healthwatch Croydon

Dementia Pathway Experiences in Croydon

The views and experiences of Croydon residents

Final report – June 2023

Executive Summary

In May 2022, Healthwatch Croydon was approached by the Alzheimer's Society to undertake some insight into the use of Dementia Pathway Experiences in Croydon services to inform the new dementia strategy for Croydon.

Healthwatch Croydon agreed to undertake three online surveys to understand more about experiences of these services from

- patients who have dementia;
- their carers
- friends and family.

The questions were closely aligned so that we could compare experiences from the different cohorts.

The Alzheimer's Society led the recruitment of the survey through their networks, and Healthwatch Croydon undertook to analysis and presentation of data.

We heard from 19 patients who have dementia, 41 carers and 20 friends and family. There were a number of themes covered across the questions considering different aspects of the pathway from diagnosis, to information and support suggested improvements to services and what it means to be dementia friendly. results by question themes including demographic Appendix A (page 64) shows all the questions and each page references the questions numbers.

The data shown in this report has already been shared with the Croydon Dementia Action Alliance (CDAA) and the Dementia and CDAA Steering Group and provide insight for the drafting of the Croydon Dementia Strategy.

Limitations:

- It was hard to reach a large sample of people despite the best efforts of the Alzheimer's Society to engage with their service users. The length and detail expected by respondents of the survey may have been a barrier to uptake.
- It is a snapshot of services as delivered between September and December 2022, (October for Patients).
- The online methodology gives better responses for some demographics than others and so alternative engagement methods should be applied to ensure good representation in future work of this nature.

Demographics

Sample profile: 40% had patients or people caring with Alzheimer's. Around 10-12% ‘just know’(1, see page). The sample represents a mixture of caring responsibility situations for both carers and friends and family (2).

Residence and caring responsibility: Most patients live their own home, with nearly half of carers living in their own home with them and other in the community. Patients of friends and family used a wider range of accommodation.(3)

Age: Patients sample tends to be 65-74, 75-84 and 85+ Carers sample shows highest responders also 75-84 followed by 55-64, with Carer’s patient being highest at 75-84 and 85+ suggesting older people care Friends and family patients also cover the main groups with higher numbers in 85+. Friends and family are spread across the ages more. (20)

Gender: Patient respondents were more male. Carers were more female. Both friend and family members and patients more female (21)

More details of demographics are shown in the Demographics section.

Key findings

- **Diagnosis times:** Variability in diagnosis times some getting seen within a month but some waiting over a year *(see 4, p.12)*.
- **Information:** Better information needed on legal and financial entitlements and improved communication on support services *(see 5, p.13-16)*.
- **GP follow up appointment:** Greater awareness of follow up appointment is needed with over half stating they did not have it or did not know which levels higher for carers and friends and family*(see 6, p.17)*.
- **Issues around diagnosis:** The length of time to see a specialist is an issue for all but particularly with carers. More patients felt they could manage but others do not. High level of denial particularly for carers. Friends and family felt it was part of getting older *(see 7, p.18)*.
- **After diagnosis:** There is a need for a better information and communications *(see 8, p.19)*.
- **Discussion of support and care needs:** Patients and friends and family do feel there has been a discussion, but carers felt they did not and friends and family could have more *(see 9,p.20)*.
- **Advanced care planning:** It not being provided or accessed effectively even though it should be offered after diagnosis and each review *(see 10, p.21)*.
- **Carers support and information services:** Despite these services being available, many carers need easier ways to be access information and support they need *(see 11, p.22-24)*.
- **Confidence of person and carers:** More needs to be done to support carers in the manging the dementia of the person they care for *(see 12, p.25)*.
- **Appropriate services to needs and preferences:** There is a need for more understanding of services appropriate to their needs for patients maybe with better coproduction with patients, carers and family and friends. *(see 13, p.26-30)*.
- **Caring support services:** Carers need better communication and awareness of services available to them *(see 14, p.31-32)*.
- **Reassessment of dementia and care needs:** There is a need to look at the low accessibility or uptake in dementia or care need reassessments *(see 15, p.33)*.

Key findings

- **Improvements:** Patients would like to see words put into action, good support when leaving hospital and less variability in the quality of home help. Carers would like time for a break, support within the home and day centres. Friends and family also would like to see more home help, more day centres and that they are being listened to *(see 16, p.24-40)*.

- **Concerns about sheltered accommodation and care homes:** Patients said they would be too restrictive –with loss of freedom, lost possessions when put in storage, others just never want to go. Carers want to ensure care come is adapted to come with dementia and understand what patients need, as well as being nearby to where they live, having an activity programme and good well-paid staff who have respect for the person. Friends and family want to be able to choose home with a good CQC rating, as well as help as finances *(see 17, p.41-45)*.

- **Concerns about going into hospital:** Patients said a need to ensure that dementia patients have a dedicated pathway if going into hospital ensuring they have the specialist support hey need with these issues considered. Carers need to be easily identified as advocates. Being discharged with the right support is also an important priority*(see 18, p.46-49)*.

- **What makes Croydon dementia friendly:** Patient say this is creating a choice of activities, increased understand and education. Carers say this training for services and retailers, education, quiet spaces and information. Friends and family also talk about greater understanding and providing services that are theoretically possible *(see 19 p.50-54)*.

Recommendations

Communications and information

- Better information needed on legal and financial entitlements and improved communication on support services and after diagnosis.
- Greater awareness or access to GP follow up appointments, advanced care planning and dementia and care need assessments.

Diagnosis, care planning and reassessments:

- Improve the time it takes to see a specialist Issues around diagnosis.

Increased carers support

- Discuss more about support and care needs with carers.
- Improve the awareness and communication of carers support and information services.
- Find ways to increase confidence of patient and carers to manage the condition.

Understanding needs and preferences

- Coproduce services to understand needs and preferences and align services accordingly.
- Understand concerns about care homes and sheltered accommodation, particularly around their understanding about dementia, quality of service, staff training, a person-centred approach with residents, access and support with finances.

Hospitals

- Design a dedicated pathway if going into hospital ensuring they have the specialist support they need with these issues considered.
- Ensure carers can be easily identified as advocates.
- Make sure patients are discharged with the right support is also an important priority.

Suggested improvements from residents

- More support, quality of care, information and wayfinding.

What makes Croydon dementia friendly

- Ensure effective support and increase awareness.

Statement from stakeholders

"The Dementia & Older Adults Steering Group have found the survey useful to understand the views of people with dementia, their families and carers living within Croydon. We heard about how communication at all parts of their journey was important and how people wanted to be supported and heard by those providing services. The findings have underpinned the development of the Croydon Dementia Strategy which is due to be published later in 2023. The Croydon Dementia Strategy focuses on the diagnosis and support available for dementia; and how to ensure people in Croydon are able to live well with dementia as well as coming to the end of their life well. We have been able to take the different responses and apply these within each part of the dementia pathway, weaving in feedback comments and emphasising the importance of information and support at every stage. As a part of the development process, we have been able to feedback to system partners points about specific services and think about what could be changed to meet the identified needs. Healthwatch Croydon is a valued partner, and we would like to thank Gordon and team for their hard work on this report. We look forward to exploring future possibilities with the Croydon Healthwatch team as we begin to implement the dementia strategy and measure its outcomes."

Dr Emily Symington

GP - Parchmore Medical Centre, Croydon

Clinical Lead - Personalised Care, Population Health Management, Long Term Conditions, Croydon Place

Insight

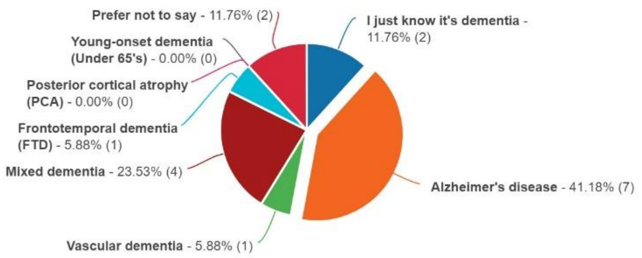
1 -What kind of dementia does the person have? (PQ4, CQ2 FQ2)

- **Patients: 41% said they had Alzheimer’s, 23% mixed dementia, and 12% just knowing it is dementia. Carers reported similar proportion with Alzheimer’s (41%), higher proportion mixed dementia (30%) and 10% just knowing. Friends and family reported similar for Alzheimer’s (45%), vascular dementia (30%) and 10% just knowing.**

- **Profile: Sample is small, but leans heavier to Alzheimer's, and mixed amongst patients and carers with more vascular dementia reported by friends and family in this sample. Consistently 10-12% just knowing.**

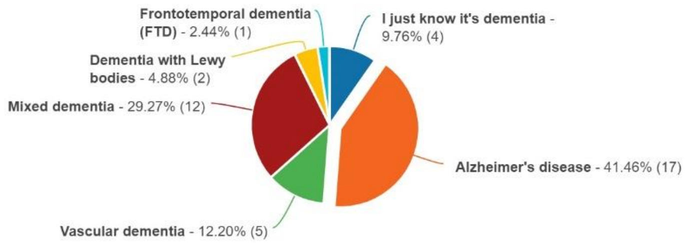
Patient (n-17)

What type of dementia do you have?



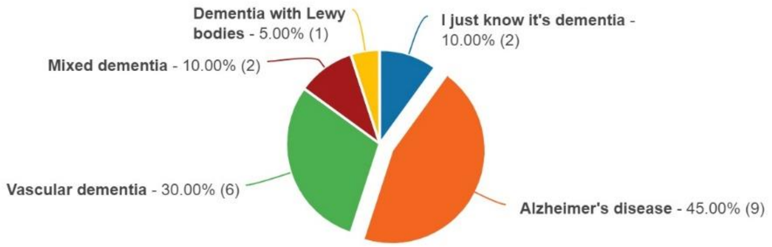
Carers (n=41)

What type of dementia does the person have?



Friends and family (n=20)

What type of dementia does the person have?

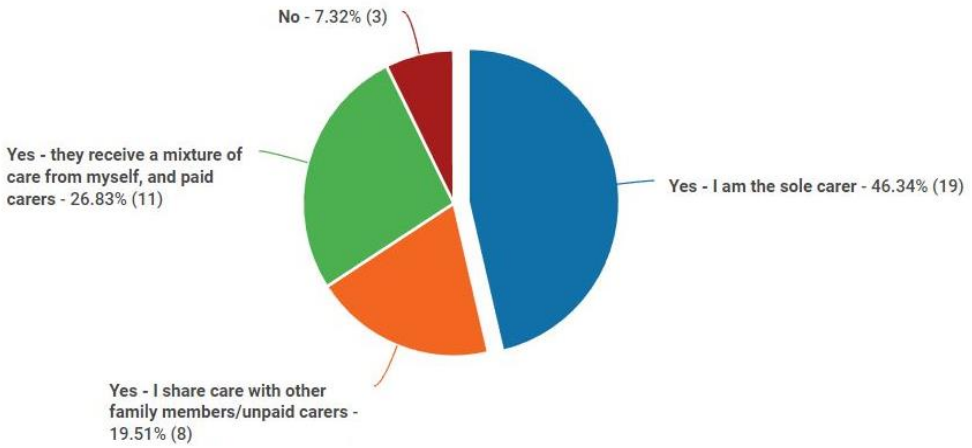


2 – Caring responsibilities (CQ3, FQ3)

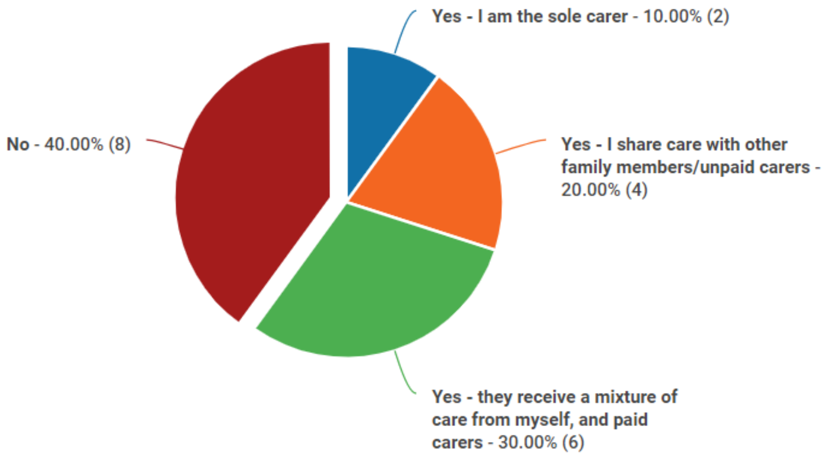
- **Carers: 46% were sole carers, 26% received a mixture of care from themselves and paid carers and 19% shared with family.**
- **Friends and Family: 20% said they share caring responsibilities, and 40% said they did not have any caring role.**

- **Profile: Sample is small, but represent a mixture of caring responsibility situations for both carers and friends and family.**

Carers (n=41)



Friends and family(n=20)

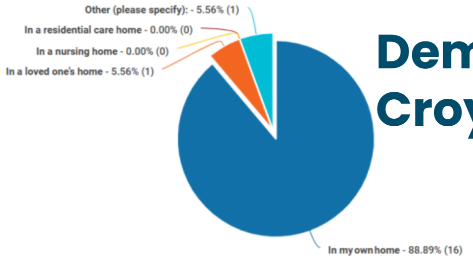


3 – Residence of person with dementia (PQ3, CQ4, FQ4, FQ6)

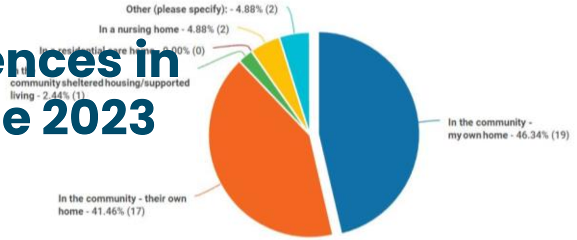
- **Most patients (89%) were living in their own home, one was living with a loved one, and one in sheltered accommodation. Most Carers (46%) lived with the patient in their home, or the patient lived in their own home (41%), whilst some stayed in a nursing home and others were supported. Few Friends and Family (9) have patients living with them in their home (10%), with 45% living in their own home with 25% in residential care homes.**

- **Sample profile: Most patients live their own home, with nearly half of carers living in their own home with them and other in the community. Patients of friends and family used a wider range of accommodation.**

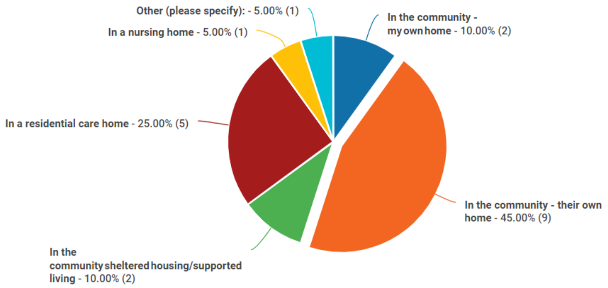
Patient (n-19)



Carers (n=41)



Friends and family(n=20)

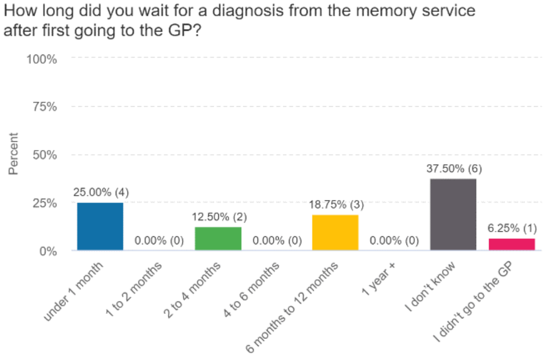


4- Waiting time for diagnosis after first GP visit (PQ4, CQ5 FQ7)

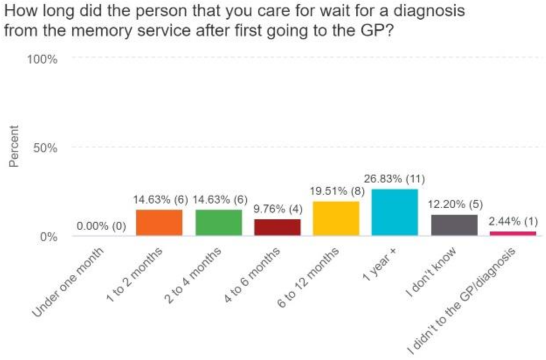
- Over a third of patients could not be sure with 25% saying they were seen with a month and some waiting 6-12 months.
- No carers stated a month with 14% for 1-2 months and same for 2-4 months, 20% waited 6-12 months and over 25% waited over a year.
- Likewise friends and family saw higher waits with 30% waiting between 6 months and 1 year.

- Variability in diagnosis times with some getting seen within a month but some waiting over a year.

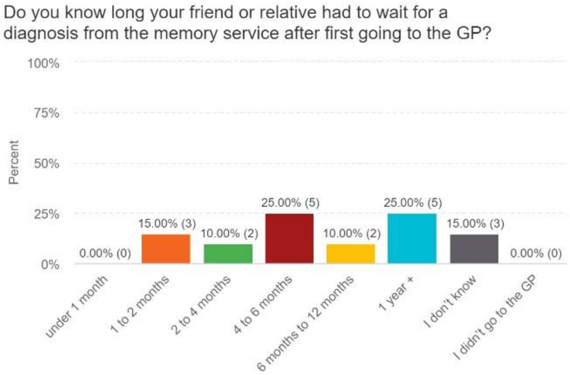
Patient (n-19)



Carer (n=41)



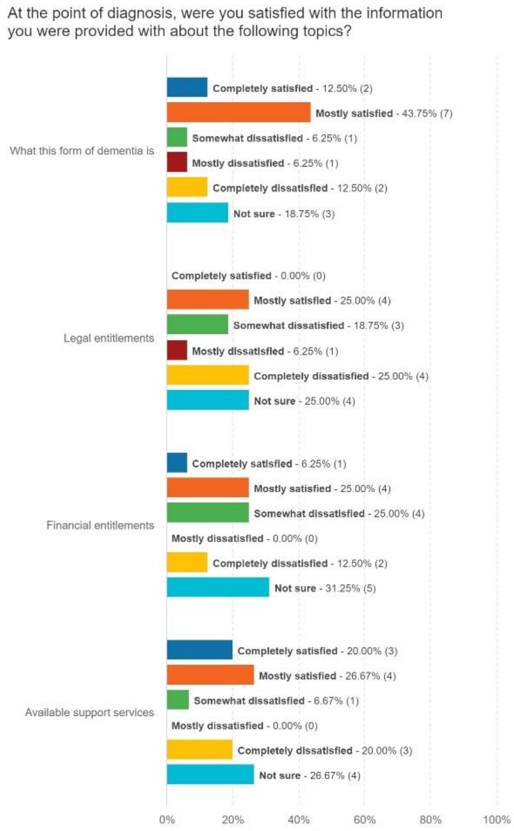
Friends and family(n=20)



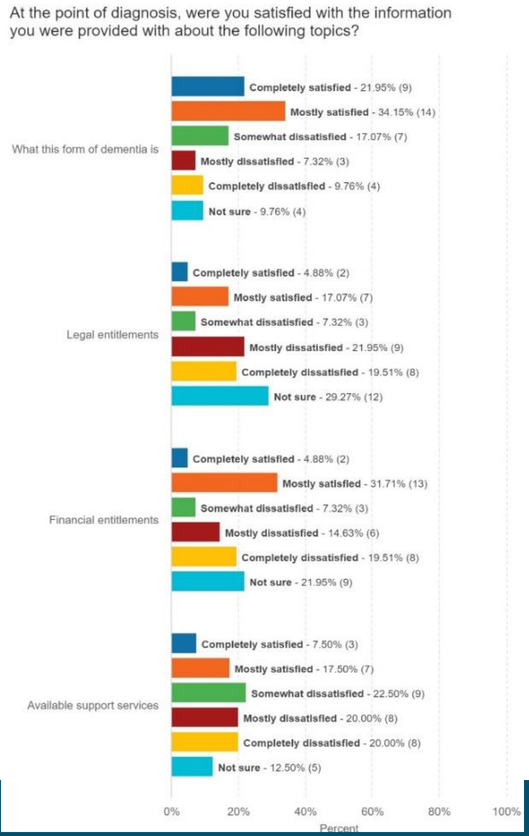
5 – Information satisfaction at diagnosis (PQ5, CQ6 FQ8)

- **Information on dementia: Most were satisfied with information on what type of dementia, but carers and friends and family more dissatisfied.**
- **Legal entitlements: Higher levels of dissatisfaction particularly with carers and friends and family.**
- **Financial entitlements: Around 30% satisfied and 40% not satisfied.**
- **Available support services: Patients rated this more highly (45%), with carers most dissatisfied (60%) and friends and family 50% dissatisfied.**
- **Better information needed on legal and financial entitlements and improved communication on support services.**

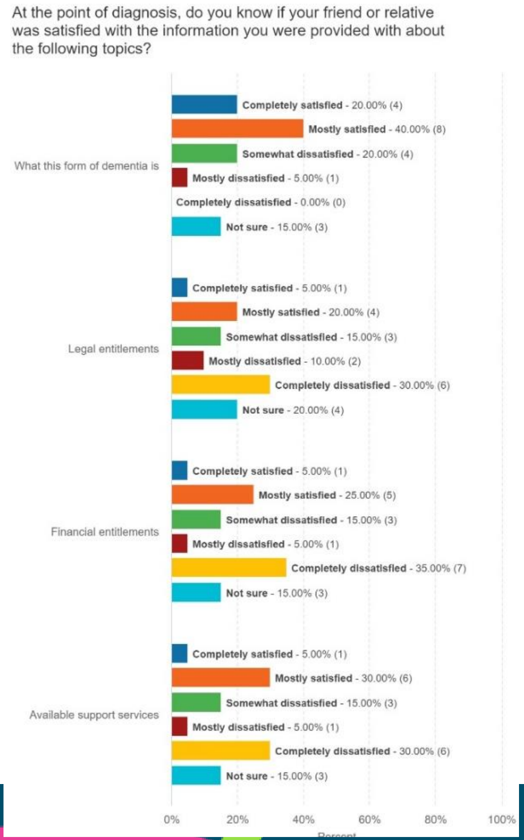
Patient (n-19)



Carer(n=41)



Friends and family(n=20)



5 – Information satisfaction at diagnosis

Those living with Dementia / Patients

“Initially legal and financial entitlements were not discussed apart from power of attorney. However, the mental health did give a lot of support at a later date. They helped me get a blue badge, and PIP.”

“I don’t remember being advised about any financial or legal entitlements that I may be entitled to.”

“I wasn't told much of anything. I was told I wasn't too bad or too far along. I didn't believe I had dementia and still don’t. I have the same GP now though so this is good.”

“They just told me it's dementia. They didn't tell me any more than this. I had a form to fill in an assessment form from Croydon Council. I had to do some research myself on some cost issues.”

“We have never been told of any legal entitlements.”

“We had to find everything out by ourselves about help. I get financial entitlements but I didn't get told about this or available support services. For financial help we had to go to a tribunal.”

5 – Information satisfaction at diagnosis

Carers

"I was mistreated by the finance advisor. Until I informed the person that no one chose to take care of their parent. It may just happen to a person. I was very frustrated with parts of the finance processing."

"They diagnosed quickly but didn't take it very seriously, they acted like he wasn't very far along, but he was deteriorating quickly his licence was taken away and this was horrible for him. He had been having accidents and getting lost while driving for a while before his diagnosis."

"So far I have been given extra carer support for my mum double up even that at times is stressful for them as my mum can get angry and scream a lot.. I find it depressing seeing her this way as it's not how she once was."

"No advice whatsoever was given by professionals or Alzheimer's Society. Our GP has never seen my husband since his diagnosis apart from one appt for a chest infection. My husband has also developed speech aphasia but was offered no support. I eventually got help from an excellent Speech Therapist via our GP. Sadly my husband's ability to communicate hasn't improved."

5 – Information satisfaction at diagnosis

Friends and family

"The person lives alone and has no close relatives. Elderly neighbours do what they can but are not in a position to supply the amount of care she really needs. I believe a social worker was appointed, but they seem happy to leave everything to the neighbours and good luck. This lady is actually well off financially but the system is so useless it cannot even help her. God help those who have less resources because the authorities don't have a clue. She has a number of health problems but the doctors responsible for dealing with them act as if she was capable of dealing with appointments and medication herself - when the neighbour accompanies her to a consultation most ignore her even though the lady cannot remember anything said to her, they address all their remarks to her."

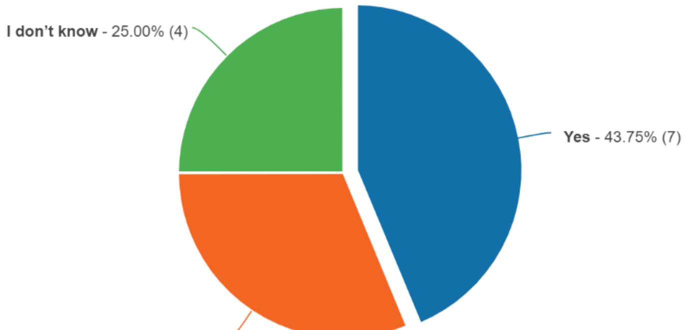
"Friend has no next of kin and no power of attorney for health or finance. We cannot access her money to pay for residential care. If finance team worked faster on paperwork, my friend could be moved out of an acute hospital bed and into care home of our choice at no cost to Croydon Council."

"Aware of support via the memory clinic. No help with accessing funding for care home Not aware of financial help re access to benefits/reduction of council tax."

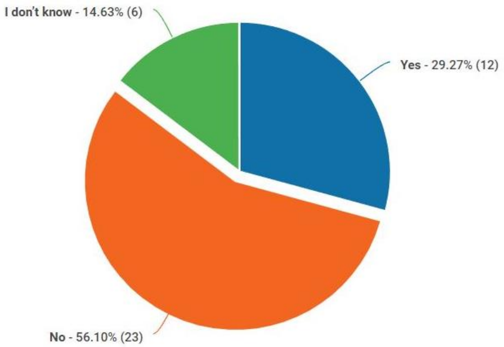
6 – Discussing dementia with GP or health professional at a follow up appointment (PQ7, CQ8, FQ9)

- Patients: 44% did say have an opportunity to discuss dementia with a professional, 31% said they didn't and 25% did not know.
- Carers: 56% of carers were not aware they could discuss Dementia with a GP, 29% was aware they could, and 14% did not know.
- Friends and Family: 55% were not aware that they could discuss Dementia needs with a GP, while 20% said they don't know and 25% said they did know.
- Greater awareness of follow up appointment is needed with over half stating they did not have it or did not know which levels higher for carers and friends and family.

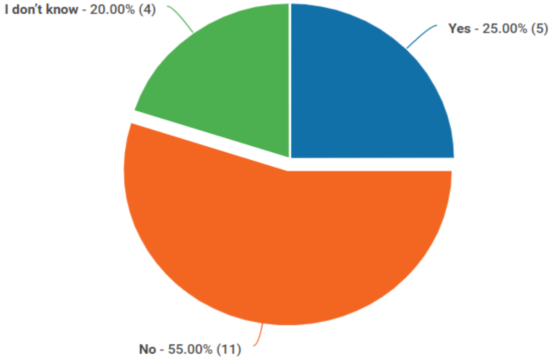
Patient (n-16)



Carers (n=41)



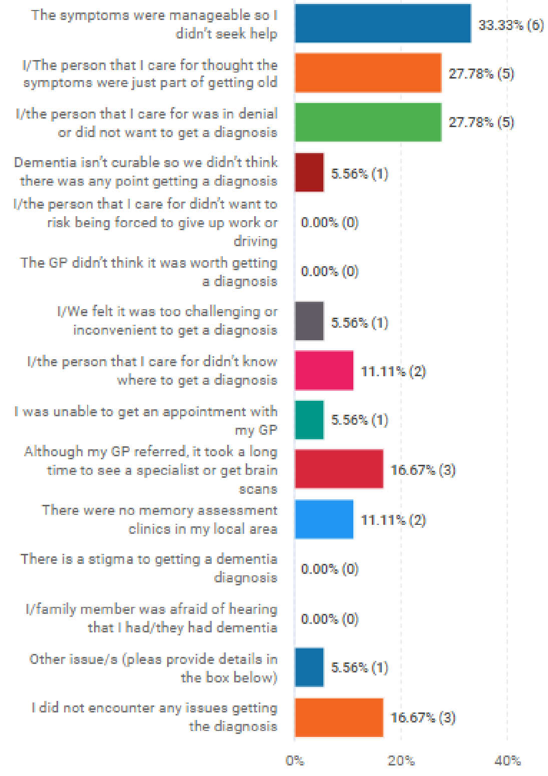
Friends and family(n=19)



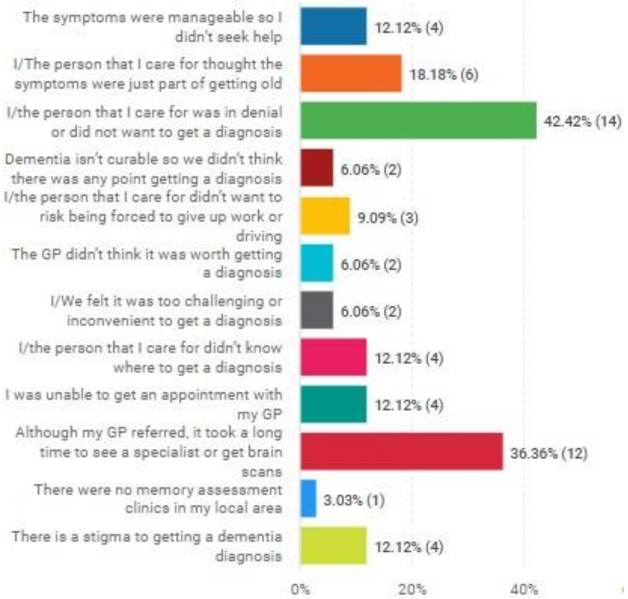
7 – Issues of diagnosis with healthcare provider (PQ8, CQ10, FQ10)

- **Patients sometimes felt issues were manageable (33%) or part of getting older, or did not want a diagnosis/or in denial (28%). Eight could not access services due to waits (3) , lack of services,(3) and lack of information (2).**
- **Carers reported that 42% were in denial, 12% managed and did not seek help, while 36% said it took long to see a specialist.**
- **Friends and Family: 33% thought that symptoms were just part of getting old and 16% said they were in denial.**
- **The length of time to see a specialist is an issue for all but particularly with carers. More patients felt they could manage but others do not. High level of denial particularly for carers. Friends and family felt it was part of getting older.**

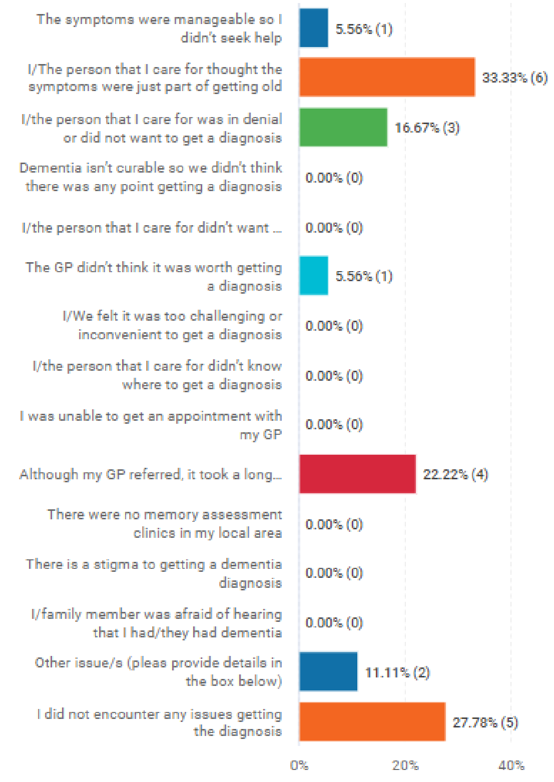
Patient (n-18)



Carers (n=41)



Friends and family(n=20)

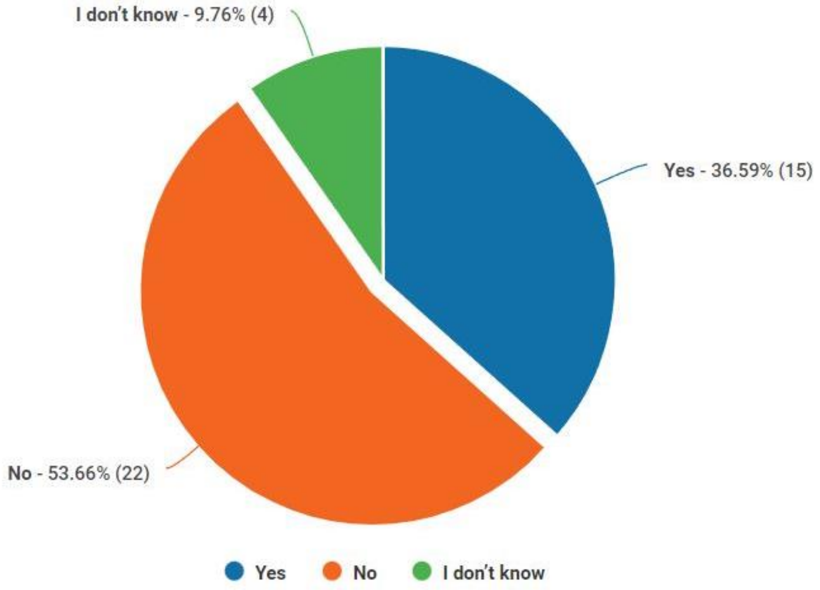


8 – Information for carers after diagnosis (CQ9)

- 36% of carers received information and support available while 53% said they did not. Another 10% was not aware of the information available after the diagnosis.

- There is a need for a better after diagnosis information and communications for carers.

Carers (n=41)

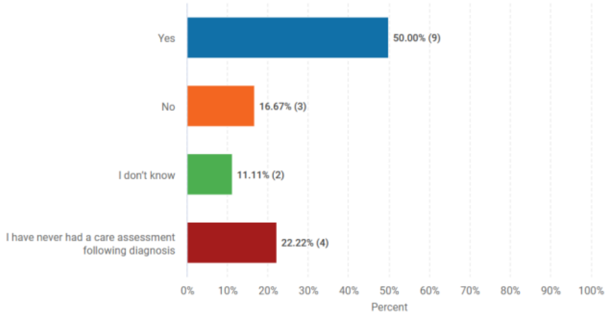


9 – Discussion on care and support needs (PQ9, CQ12, FQ11)

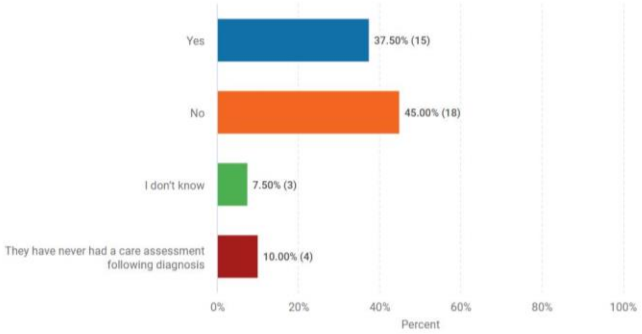
- Half of patients (50%) have had a discussion in the last year about their care and support needs, 17% had not, and 22% had never had an assessment following diagnosis. Two did not know.
- 45% said they didn't discuss their care, but 37% did. Some had not had a care assessment at all.
- Friends and family: 40% did have a discussion, but 30% did not. Some had a discussion with a GP.

- Patients and friends and family do feel there has been a discussion, but carers felt they did not and friends and family could have more.

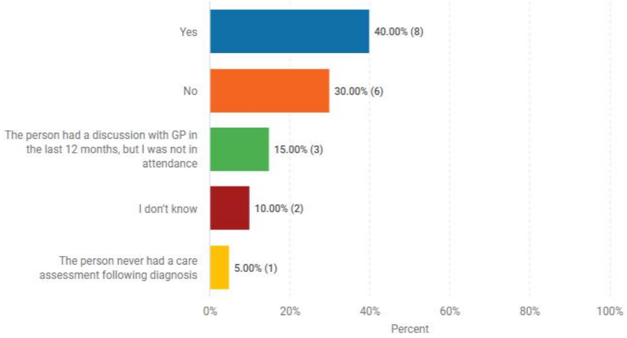
Patient (n-17)



Carers (n=40)



Friends and family(n=20)

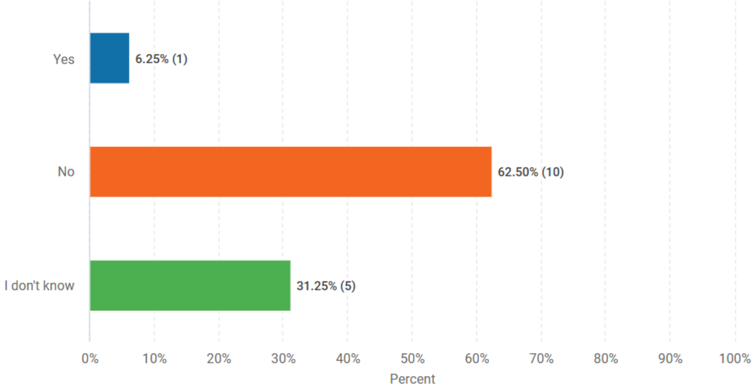


10 - Advance care planning (PQ10, CQ13)

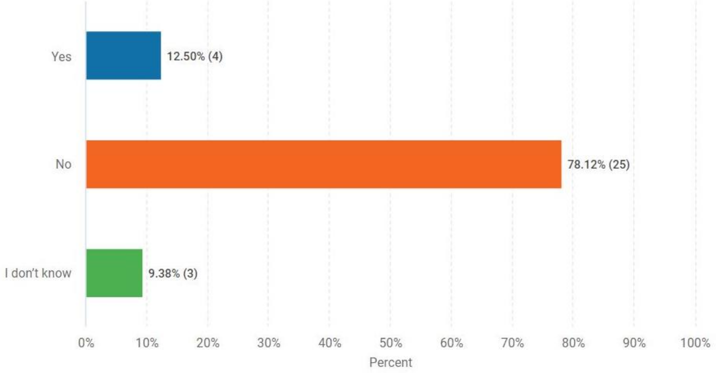
- A single patient discussed advanced care planning, 10 said they did not, and five did not know. In recent appointments one talked about how they were coping, another how they were feeling, two reiterated that they have never had discussions about their future care.
- Majority of the carers (78%) did not talk or plan for advance care planning . 12% reported that they did advance care planning if they cannot communicate their healthcare choices.

- Advanced care planning is not being provided or accessed effectively even though it should be offered after diagnosis and each review. Quality statement 3: Advance care planning | Dementia | Quality standards | NICE

Patient (n-16)



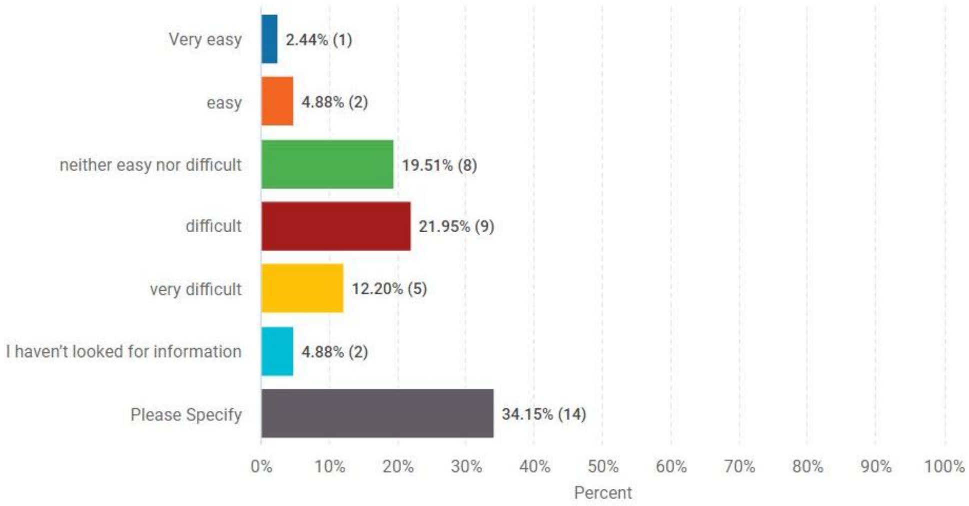
Carers (n=41)



11- Finding information about caring and entitlements (CQ11)

- Few reported it was easy to find information about caring and entitlements with around 20% finding it neither easy or difficult 12% had said it was very difficult to find information and also their entitlement as a carer.
- The specific issues (next page) illustrate that some are getting information from expected sources, others by chance and some not at all.
- Despite caring support and information services being available, many carers need easier ways to be access information and support they need.

Carers (n=41)



11 Patient offered/received appropriate services

(PQ12, CQ15, FQ12)

Theme	Patient	Carers	Friends and Family	Total
Needing more support	6	14	6	26
Accessibility	0	10	3	13
Communication/information	2	7	4	13
Support was good	0	7	1	8
Activities	3	4	1	8
Awareness	2	5	0	7
Waiting for services	0	7	0	7
Satisfied	0	2	3	5
Communication/information – positive	0	0	2	2
Total	13	56	20	89

Highest response for more support – only seven carers had positive experiences of support. Ten carers spoke about accessibility to services, including culturally appropriate services. People living with dementia and their friends and family did not report waiting as an issue, in contrast with carers.

11- Specify issues

Carers

“There is not a one stop shop to see what help you are entitled to, if you don't know what help there is.”

“Where do you start GPS are too busy.”

“Lots of information I've found out subsequently in passing from other people."

“The information given was through the Alzheimer's Society.”

“Plenty online, YouTube, etc.”

“I personally had to help myself. My neighbour introduced me Age UK and they were quite helpful.”

“It could be made easier with more personal contact with carer.”

“I know information because of my job but still waiting to find out about support locally.”

“No one ran through what would help, with health or financially.”

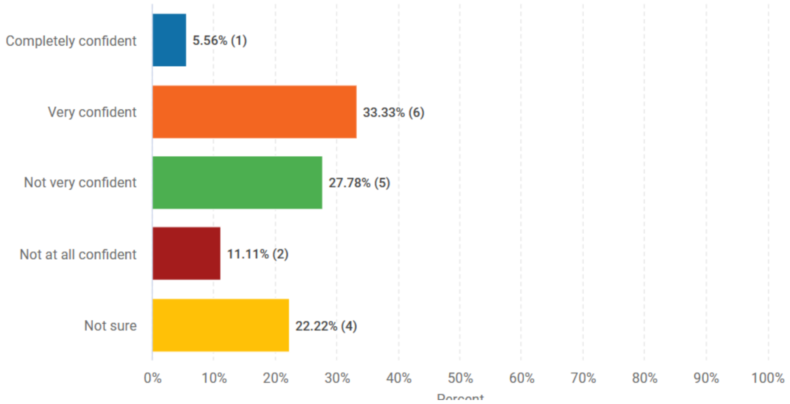
“Access to information is not the problem, it is the services on offer that are the real problem.”

12 - Confidence in managing dementia in last 12 months (PQ11, CQ14)

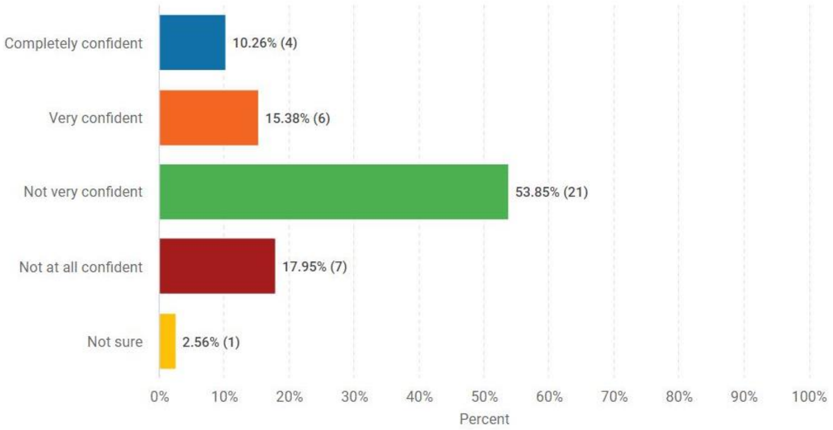
- **Patients: 38% felt confident while 39% felt they were not, 22% not sure.**
- **Carers: 70% felt less confident with just 1 in 4 feeling more confident.**

- **More needs to be done to support carers in the manging the dementia of the person they care for.**

Patient (n-18)



Carers (n=41)



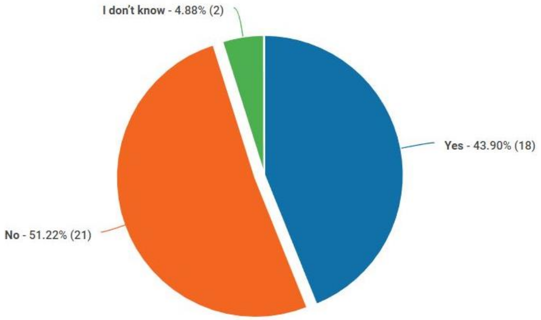
13 – Patient offered/received appropriate services (PQ12, CQ15, FQ12)

- 63% patients said they had been offered care and services appropriate to their needs and preferences, but 1 in 3 that they had not.
- Carers rated this much lower for carers with 51% stating that those they care for had not been offered or received services to their needs and preferences.
- Friends and Family: More than half had not received service 35% or did not know (25%).

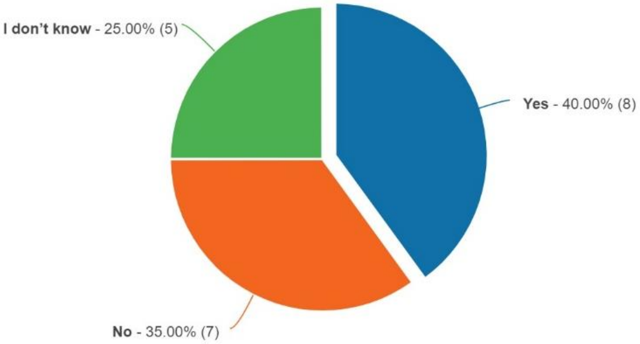
- There is a need for more understanding of services appropriate to their needs for patients maybe with better coproduction with patients, carers and family and friends.

Patient (n=16)

Carers (n=41)



Friends and family(n=20).



13 Patient offered/received appropriate services

(PQ12, CQ15, FQ12)

Theme	Patient	Carers	Friends and Family	Total
Needing more support	6	14	6	26
Accessibility	0	10	3	13
Communication/information	2	7	4	13
Support was good	0	7	1	8
Activities	3	4	1	8
Awareness	2	5	0	7
Waiting for services	0	7	0	7
Satisfied	0	2	3	5
Communication/information – positive	0	0	2	2
Total	13	56	20	89

Highest response for more support – only seven carers had positive experiences of support. Ten carers spoke about accessibility to services, including culturally appropriate services. People living with dementia and their friends and family did not report waiting as an issue, in contrast with carers.

13 Offered/received appropriate services (PQ12, CQ15, FQ12)

Patients

“I have been offered no services.”

"The dementia day centre is appropriate for me, I come here multiple times a week and it is modern and clean and has lots of things to do. This is Council run and they also organise a minibus to pick me up from my house and take me here which is really good. Someone comes into my home to help with cleaning and to support me. This is good."

"I go to the dementia day centre 2 times a week. I enjoy crosswords and talking to others and being around other people. Sometimes it's not to my level - I don't like all the art and crafts but it's better than being at home alone. The minibus picks me up from home and takes me to the centre and then takes me back at the end of the day so it works really well for me. I don't do any other social groups or activities or have any other support other than my sons. One takes me to mass on Sundays and one son comes to my house and helps me with money. I really struggle with dealing with money and wouldn't be able to do it without my son's support.”

“I have a daily carer who comes in and makes sure I am fine and that I take my meds. she checks blood pressure.“

“I need more support.”

13 Offered/received appropriate services (PQ12, CQ15, FQ12)

Carers

“Services are not culturally appropriate. After decades of equality legislation, surely we can expect to be treated well and have equitable access to services.”

“Several years ago I was able to access planned respite at a care home for me to be able to go away on holiday for breaks through the council. Since then I have had to find more costly support privately.”

“She was able to get respite when we needed to go away for a break.”

"No culturally appropriate options. No mental health services.”

“Age Concern; Alzheimers Society; Information about daytime options that offer support and activities- The Men's shed scheme. Financial support from government and local council - allowance and reduced rates.”

“There has been recent deterioration but when I asked for a new care assessment I was told we'd have to wait another 3 months.”

“Now goes to a day centre. But it took 6 months before getting it arranged since the referral was first requested.”

“We were referred to the Falls Clinic, following several falls, who were most helpful and caring.”

13 Offered/received appropriate services (PQ12, CQ15, FQ12)

Friends and Family

“She is in a very good Care Home with strong support.”

“The difficulty with my mum is that she refused help as her dementia meant that she thought she was managing. We had to care for her surruptiously for 7 years, until she lost capacity :(“

“The GP would probably argue that as care was already being received it could be taken into account in those care reviews. Fortunately, this was partially true, as the care manager of the care agency was very experienced and had experience of dementia clients. Also we have another relative that is a trained care manager in a dementia care home. Tough on anybody that does not have this sort of support.

My husband is bedridden and had to have an urgent hip replacement because of previous falls. My family and I felt he should have been offered more physiotherapy to maybe help him to walk.”

“In care home now …. Was at home with carers four times a day.”

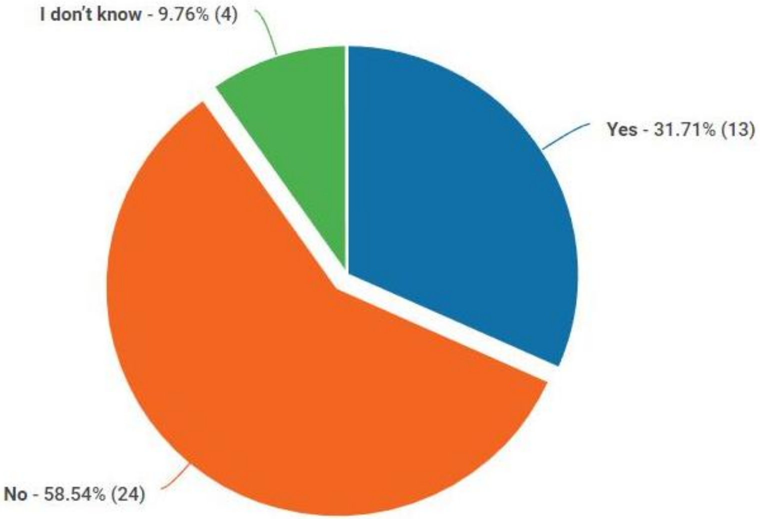
“We have had to look on to all this ourselves.”

“Not much available.”

14 – Carer offered/received help or support services (CQ16)

- **Majority of the carers (58%) reported they had not been offered support from services. However, 31% already knew what was appropriate to them.**
- **Carers need better communication and awareness of services available to them.**

Carers (n=41)



14 - Details of carers support

“Not been offered any support.”

“Mind workshops which have now stopped.”

“I have attended courses about dementia care and before the covid pandemic attended a monthly support group at the daycentre. This support group is restarting next week.”

“I've been offered groups but I've not found that helpful. I've asked for respite care but none has been forthcoming.”

“Have been talking to Age UK Croydon, who have advised me what is on offer, but of no use if you cannot get someone to house sit.”

“Respite.” “Only recently after many years have I had a successful respite after 10 years of living with Dementia.”

“I attended a series of talks by professionals, which was specifically aimed at carers.”

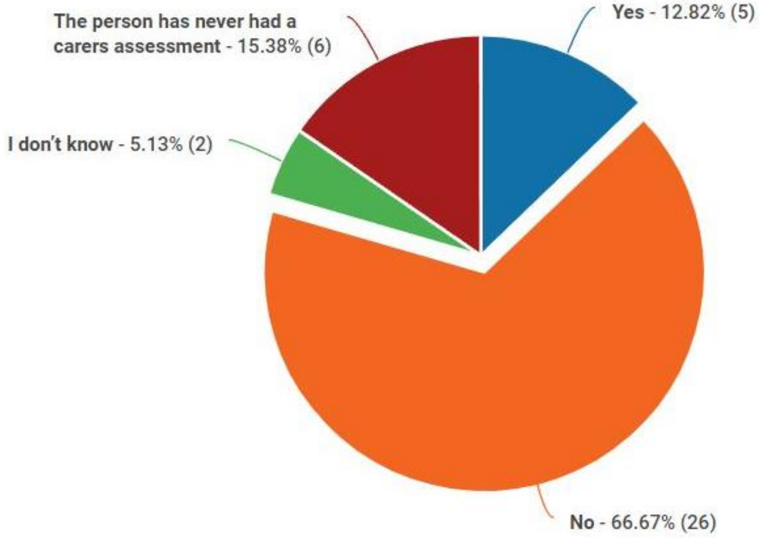
“All services if appropriate, are offered during the daytime. I am a working carer.”

“I heard about a carers support group but didn't access it. I didn't know there was anything else.”

15 - Reassessment of dementia or care needs (CQ17)

- In terms of reassessment of dementia and care needs 13% was aware. Majority (66%) reported they had not done a re-assessment within 12 months nor neither had care needs.
- There is a need to look at the low accessibility or uptake in dementia or care need reassessment.

Carers (n=41)



16- Improvements (PQ13, CQ18 FQ13)

Theme	Patient	Carers	Friends and Family	Total
Support	4	21	8	33
Quality	3	10	6	19
Wayfinder	2	11	3	16
Information and Comms	2	10	4	16
Respite	0	11	1	12
Training	1	4	2	7
Biomedical	1	4	2	7
Adaptations	1	3	1	5
Finances	0	4	1	5
Total	14	78	28	120

The need for more support was the most important improve respondents want to see. Other issues were a need for a someone to help navigate the system, information and communication, respite and medical services such as counselling and testing. Finances, staff training, and adaptations scored lower, but were still repeatedly mentioned.

16- Improvements (PQ13, CQ18 FQ13)

Patients/those living with Dementia

“Deeds not words. Most council support is a series of tick boxes that makes them feel they achieved something. I would like to see true on going support from doctors to services.”

“At the dementia day centre the staff are very friendly and capable - I think they have a really good understanding of dementia and are very well trained. They seem dementia friendly. The place here is really nice and has lots of space, a quite room and different people to talk to and things to do. I think dementia training is very important and I worry about people elsewhere where staff may not be as good. Religious places need to be friendly to all people and accept older people with issues. I go to mass every Sunday and have been able to keep doing that which is really good for me to keep that routine. Many people lose their old routines if they can't access places.”

“Good support when leaving hospital. As well as home help I saw the physio on Saturday mornings. It is good to know that support with all organisations and professionals can be organised well to keep me out of hospital.”

“However other companies who do home help are not good and I think this is the biggest problem I've had. I really think that dementia training should be in place for home help and that staff should be held accountable as it is so expensive and my life depends on it. I'm in my last days, and they need to make it easy and comfortable and enjoyable for you. You need to be able to trust them. My son lives out of the country so I have no other help.”

16- Improvements (PQ13, CQ18 FQ13)

Patients/those living with Dementia

“There should also be more activities for people like me and I should know who to go to Sunday ask about these. The transport getting me to the day centre makes a big difference. Taxi card and dial a ride can be difficult and expensive. I'm never sure how much money they are taking off me. I think the prices are changing but I don't know because they don't tell me. It can be really expensive for me to go and get my eye check ups."

“Having transport to get to the activities I need to. Keeping my life as normal as possible. Having access to a good library that is dementia friendly. Being able to go to my church. The vicar is changing again which I don't mind but I hope that they will be nice and that they will understand me. Dementia friendly means friendly people who have awareness and are nice, and I can carry on doing what I like.”

“For everyone to be nice and understanding. For staff everywhere to treat you with respect and understanding. I was a nurse and I treated people as individuals. Everyone with dementia needs to be treated as an individual not a group. People need to be active and need help to do this. It is difficult to stay active. I would like there to be more ways to do this.”

“Home help needs to be improved massively. When I had home help before I moved to sheltered accommodation, they were awful. They would come in late, leave early, sit and play on their phones and not help me. They weren't trained in anything at all, no sympathy for me and didn't want to help me when I asked. They didn't understand me either, I don't think they had dementia training. What was the point? They were so expensive as well. I had to do everything myself in the end anyway which was really hard. Some of them didn't seem to understand me when I speak with my accent.”

16- Improvements (PQ13, CQ18 FQ13)

Carers

"As a carer I was restricted. I was working and had three children to take care of and looked after my mother-in-law in the same home. My husband cared for her too, but it was still too difficult to juggle all of these things. We never had a break, I was caring and working non-stop."

"Day centres that cater for elders with minoritised communities' Social outings for Asian elders Support for residents and their carers south of the Borough Support and activities for working carers during evenings and weekends Counselling Some advocacy services for working carers Travel Support for people with dementia Better adult mental health services for people with dementia Sheltered accommodation."

"Someone coming to the house to support the carer. More information on what to do when the person with dementia is in total denial. How to get a carer to take respite."

"Readily available respite care.“

“Treat us like human being, don't you, don't use unpaid labour to prop up services, older people with mental problems should be cared for properly and their families free to choose how to live their lives. Do not charge us for care, we deserve this much.”

“A central point where support with medical, financial, physical issues is offered. We visited Sage House, Tangmere, Sussex, a one-stop shop for people with dementia - the only one in the country. We live outside their area but I've been allocated a Wayfinder, Jackie, who is there when I need her.”

16- Improvements (PQ13, CQ18 FQ13)

Carers

"Having someone to help when her condition gets worse at present is starting to detorate as has been stuck in bed since June. And not walked with her Zimmer frame since last Christmas due to catching COVID. Just knowing someone is there to advice me as I am feeling emotional all the time

“Staff at hospitals should be better educated in dealing with people with dementia.”

“Culturally appropriate options. Translators during diagnoses. Social prescribing options that are culturally appropriate south of the Borough. Advice and support on management of dementia symptoms. Advice and support with forms. Support for working carers. Befrienders for affected. Day centres for people with dementia to reduce social isolation. General point of contact.”

“More support for me as a carer and someone to explain what help we might be eligible for.”

"Day centres that cater for elders with minoritised communities; Social outings for Asian elders; Support for residents and their carers south of the Borough ;Support and activities for working carers during evenings and weekends; Counselling; Some advocacy services for working carers; Travel Support for people with dementia; Better adult mental health services for people with dementia; Sheltered accommodation.“

“Introduction to support groups or people.”

16- Improvements

Friends and family

“There needs to be more at home care available before the patient becomes unable to live alone.”

“Being listened to. Having response from healthcare professionals. Fully mobile person (walked into Croydon) was admitted after a fall and is now curled up in bed.”

“Obviously not going to happen given the state of social care. When my mother was diagnosed with dementia in the 1990's - social services were on the ball, the carer provided was wonderful and my mother had 3 visits a day one for about 45 minutes and 2 for about half an hour each. She eventually had to go into a care home (Cheriton House Thornton Heath - then run by LBC) The care was superb although the building was a bit shabby. The genuine love of the staff more than made up for that.”

“More information ! Involve carers/family.” “Helpline when the things aren't going right.”

“More day centres for people with dementia.” “More financial help, care and advice needed.” “Simplify processes. Join up information. Help carers to get help. Stop people feeling isolated. Help GPs to see people in their own homes. Have one place to access info. Dentistry for people living with dementia is so tough.”

“You could start with a change in attitude of some GPs to older patients. The right sort of support appears to be available in theory, but because of under-funding you have to know the ropes and push to make progress.”

16- Improvements (PQ13, CQ18 FQ13)

Friends and family

“Simplify processes. Join up information. Help carers to get help. Stop people feeling isolated. Help gps to see people in their own homes. Have one place to access info. Dentistry for people living with dementia is so tough.”

“More support groups, activity groups, talking therapies etc would be helpful.”

“You could start with a change in attitude of some GPs to older patients. The right sort of support appears to be available in theory, but because of under-funding you have to know the ropes and push to make progress.”

“Financial help towards paying for carers and respite.”

“After care is needed, more groups for people to attend,you just left to find things out yourself.”

“Simplify processes. Join up information. Help carers to get help. Stop people feeling isolated. Help gps to see people in their own homes. Have one place to access info. Dentistry for people living with dementia is so tough.”

“You could start with a change in attitude of some GPs to older patients. The right sort of support appears to be available in theory, but because of under-funding you have to know the ropes and push to make progress.”

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17- Importance going into sheltered accommodation or care home (PQ14)

Theme	Patient	Carers	Friends and Family	Total
Support, quality care	4	7	8	19
Staff training, understanding of dementia	4	8	6	18
Person-centred	3	10	3	16
Safety	1	7	1	9
Activities, quality of life	0	7	2	9
Location	1	6	1	8
Familiarity	2	4	0	6
Independence	3	1	0	4
Cost	1	2	1	4
Total	19	52	22	93

Again the importance of good support and quality care, staff training and understand of dementia and a person-centred approach were considered most important themes.

17- Importance going into sheltered accommodation or care home (PQ14)

Those living with Dementia / Patient

“I would never go in to a home. My biggest fear is being a burden on my sons. But it could never appeal to me to go into a home - it seems too restrictive and I need freedom. I can't be told what to do. I don't want to pay for it either. I prefer to be alone and have my own space. I'd rather do anything other than go into a home. Maybe one day if I wake up and I don't know who I am then I would be fine with it - I wouldn't know what was going on so that would be okay.”

“When I moved to sheltered accommodation I had loads of problems. I had to move most of my things to storage, which was upsetting, and the person helping me cause me lots of problems - they charged me £1000 extra on the day. It was during lockdown so it was really hard and I had to accept this and give them the extra money. Now it seems that most of my things have been lost. I couldn't check what was being move where. Now when I look I can't find my clothes, cooking pans, jewellery, furniture. Now where I live I don't have any of my nice things. On top of this, when I tell people this they think I am crazy or lying. Because I have dementia they think I am losing it."

“I would never go. I will stay with my daughter until I die."

17- Importance going into sheltered accommodation or care home (PQ14)

Those living with Dementia / Patient

“If it is forced on me I don't want to do it. I need to have choice about where I go. I would fear that nobody there knows me. Everybody knows me at the dementia day centre. We get meals here and I feel safe here. I would feel scared that they are not trained in a home and that they don't know me. I would want the home to be council run home. I would be worried about having my belongings with me.”

“Things that are familiar from home, to feel like I still feel that my possessions are close by That family and friends can still visit that staff and other people are friendly and supportive and trained."

“The support that will be available and whether it will be near to family relatives “I'd be worried that the staff wouldn't have time to get to know me in time before I deteriorate. They might not be able to understand me when I get older and I worry that care wouldn't be personalised to me but that we'd all be shoved in one place and told what to do.”

“To take time when being fed.”

17- Importance going into sheltered accommodation or care home (PQ5, CQ6 FQ8)

Carers

"That the care home staff are all trained to cope with people who have dementia. Too many carers just shout louder if the person does not do as asked immediately. I have had to sack carers for this."

"I am hoping to be able to continue to care for him at home until he dies. Any care home would need to be nearby me or if I die first, near to our son and to have easy access to visiting. A good activity programme suitable for him as he cannot use understandable language now. Adequate care staff to help him get around safely, eat as he needs a soft diet due to having too few teeth, and be dry/clean/toileted and have some appropriate stimulation, eg books, getting outside, quiet time when needed."

"Support for both of us, respect for the person in this situation and mindfulness of how this is affecting the person and the family."

17- Importance going into sheltered accommodation or care home (FQ14)-

Friends and family

“To be able to choose a Care Home and that it has a good CQC rating. That staff are kind and caring.”

”That she was looked after by staff who had enough money to live on and who truly cared.” “To be part of the decision making process as to where. Not hear that friend had ZOOM call with no support of friend or a nurse or had hearing aids in - very poor.”

“Help with finances ….. fees are so expensive…… shouldn’t have to sell family homes General help …. Accessible People that know what they are talking about.”

“It is important that they are given care and respect that they deserve. Staff to exercise patients.”

“It would be a care home in this case. It would be very important that the care home has good record of experience with dementia residents.”

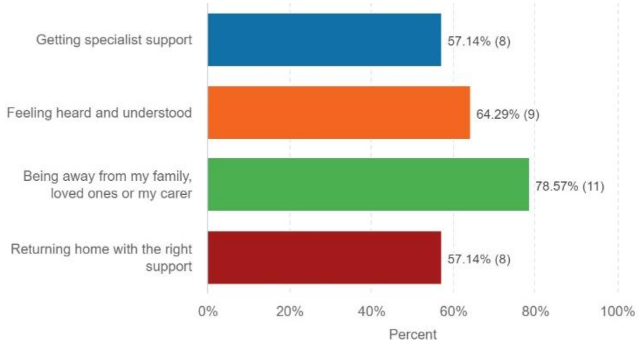
“That I have complete access to stay or visit.” “Making sure it is the best for them.”

18 – Concerns about going into hospital (PQ15, CQ20, FQ15)

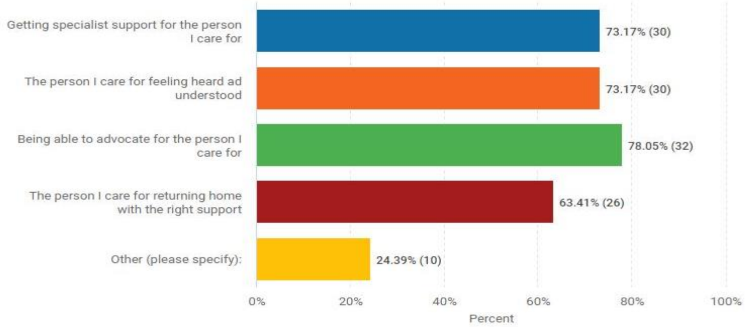
- Patients were most concerned about being separated from their loved ones (79%), being heard and understood (64%) getting specialist support and returning home (both 57%).
- Carers wanted to be able to advocate for the person (78%), patient being heard and understood and getting specialist support (both 73%) and returning home with right support (63%).
- Friends and Family: 80% wanted them to get the specialist support (80%), the person being heard and understood and returning home with right support (both 70%).

- Need to ensure that dementia patients have a dedicated pathway if going into hospital ensuring they have the specialist support they need with these issues considered. Carers need to be easily identified as advocates. Being discharged with the right support is also an important priority.

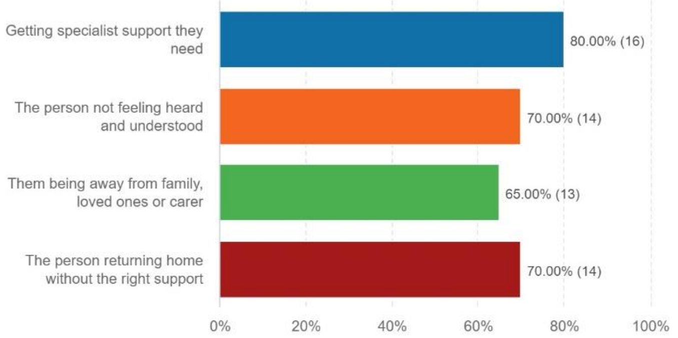
Patient (n-19)



Carers (n=41)



Friends and family(n=20)



18- Concerns about going into hospital (PQ15, CQ20, FQ15)

Theme	Patient	Carers	Friends and Family	Total
Quality of care	1	8	3	12
Communication	3	4	2	9
Lack of Support	3	2	3	8
Total	7	14	8	29

"I would be concerned if I came out of hospital I may not have support to stop me from going back because I am not supported in the community and don't have a lot of family support."

"My son lives away so it would be really hard to communicate with everyone and make sure everyone is informed and aware of my case. If I had a fall or something and had to go to hospital I would be really concerned because when I went before the ambulance took 3 hours to come and left me on the floor by myself. On the other hand, after being in hospital I was sent home quickly with help at home 4x a day and this support kept me out of hospital."

18- Concerns about going into hospital (PQ15, CQ20, FQ15)

Carers

“This just happened and I had a battle royal with Mayday hospital first doctors that would not believe me I actually had to go in and record responses and play them to the doctors to stop them pulling out feeding tubes. I had to go in again to prove the person could swallow even though I was told several professionals and specialists had agreed the person was beyond hope and show move out to be tended until they passed. Currently a week later they are getting better and improving!. A care home. Its crazy. As I pointed out the person is not dead yet.”

“Dad's safety.”

“Bring treated with dignity and care.”

“The nursing staff being trained to understand a patient with dementia.”

“Being neglected and left for hours with no contact.”

“Him not becoming immobile if having to spend too long in bed.”

“The staff trained in the care of patients with dementia.”

“Keeping mobile.”

18- Concerns about going into hospital (PQ15, CQ20, FQ15)

Friends and family

“The last time my relative was in hospital they bent over backwards to keep me around in the ward during the day. My relative was not always fully understanding things and could get very upset at times. They sometimes made pretty blunt observations to staff out of fear or frustration. Looking at it from another perspective it was clear that the flare ups arose when an uninformed, inexperienced or rushed staff member appeared to do something. Twice such persons arrived saying 'no problem we can handle this' and then a few unsuccessful minutes later they would ask me to come and speak to my relative to progress. Some of the other staff knew the perfect way to handle the situation.”

“All of the above My Mum was in hospital…. People did not understand she had Dementia.”

“The last time Mum went into hospital when she had mental health issues, she was not given the correct support and kept in in unsafe environment which led to them losing her and several instances of injury. Staff were not able to provide the care and support she needed.”

“

19 – Croydon dementia friendly (PQ16, CQ21, FQ16)

Theme	Patient	Carers	Friends and Family	Total
Effective support	6	13	10	29
Awareness	5	18	6	29
Well trained staff	2	9	2	13
Friendly staff	3	4	5	12
Actions not words	1	8	1	10
Access to public spaces	3	4	1	8
Activities	4	0	0	4
Pleasant care environment	1	0	2	3
Total	25	56	27	108

Effective support and awareness were the top themes for for all, well trained staff was the next most important issue.

19 – Croydon dementia friendly – Patients (PQ16)

“Having a choice of services and support and not just being stuck with one thing that might not work. Some activities are not suitable for me or I don't enjoy - I don't want to do arts and crafts, I want to be outside I want to be with other people like me if it's dementia friendly it means everyone understands dementia and is patient and all services are prepared to deal with different people I want to be able to go to the doctor and they can give me a list of activities and groups and advisers and for them to know what's happening If there could be groups for people who speak Punjabi or Urdu that would be nice.”

“People will understand and know how to support people with dementia. People in the community will be educated.”

“For people to be helpful everywhere I go. A range of support available and to be able to call an adviser when I have a problem, even a medical problem.”

“It means people will be educated and the community will care and support people with dementia. "I heard about a carers support group but didn’t access it. I didn't know there was anything else.”

“Very important for people to understand dementia in Alzheimer's is an illness but not contagious…..public awareness of life and the best support for the carer/s and family.”

19 – Croydon dementia friendly – Patients (PQ16)

"At the dementia day centre the staff are very friendly and capable - I think they have a really good understanding of dementia and are very well trained. They seem dementia friendly. The place here is really nice and has lots of space, a quite room and different people to talk to and things to do. I think dementia training is very important and I worry about people elsewhere where staff may not be as good. Religious places need to be friendly to all people and accept older people with issues. I go to mass every Sunday and have been able to keep doing that which is really good for me to keep that routine. Many people lose their old routines if they can't access places."

19 – Croydon dementia friendly – Carers (CQ21)

“Training for services and retailers. Education for school age children. Taking scooters and cycles of (sic) streets. Having a helpline. Registering people with dementia. Quiet spaces for people with dementia and their carers. Spreading awareness of the blue flower. More disabled bays. More accessible streets. Good town planning: consult with us. Educate GPs. Work with supermarkets e.g. set hours for people with dementia etc.”

“Information campaign. Encouraging local people to look out for people who may be alone and not managing.”

“With the huge amount of elderly dementia patients, more money needs to be invested in Day Centres and information for carers re home visits.”

“Help and time when needed. Not have to wait for months for help, support, advice. Always someone at the end of the phone.”

“More services south of the Borough - transport is an issue and without me being able to drive, my husband couldn't access any services.”

“A total overhaul of the entire system. Right now it's not fit for purpose.”

19 – Croydon dementia friendly – Friends & family (FQ16)

“For there to be understanding of people with Alzheimer's, they can still give a lot to society. Places they can go and feel safe.”

“Everyone should be able to have the necessary support and treatment available to them in order to give them the best quality of life and the best support for the carer/s and family.”

“People (including medical professionals) being aware of the full implications of dementia. Specialist staff are fine, but when a person with dementia needs care for some unrelated problem they should be treated as a person with dementia who has a health problem- not as a kidney or a bowel or a heart or whatever.”

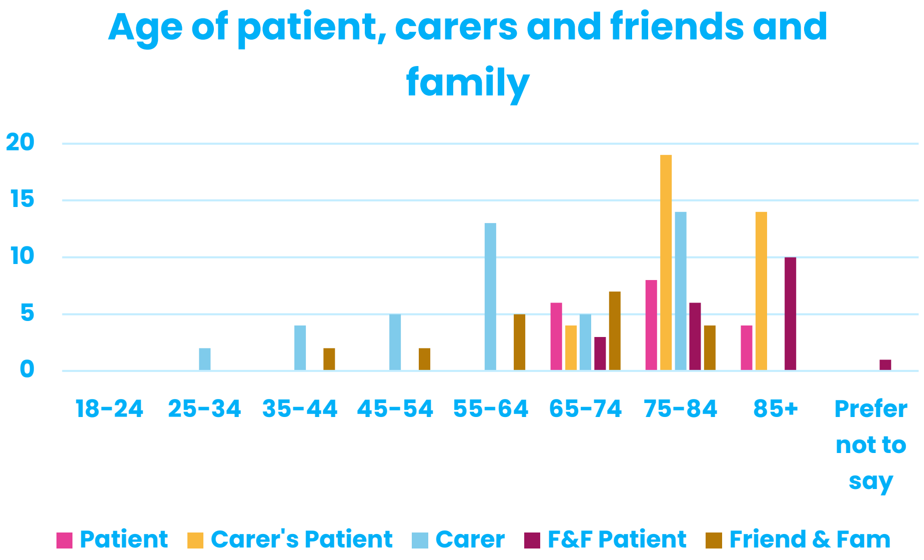
“Getting primary care services to actually provide the services that are theoretically available. Getting other public and private sector organisations to be more aware of the issues facing customers with dementia. Getting the general population a bit more aware of the condition.”

“Everyone should be able to have the necessary support and treatment available to them in order to give them the best quality of life and the best support for the carer/s and family.”

Demographics

20- Demographics - Age group (PQ17, CQ22, FQ17)

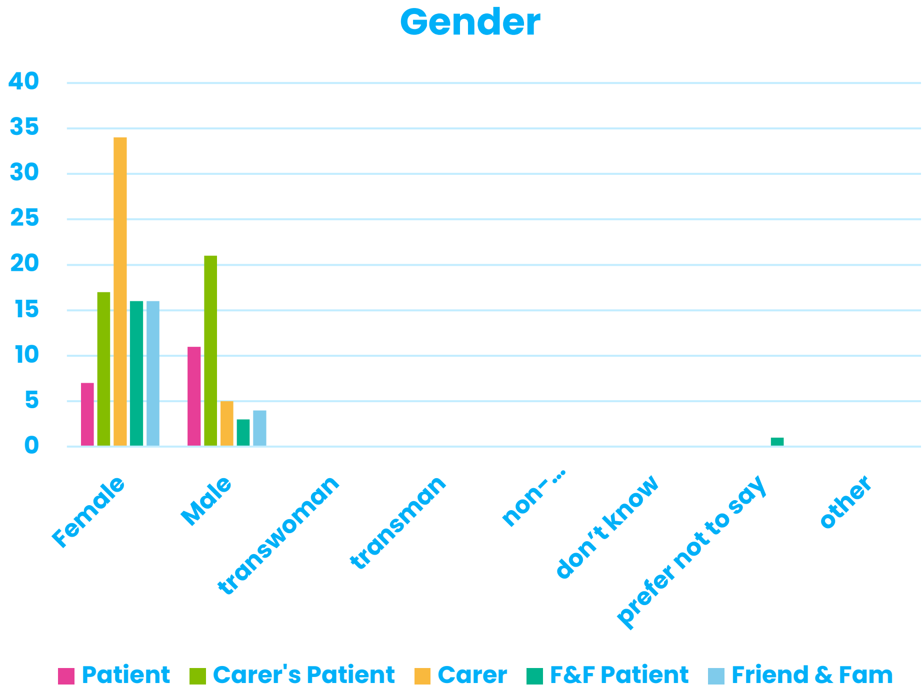
- Patients sample tends to be 65-74, 75-84 and 85+
- Carers sample shows highest responders also 75-84 followed by 55-64, with Carer's patient being highest at 75-84 and 85+ suggesting older people care
- Friends and family patients also cover the main groups with higher numbers in 85+. Friend and family are spread across the ages more.



Age group	Patient	Carer's Patient	Carer	F&F Patient	Friend & Fam
18-24	0	0	0	0	0
25-34	0	0	2	0	0
35-44	0	0	4	0	2
45-54	0	0	5	0	2
55-64	0	0	13	0	5
65-74	6	4	5	3	7
75-84	8	19	14	6	4
85+	4	14	0	10	0
Prefer not to say	0	0	0	1	0
Total	18	37	43	20	20

21 – Demographics - Gender (PQ18, CQ23, FQ18)

- Patient respondents were more male. Carers were more female, but the patients were slightly more male.
- Both friend and family members and patients more female.



Answer Choices	Patient	Carer's Patient	Carer	FA&F Patient	Friend & Fam
Female	7	17	34	16	16
Male	11	21	5	3	4
transwoman		0	0	0	0
transman		0	0	0	0
non-binary/genderqueer/agender/gender fluid		0	0	0	0
don't know		0	0	0	0
prefer not to say		0	0	1	0
other		0	0	0	0
Total	18	38	39	20	20

22- Demographics - GP surgery (PQ19, CQ24, FQ19)

- Patients were registered at AT Medics Thornton Road Surgery (1), East Croydon Medical Practice (3) Keston Medical Practice (1), Mersham Medical Centre (1), Norbury Health Centre (2), Shirley Medical Centre (1), Stovell House (1), The Addiscombe Road Surgery (1), Selsdon Park Medical Practice (2) Thornton Heath Medical centre (1) and Upper Norwood Group Practice (1). One was registered out of Borough.
- Patients/Carers – Addington Medical Practice/Parkway Health Centre (1/1), Auckland Surgery (1/1), Brigstock and South Norwood Medical Partnership (0/2), Broughton Corner Medical Centre (1/1), Country Park (1/0), Eversley Medical Practice (2/1), Farley Road Surgery (2/3), Fieldway (1/1), Friend's Road Medical Practice (0/1), Norbury Health Centre (2/0), Old Coulsdon Medical Practice (2/1), Parchmore Medical Centre (1/1), Parkside Group Practice (1/1), Portland Medical Centre (1/1), Queenhill Medical Practice (2/2) Selhurst Medical Centre (2/2), Shirley Medical Centre (2/2), South Norwood Medical Centre (1/1), Stovell House Surgery (1/0), Selsdon Park Medical Practice (4/3), Whitehorse Practice (0/1), Violet Lane Medical Practice (3/2); Woodcote Medical (3/3).
- Patient/Family and Friends: Addington Medical Practice/Parkway Health Centre (1/0), Cousldon Branch (1/1), Farley Road Surgery (1/3), Friend's Road Medical Practice (0/1), Gravel Hill Surgery (1/0), Leander Road Primary Care Centre (1/0), Morland Road (0/2), Old Coulsdon Medical Practice (0/1), Parchmore Medical Centre (1/0), Parkside Group Practice (1/0), Queenhill Medical Practice (2/4), Shirley Medical Centre (1/0), The Moorings Medical Practice (0/1), The Selsdon Park Medical Practice (1/0), The Whitehorse Practice (1/0), Thornton Heath Medical Centre (0/1), Woodcote Medical Centre(1/0), 2 did not have a GP.

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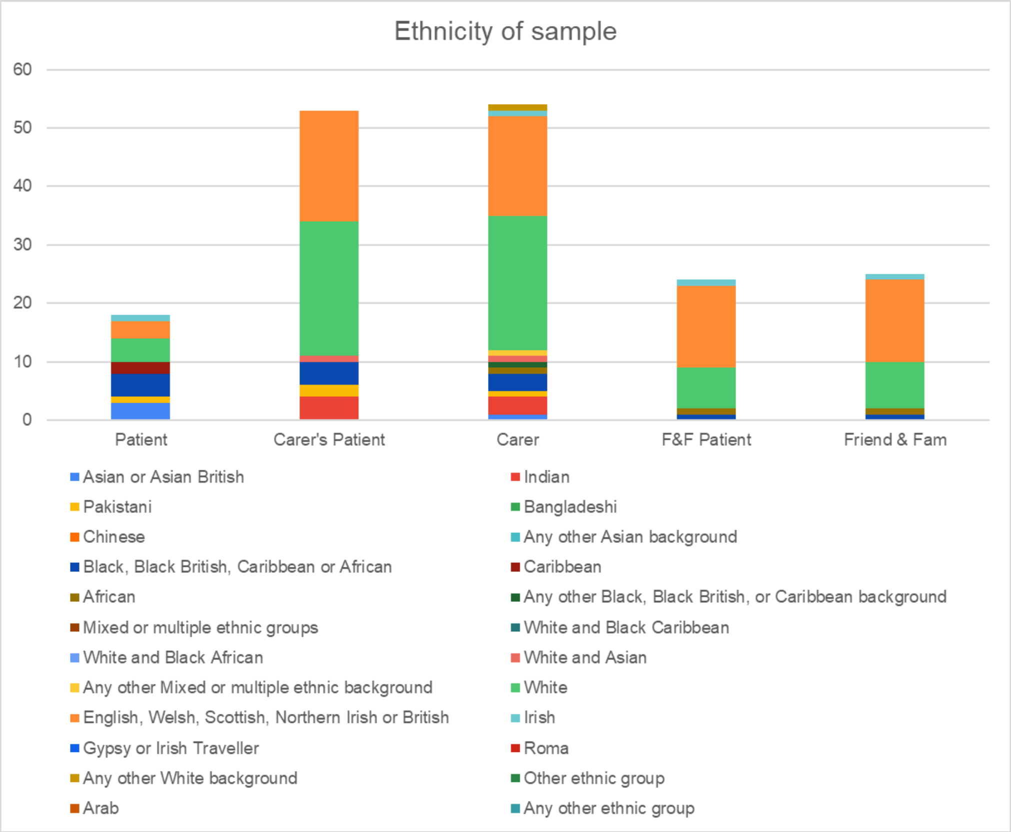
23 – Demographics - Ethnicity (PQ20, CQ25, FQ20)

- **Patient sample was more mixed with patients who were Black or Black British, White, three patients were English, Welsh Scottish or Irish, three were Asian or Asian British, Caribbean, Pakistani and Irish.**
- **Carers sample : Both carers and carer's patients came from English, Welsh, Scottish, Northern Irish or British with smaller numbers of Black and Indian and Pakistani responses**
- **Friends and family sample was also heavily toward British and white will small number of other ethnicities represented.**
- **This is not unusual for this type of survey.**

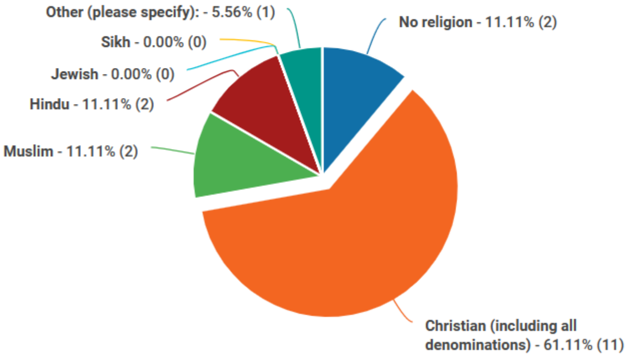


Answer Choices	Patient	Carer's Patient	Carer	F&F Patient	Friend & Fam
Asian or Asian British	3	0	1	0	0
Indian	0	4	3	0	0
Pakistani	1	2	1	0	0
Bangladeshi	0	0	0	0	0
Chinese	0	0	0	0	0
Any other Asian background	0	0	0	0	0
Black, Black British, Caribbean or African	4	4	3	1	1
Caribbean	2	0	0	0	0
African	0	0	1	1	1
Any other Black, Black British, or Caribbean background	0	0	1	0	0
Mixed or multiple ethnic groups	0	0	0	0	0
White and Black Caribbean	0	0	0	0	0
White and Black African	0	0	0	0	0
White and Asian	0	1	1	0	0
Any other Mixed or multiple ethnic background	0	0	1	0	0
White	4	23	23	7	8
English, Welsh, Scottish, Northern Irish or British	3	19	17	14	14
Irish	1	0	1	1	1
Gypsy or Irish Traveller	0	0	0	0	0
Roma	0	0	0	0	0
Any other White background	0	0	1	0	0
Other ethnic group	0	0	0	0	0
Arab	0	0	0	0	0
Any other ethnic group	0	0	0	0	0
Total	18	53	54	24	25

24- Demographics - Religion or Belief (PQ21, CQ26, FQ21)

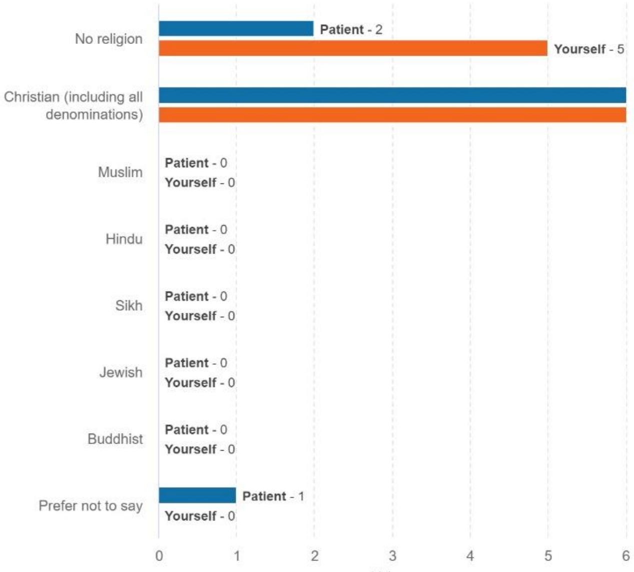
- **Most patient respondents were Christian as were carers with no religion being the next largest.**

Patient (n-18)



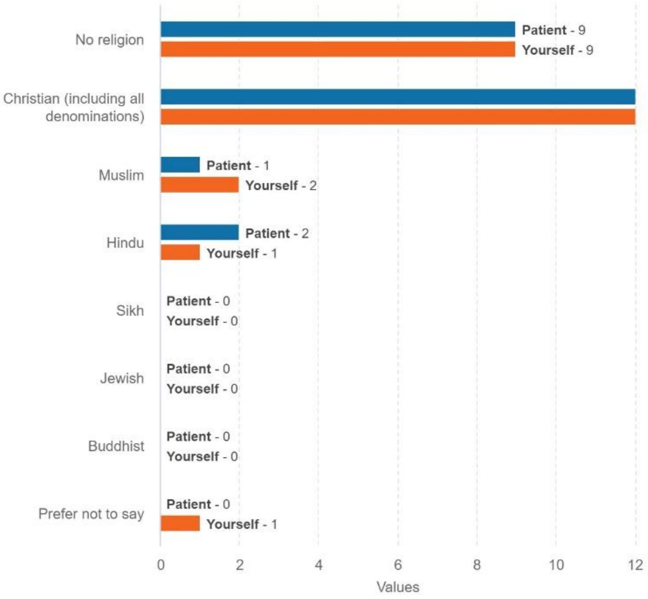
Friends and family(n=20)

What is your religion or belief?



Carers (n=41)

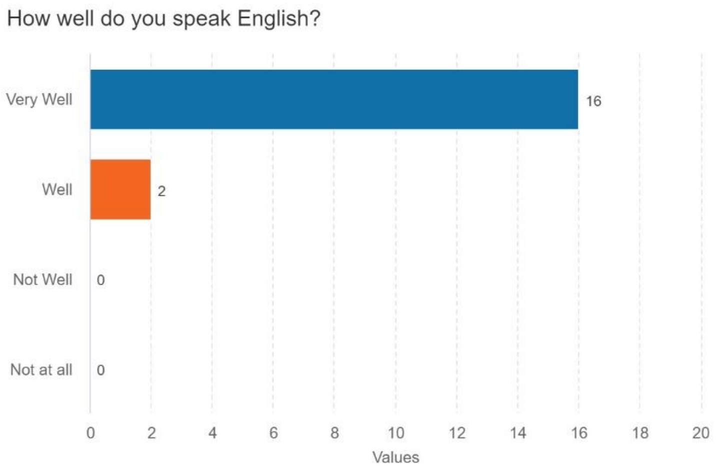
What is your religion or belief?



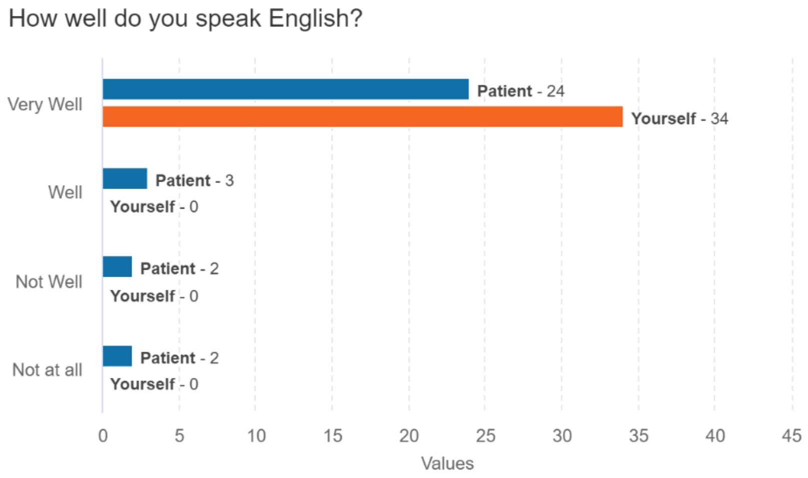
25- Level of English(PQ22, CQ27, FQ22)

- **Patients all spoke good English, either very well (16) or, well (2). Carers- Most patients (24) spoke English very well compared to 2 others who did not speak English.**

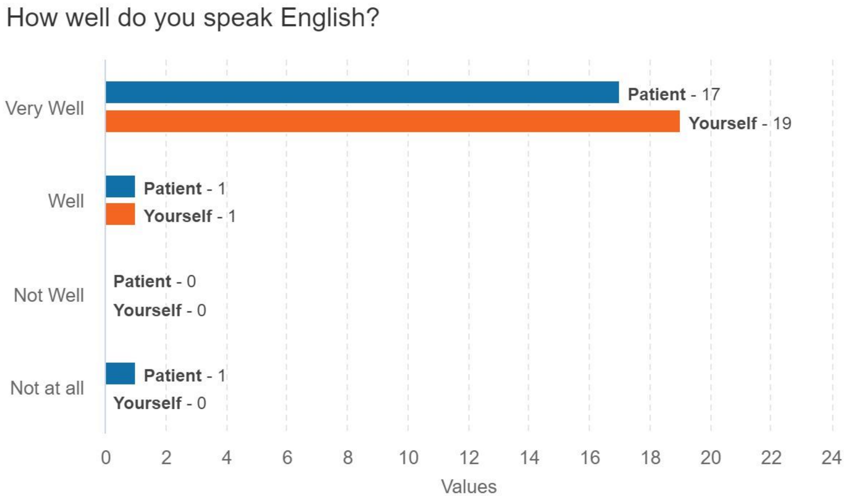
Patient (n=18)


How well do you speak English?

Carers (n=41)


How well do you speak English?

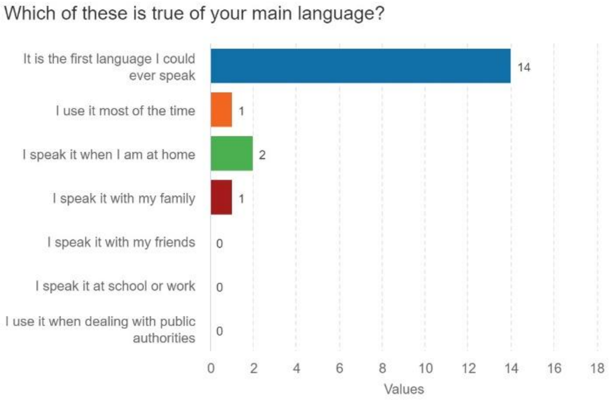
Friends and family(n=20)


How well do you speak English?

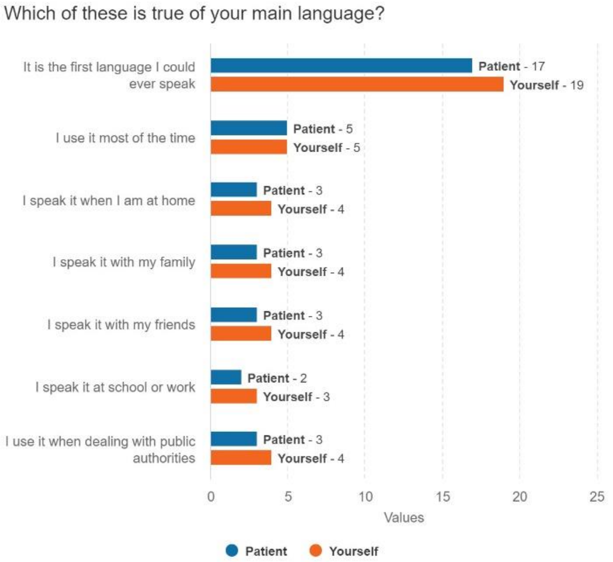
26 - Main Language (PQ23 and 24, CQ28 and 29, FQ23 and 24)

- **Patients, 13 speak English as main language, 5 speak others including Punjabi and Urdu, Tamil, Gujarati, Jamaican English and Spanish; Carers:-. 35 of carers spoke English and 2 others. 31 of the patients' main language was English with 4 others. Friends and Family: All 20 spoke English as main language 18 patient spoke English, one another language.**

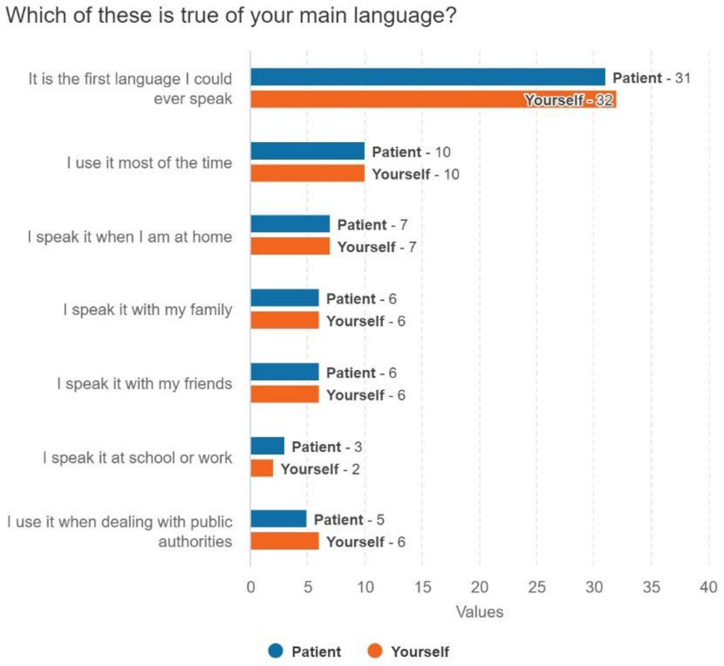
Patient (n-19)



Friends and family(n=20)



Carers (n=41)



27 - Area of Croydon (PQ25, CQ30, FQ25)

- Responses came from a range of areas in Croydon.

	Patient	Patient	Carer	Patient	Friend/ Family		Patient	Patient	Carer	Patient	Friend/ Family
Addington		1	1	1		**Sanderstead**		4	1	1	2
Addiscombe	2	1			3	**Selhurst**	1		2		
Ashburton						**Selsdon**	1	5	6	3	5
Beddington						**Shirley**	2	3	4	1	
Broad Green				1		**South Croydon**	1	3	4	1	
Coombe						**South Norwood**		2	1		
Coulsdon		1	1	1	2	**Thornton Heath**	2	6	6	1	1
East Croydon						**Upper Norwood**	1		1	1	
Crystal Palace		1	1			**Upper Shirley**					
Forestdale				1	1	**Waddon**		1	3	2	1
Hamsey Green						**West Croydon**	1		1	1	1
Kenley	1	1			1	**Woodcote**					
Monks Orchard						**Woodside**		1	1		
New Addington		2	1			**Whyteleafe**					
Norbury	2	1	1			**Merton- Borough**			1		
Norwood New Town						**Sutton- Borough**					
Old Coulsdon		1				**Bromley – Borough**					
Pollards Hill						**Surrey – County**				1	
Purley	1	4	4	1		**Wandsworth – Borough**					
Purley Oaks						**Southwark – Borough**					
Roundshaw						**Lewisham - Borough**					
						Lambeth - Borough		2			1

Appendix A - Question sets and methodology

Patient Questions	Question code	Carer Questions	Question code	Friends and Family Questions	Question code
		Are you a Carer of a person diagnosed with dementia?	CQ1	Do you have a relative or close friend diagnosed with dementia?	FQ1
Have you been diagnosed with dementia yourself?	PQ1				
What type of dementia do you have?	PQ2	What type of dementia does the person have?	CQ2	What type of dementia does the person have?	FQ2/ FQ5
		Do you have caring responsibilities for the person with dementia	CQ3	Do you have caring responsibilities for the person with dementia	FQ3
Please tell us where you live?	PQ3	Please tell us where the person with dementia lives?	CQ4	Please tell us where the person with dementia lives?	FQ4
				Please tell us where you live?	FQ6
How long did you wait for a diagnosis from the memory service after first going to the GP?	PQ4	How long did the person that you care for wait for a diagnosis from the memory service after first going to the GP?	CQ5	Do you know long your friend or relative had to wait for a diagnosis from the memory service after first going to the GP?	FQ7
At the point of diagnosis, were you satisfied with the information you were provided with about the following topics?	PQ5	At the point of diagnosis, were you satisfied with the information you were provided with about the following topics?	CQ6	At the point of diagnosis, do you know if your friend or relative was satisfied with the information you were provided with about the following topics?	FQ8
If you were dissatisfied with the level of information you received about any other topics related to the diagnosis, please provide details below:	PQ6	If you were dissatisfied with the level of information you received about any other topics related to the diagnosis, please provide details below:	CQ7		FQ8
Were you offered an opportunity to discuss your dementia with a GP or other health professional at a follow up appointment?	PQ7	Was the person that you care for offered an opportunity to discuss their dementia with a GP or other health professional at a follow up appointment?	CQ8	Do you know if the person was offered an opportunity to discuss your dementia with a GP or other health professional at a follow up appointment?	FQ9

Appendix A - Question sets and methodology

If you answered yes, did you talk about advance care planning?	PQ10	If yes, did they talk about advance care planning?	CQ13		
		How easy or difficult has it been to find information about caring and what you are entitled to as a carer of someone with dementia?	CQ11		
In the last 12 months, how confident have you felt in managing your dementia	PQ11	In the last 12 months, how confident have you felt in managing the dementia of the person you care for?	CQ14		
Have you been offered/received services that are appropriate to your needs and preferences?	PQ12	Has the person you care for been offered/received services that are appropriate to their needs and preferences?	CQ15	Do you feel that your friend or relative has been offered/received services that are appropriate to their needs and preferences?	FQ12
		In your experience, have you received or been offered help or support services that are appropriate for you in your role as a carer? (For example, learning courses, respite, peer support groups)	CQ16		
		Have you had a re-assessment of your dementia or care needs within the last 12 months?	CQ17		
What improvements to care and support services would be most useful?	PQ13	What improvements to care and support services would be most useful to the person you care for, and for you as a carer?	CQ18	n your opinion what improvements to care and support services would be most useful?	FQ13
In the event of moving into sheltered accommodation or care home, what is/would be important to you?	PQ14	In the event of the person you care for moving into sheltered accommodation or care home, what is/would be important to you?	CQ19	In the event of your friend or relative moving into sheltered accommodation or care home, what is/would be important to you?	FQ14
What would concern you most if you had to go into hospital?	PQ15	What would concern you most if the person you cared for had to go into hospital?	CQ20	What would concern you most, if your friend or relative had to go into hospital?	FQ15
What does making Croydon dementia friendly mean to you?	PQ16	What does making Croydon dementia friendly mean to you?	CQ21	What does making Croydon dementia friendly mean to you?	FQ16

Appendix A - Question sets and methodology

What is your age group?	PQ17	What is your age group?	CQ22	What is your age group?	FQ17
What is your gender?	PQ18	What is your gender?	CQ23	What is your gender?	FQ18
Which GP surgery is the person you care for/are you registered with?	PQ19	Which GP surgery is the person you care for/are you registered with?	CQ24	Which GP surgery is the person you care for/are you registered with?	FQ19
Which of the following best describes your ethnic group?	PQ20	Which of the following best describes your ethnic group?	CQ25	Which of the following best describes your ethnic group?	FQ20
What is your religion or belief?	PQ21	What is your religion or belief?	CQ26	What is your religion or belief?	FQ21
How well do you speak English?	PQ22	How well do you speak English?	CQ27	How well do you speak English?	FQ22
What is your main language?	PQ23	What is your main language?	CQ28	What is your main language?	FQ23
Which of these is true of your main language?	PQ24	Which of these is true of your main language?	CQ29	Which of these is true of your main language?	FQ24
Which area of Croydon do you currently live in?	PQ25	. Which area of Croydon do you currently live in?	CQ30	Which area of Croydon do you currently live in?	FQ25

Methodology:

This insight was derived from three separate surveys, which shared the same themes. Carers had some extra questions. To analyse we showed the results for each theme for patients, carer and their patient, and friends and family for each patient.

All surveys were completed online between 3 September 2022 and 25 October 2022 (Patients), 4 December 2022 (Carers), 5 December 2002 (Friends and Family).

Healthwatch Croydon

24 George Street
Croydon
CR0 1PB
www.healthwatchcroydon.co.uk
t: 0300 012 0235
e: info@healthwatchcroydon.co.uk

@HealthwatchCR0

HealthwatchCR0

healthwatch
Croydon