side by Side Befriending service, Carer's Groups and support provided by the Dementia Support Workers and Advisers. We asked people to rate their experiences of these services. Where people had not accessed any services at the point of completion, we asked why?

How we collected responses...

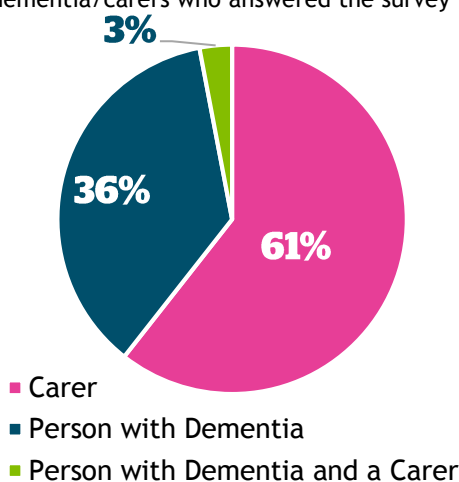
We gathered views from local people with dementia and/or their carers across Nottingham City and County in the following ways:

- Face to face with local people at 21 dementia groups run by the Alzheimer's Society in the City and County.
- Through a mail out of contacts held by the Alzheimer's Society. Healthwatch provided the full Insight survey and the additional questions about Alzheimer's Society services specifically and posted these to their contacts. We provided freepost envelopes so that people could return their completed questions back to us directly. In total 120 surveys were posted.

Who answered our survey?

We had 33 responses from people with dementia and/or their carers.

Figure 1. Number of people with dementia/carers who answered the survey (n = 33).



Diagnosis date ranged from 2009 to 2016, though the majority of these (n = 22, 67%) were made in 2015 and 2016.

What we were told...

64% (n = 22) told us that they had use an Alzheimer's Society service. We asked people to rate their experience using a five-star rating where one is the worst and five is the best. The average rating was 4.3, and the mode rating was 5.

Figure 2. Average rating of experience for respondents who had used a service



Source: Responders who had used an Alzheimer's Society service (n=20); two respondents did not give a rating

We heard some really positive comments about the support received by individuals and the difference t this had on them/the person they care for:

"It's wonderful and really brings the person I care for out of himself. He sings all evening afterwards and can remember the way to and from the group."

Carer talking about Singing for the Brain

"We have received tremendous, helpful support."

Carer talking about the Dementia Support Workers

"My sister and I both went on Alzheimer's course which was very informative and excellent."

Carer talking about CriSP

"These sessions give stimulus to both the person with dementia as well as the carer and give initial opportunities for social contact with others in a similar situation."

Staff were also highly regarded by people who completed the survey.

"They listened to my concerns and sent me a number of relevant info leaflets and information to help me with my father's recent diagnosis (and in large font for my dad to read too)! Very helpful and friendly approach, showed an understanding."

Carer talking about the Dementia Support Workers

"The people and staff of are engaging and supportive"

Carer talking about a Memory Group

36% (n = 11) told us that they had not accessed any Alzheimer's Society services. These responses told us that people had not felt that the services were needed at the time of survey completion, that they had only very recently received information about the Alzheimer's Society support services and had not yet attended, or that they felt too busy with their caring responsibilities to go.

9 Appendix 2

9.1 Experiences of the Memory Assessment Service

We collected 60 completed surveys from individuals sharing their experiences of the Memory Assessment Service in Nottinghamshire

Figure 1. Characteristics of respondents. Diagnosis made more than 12 months ago: 14 people; diagnosis made in the last 12 months: 46 people. Total: 60 people

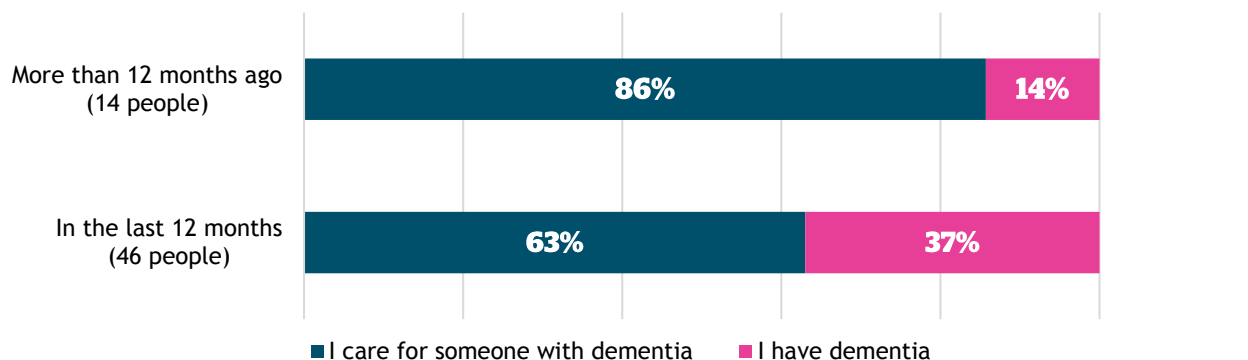


Figure 2. Waiting time from referral to be seen at the Memory Assessment Service. Total: 60 people.

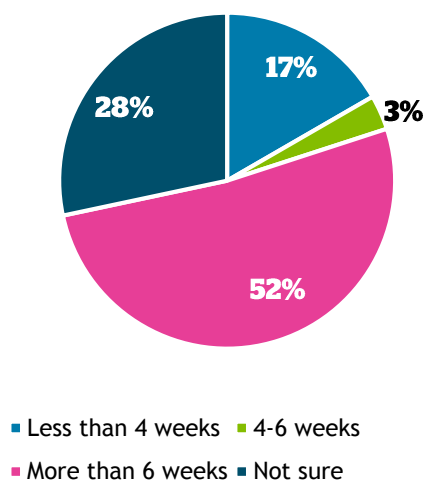


Figure 3. Waiting time by location. Total: 60 people.

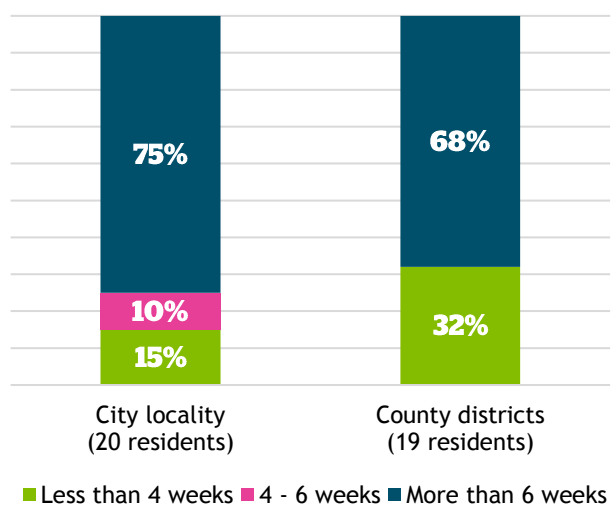


Table 1. Star ratings for making an appointment

Responses from experiences in the last 12 months	Group	Count	Average	Most frequent
It was easy to get an appointment	Person with dementia	16	3.25	1 5
	Carer	28	3.57	4
Responses from experiences more than 12 months ago				
It was easy to get an appointment	Person with dementia	2	4	3 5
	Carer	12	4.25	5

Figure 4. Overall experience by service

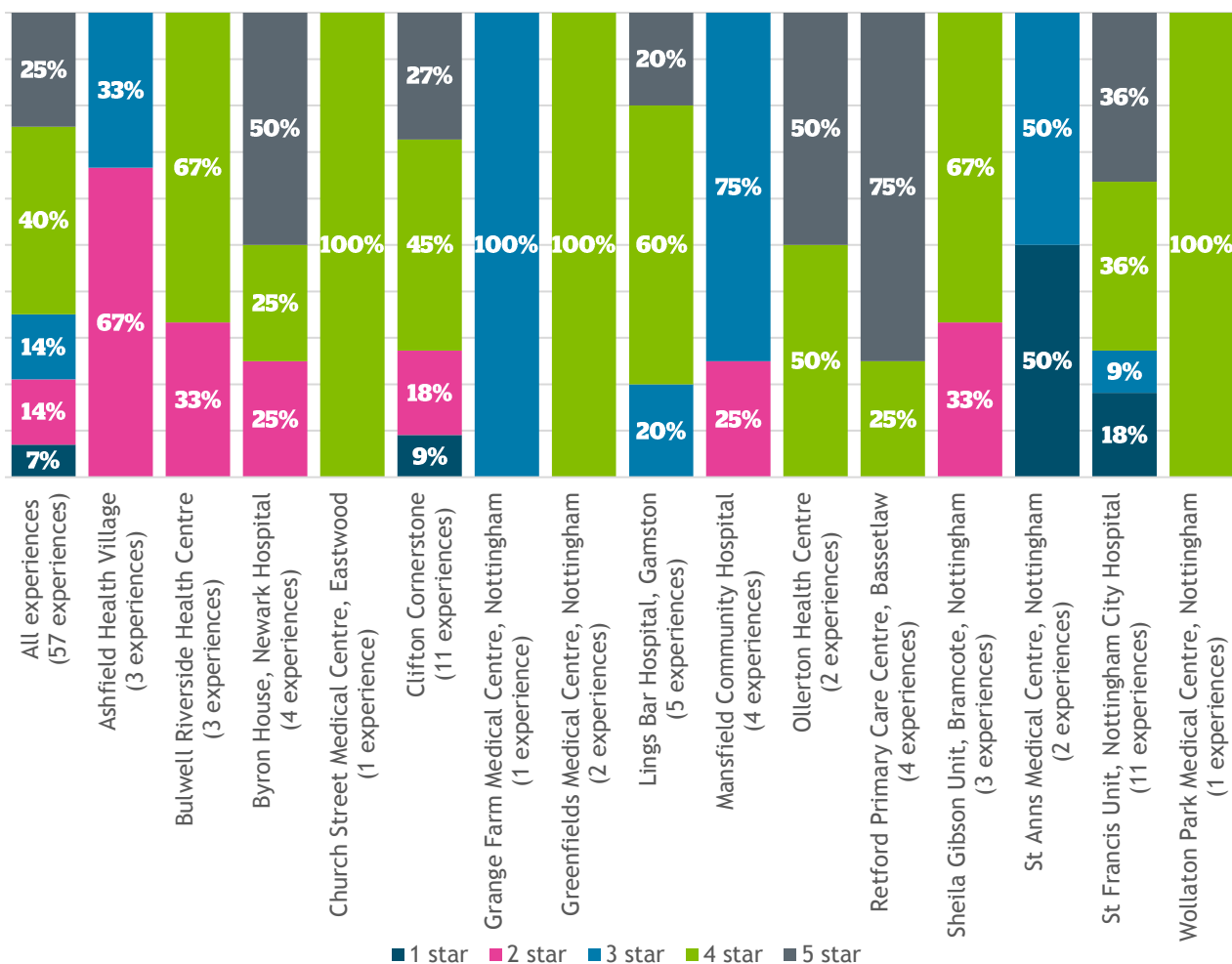


Table 2. Star ratings for communication and how caring the staff were.

Responses from experiences in the last 12 months	Group	Count	Average	Most frequent
Everything was clearly explained to me about the diagnosis/condition	Person with dementia	16	3.6	1 and 5
	Carer	28	3.7	4
I felt like they cared about me	Person with dementia	17	3.8	4
	Carer	27	3.6	4
Responses from experiences more than 12 months ago				
Everything was clearly explained to me about the diagnosis/condition	Person with dementia	2	3	3
	Carer	12	3.8	4
I felt like they cared about me	Person with dementia	2	3	3
	Carer	12	3.8	5

Figure 5. Experiences of the information provision and support received from 46 people diagnosed in the last 12 months. Note: not all respondents answered each question.

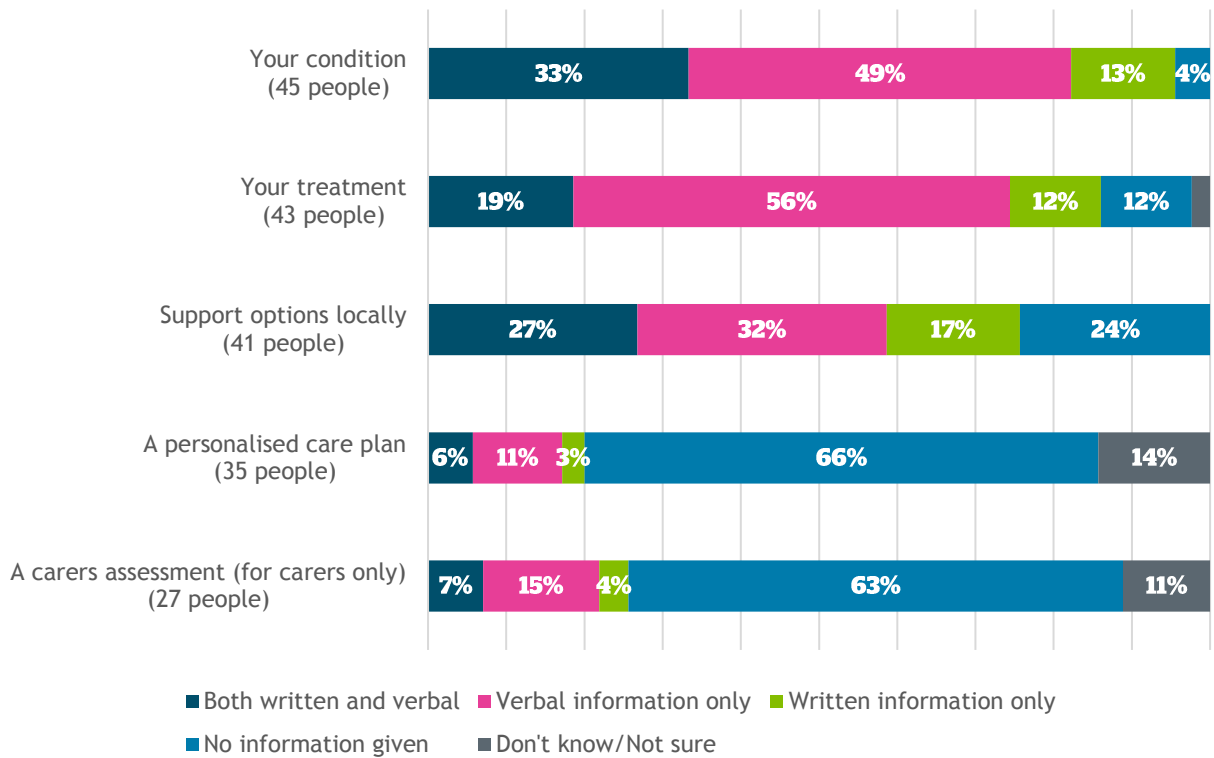
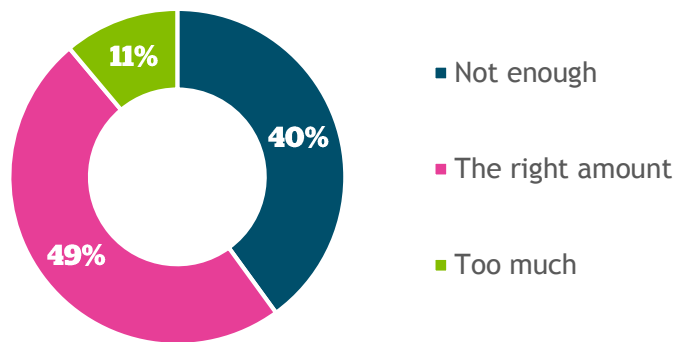


Figure 6. Experiences about the amount of information received from 45 people diagnosed in the last 12 months.



10 Appendix 3

10.1 Experiences of the other services where a dementia diagnosis was given.

We collected 18 completed surveys from individuals sharing their experiences diagnosis in services other than the Memory Assessment Service.

Figure 1. Characteristics of respondents. Diagnosis made more than 12 months ago: 12 people; diagnosis made in the last 12 months: 6 people. Total: 18 people

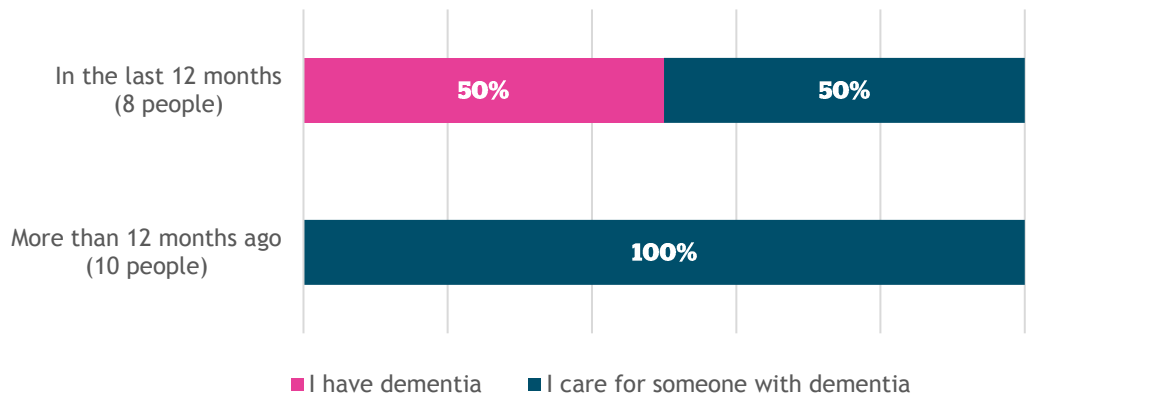


Figure 2. Waiting time from referral to be seen at the Memory Assessment Service. Total: 18 people.

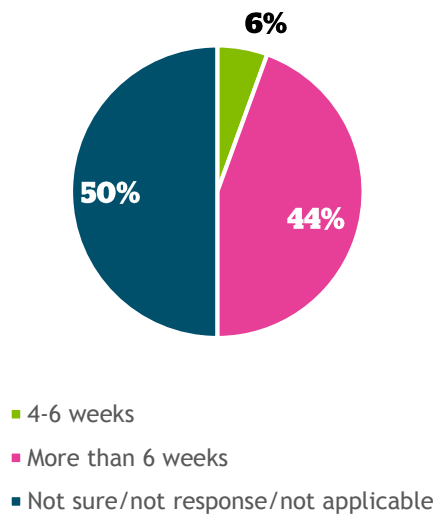


Figure 3. Overall experience by service/service type

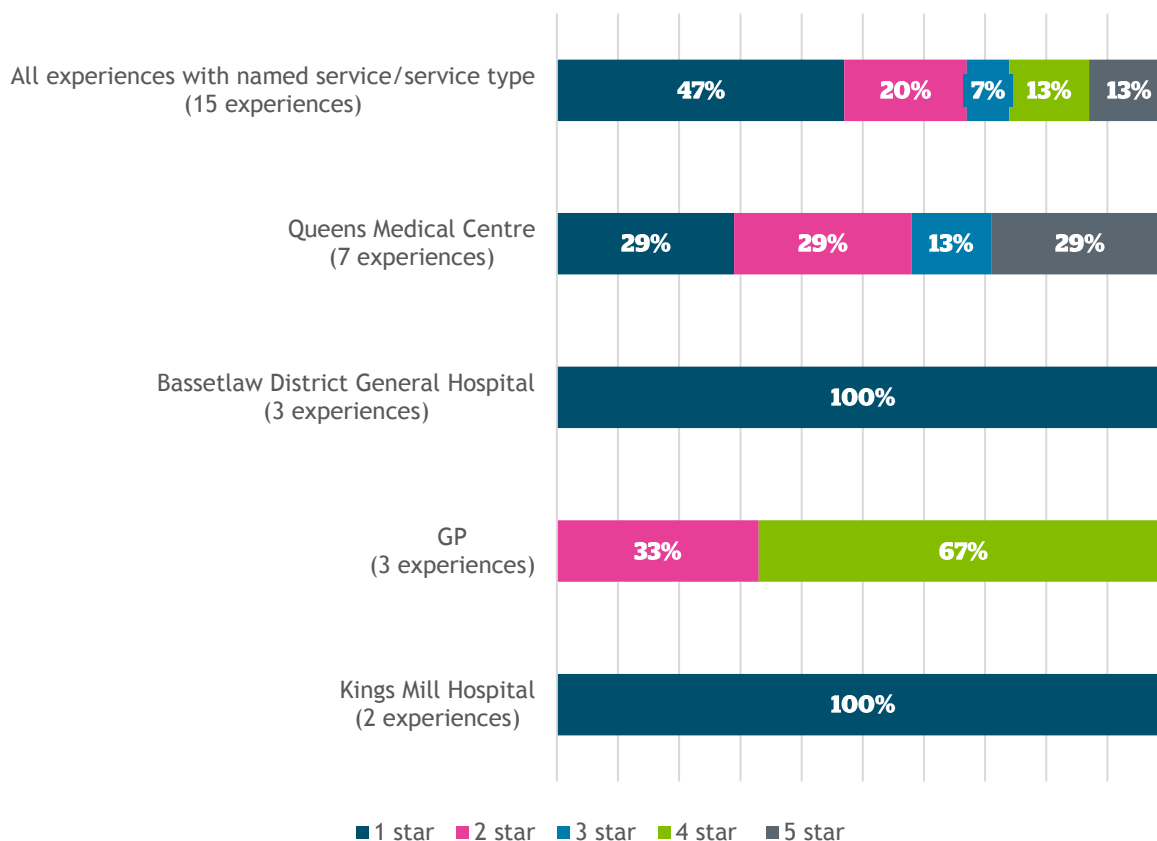


Table 1. Star ratings for communication and how caring the staff were.

Responses from experiences in the last 12 months	Group	Count	Average	Most frequent
Everything was clearly explained to me about the diagnosis/condition	Person with dementia	4	1.75	1
	Carer	4	1.75	1
I felt like they cared about me	Person with dementia	4	2.75	1
	Carer	4	2	2
Responses from experiences more than 12 months ago				
Everything was clearly explained to me about the diagnosis/condition	Person with dementia	0	NA	NA
	Carer	10	2.9	1 and 4
I felt like they cared about me	Person with dementia	0	NA	NA
	Carer	10	3.6	4

Figure 4. Experiences of the information provision and support received from 8 people diagnosed in the last 12 months. Note: not all respondents answered each question.

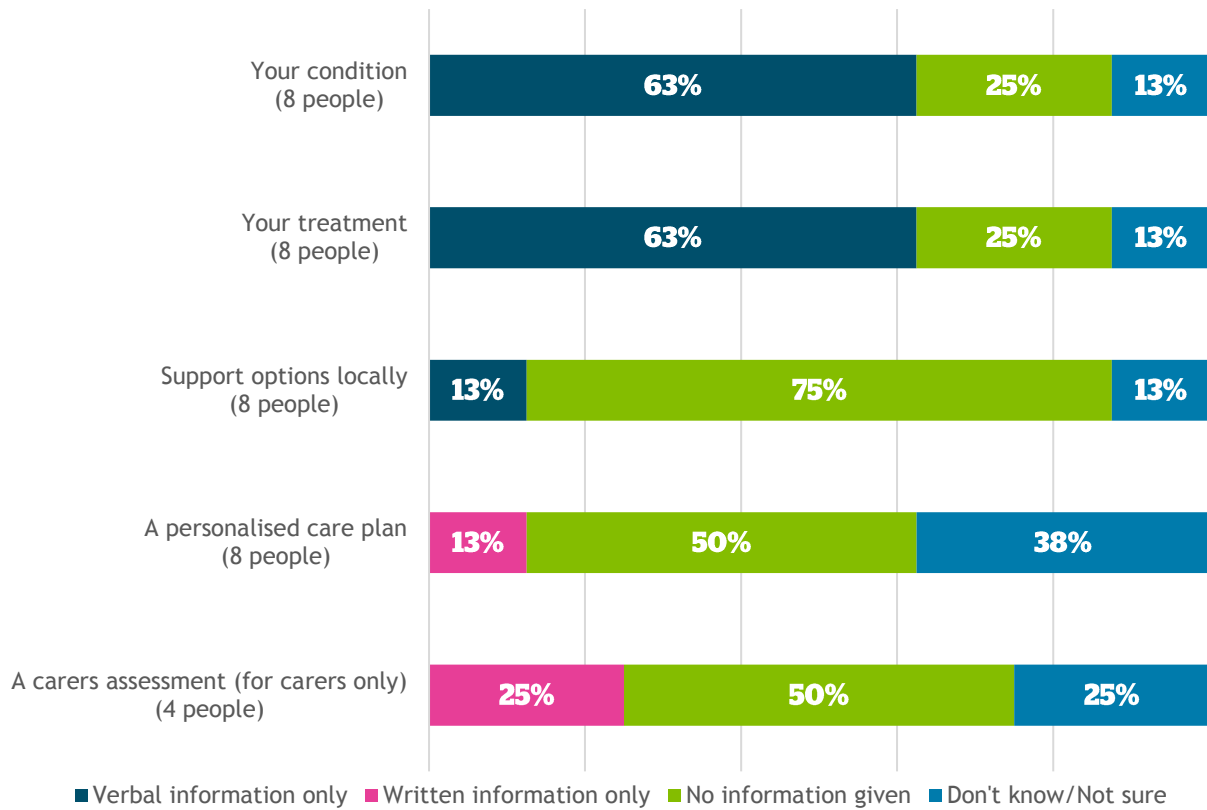
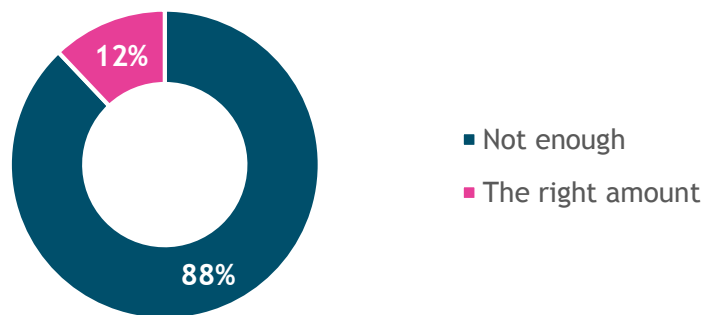


Figure 5. Experiences about the amount of information received from 8 people diagnosed in the last 12 months.



Acknowledgements

We would like to take the opportunity to thank everyone involved in this project.

To all patients and carers, thank you for giving up your time to talk to us.

To our volunteers, thank you for also giving up your time to prepare for and undertake the interviews.

healthwatch
Nottinghamshire

Unit 2 Byron Business Centre
Duke Street
Hucknall
Nottinghamshire
NG15 7HP

Phone: 0115 963 5179
www.healthwatchnottinghamshire.co.uk
Twitter: @HWNotts

Healthwatch Nottinghamshire is registered in England and Wales.
Company registration number 8407721.
Healthwatch Nottinghamshire is a registered charity number 1159968.

healthwatch
Nottingham

21 Clarendon Street
Nottingham
NG1 5HR

Phone: 0115 859 9510
www.healthwatchnottingham.co.uk
Twitter: @HWNtingham

Healthwatch Nottinghamshire is registered in England and Wales.
Company registration number 8525544.