

BIRMINGHAM DEMENTIA STRATEGY REFRESH

PROGRESS REPORT – 15TH OCTOBER 2019

FOR BIRMINGHAM HEALTH & SOCIAL CARE OVERVIEW & SCRUTINY COMMITTEE

1. BACKGROUND AND INTRODUCTION

The Birmingham and Solihull Dementia Strategy 2014-17 'Give me something to believe in' was adopted by Birmingham City Council, Solihull Metropolitan Borough Council, Birmingham and Solihull CCGs and other partners in 2014. Its overarching purpose was to understand the experiences of people with dementia, to identify what was already in place, and what was required to improve the outcomes for people with dementia and their carers. The strategy was also used as a commissioning framework to support the development of robust pathways for people with dementia and their carers and supports person-centred, integrated care alongside a 'whole pathway' approach to good quality dementia care.

A Strategy Steering Group has been established to support the refresh document with representation from primary care, Birmingham City Council, mental health services, community services, learning disabilities, Alzheimer's Society, Age Concern, Dementia Information and Support for Carers, Crossroads Care, fire service, police service, Birmingham LGBT, Birmingham public health, hospice services and healthcare commissioners.

Stakeholder engagement events were held during July and August 2019 the findings of which will inform the strategy going forward.

In 2015 the Dementia commissioning moved into the Better Care Fund, a national programme where NHS and local government work collaboratively to improve the lives of the most vulnerable people in our society. This arrangement has helped to align and protect budgets for services and ensure a more integrated approach to pathway development for people with dementia and their families and carers.

Dementia now sits under the Ageing Well and Later Life work stream of the Birmingham and Solihull sustainability and transformation partnership (STP) and regular progress reports are provided.

There has been a great deal of progress since the first strategy, but also a recognition that more work is still to be done to further support those living with dementia and their families/carers.

It should be noted that Solihull Metropolitan Borough Council have developed their own refreshed dementia strategy.

2. PROGRESS TO DATE

2.1 Pre-Diagnostic / Assessment Pathways

2.1.1 Learning Disability Health Check Scheme

People with learning disabilities (LD), particularly those with Down's syndrome are at an increased risk of developing dementia at a younger age. An annual health check can improve people's health by spotting problems earlier.

All practices in the CCG have signed up to the learning disability health check incentive scheme, which includes a review of physical and mental health with referral through the usual practice routes if health problems are identified.

Annual Health Checks can identify undetected health conditions early, ensure the appropriateness of ongoing treatments and establish trust and continuity care. GPs and practice nurses have the much needed generalist skills to help people with LD get timely access to increasing complex health systems.

2.1.2 Memory Assessment Service

The Memory Assessment Service (MAS) provides assessment and diagnosis for users suspected of developing dementia, when all other causes have been ruled out, including physical, mental health and alcohol. Prior to April 2019, referrals into this service could only be made by GPs. As from 1st April 2019, referrals are now accepted from GPs, hospital consultants/nurse consultants, and community matrons/advance nurse practitioners. Although we have limited data, there is evidence that the diagnosis rates of dementia may be increasing across the healthcare economy, although undoubtedly continued effort will be required to achieve nationally aspired levels.

It is anticipated that more patients with suspected dementia will be identified and referred to the MAS, so that they can access the Dementia Navigator Service following diagnosis.

We have worked with our secondary care MAS to develop 'fast track pathways' for 'non-complex' diagnoses aimed at reducing the time from identification to diagnoses and we have increased capacity in MAS to support this.

2.2 Post-Diagnostic Pathways

Birmingham and Solihull CCG has commissioned a Dementia Navigator Service and Dementia Cafes/Activity Groups for Birmingham jointly with Birmingham City Council under the Better Care Fund. It also aims to reduce the number of people who attend hospital who have reached crisis point by focussing on how to prevent the crisis in the first place. The services commenced on 1st October 2019.

The Dementia Navigator Service can be accessed following diagnosis at the Memory Assessment Service, and also has a social prescribing element. The person living with dementia and their family/carer will be allocated a dedicated dementia advisor. There is new evidence which shows that the provision of dementia advisors keeps people in the community and the estimates are for every £1 spent, £4 are saved.

The service will operate across the entire span of an individual's dementia journey and will work directly with carers, even when the person with dementia does not desire support or is no longer able to participate in support sessions. The service will provide early intervention / preventative support through:

- A single point of access for information and advice about dementia, information about what support is available pre and post-diagnosis, and how to access this support.
- Signposting to other support services available.
- Practical and low level emotional support to promote greater emotional resilience in service users by creating a sense of safety and an atmosphere of calm.
- Empowering healthier lifestyle choices in local communities (Making Every Contact Count).
- Practical coaching and support to people with dementia and their carers around best strategies and good practice to live well with the condition.
- Advise on and facilitate access to peer-led group support, e.g. dementia cafes and groups.

Solihull Metropolitan Borough Council have also commissioned a Dementia Navigator Service for Solihull which commenced on 1st April 2019, thereby creating a consistent service across Birmingham and Solihull STP.

2.3 Improving Access to Dementia Services to all Communities

An independent service evaluation highlighted the need for the Birmingham and Solihull CCG to address its approach to working with Black, Asian and Minority Ethnic (BAME) communities. The evaluation of the dementia support service across Birmingham (March 2018) identified that some communities were not accessing these services, particularly those from BAME communities, and highlighted the fact that it is likely that dementia will be more common among Asian and Black Caribbean older people, because high blood pressure, diabetes, stroke and heart disease, which are risk factors for dementia, are more common in these communities. Some of the key issues in relation to BAME communities include an unfamiliarity with dementia; negative perceptions resulting from poorly translated terms; and stigma.

Another inequality identified related to those with learning disabilities, particularly those with Down's syndrome who are at an increased risk of developing dementia at a younger age. People with learning disabilities will need specific support to understand the changes they are experiencing and to access appropriate services after diagnosis and as dementia progresses.

The CCG is working to bridge these gaps and have subsequently revised the service specifications so that providers of dementia support services engage with these communities in a more proactive way and developed an incentivised quality initiative to improve access to the service to all communities. Other strategies include engaging with primary care networks that have a greater level of diversity.

2.4 Engagement Events

There was a commitment to prioritising engagement with people living with dementia and their families/carers in the refresh of the Birmingham strategy.

Six events were held across Birmingham in July and August 2019 with patients, carers / family members and health and social care professionals. The events were designed to gather their views on how dementia services are provided and understand the performance of services at present.

During the events, participants had the opportunity to share their experiences and give feedback on the following areas:

- Diagnosis
- Access to services
- Ongoing support
- Respite for carers
- Advance care planning/End of life care.

A full copy of the report outlining the findings and recommendations from these events is attached as Appendix 1.

2.5 Dementia Education and Training

There is a commitment to provide extra education and training for GPs and practice nurses on the early identification and management of dementia. Early diagnosis is crucial not only to allow early planning for the future but also to allow dementia medication to be commenced at an earlier stage, and allow preservation of existing memory. GPs are the first point of contact for most people suspected with dementia, and so they need to be kept up-to-date with how this should be carried out is essential.

The next education session on 'The Identification of Dementia', is planned for November 2019 and will be delivered by the National Clinical Director for Dementia and Older People's Mental Health at NHS England and NHS Improvement.

2.6 Dementia Diagnosis Rate

Birmingham and Solihull CCG wants to achieve a dementia diagnosis rate of 77% by 2022/23. The national dementia target is for at least two thirds of people 65+ with dementia to be diagnosed (66.7%). The current CCG performance as at August 2019 was 67.50%. In order to achieve the CCG target of 77%, it is anticipated that the CCG will maintain a dementia diagnosis rate of 66.7% in 2019/20 and thereafter increase by 5% each year in 2020/21 and 2021/22.

The diagnosis rates for August 2019 are outlined below:

1. Nationally – **67.8%**
2. Regional level:
 - North of England – **North West 73.7% North East & Yorkshire 72.5%**
 - Midlands and East of England - **Midlands 68.7% East of England 66.2%**
 - London - **73.6%**
 - South West of England – **62.5%**
 - South East of England - **65.7%**
3. Birmingham and Solihull CCG - **67.5%**

As at the end of August 2019, the dementia diagnosis rate for Birmingham and Solihull CCG was as follows:

Population aged 65+ as at April 2019	Estimated prevalence (Aug 2019)	Target register (66.7%)	Latest diagnosis rate
191,777	13,017	8,682	67.50%

This commitment to raise the dementia diagnosis rate to an ambitious target, is supported by a robust action plan which started to be implemented across practices in September 2019.

3. OTHER PROGRESS

3.1 Primary Care Networks

Primary Care Networks are a key part of the NHS Long Term Plan where general practice has become organised into clusters of GP practices, serving a population of 30,000-50,000 patients. These networks are able to deliver a more resilient and responsive service provision compared to the former organisations and will have strong, effective clinical leadership, with each organisation headed by a Primary Care Network Clinical Director. These will allow system partners, including the CCG, to engage with primary care working at scale, and represents a fantastic opportunity to plan and implement health and social care improvements.

3.2 Dementia Drug Prescribing

Currently in Birmingham and Solihull, dementia drug prescribing is through our local Mental Health Trust. This causes issues for both patients and their carers, as all other medications for such patients will often be through their GP practice, with the exception of these drugs, hence leading to an additional burden upon patients and families to arrange prescription from two different providers. The underlying reasons for this historic arrangement is complex in nature, however, the CCG has been working with system partners for a considerable period of time, and is now very close to finalising agreement on the transfer of dementia drug prescribing to primary care.

3.3 Dementia Advisors for Primary Care Networks

Birmingham and Solihull CCG has agreed with the provider of the Dementia Navigator Service (Alzheimer's Society) to have a named dementia advisor for each primary care network. This will be notified to all 33 primary care networks across Birmingham and Solihull during October 2019.

3.4 Integrated Dementia Care – Reducing Hospital Admissions and Length of Stay for People with Dementia Through STPs

Birmingham and Solihull CCG is one of three national pilot sites to work on reducing avoidable hospital admissions; the other two sites are West Yorkshire and Harrogate STP; and North Central London STP. The CCG successfully bid for £183k for an Advance Care Planning Project Manager, and four additional qualified staff for Birmingham and Solihull Mental Health Trust to expand its enablement work in care homes during 2019/20.

- **Advance Care Planning Project Manager**

Commenced in April 2019 and has made good progress in understanding when advance care planning currently commences for people living with dementia and how it is included within training, e.g. safeguarding. There is an STP Advance Care Planning Working Group established to agree advance care planning documentation, which will include all conditions.

- **Enhancing Old Age Mental Health Teams**

Old Age Mental Health Teams are key in providing support to care homes not only for individual clinical advice around dementia and rapid response but also for general learning and support, yet their availability is scanty. Their effect in reducing hospital admissions has been clearly demonstrated but the cost is estimated to be half that of traditional care with a reduction of 50% in hospital admissions. The successful bid will enhance this service by recruiting four additional qualified staff in their community services to enhance admission avoidance work and support to other services.

4. NEXT STEPS

The strategy is currently being refreshed for Birmingham to reflect progress to date and future planning.

The key priorities of the strategy refresh will be:

- Enabling access to a timely diagnosis and post-diagnostic support.
- Information and services that focus on early intervention and prevention.
- Preventing crises and supporting people with dementia within their communities.
- Improving the quality of care for people with dementia and ensuring services are person-centred, integrated across health and social care and fit for purpose.
- Improving advance care planning/end of life care.

A small group is being established to write up the strategy following feedback from the engagement events, and the Strategy Steering Group will be used as a Reference Group during its development. The timetable for this is as follows:

Task	Activity	Oct	Nov	Dec	Jan	Feb	Mar	Apr
Strategy Refresh Group	Establish group to refresh strategy							
Gather and Analyse Information	Analysis of information gained							
Formulate Strategy	Formulate the strategy with Strategy Refresh Group							
Seek views from Reference Group	Obtain comments on strategy from Reference Group							
Finalise strategy	Finalise strategy following Reference Group comments							
Governance Approval	Obtain approval from Better Care Fund							
Update Birmingham Health and Social Care Overview and Scrutiny Committee	Provide update to Committee on strategy							
Implement Strategy	Strategy communication and implementation							
Evaluate and Control	Review of internal/external issues including targets							

The refreshed strategy will also consider the summary and recommendations from the Birmingham Local Dementia Profile (July 2019) produced by the Alzheimer's Society, and Why it's important to review the care of people with dementia (July 2019) produced by Healthwatch.

5. APPENDICES

Appendix 1: Dementia Strategy Review Engagement Report

Dementia Strategy Review Engagement - DRAFT

Birmingham and Solihull Clinical Commissioning Group

Friday, 4 October 2019

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1 Executive summary

1.1 Introduction

This report summarises the feedback from engagement events held across Birmingham to inform the development of Birmingham and Solihull CCG's dementia strategy for Birmingham.

1.1.1 Background

This background information is taken from the engagement event presentation.

The Birmingham and Solihull Dementia Strategy 2014-2017, '*Give me something to believe in*', was adopted by Birmingham City Council, Solihull Metropolitan Borough Council, Birmingham and Solihull Clinical Commissioning Group (CCG) and other partners in 2014. Its overarching purpose was to understand the experiences of dementia patients, to identify what was already in place, and what was required to improve the outcomes for patients and their carers. The refreshed strategy will reflect progress to date and future planning requirements.

The key priorities of the strategy refresh will be:

- Enabling access to a timely diagnosis and post-diagnostic support.
- Information and services that focus on early intervention and prevention.
- Preventing crises and supporting people with dementia within their communities.
- Improving the quality of care for people with dementia and ensuring services are person-centred, integrated across health and social care and fit for purpose.

1.2 Communications and engagement methodology

Six events were held across Birmingham in July and August 2019 with patients, carers / family members and health and social care professionals. The events were designed to gather their views on how dementia services are provided and understand the performance of services at present.

During the events, participants had the opportunity to share their experiences and give feedback on the following areas:

- Diagnosis
- Access to services
- Ongoing support
- Respite for carers
- End of life care.

The events were structured with a presentation giving background to the strategy, followed by a discussion on each of the five areas.

To facilitate the discussions and ensure everybody had the opportunity to share their views, participants were split into smaller groups. Each group had a facilitator who moderated the discussions and ensured participants stayed on task. Facilitators captured the feedback shared in a facilitator feedback booklet, which followed the same structure as the discussions.

Event participants were also asked to complete a work pack containing demographic profiling questions and questions allowing each participant to rate their experience of each of the five areas:

diagnosis, access to services, ongoing support, respite for carers and end of life care. The findings from the participant work packs have also been presented in this report.

1.3 Participant profiling

Overall, there were 88 participants across the six events. 60 participants completed event workbooks, with a summary of the demographic profile of participants provided below:

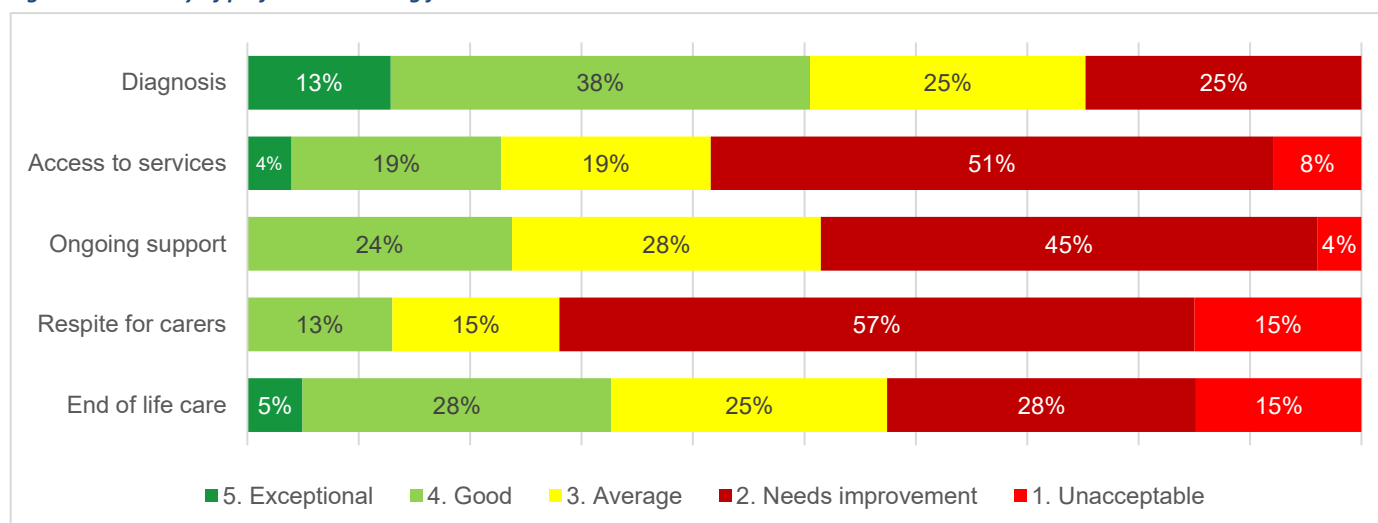
- **Age:** 37 (63%) were aged 65 or over
- **Ethnicity:** 53 (89%) were White British
- **Religion:** 44 (77%) were Christian
- **Sex:** 38 (68%) were female
- **Relationship status:** 40 (72%) were married
- **Health problem or disability:** 23 (43%) had a health problem or disability that limited day-to-day activities
- **Armed services:** 8 (14%) had served in the armed services.

For further information, see Table 2.

1.4 Findings

Figure 1 shows performance rating for each area, showing that participants' experiences varied.

Figure 1. Summary of performance rating for each area



Access to services and respite for carers were identified as key areas for improvement

1.4.1 Diagnosis

Participants had mixed experiences of the diagnosis process, with 28 (50%) participants rating it as 'exceptional' or 'good'. The experiences of patients suggest that dementia is difficult to diagnose, therefore it can take a long time, which can cause delays in patients accessing services. There was concern that some patients resist seeking a diagnosis for their symptoms, due to social stigma and lack of knowledge around dementia.

Participants identified the following key recommendations:

- Clearer referral pathways to services from GPs and other healthcare professionals

- Increased awareness and training around dementia and dementia services for GPs and other healthcare professionals
- More person-centred approach to diagnosis with assessments at home and less reliance on tests
- Prospective screening at optimal level of functioning for individuals with learning difficulties for future comparison of any changes in global functioning.
- Improved support and information for patients and their carers following diagnosis.

1.4.2 Access to services

Participants highlighted issues in accessing services, with provision and access to services varying across the city. Patients and carers commented they were being signposted to many different services, which was causing confusion over who they should contact.

Participants also emphasised a lack of awareness of services, with carers typically finding out information about services via word-of-mouth, increasing the importance of peer support networks like carers' cafes.

Participants identified the following key recommendations:

- A single helpline or point of access to services for clarity over where to access support.
- Increased awareness to support services available, such as dementia cafes, with an updated website of services, but also offline information for those without access to the internet.
- Access to practical support services for carers.
- Greater consistency in access to services and a lack of variation across the city.
- Greater access to dementia nurses for holistic care and continuity of care.
- Shorter waiting times and accessing services sooner.

1.4.3 Ongoing support

Participants had mixed experiences of ongoing support, with 12 (24%) of participants rating ongoing support as 'good', compared to 25 (49%) who rated it as 'needs improvement' or 'unacceptable'.

Although participants highlighted positive experiences of support services, such as dementia cafes and DISC, they also recognised support for carers, early intervention services, and access to support in a crisis, as lacking.

Participants identified the following key recommendations:

- Access to support in a crisis 24/7 without calling 999
- Access to early intervention services to prevent crises occurring
- More education and information available for carers – e.g. around practical aspects of dementia
- A greater focus on the health and wellbeing of carers
- Improved communication within services, to make it easier to contact services
- Communication led by health professionals rather than patients and carers; for example, health professionals regularly contacting to check how patients and carers are doing, rather than patients and carers having to contact when there is an issue.
- Increased integration between health and social care.

1.4.4 Respite for carers

Participants highlighted respite for carers as an area in need of improvement. Many carers participating in the events commented that they had a lack of access to respite or had not received any. Financial arrangements around respite were also highlighted as an area of concern; for example, respite care being too expensive. A key consideration was that respite carer should be person-centred and consider the needs of the patient such as the level of dementia they have.

Although some patients and carers accessing respite services commented that the quality of care received was excellent and that the quality of paid carers should be considered in the strategy.

Participants identified the following key recommendations:

- Simplifying the process to access respite with clear guidelines for carers and healthcare professionals
- Improvements to the financial arrangements around respite with carer fees aligning with direct payments
- Improvements to booking respite with care being available at shorter notice and being confirmed earlier
- Increased access to short-term respite care in the home where patients may feel more at ease.

1.4.5 End of life care

Participants recognised that end of life care is a difficult topic to discuss, which was reflected in the low level of response for this area in the events. It was, however, highlighted that it is important to have these discussions when patients have capacity, as well as for carers to make plans for themselves. The need for greater education and awareness around dementia more generally was also highlighted.

Participants identified the following key recommendations:

- Support and information around practical aspects such as Power of Attorney, wills and benefits
- Provision of a checklist or information pack for planning end of life care and arrangements to support patients and carers to make decisions when patients have capacity
- Greater use and awareness of ReSPECT forms.

2 Introduction

This report summarises the feedback from the six engagement events held across Birmingham to inform the development of Birmingham and Solihull CCG's dementia strategy for Birmingham. The events took place across July and August 2019.

2.1 Report authors

Birmingham and Solihull CCG commissioned NHS Midlands and Lancashire Commissioning Support Unit (MLCSU) Communications and Engagement Service to coordinate the independent analysis of the feedback from the engagement events to produce this report.

2.2 Report structure

This report is structured into the following sections:

- **Section 1:** Executive summary
- **Section 2:** Introduction
- **Section 3:** Communications and engagement methodology
- **Section 4:** Respondent profiling
- **Section 5:** Findings
- **Section 6:** List of participants' recommendations

2.3 Overview of engagement

Six events were held with patients, carers / family members and health and social care professionals to gather their views on how dementia services are provided and understand the performance of the following key areas:

- Diagnosis
- Access to services
- Ongoing support
- Respite for carers
- End of life care.

The events allowed participants to share their views and experiences and learn more about the revised strategy.

2.4 Background

The Birmingham and Solihull Dementia Strategy 2014-2017, '*Give me something to believe in*', was adopted by Birmingham City Council, Solihull Metropolitan Borough Council, Birmingham and Solihull Clinical Commissioning Group (CCG) and other partners in 2014. Its overarching purpose was to understand the experiences of dementia patients, to identify what was already in place, and what was required to improve the outcomes for patients and their carers. The refreshed strategy will reflect progress to date and future planning requirements.

This refreshed strategy is for Birmingham only as Solihull Metropolitan Borough Council developed their own refreshed strategy in 2017.

To support the development of the strategy a steering group has been created consisting of a range of stakeholders including; primary care, Birmingham City Council, mental health services, community services, BCHC Foundation Trust Learning Disability service, Alzheimer's Society, Age Concern, Dementia Information and Support for Carers (DISC), Crossroads Care, fire service, police service, Birmingham LGBT, Birmingham public health, hospice services and healthcare commissioners.

2.5 The new strategy

The key priorities of the strategy refresh will be:

- Enabling access to a timely diagnosis and post-diagnostic support.
- Information and services that focus on early intervention and prevention.
- Preventing crises and supporting people with dementia within their communities.
- Improving the quality of care for people with dementia and ensuring services are person-centred, integrated across health and social care and fit for purpose.

2.6 Next steps

A Dementia Strategy Update will also be provided to the Birmingham Health and Social Care Overview and Scrutiny Committee on 15th October 2019. Copies of this report will also be available for event participants in September 2019.

3 Communications and engagement methodology

3.1 Engagement events

Table 1 provides an overview of the events that were conducted across the city. Birmingham and Solihull CCG contacted Birmingham Dementia Strategy Steering Group members, community hospital trust and mental health trust to promote the events with their groups. The events were also promoted through GP surgeries and on social media.

Table 1. Details of engagement events held

Date of event	Location	Audience	No. of groups	No. of participants

During the events, participants had the opportunity to share their experiences and give feedback on the areas of diagnosis, access to services, ongoing support, respite for carers and end of life care.

To facilitate the discussions and ensure everybody had the opportunity to share their views, participants were split into smaller groups. Each group had a facilitator who moderated the discussions and ensured participants stayed on task. Facilitators also captured the insights that were shared in a facilitator feedback booklet, which followed the same structure as the discussions.

The feedback captured in these feedback booklets has been read and themed and presented in this report of findings. To ensure as much feedback as possible was used in the production of this report, where possible the events were recorded, and the recordings used to supplement the notes captured in the facilitator feedback booklets.

Event participants were also asked to complete a work pack containing demographic profiling questions and questions allowing each participant to rate their experience of each of the five areas: diagnosis, access to services, ongoing support, respite for carers and end of life care. The findings from the participant work packs have also been presented in this report.

4 Participant profiling

4.1 Participant types

Table 2 shows the different respondent types attending the events. 35 (61%) participants were the carer of a patient.

Table 2. Details of participant types at engagement events

Respondent type	No.	%

Table 2 is based on the 57 participants answering this question in the demographic profiling questionnaire. Overall, there were 88 participants across the events, meaning this question was not answered by 31 participants, as a result their respondent type has not been recorded. Some of those not completing the demographic profiling questionnaire could have been social care professionals.

4.2 Demographic profile

Table 3 summarises the demographic profile of event participants.

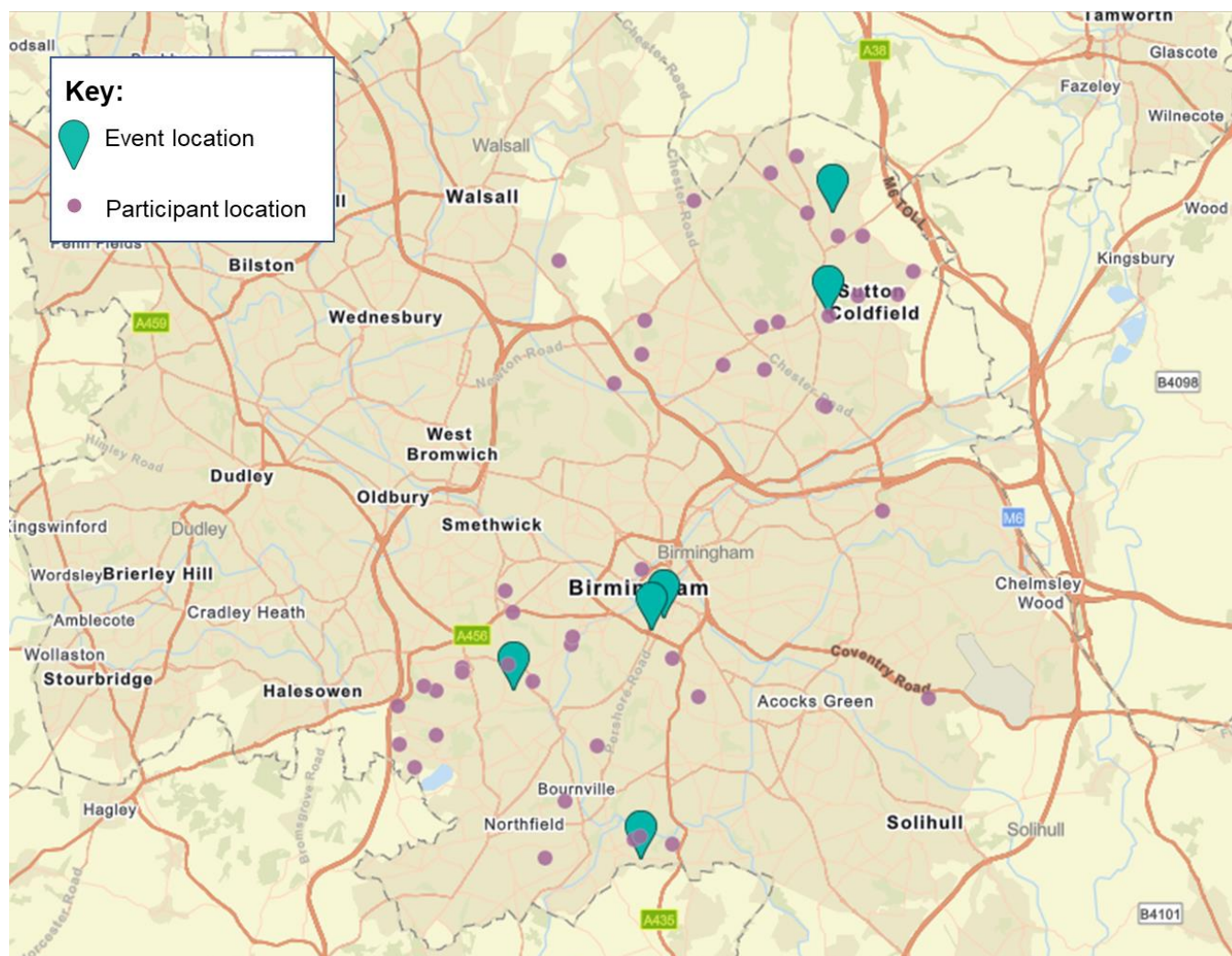
Table 3. Demographic profile of event participants

Ethnicity			Sexual orientation		
White: British	53	89%	Heterosexual	51	96%
White: Irish	1	2%	Lesbian	-	-
White: Gypsy or traveller	-	-	Gay	-	-
White: Other	-	-	Bisexual	1	2%
Mixed: White and Black Caribbean	-	-	Other	-	-
Mixed: White and Black African	-	-	Prefer not to say	1	2%
Mixed: White and Asian	-	-	Base	53	100%
Mixed: Other	1	2%	Relationship status		
Asian/Asian British: Indian	2	3%	Married	40	72%
Asian/Asian British: Pakistani	1	2%	Civil partnership	-	-
Asian/Asian British: Bangladeshi	-	-	Single	4	7%
Asian/Asian British: Chinese	-	-	Divorced	2	3%
Asian/Asian British: Other	-	-	Lives with partner	2	3%
Black/Black British: African	-	-	Separated	1	2%
Black/Black British: Caribbean	1	2%	Widowed	7	13%
Black/Black British: Other	-	-	Other	-	-
Other ethnic group: Arab	-	-	Prefer not to say	-	-
Any other ethnic group	-	-	Base	56	100%
Base	59	100%	Pregnant currently		
Age category			Yes	-	-
16 - 19	-	-	No	54	100%
20 - 24	1	2%	Prefer not to say	-	-
25 - 29	1	2%	Base	54	100%
30 - 34	1	2%	Recently given birth		
35 - 39	2	3%	Yes	-	-
40 - 44	1	2%	No	54	100%
45 - 49	4	7%	Prefer not to say	-	-
50 - 54	3	5%	Base	54	100%
55 - 59	4	7%	Health problem or disability		
60 - 64	4	7%	Yes, limited a lot	12	23%
65 - 69	6	10%	Yes, limited a little	11	21%
70 - 74	12	20%	No	28	53%
75 - 79	6	10%	Prefer not to say	2	3%
80 and over	13	22%	Base	53	100%
Prefer not to say	1	2%	Disability		
Base	59	100%	Physical disability	11	32%
Religion			Sensory disability	5	15%
No religion	9	16%	Mental health need	5	15%
Christian	44	77%	Learning disability or difficulty	1	3%
Buddhist	-	-	Long-term illness	6	18%
Hindu	-	-	Other	4	11%
Jewish	-	-	Prefer not to say	2	6%
Muslim	3	5%	Base	34	100%
Sikh	-	-	Carer		
Any other religion	1	2%	Yes - young person(s) aged under 24	1	2%
Prefer not to say	-	-	Yes - adult(s) aged 25 to 49	1	2%
Base	57	100%	Yes - person(s) aged over 50 years	32	58%
Sex			No	19	35%
Male	18	32%	Prefer not to say	2	3%
Female	38	68%	Base	55	100%
Intersex	-	-	Gender identity		
Prefer not to say	-	-	Yes*	1	2%
Other	-	-	No	45	94%
Base	56	100%	Prefer not to say	2	4%
Armed services			Base	48	100%
Yes	8	14%	*Have you gone through any part of a process or do you intend to (including thoughts and actions) to bring your physical sex appearance and/or your gender role more in line with your gender identity? (This could include changing your name, your appearance and the way you dress, taking hormones or having gender confirming surgery)		
No	48	86%			
Prefer not to say	-	-			
Base	56	100%			

4.3 Mapping of participants

Figure 2 shows the mapping of postcodes for participants, excluding health care professionals. 47 of these participants provided their postcode.

Figure 2. Mapping of respondents and event locations



Postcodes for patients, carers and family or friends have also been mapped according to their Indices of Multiple Deprivation. This is a measure of deprivation of neighbourhoods in England, where 1 represents the 10% most deprived and 10 represents the 10% least deprived areas. Table 4 shows the number of respondents within each deprivation decile.

Table 4. IMD decile of respondents

IMD Decile	No. of respondents	%
1	9	20%
2	3	7%
3	5	11%
4	5	11%
5	5	11%
6	4	9%
7	5	11%
8	3	7%
9	3	7%
10	3	7%
Base	45	

5 Findings

This section presents the feedback participants shared at the events on the following areas:

- Diagnosis
- Access to services
- Ongoing support
- Respite care
- End of life care

5.1 Reporting and analysis notes

At each of the events, table facilitators made notes on the feedback raised by participants. These notes were then read, with themes identified. These themes formed codes and a coding frame. All responses were read and themes coded against the coding frame. During the coding we have recorded the number of times the theme was mentioned across the six events and which respondent types they were raised by. Appendix A to E presents the results of the coding that was undertaken. The coded data was supplemented with recordings of the events to give further detail around the themes raised.

Event participants were also asked to complete a work pack which consisted of a demographic profiling questionnaire and questions allowing them to rate each of the five service areas and from their experience rate the performance of each of these. These ratings have been used to create the charts shown in the report. The charts show the rating overall and by respondent type. Some respondents provided a rating, but not a respondent type, therefore the total base for the two respondent types may not be the same as the base for all respondents. Percentages may not add up to 100% due to rounding.

Participants could also write comments in the work packs. These have been read and coded and included in the Appendices.

Throughout the findings section of the report we have grouped participants into two types:

- Patients and carers
- Health and social care professionals.

5.2 Diagnosis

Figure 3 shows how event participants rated their experience of the diagnosis process. Overall, 28 (50%) participants rated their experience of diagnosis as ‘exceptional’ or ‘good’, compared to 14 (25%) who rated it as ‘needs improvement’. No respondents rated this experience as ‘unacceptable’.

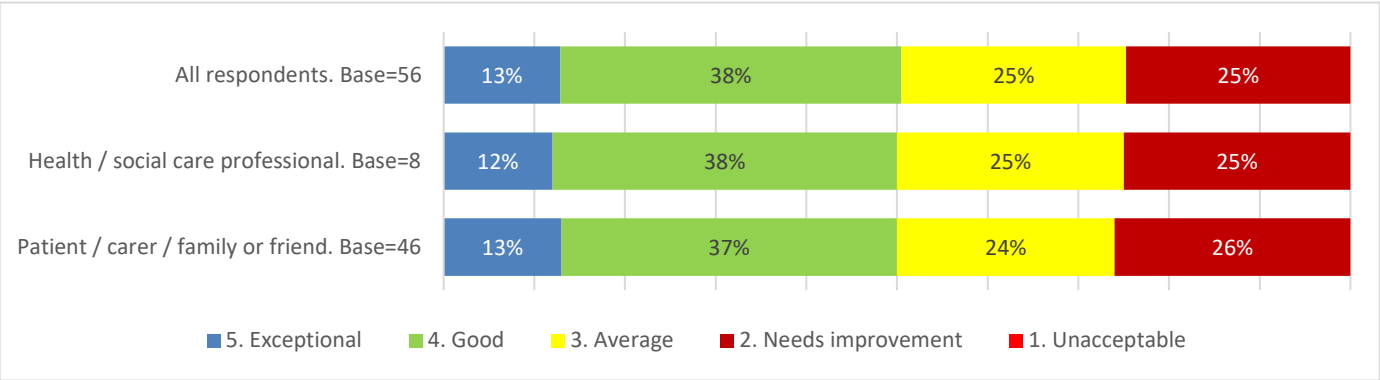


Figure 3. Diagnosis performance rating by respondent type

The following sections present the themes raised around the area of diagnosis during the group discussions. For a detailed breakdown of the themes please refer to Appendix A.

5.2.1 The referral processes

Participants highlighted lengthy referral waiting times and being referred to the correct services as areas for improvement. It was commented that GPs may not always identify dementia as the cause of patients’ symptoms, and consequently, may refer patients to the incorrect services.

A healthcare professional said dementia should be considered as the cause of symptoms earlier in the diagnostic process, rather than ruling out other conditions first. However, another healthcare professional highlighted the importance of treating potentially reversible causes which may be overlooked if dementia is considered first.

Both patients and carers and health and social care professionals said there needs to be clearer pathways between GPs and other healthcare professionals who are involved in the diagnosis process, and raising awareness of the available services may help, as it was stated that GPs may be unaware of which services are available that they can refer to.

5.2.2 Role of the GP and healthcare staff

Some patients and carers shared positive experiences of GPs supporting them in the diagnosis of dementia. However, others highlighted negative experiences, for example, GPs not asking appropriate questions during their assessments and therefore not being able to diagnose the condition appropriately.

It was commented by patients and carers that GPs should have increased awareness and better training in dementia. Additionally, both patients and carers and health and social care professionals stated the need for staff other than the GP to specialise in or have knowledge of dementia and its corresponding care requirements.

The need for more staff in the Memory Assessment Service was also emphasised by patients and carers.

5.2.3 Communication

Participants raised communication as an area for improvement. Carers of dementia patients said family members should also be able to raise concerns with a healthcare professional without the patient being present. This is because dementia is a sensitive subject and often patients will say they are 'fine' to appease the GP.

Both patients and carers and health and social care professionals commented that communications need to be tailored to each individual.

5.2.4 Diagnostic process

Participants highlighted the diagnosis process and the initial tests as an area for improvement. Participants reported that some patients resisted diagnostic tests, and other symptoms, behavioural changes and the effects of medication should be taken into consideration.

Participants commented that the diagnostic test is ineffective and does not identify whether patients have impaired memory capability. There was some polarisation between participants when discussing the questions GPs asked patients during the initial assessment. While some participants stated that questions were too difficult, others felt they were too easy. Those who felt the questions were too easy said patients were able to provide appropriate responses, which meant GPs were not referring them for additional tests leading to a delay in the diagnosis. Those stating the questions were too difficult said the questions were too hard, even for those not experiencing impaired memory.

Participants also commented that assessments taking place at home where the patient is most at ease would avoid the stress of travel.

A health and social care professional suggested that rather than relying on tests, a more person-centred approach is required utilising a variety of assessment methods, over a specific period to gain a longitudinal overview of a patient's behaviour.

The importance of completing physical health checks was raised and the difficulties with reasonable adjustments being made in primary care for individuals with learning difficulties to get relevant health checks specifically blood tests. Therefore, there is a need for Health Facilitation Nurses to strengthen those links between services.

Learning Disability Improvement Standards Compliance with NHSI standards is monitored to ensure Trusts respond to the needs of people with learning difficulties, their families and carers specifically making reasonable adjustments.

Some participants stated dementia diagnosis can take a long time, leading to delays in accessing treatment causing stress and tension for families. This delay in diagnosis also delays patients and carers access to support services. However, it was acknowledged by patients and carers and health and social care professionals that dementia is difficult to diagnose. One health and social care professional said that sometimes the illness needs to unfold before a diagnosis is possible.

*'Once you get the diagnosis, it just seems like everything falls into place.
It's just the time it takes to get the diagnosis'*

Carer, Event 5

5.2.5 Existing conditions

Participants found that patients with multiple conditions often find that diagnosis takes longer because other conditions may affect their symptoms, making dementia harder to diagnose.

Participants also highlighted that dementia is difficult to diagnose in patients with learning difficulties due to changes in functioning often being associated with the learning disability rather than other causes and other comorbidities. Therefore, an increase in education about dementia and learning difficulties for carers and family are required to ensure early recognition. In addition, an MDT approach to diagnosis is needed to ensure a holistic assessment and support throughout a patient's journey of care. This links to the Learning Disability Mortality Review (LeDeR).

5.2.6 Seeking support from a healthcare professional

Participants reported a number of barriers to accessing support. Both patients and carers and health and social care professionals commented that there is a stigma around mental health and dementia, which can be a barrier to patients seeking support from healthcare professionals. For example, patients may avoid discussing symptoms with their GP because they are afraid of being labelled as having dementia, and how this could negatively impact people's perceptions of them.

Healthcare professionals identified the Dementia Friends initiative and the Dementia Engagement and Empowerment Project as helping to tackle the stigma and lack of education around dementia.

Patients and carers found that it can be difficult to recognise the cause of symptoms and there should be consideration for patients who do not have family to assist in identifying symptoms or to help care for them.

5.2.7 Support and information

Patients and carers commented that information and services available for other conditions is better than those available for dementia.

Patients and carers experienced different levels of information support following initial diagnosis: some were not provided with anything, while others felt they were given too much and almost bombarded. This lack of consistency in approach included signposting to services with some receiving little navigational support compared to others.

As a result, there is a need for clarity in the information patients and their carers are provided following diagnosis. The importance of accessible information about growing older and dementia for individuals with learning difficulties, their carers and family was also discussed, specifically regarding pre and post diagnostic counselling.

5.2.8 Summary and participants' recommendations

Participants had mixed experiences of the diagnosis process, with 28 (50%) participants rating it as 'exceptional' or 'good'. The experiences of patients suggest that dementia is difficult to diagnose, therefore it can take a long time, which can cause delays in patients accessing services. There was concern that some patients resist seeking a diagnosis for their symptoms, due to social stigma and lack of knowledge around dementia.

Participants identified the following key recommendations:

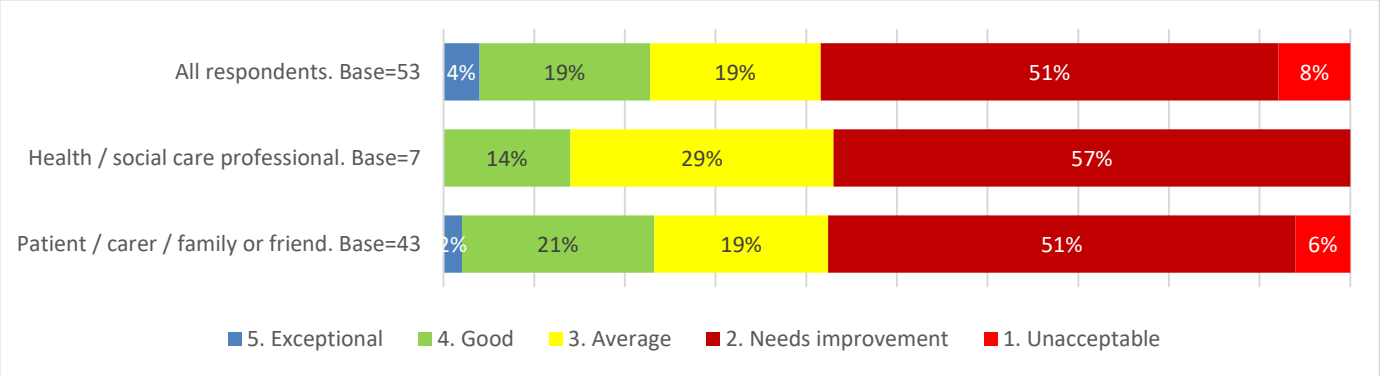
- Clearer referral pathways to services from GPs and other healthcare professionals

- Increased awareness and training around dementia and dementia services for GPs and other healthcare professionals
- More person-centred approach to diagnosis with assessments at home and less reliance on tests
- Prospective screening for patients with learning difficulties to provide a reliable baseline of premorbid functioning to compare any future changes in global functioning.
- Improved support and information for patients and their carers following diagnosis.

5.3 Access to services

Figure 4 shows how event participants rated their experience of access to services. Overall, 12 (23%) participants rated their experience of accessing services as ‘exceptional’ or ‘good’, compared to 31 (58%) who rated it as ‘needs improvement’ or ‘unacceptable’.

Figure 4. Access to services performance rating by respondent type



The following sections present the key themes raised around access to services during the group discussions. For a detailed breakdown of the themes please refer to Appendix B.

5.3.1 Signposting and navigating services

Participants highlighted service navigation as an area requiring improvement. Both patients and carers and health and social care professionals commented that patients and carers may be signposted to a variety of services, which can be confusing. As a solution, patients and carers suggested that more support is required to assist in navigating these services. This could be facilitated through a single point of contact, such as one telephone number, where carers can access the appropriate service.

‘It’s great that there’s all these organisations, but when you’re given a list like that and there’s a problem, I’m thinking, ‘right, who do I phone?’ There’s not just one, central phoneline that can be diverted’

Carer, Event 6

5.3.2 Accessing support for carers

Patients and carers discussed a lack of access to support following diagnosis, with some participants finding this to vary by area causing some to describe it as a ‘postcode lottery’. Patients and carers also suggested: dementia care should be integrated into other services; more resources are required for support in social care and that provision should be person centred as a one size fits all approach does not work for everyone.

The availability of support services for families and carers to help with the practical aspects of care, including; getting a driving license revoked, obtaining a Power of Attorney, registering for the carers allowance and dealing with challenging behaviour was also raised as a concern.

Patients and carers felt that carers need access to training and education, so they can provide suitable care for the patient. Additionally, health and social care professionals commented that NHS staff need training in dementia, such as occupational therapists.

However, as raised by a health and social care professional, consideration needs to be made for working carers, who cannot attend carers' cafes and access peer support.

Another health and social care professional commented there are limitations on which services patients can be referred to and there needs to be improved access to early intervention services.

"Once diagnosis is made I think the carer should be provided with the details of all the help they can get, like the attendance allowance, or the tax relief plus where they can take their husbands for day care."

Carer, Event 6

5.3.3 Accessing support services and assessments

Long waiting times for support and assessments was a reoccurring theme raised by patients and carers.

Patients and carers also commented the criteria to access services is too strict. Patients need to have access to services sooner and more regular assessments are needed.

"It's practical help I want. When you're at your lowest, that's when you can't get the service. It's ludicrous. That's when they should be jumping in and giving you the help you need"

Carer, Event 5

5.3.4 Services for patients with learning difficulties

Both patients and carers and health and social care professionals commented on the perceived limited availability of services such as dementia cafes and day centres tailored for individuals with a learning disability and dementia. This is because their needs are different; for example, they are likely to be younger than other dementia patients. Although there are Growing Older with Learning Disabilities and Dementia (GOLDD) day provision within BCC the provision is not equitable across Birmingham due to the closure of centres in the South of the city. Therefore, there is a need to ensure services make reasonable adjustments for individuals with a learning disability and environments are dementia friendly was also raised.

A carer of a patient highlighted the need for those caring for people with learning difficulties and dementia to access peer support groups which carers in mainstream services have access to. The accessibility of resources specifically for individuals with learning difficulties created by Growing Older with Learning Disabilities in Birmingham (GOLD) group was highlighted as a concern. However, health care professionals highlighted that resources were available from BCHC Learning Disability service and on the internet.

A health and social care professional said that there is a lack of funding to provide training in dementia and learning difficulties at day centres.

'We've got a dementia café half a mile away from us and we've been invited and been a few times. They're absolutely lovely, there's no two ways about it, but they're for very, very old people and the things they do are for very old people. Not one single one is a person with learning disabilities, not one of them'

5.3.5 Dementia nurses

Dementia nurses were highly regarded due to the excellent service they provide. However, participants said there is a need for improved awareness and access to Admiral Nurses / dementia nurses. One health and social care professional suggested that dementia care needs the same level of service provision as cancer services. Another added there should be more dementia nurses, so everyone with dementia has access to a dementia nurse for holistic care.

Improving the continuity of care was an issue raised by both patients and carers and health and social care professionals.

5.3.6 Awareness of services

Finding out about services was highlighted as an issue by participants. Patients and carers commented that they find out about services through peers or word-of-mouth. Consequently, peer support networks like carers' cafes and dementia cafes are important. During one of the events a carer said they found out about the Attendance Allowance through the Alzheimer's Society at a dementia café.

Health and social care professionals commented that an updated website of contacts and services is required. However, there is also a need for information that is available offline as some patients and carers do not have internet access.

"You don't know what you don't know. There has to be some way to say in your area there is this, this, this and this."

Social care professional, Event 4

5.3.7 Other themes raised around accessing services

Patients and carers highlighted the location of services as being an issue. It was commented that appointments and services can be too far from patients' homes, making it difficult to arrange transport and travel to them.

"The memory clinic do tell you about places, but I don't drive and my husband can't drive anymore. The kind of places they were suggested I wouldn't get to. Here was convenient for me to come by bus."

Carer, Event 6

Considerations were raised about the quality of care provided by paid carers.

Patients and carers highlighted effective care received from community nurses and GPs.

5.3.8 Summary and participants' recommendations

Participants highlighted issues in accessing services, with provision and access to services varying across the city. Patients and carers commented they were being signposted to many different services, which was causing confusion over who they should contact.

Participants also emphasised a lack of awareness of services, with carers typically finding out information about services via word-of-mouth, increasing the importance of peer support networks like carers' cafes.

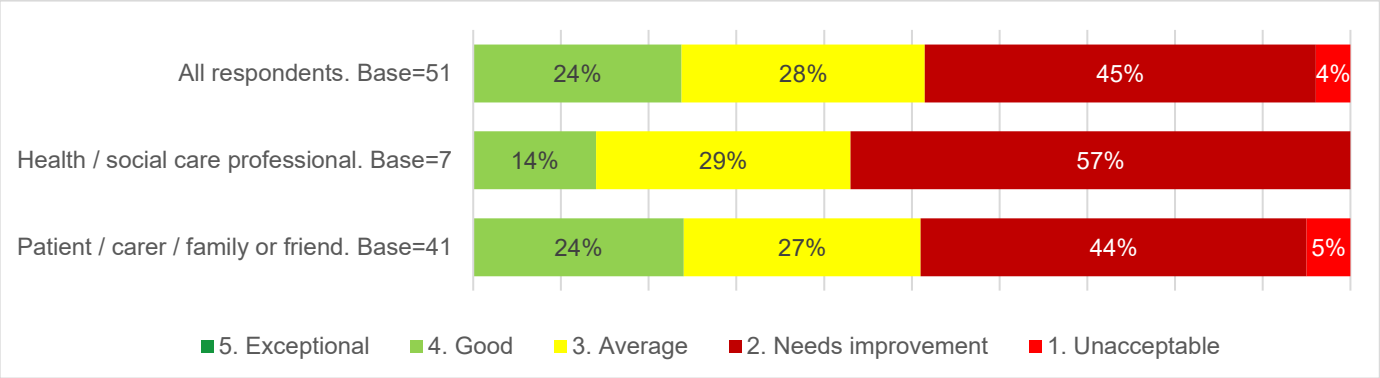
Participants identified the following key recommendations:

- A single helpline or point of access to services for clarity over where to access support.
- Increased awareness to support services available, such as dementia cafes, with an updated website of services, but also offline information for those without access to the internet.
- Access to practical support services for carers.
- Greater consistency in access to services and a lack of variation across the city.
- Greater access to dementia nurses for holistic care and continuity of care.
- Shorter waiting times and accessing services sooner.

5.4 Ongoing support

Figure 5 shows how event participants rated their experience of ongoing support. Overall, 12 (24%) of participants rated ongoing support as ‘good’, compared to 25 (49%) who rated it as ‘needs improvement’ or ‘unacceptable’.

Figure 5. Ongoing support performance rating by respondent type



The following sections present the key themes raised around the area of ongoing support during the group discussions. For a detailed breakdown of the themes please refer to Appendix C.

5.4.1 Crisis care

Participants found that services are designed for those in a crisis, rather than supporting early intervention to prevent crises, which would provide better care for patients and reduce costs.

Participants suggested that a single point of contact is required who can be called during a crisis, because currently carers are calling 999. Participants also state this care should be available 24 hours a day, seven days a week.

Both Patients and carers and health and social care professionals commented that it may take a crisis, such as an unplanned hospital admission, to access services.

“What we find is that referrals are coming through far too late in a lot of respects where people are really at risk of breakdown and managing for themselves at home. Whereas I think there is a gap between when people are diagnosed and that cognitive rehab work in order to help people maintain their skills”

Healthcare professional, Event 4

5.4.2 Support for carers

Participants said there is a lack of education and information available to support carers. Patients and carers found there is insufficient assistance and support for carers and a lack of awareness on what they are entitled to. The focus is on the patient, not the carers and there is a need to consider the emotional wellbeing and health of carers.

A carer at one of the events described being placed on a six-week course which gave them an overview of dementia and allowed them to meet other carers. However, in hindsight the carer stated the course needed to provide support around the practical aspects and skills required once the condition progresses, such as showering patients and getting them into and out of the bed.

Another theme raised by patients and carers was the lack of counselling services. Peer support was highlighted as important, as well as access to respite care and offline resources for carers who do not use the internet.

A discussion within the learning disability focus group covered the needs of older carers supporting their child who has a diagnosis of dementia. In contrast to mainstream services health care professionals working within this area work with many individuals with learning difficulties living with dementia who are supported by their parents. This is a different relationship dynamic where elderly parents are experiencing their own health conditions whilst caring for their child living with dementia.

“They should be focussing on carers. Patients with dementia are following a pathway. The carers seem to wear out quicker than the people with dementia. There is no support for the carers and they ought to be looking at what they are doing for carers they are the people that are virtually carrying the system.”

Carer, Event 6

5.4.3 Support services

Patients and carers highlighted positive experiences of support services such as DISC (Dementia Information and Support for Carers) and dementia cafes and there is a need for greater funding for these voluntary groups. Other themes raised included the need for continuity of care and paid carers / dementia nurses to provide dementia care.

5.4.4 Communication

Patients and carers stated they found it difficult to contact some services, such as social services and district nurses. Carers highlighted the district nurse service needs better communication and co-ordination to fit around patients' needs.

It was also commented that contact should be led more by health professionals rather than patients and carers. For instance, healthcare professionals should regularly contact patients and carers to check on their wellbeing and provide advice on support, rather than patients and carers having to call them when there is a problem and they are too busy living with the condition.

5.4.5 Integrating services

Participants commented there needs to be greater integration between health and social care. Health and social care professionals commented there needs to be increased access to dementia services from learning disability services.

5.4.6 Other themes raised around ongoing support

Patients and carers commented they need to have ongoing access to Admiral Nurses, as they provide excellent support; health and social care staff need to have more training in dementia; the financial aspect of care needs to be considered and the requirement for personalised care and support needs to be provided that considers the different types and stages of dementia.

5.4.7 Summary and participants' recommendations

Participants had mixed experiences of ongoing support, with 12 (24%) of participants rating ongoing support as 'good', compared to 25 (49%) who rated it as 'needs improvement' or 'unacceptable'.

Although participants highlighted positive experiences of support services, such as dementia cafes and DISC, they also recognised support for carers, early intervention services, and access to support in a crisis, as lacking.

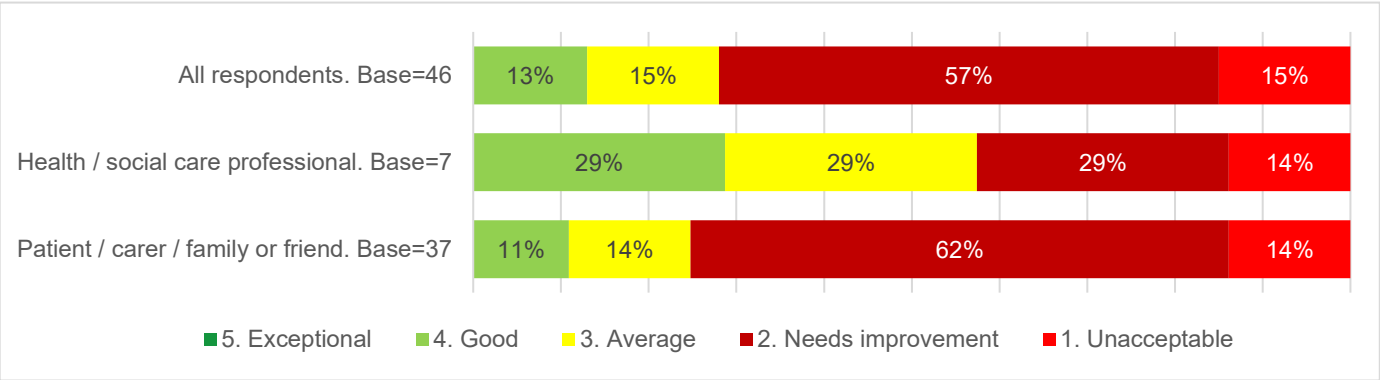
Participants identified the following key recommendations:

- Access to support in a crisis 24/7 without calling 999
- Access to early intervention services to prevent crises occurring
- More education and information available for carers – e.g. around practical aspects of dementia
- A greater focus on the health and wellbeing of carers
- Improved communication within services, to make it easier to contact services
- Communication led by health professionals rather than patients and carers; for example, health professionals regularly contacting to check how patients and carers are doing, rather than patients and carers having to contact when there is an issue
- Increased integration between health and social care.

5.5 Respite for carers

Figure 6 shows how event participants rated their experience of respite for carers. Overall, 6 (13%) participants rated respite for carers as good, compared to 33 (72%) who rated it as ‘needs improvement’ or ‘unacceptable’.

Figure 6. Respite for carers performance rating by respondent type



The following sections present the key themes raised around respite for carers during the group discussions. For a detailed breakdown of the themes please refer to Appendix D.

5.5.1 Financial support

Concerns about financial support were discussed by participants. Specific concerns raised included, respite care being too expensive, and direct payments not always aligning with care fees. This makes accessing respite more difficult.

Patients and carers said that accessing financial support payments is complicated and needs to be simplified. Some patients and carers argued that it is unfair that they are self-funding their care.

5.5.2 Access to respite

Accessing respite was an area of concern for participants. Participants commented that the process to access respite care is complicated and requires simplification, although it is considered easier to access in times of crisis. Many carers participating in the events noted difficulty in accessing respite or had not been offered any.

Concerns raised by carers included limited access to short-term respite care and qualified carers to provide this service. Carers would like better access to respite care at home, because many patients do not want to go to a care home and are more at ease when cared for in their own home. The need for access to live-in carers was also highlighted for this reason.

Patient and carers identified problems booking respite. A carer commented that respite care not being confirmed until a week before it was required, making planning difficult. The requirement for respite care to be available seven days a week, including over holiday periods was highlighted.

Health and social care professionals commented that care must be booked too far in advance. It was also highlighted that criteria to access respite depends on care packages. A social care professional commented that there are no clear guidelines on accessing respite, which means patients may be referred to multiple professionals, who feel that they cannot help. It was also

commented that there is a lack of choice in respite care, apart from residential institutions, which may be unsuitable for younger people with dementia.

5.5.3 Patient needs and wellbeing

Participants commented the level of dementia a patient has should be considered when offering these services. Patients and carers commented patients may not want to go into care homes and become confused or distressed in respite care. They also commented respite care should be patient centred.

5.5.4 Other themes

Some patients and carers accessing respite services commented that the quality of care received was excellent and that the quality of paid carers should be considered in the strategy. They further commented that a review system is needed for care homes; the emotional impact on carers should be considered, as carers may feel guilty about respite care, and day hospice services should be utilised, as they allow those with various conditions to come together.

5.5.5 Summary and participants' recommendations

Participants highlighted respite for carers as an area in need of improvement. Many carers participating in the events commented that they had a lack of access to respite or had not received any. Financial arrangements around respite were also highlighted as an area of concern; for example, respite care being too expensive. A key consideration was that respite carer should be person-centred and consider the needs of the patient such as the level of dementia they have.

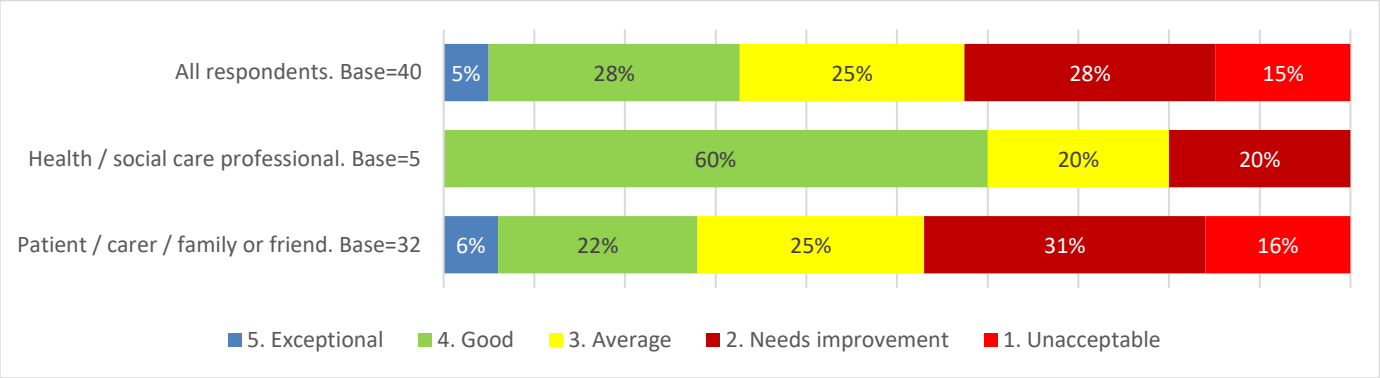
Participants identified the following key recommendations:

- Simplifying the process to access respite with clear guidelines for carers and healthcare professionals
- Improvements to the financial arrangements around respite with carer fees aligning with direct payments
- Improvements to booking respite with care being available at shorter notice and being confirmed earlier
- Increased access to short-term respite care in the home where patients may feel more at ease.

5.6 End of life care

Figure 7 shows how event participants rated their experiences of end of life care. Overall, 13 (33%) participants rated end of life and advance planning as exceptional or good, compared to 17 (43%) who rated it as ‘needs improvement’ or ‘unacceptable’.

Figure 7. Planning in advance performance rating by respondent type



The following sections present the key themes raised around the area of end of life care during the group discussions. For a detailed breakdown of the themes please refer to Appendix E.

5.6.1 Approaching the topic

Participants observed that end of life care is a difficult topic to talk about and individual wishes need to be respected if people do not wish to talk about it.

Some patients and carers said that end of life care needs to be addressed within the family.

5.6.2 Carers’ future planning

A key theme raised by respondents was the need for carers to make future arrangements as well as the patient; for example, if a carer dies before the patient.

5.6.3 Patient capacity

Patients and carers commented that decisions should be made when patients have capacity to be involved in these discussions, with some patients and carers saying that staff should make the decision if patients lack capacity.

5.6.4 Practical support

Patients and carers reported that more support, guidance and information is required around the financial implications and practicalities around elements such as Power of Attorney, wills and benefits. Patient and carers commented that they had made plans without support.

It was also commented that practical support is available from the Alzheimer’s Society.

Participants commented a checklist or information pack is needed for planning end of life care and arrangements. The ‘Planning for the Future’ booklet was highlighted as offering useful support.

5.6.5 Dementia in society

Participants commented dementia should be classed as a disease and there is a need for wider public awareness and education around dementia.

5.6.6 Other themes

Other themes raised by patients around end of life care include; patients may not want to go to hospices due to culture or religion, as hospices may be perceived to be Christian and ReSPECT forms need to be used, but there is a lack of awareness around them which needs to be changed. It was also highlighted that it is important for care homes to be aware of patients' wishes.

5.6.7 Summary and participants' recommendations

Participants recognised that end of life care is a difficult topic to discuss, which was reflected in the low level of response for this area in the events. It was, however, highlighted that it is important to have these discussions when patients have capacity, as well as for carers to make plans for themselves. The need for greater education and awareness around dementia more generally was also highlighted.

Participants identified the following key recommendations:

- Support and information around practical aspects such as Power of Attorney, wills and benefits
- Provision of a checklist or information pack for planning end of life care and arrangements to support patients and carers to make decisions when patients have capacity
- Greater use and awareness of ReSPECT forms.

6 List of participants' recommendations

Diagnosis:

- Clearer referral pathways to services from GPs and other healthcare professionals
- Increased awareness and training around dementia and dementia services among GPs and other healthcare professionals
- More person-centred approach to diagnosis with assessments at home and less reliance on tests
- Prospective screening for patients with learning difficulties to provide a reliable baseline of premorbid functioning to compare any future changes in global functioning.
- Clearer support and information for patients and their carers following diagnosis.

Access to services

- A single helpline or point of access to services for clarity over where to access support.
- Increased awareness of support services available, such as dementia cafes, with an updated website of services, but also offline information for those without access to the internet.
- Access to practical support services for carers.
- Greater consistency in access to services and a lack of variation across the city.
- Greater access to dementia nurses for holistic care and continuity of care.
- Shorter waiting times and accessing services sooner.

Ongoing support

- Access to support in a crisis 24/7 without calling 999
- Access to early intervention services to prevent crises occurring
- More education and information available for carers – e.g. around practical aspects of dementia
- A greater focus on the health and wellbeing of carers
- Improved communication within services, to make it easier to contact services
- Communication led by health professionals rather than patients and carers; for example, health professionals regularly contacting to check how patients and carers are doing, rather than patients and carers having to contact when there is an issue.
- Increased integration between health and social care.

Respite for carers

- Simplifying the process to access respite with clear guidelines for carers and healthcare professionals
- Improvements to the financial arrangements around respite with carer fees aligning with direct payments
- Improvements to booking respite with care being available at shorter notice and being confirmed earlier
- Increased access to short-term respite care in the home where patients may feel more at ease.

End of life care:

- Support and information around practical aspects such as Power of Attorney, wills and benefits
- Provision of a checklist or information pack for planning end of life care and arrangements to support patients and carers to make decisions when patients have capacity
- Greater use and awareness of ReSPECT forms.

7 Appendices

Appendix A: Diagnosis

Themes raised by event

	Total mentions	Total tables mentioning themes				
		Event 1	Event 3	Event 4	Event 5	Event 6
Diagnosis takes a long time	7	1	1	1	1	3
GP supported the diagnosis of dementia	4	2	-	1	-	1
Communication / support needs to be tailored to each individual	4	2	-	2	-	-
Medication may alter symptoms / cause confusion	3	-	1	-	-	2
No support provided following diagnosis	3	1	-	1	-	1
Diagnostic test asks the wrong questions / is ineffective	3	1	1	1	-	-
Need more awareness of dementia cafes	2	-	-	-	-	2
Assessments should take place at home	2	-	1	1	-	-
GP may not ask the right questions	2	1	1	-	-	-
GP could not diagnose the problem	2	-	-	2	-	-
Consider the stigma around mental health and dementia (e.g. in different cultures)	2	-	-	2	-	-
Lack of support / information for families and carers at diagnosis	2	1	-	-	-	1
Families need to be able to speak to healthcare professional without patient present	2	2	-	-	-	-
Patients with other conditions may have issues with diagnosis	2	1	-	-	1	-
Need GPs to be more aware / specialised in dementia (e.g. Specialist in each practice)	2	-	-	2	-	-
Difficult to recognise the issue	1	-	1	-	-	-
Signposted to lots of services following diagnosis	1	-	-	-	-	1
Difficult to navigate services and support	1	-	-	-	-	1
Need to consider symptoms over a period of time	1	-	1	-	-	-
Consider patients without family to care for them / identify symptoms	1	-	-	1	-	-
Need access to dementia nurses	1	-	-	-	1	-
Long waiting times for referrals	1	1	-	-	-	-
Diagnosis was quick	1	-	-	-	-	1
Lack of staff in Memory Assessment Service	1	1	-	-	-	-
Staff other than GPs in surgery should specialise in dementia care	1	-	1	-	-	-
Need to be referred to the correct service	1	1	-	-	-	-
Too much information provided at diagnosis	1	1	-	-	-	-
Consider learning from other areas (e.g. Devon)	1	-	-	1	-	-
Need updated website of contacts and services	1	-	-	1	-	-
Difficult to diagnose in patients with learning difficulties	1	-	-	-	1	-
Need a baseline for learning difficulty patients	1	-	-	-	1	-
Need support for learning disability patients	1	-	-	-	1	-
Need to consider that patients will resist diagnostic tests	1	1	-	-	-	-
Need to considerer dementia earlier in the diagnostic process	1	-	-	-	1	-
Need to consider all symptoms, not just memory and tests	1	1	-	-	-	-
<i>Base (total number of groups/tables at each event)</i>		3	1	2	1	3

The figures represent the number of groups/tables mentioning the theme in the events. For example, 2 means the theme was mentioned by 2 of the groups/ tables during the event. Event 2 is not shown in the table because no participants attended.

Themes raised by respondent type

	Total mentions	Themes raised by Patients and carers/ family members					Themes raised by health and social care professionals					Themes raised by both sets of respondent types on the same table				
		Event 1	Event 3	Event 4	Event 5	Event 6	Event 1	Event 3	Event 4	Event 5	Event 6	Event 1	Event 3	Event 4	Event 5	Event 6
Diagnosis takes a long time	7	1	1	1	1	3	-	-	-	-	-	-	-	-	-	-
GP supported the diagnosis of dementia	4	2	-	1	-	1	-	-	-	-	-	-	-	-	-	-
Communication / support needs to be tailored to each individual	4	2	-	1	-	-	-	-	-	-	-	-	-	1	-	-
Medication may alter symptoms / cause confusion	3	-	1	-	-	2	-	-	-	-	-	-	-	-	-	-
No support provided following diagnosis	3	1	-	1	-	1	-	-	-	-	-	-	-	-	-	-
Diagnostic test asks the wrong questions / is ineffective	3	1	-	1	-	-	-	-	-	-	-	-	1	-	-	-
Need more awareness of dementia cafes	2	-	-	-	-	2	-	-	-	-	-	-	-	-	-	-
Assessments should take place at home	2	-	-	1	-	-	-	-	-	-	-	-	1	-	-	-
GP may not ask the right questions	2	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-
GP could not diagnose the problem	2	-	-	2	-	-	-	-	-	-	-	-	-	-	-	-
Consider the stigma around mental health and dementia (e.g. in different cultures)	2	-	-	1	-	-	-	-	1	-	-	-	-	-	-	-
Lack of support / information for families and carers at diagnosis	2	1	-	-	-	1	-	-	-	-	-	-	-	-	-	-
Families need to be able to speak to healthcare professional without patient present	2	2	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Patients with other conditions may have issues with diagnosis	2	1	-	-	1	-	-	-	-	-	-	-	-	-	-	-
Need GPs to be more aware / specialised in dementia (e.g. Specialist in each practice)	2	-	-	2	-	-	-	-	-	-	-	-	-	-	-	-
Difficult to recognise the issue	1	-	1	-	-	-	-	-	-	-	-	-	-	-	-	-
Signposted to lots of services following diagnosis	1	-	-	-	-	1	-	-	-	-	-	-	-	-	-	-
Difficult to navigate services and support	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1
Need to consider symptoms over a period of time	1	-	-	-	-	-	-	-	-	-	-	-	1	-	-	-
Consider patients without family to care for them / identify symptoms	1	-	-	1	-	-	-	-	-	-	-	-	-	-	-	-
Need access to dementia nurses	1	-	-	-	1	-	-	-	-	-	-	-	-	-	-	-
Long waiting times for referrals	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Diagnosis was quick	1	-	-	-	-	1	-	-	-	-	-	-	-	-	-	-
Lack of staff in Memory Assessment Service	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Staff other than GPs in surgery should specialise in dementia care	1	-	-	-	-	-	-	-	-	-	-	-	1	-	-	-
Need to be referred to the correct service	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Too much information provided at diagnosis	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Consider learning from other areas (e.g. Devon)	1	-	-	-	-	-	-	-	1	-	-	-	-	-	-	-
Need updated website of contacts and services	1	-	-	-	-	-	-	-	1	-	-	-	-	-	-	-
Difficult to diagnose in patients with learning difficulties	1	-	-	-	1	-	-	-	-	-	-	-	-	-	-	-
Need a baseline for learning difficulty patients	1	-	-	-	-	-	-	-	-	-	-	-	-	-	1	-
Need support for learning disability patients	1	-	-	-	-	-	-	-	-	-	-	-	-	-	1	-
Need to consider that patients will resist diagnostic tests	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Need to consider dementia earlier in the diagnostic process	1	-	-	-	1	-	-	-	-	-	-	-	-	-	-	-
Need to consider all symptoms, not just memory and tests	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
<i>Base (total number of groups/tables at each event)</i>	1	3	1	2	1		3	1	2	1		3	1	2	1	

The figures represent the number of groups/tables mentioning the theme in the events. For example, 2 means the theme was mentioned by 2 of the groups/tables during the event. Event 2 is not shown in the table because no participants attended.

Themes raised in participant work packs

	Total	Patients and carers/ family members	Health and social care professionals
General comment regarding needing improvement	1	1	-
GP supported the diagnosis of dementia	1	1	-
Need a baseline for learning difficulty patients	2	-	2
Long waiting times for referrals	1	1	-
Consider patients without family to care for them / identify symptoms	1	-	1
Need support for learning disability patients	1	1	-
Received good support following diagnosis	1	1	-
More support to access health checks required	1	-	1
Ensure that LD patients can access blood tests	1	-	1
Signposted to assessment quickly	1	1	-
Lack of support / information for families and carers at diagnosis	1	-	1
Other	1	-	1
<i>Base</i>	<i>11</i>	<i>6</i>	<i>5</i>

Appendix B: Access to services

Themes raised by event

	Total mentions	Total tables mentioning themes				
		Event 1	Event 3	Event 4	Event 5	Event 6
Signposting to lots of services / need to support with navigating services / single helpline	6	2	1	1	-	2
Waiting times are too long for support	4	3	1	-	-	-
Lack of access to support following diagnosis	4	-	-	1	1	2
Lack of support for families and carers	4	2	-	1	-	1
Find out about services through peers / word of mouth	3	-	-	-	-	3
Need access to training and education for carers	2	-	1	1	-	-
Need more awareness of Admiral Nurses	2	-	1	-	1	-
Consider that one size does not fit all / need to be person-centred	2	-	-	1	-	1
Appointments / services too far from patient's home / transport difficult	2	1	-	-	-	1
Need support with practicalities e.g. Power of attorney, driving	2	1	-	-	-	1
Need access to support in a crisis (without calling 999)	2	1	1	-	-	-
Consider quality of paid carers	2	1	-	1	-	-
Accessibility is variable / hit and miss / postcode lottery	2	-	-	-	-	2
Need more up-to-date information about services	1	-	-	-	-	1
NHS staff need training in dementia (e.g. occupational therapists)	1	-	-	1	-	-
Need access to early intervention services	1	-	-	1	-	-
Community nurses are effective	1	1	-	-	-	-
Limitations on services patients can be referred to	1	-	1	-	-	-
GPs are effective	1	-	-	-	-	-
Need support with challenging behaviour	1	1	-	-	-	-
Dementia cafes provide excellent peer support	1	-	-	1	-	-
Need to integrate dementia into other services	1	-	-	1	-	-
Carers Allowance is not enough	1	1	-	-	-	-
Need time to accept diagnosis	1	-	-	1	-	-
Need access to day centres / dementia cafes for younger patients with learning difficulties	1	-	-	-	1	-
Need more resources for support in social care	1	-	-	-	-	1
Consider support for working carers (e.g. can't attend carers cafes)	1	-	-	-	-	1
Need provision like in cancer services	1	-	-	-	-	1
<i>Base (total number of groups/tables at each event)</i>		3	1	2	1	3

The figures represent the number of groups/tables mentioning the theme in the events. For example, 2 means the theme was mentioned by 2 of the groups/tables during the event. Event 2 is not shown in the table because no participants attended.

Themes raised by respondent type

	Total mentions	Themes raised by Patients and carers/ family members					Themes raised by health and social care professionals					Themes raised by both sets of respondent types on the same table				
		Event 1	Event 3	Event 4	Event 5	Event 6	Event 1	Event 3	Event 4	Event 5	Event 6	Event 1	Event 3	Event 4	Event 5	Event 6
Signposting to lots of services / need to support with navigating services / single helpline	6	2	-	1	-	2	-	-	-	-	-	-	1	-	-	-
Waiting times are too long for support	4	3	1	-	-	-	-	-	-	-	-	-	-	-	-	-
Lack of access to support following diagnosis	4	-	-	1	1	2	-	-	-	-	-	-	-	-	-	-
Lack of support for families and carers	4	2	-	1	-	1	-	-	-	-	-	-	-	-	-	-
Find out about services through peers / word of mouth	3	-	-	-	-	3	-	-	-	-	-	-	-	-	-	-
Need access to training and education for carers	2	-	1	-	-	-	-	-	1	-	-	-	-	-	-	-
Need more awareness of Admiral Nurses	2	-	-	-	1	-	-	-	-	-	-	-	1	-	-	-
Consider that one size does not fit all / need to be person-centred	2	-	-	-	-	1	-	-	-	-	-	-	-	1	-	-
Appointments / services too far from patient's home / transport difficult	2	1	-	-	-	1	-	-	-	-	-	-	-	-	-	-
Need support with practicalities e.g. Power of attorney, driving	2	1	-	-	-	1	-	-	-	-	-	-	-	-	-	-
Need access to support in a crisis (without calling 999)	2	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-
Consider quality of paid carers	2	1	-	1	-	-	-	-	-	-	-	-	-	-	-	-
Accessibility is variable / hit and miss / postcode lottery	2	-	-	-	-	2	-	-	-	-	-	-	-	-	-	-
Need more up-to-date information about services	1	-	-	-	-	1	-	-	-	-	-	-	-	-	-	-
NHS staff need training in dementia (e.g. occupational therapists)	1	-	-	-	-	-	-	-	-	-	-	-	-	1	-	-
Need access to early intervention services	1	-	-	-	-	-	-	-	1	-	-	-	-	-	-	-
Community nurses are effective	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Limitations on services patients can be referred to	1	-	-	-	-	-	-	1	-	-	-	-	-	-	-	-
GPs are effective	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Need support with challenging behaviour	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Dementia cafes provide excellent peer support	1	-	-	1	-	-	-	-	-	-	-	-	-	-	-	-
Need to integrate dementia into other services	1	-	-	1	-	-	-	-	-	-	-	-	-	-	-	-
Carers Allowance is not enough	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Need time to accept diagnosis	1	-	-	-	-	-	-	-	1	-	-	-	-	-	-	-
Need access to day centres / dementia cafes for younger patients with learning difficulties	1	-	-	-	1	-	-	-	-	-	-	-	-	-	-	-
Need more resources for support in social care	1	-	-	-	-	1	-	-	-	-	-	-	-	-	-	-
Consider support for working carers (e.g. can't attend carers cafes)	1	-	-	-	-	-	-	-	-	-	1	-	-	-	-	-
Need provision like in cancer services	1	-	-	-	-	-	-	-	-	-	1	-	-	-	-	-
Base (total number of groups/tables at each event)	1	3	1	2	1	3	3	1	2	1	3	3	1	2	1	3

The figures represent the number of groups/tables mentioning the theme in the events. For example, 2 means the theme was mentioned by 2 of the groups/tables during the event. Event 2 is not shown in the table because no participants attended.

Themes raised in participant work packs

	Total	Patients and carers/ family members	Health and social care professionals
Need access to services (e.g. day centres) for younger patients with learning difficulties	4	-	4
General negative comment	2	2	-
General positive comment	1	1	-
Accessibility is variable / hit and miss / postcode lottery	1	-	1
Need to increase awareness of services	1	1	-
Need access to training and education for carers	1	1	-
Lack of support for families and carers	1	-	1
Need funding to support voluntary groups	1	-	1
Need access to 24/7 support	1	1	-
Need to integrate dementia into other services (e.g. learning disability)	1	-	1
Waiting times are too long for support	1	-	1
Need more training in learning difficulties for dementia professionals	1	-	1
<i>Base</i>	<i>11</i>	<i>6</i>	<i>5</i>

Appendix C: Ongoing support

Themes raised by event

	Total mentions	Total tables mentioning themes				
		Event 1	Event 3	Event 4	Event 5	Event 6
No-one to contact in an emergency apart from 999 / need crisis care	4	2	-	1	-	1
Lack of access to assistance for carers	4			1	1	2
Lack of education and information to support carers	4	1	1	1	-	1
Focus is on patient, not carers / need to consider emotional wellbeing and health of carers	3	2	-	-	-	1
DISC provides excellent support	2	2	-	-	-	-
Need access to 24/7 support	2		1	-	1	-
Need to have access to Admiral nurses	2	2	-	-	-	-
Health and social care staff need to have training in dementia	2	1	-	1	-	-
Criteria to access services is too strict	2	2	-	-	-	-
Need to have access to services sooner	2	-	-	2	-	-
Need more integration between health and social care	2	-	-	1	-	1
Admiral Nurses provide excellent support	1	1	-	-	-	-
Lack of counselling services	1	1	-	-	-	-
Need funding to support voluntary groups	1	1	-	-	-	-
Long waiting times for assessments	1	1	-	-	-	-
Need to have continuity of care	1	1	-	-	-	-
Need access to respite	1	-	1	-	-	-
Consider financial aspect of care	1	-	-	-		1
Need to have regular assessments	1	-	-	1	-	-
Services are geared around those in crisis	1	-	-	1	-	-
Peer support is important	1	-	-	1	-	-
Need to consider different types of dementia	1	-	-	1	-	-
Need access to dementia services from LD services	1	-	-	-	1	-
Need access to offline resources for carers who don't use the internet	1	-	-	-	1	-
Need paid carers / dementia nurses to provide personal care	1	1	-	-	-	-
Base (total number of groups/tables at each event)		3	1	2	1	3

The figures represent the number of groups/tables mentioning the theme in the events. For example, 2 means the theme was mentioned by 2 of the groups/tables during the event. Event 2 is not shown in the table because no participants attended.

Themes raised by respondent type

	Total mentions	Themes raised by Patients and carers/ family members					Themes raised by health and social care professionals					Themes raised by both sets of respondent types on the same table				
		Event 1	Event 3	Event 4	Event 5	Event 6	Event 1	Event 3	Event 4	Event 5	Event 6	Event 1	Event 3	Event 4	Event 5	Event 6
No-one to contact in an emergency apart from 999 / need crisis care	4	2	-	1			-	-	-	-	1	-	-	-	-	-
Lack of access to assistance for carers	4		-	1	1	2	-	-	-	-	-	-	-	-	-	-
Lack of education and information to support carers	4	1	-	1		1	-	-	-	-	-	-	1	-	-	-
Focus is on patient, not carers / need to consider emotional wellbeing and health of carers	3	2	-	-		1	-	-	-	-	-	-	-	-	-	-
DISC provides excellent support	2	2	-	-			-	-	-	-	-	-	-	-	-	-
Need access to 24/7 support	2	-	1	-	1		-	-	-	-	-	-	-	-	-	-
Need to have access to Admiral nurses	2	2		-	-	-	-	-	-	-	-	-	-	-	-	-
Health and social care staff need to have training in dementia	2	1	-	1	-	-	-	-	-	-	-	-	-	-	-	-
Criteria to access services is too strict	2	2	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Need to have access to services sooner	2	-	-	2	-	-	-	-	-	-	-	-	-	-	-	-
Need more integration between health and social care	2	-	-	1	-	-	-	-	-	-	-	-	-	-	-	1
Admiral Nurses provide excellent support	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Lack of counselling services	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Need funding to support voluntary groups	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Long waiting times for assessments	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Need to have continuity of care	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Need access to respite	1	-	1	-	-	-	-	-	-	-	-	-	-	-	-	-
Consider financial aspect of care	1	-	-	-	-	1	-	-	-	-	-	-	-	-	-	-
Need to have regular assessments	1	-	-	-	-	-	-	-	-	-	-	-	-	1		-
Services are geared around those in crisis	1	-	-	-	-	-	-	-	1	-	-	-	-	-	-	-
Peer support is important	1	-	-	1	-	-	-	-	-	-	-	-	-	-	-	-
Need to consider different types of dementia	1	-	-	1	-	-	-	-	-	-	-	-	-	-	-	-
Need access to dementia services from LD services	1	-	-	-	-	-	-	-	-	1	-	-	-	-	-	-
Need access to offline resources for carers who don't use the internet	1	-	-	-	1	-	-	-	-	-	-	-	-	-	-	-
Need paid carers / dementia nurses to provide personal care	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
<i>Base (total number of groups/tables at each event)</i>	<i>1</i>	<i>3</i>	<i>1</i>	<i>2</i>	<i>1</i>	<i>3</i>	<i>3</i>	<i>1</i>	<i>2</i>	<i>1</i>	<i>3</i>	<i>3</i>	<i>1</i>	<i>2</i>	<i>1</i>	<i>3</i>

The figures represent the number of groups/tables mentioning the theme in the events. For example, 2 means the theme was mentioned by 2 of the groups/tables during the event. Event 2 is not shown in the table because no participants attended.

Themes raised in participant work packs

	Total	Patients and carers/ family members	Health and social care professionals
DISC provides excellent support	6	6	-
Lack of access to assistance for carers	2	-	2
Need to have continuity of care	2	1	1
Need to integrate dementia into other services (e.g. learning disability)	2	-	2
Admiral Nurses provide excellent support	1	1	-
General negative comment	1	1	-
Need to ensure new service offer is clear and patients/carers are aware	1	-	1
Lack of education and information to support carers	1	-	1
Need access to services sooner	1	1	-
Need more training in learning difficulties for dementia professionals	1	-	1
Other	2	2	-
<i>Base</i>	<i>17</i>	<i>12</i>	<i>5</i>

Appendix D: Respite care

Themes raised by event

	Total mentions	Total tables mentioning themes				
		Event 1	Event 3	Event 4	Event 5	Event 6
Respite care is too expensive	5	2	-	1	-	2
Process to access respite care is too complicated	5	1	1	1	-	2
Lack of access to respite / not been offered respite	4	-	-	2	-	2
Patients do not want to go into care homes	2	1	-	-	-	-
Patients can become confused / distressed in respite	2	1	-	1	-	-
Carers may feel guilty / emotional impact on carers	2	1	-	1	-	-
More assistance is required in the home	2	1	1	-	-	-
Access to respite is easier in a crisis	2	-	-	2	-	-
Respite care received is excellent	2	-	-	-	1	1
Consider quality of paid carers	2	2	-	-	-	-
Direct payments and care fees do not align	1	1	-	-	-	-
Direct payments are too restricted / need to be simplified	1	1	-	-	-	-
Need a review system for care homes	1	-	1	-	-	-
Need to consider the level of dementia the patient has	1	-	1	-	-	-
Need to ensure care is patient-centred	1	-	1	-	-	-
Can't get respite confirmed until a week before	1	-	-	-	-	1
Care has to be booked far in advance	1	-	-	-	-	-
Criteria to access respite depends on care package	1	-	1	-	-	-
Need access to live-in carers	1	-	-	1	-	-
Consider utilising day hospice services	1	-	-	1	-	-
Care home will accommodate the dates required	1	-	-	-	1	-
Need access to personal care	1	-	-	-	-	1
<i>Base (total number of groups/tables at each event)</i>		3	1	2	-	3

The figures represent the number of groups/tables mentioning the theme in the events. For example, 2 means the theme was mentioned by 2 of the groups/tables during the event. Event 2 is not shown in the table because no participants attended.

Themes raised by respondent type

	Total mentions	Themes raised by Patients and carers/ family members					Themes raised by health and social care professionals					Themes raised by both sets of respondent types on the same table				
		Event 1	Event 3	Event 4	Event 5	Event 6	Event 1	Event 3	Event 4	Event 5	Event 6	Event 1	Event 3	Event 4	Event 5	Event 6
Respite care is too expensive	5	2	-	-	-	2	-	-	1	-	-	-	-	-	-	-
Process to access respite care is too complicated	5	1	-	-	-	2	-	-	-	-	-	-	1	1	-	-
Lack of access to respite / not been offered respite	4	-	-	2	-	-	-	-	-	-	-	-	-	-	-	-
Patients do not want to go into care homes	2	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-
Patients can become confused / distressed in respite	2	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Carers may feel guilty / emotional impact on carers	2	1	-	1	-	-	-	-	-	-	-	-	-	-	-	-
More assistance is required in the home	2	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-
Access to respite is easier in a crisis	2	-	-	1	-	-	-	-	1	-	-	-	-	-	-	-
Respite care received is excellent	2	-	-	-	1	1	-	-	-	-	-	-	-	-	-	-
Consider quality of paid carers	2	2	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Direct payments and care fees do not align	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Direct payments are too restricted / need to be simplified	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Need a review system for care homes	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Need to consider the level of dementia the patient has	1	-	-	-	-	-	-	-	-	-	-	-	1	-	-	-
Need to ensure care is patient-centred	1	-	-	-	-	-	-	-	-	-	-	-	1	-	-	-
Can't get respite confirmed until a week before	1	-	-	-	-	1	-	-	-	-	-	-	-	-	-	-
Care has to be booked far in advance	1	-	-	-	-	-	-	1	-	-	-	-	-	-	-	-
Criteria to access respite depends on care package	1	-	-	-	-	-	-	1	-	-	-	-	-	-	-	-
Need access to live-in carers	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Consider utilising day hospice services	1	-	-	-	-	-	-	-	1	-	-	-	-	-	-	-
Care home will accommodate the dates required	1	-	-	-	1	-	-	-	-	-	-	-	-	-	-	-
Need access to personal care	1	-	-	-	-	1	-	-	-	-	-	-	-	-	-	-
Base (total number of groups/tables at each event)		3	1	2	1	3	3	1	2	1	3	3	1	2	1	3

The figures represent the number of groups/tables mentioning the theme in the events. For example, 2 means the theme was mentioned by 2 of the groups/tables during the event. Event 2 is not shown in the table because no participants attended.

Themes raised in participant work packs

	Total	Patients and carers/ family members	Health and social care professionals
Care has to be booked far in advance	1	-	1
Respite care received is excellent	2	1	1
More information and awareness required	3	1	2
Would like carers groups at respite home	1	1	-
Respite care is too expensive	1	1	-
Lack of access to respite / not been offered respite / more access required	4	2	2
Respite is important / need access to respite	1	1	-
Other (no comment / don't know / can't comment)	5	5	-
Base	14	10	4

Appendix E: End of life care

Themes raised by event

	Total mentions	Total tables mentioning themes				
		Event 1	Event 3	Event 4	Event 5	Event 6
Need to consider that death is a difficult topic	4	3	1	-	-	-
Consider the need for future arrangements for carers (e.g. if a carer dies first)	3	-	-	1	1	1
Decision should be made when patients have capacity	2	2	-	-	-	-
Need support with financial implications / practicalities e.g. Power of Attorney, wills, benefits	2	1	-	-	1	-
Need to respect individual wishes	2	-	1	1	-	-
Need to be addressed within the family	2	-	1	-	-	1
Staff should make decision if patients lack capacity	2	2	-	-	-	-
Planning for the Future' booklet offers useful support	2	-	-	2	-	-
Have made plans without support	2	-	-	1	-	1
Need to use RESPECT forms	1	-	-	-	-	1
Dementia should be classed as a disease	1	-	1	-	-	-
Need information pack	1	-	-	-	-	1
Need for wider public awareness of dementia	1	-	-	-	-	1
Received practical support from Alzheimer's Society	1	-	-	-	-	1
Lack of awareness of Respect forms	1	1	-	-	-	-
Patients may not want to go to hospices due to culture / religion (e.g. seen as Christian)	1	-	-	1	-	-
<i>Base (total number of groups/tables at each event)</i>		3	1	2	1	3

The figures represent the number of groups/tables mentioning the theme in the events. For example, 2 means the theme was mentioned by 2 of the groups/tables during the event. Event 2 is not shown in the table because no participants attended.

Themes raised by respondent type

	Total mentions	Themes raised by Patients and carers/ family members					Themes raised by health and social care professionals					Themes raised by both sets of respondent types on the same table				
		Event 1	Event 3	Event 4	Event 5	Event 6	Event 1	Event 3	Event 4	Event 5	Event 6	Event 1	Event 3	Event 4	Event 5	Event 6
Need to consider that death is a difficult topic	4	3	-	-	-	-	-	1	-	-	-	-	-	-	-	-
Consider the need for future arrangements for carers (e.g. if a carer dies first)	3	-	-	1	1	1	-	-	-	-	-	-	-	-	-	-
Decision should be made when patients have capacity	2	2	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Need support with financial implications / practicalities e.g. Power of Attorney, wills, benefits	2	1	-	-	1	-	-	-	-	-	-	-	-	-	-	-
Need to respect individual wishes	2	-	-	1	-	-	-	-	-	-	-	-	1	-	-	-
Need to be addressed within the family	2	-	1	-	-	1	-	-	-	-	-	-	-	-	-	-
Staff should make decision if patients lack capacity	2	2	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Planning for the Future' booklet offers useful support	2	-	-	1	-	-	-	-	-	-	-	-	-	1		
Have made plans without support	2	-	-	1	-	1	-	-	-	-	-	-	-	-	-	-
Need to use RESPECT forms	1	-	-	-	-	1	-	-	-	-	-	-	-	-	-	-
Dementia should be classed as a disease	1	-	-	-	-	-	-	-	-	-	-	-	1	-	-	-
Need information pack	1	-	-	-	-	1	-	-	-	-	-	-	-	-	-	-
Need for wider public awareness of dementia	1	-	-	-	-	1	-	-	-	-	-	-	-	-	-	-
Received practical support from Alzheimer's Society	1	-	-	-	-	1	-	-	-	-	-	-	-	-	-	-
Lack of awareness of Respect forms	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Patients may not want to go to hospices due to culture / religion (e.g. seen as Christian)	1	-	-	1	-	-	-	-	-	-	-	-	-	-	-	-
<i>Base (total number of groups/tables at each event)</i>	1	3	1	2	1	3	3	1	2	1	3	3	1	2	1	3

The figures represent the number of groups/tables mentioning the theme in the events. For example, 2 means the theme was mentioned by 2 of the groups/tables during the event. Event 2 is not shown in the table because no participants attended.

Themes raised in participant work packs

	Total	Patients and carers/ family members	Health and social care professionals
Consider different needs of learning disability patients	3	-	3
Consider the need for future arrangements for carers (e.g. if a carer dies first)	1	-	1
Need further information	1	1	-
Needs to be discussed when appropriate	1	1	-
Need access to dementia nurses	1	-	1
Need to consider that death is a difficult topic	1	-	1
Other	6	6	-
<i>Base</i>	12	8	4

