



# Gathering views and experiences of Dementia Support Services

## FINAL REPORT

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## **1. Introduction**

Healthwatch was established by the Health and Social Care Act 2012 to act as the community champion, supporting local people to get the best out of their services. Healthwatch Greenwich is an independent body of local voices working to influence the design and delivery of health and social care services, not just for the people who use them, but anyone who might need to use them in future.

In August 2015, Healthwatch Greenwich was commissioned by Royal Borough of Greenwich and Greenwich Clinical Commissioning Group to engage with people with dementia and carers of people with dementia to gather their views and experience of the support services in the borough. This report outlines the finding of this research.

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## **2. Background**

Locally and nationally, dementia is one of the greatest challenges facing our ageing population. As the size of the population increases and the longer people live, the number of people with dementia also grows. In the UK, it is estimated that there were 821,884 people living with dementia in 2014 and that it is predicted to be 850,000 in 2015. In Greenwich, it is predicted that there is 1,874 people living with dementia, with a predicted rise to 2,251 by 2021.

Because of this, improving dementia services is a national and local priority and in order to ensure services are shaped and delivered to fit local needs, Healthwatch Greenwich was tasked to find out service user and carers views and experiences of dementia support services. This way service users could be at the heart of designing the right service to achieve the best outcome.

## **3. Aim**

The main aim of the research was to undertake meaningful engagement with service users and carers to gain insight into the effectiveness of dementia support services and to what extent services are meeting their needs.

The focus was to find out:

- What services are being accessed?
- What is good?
- What is bad?
- What can be improved?
- Are there any gaps in service?

#### 4. Reach - Engaging widely

With the need to engage widely with a diverse population, Healthwatch Greenwich took extensive efforts to raise awareness of the research project with a comprehensive communications plan.

A specific flyer and poster were designed to promote the opportunity to take part in the research. These were distributed at all Healthwatch Greenwich's engagement activities. Following an identification that there was a lack of representation from the Somali community, a Somali translated poster was put up in the Islamic Centre, Woolwich Mosque and other venues frequented by members of the Somali community.

A dedicated section was created in the Healthwatch Greenwich website to provide information on the research and links to the online surveys. Both the September and October issue of the Healthwatch Greenwich eBulletin featured an article on the research encouraging people with dementia and carers to share their views of local support services. The research was promoted in a radio interview with Maritime Radio as well as our social media platforms, Twitter and Facebook.

To access service users and their carers, several visits were made to the services available to them. These included:

- Memory Clinic at Rowntree Centre in Memorial Hospital
- Crossroads Dementia Café
- Alzheimer's Society Dementia Café
- GAD's Let's Not Forget Club
- Carer's Centre Bistro

Part of our remit was to engage with minority and diverse groups including those with limited knowledge of English and to identify those not accessing services. Because of the established networks built in Healthwatch Greenwich's years of working within the community, Healthwatch Greenwich was able to work with a number of community groups and voluntary organisation to conduct the outreach. These included:

- Greenwich Pensioners Forum
- Caribbean 50+ Social Forum
- Greenwich Inclusion Project (GrIP)
- Carers Centre
- METRO Charity
- SAFFA - Gurkha group
- British Deaf Association - Greenwich

Targeted engagement was conducted using established contacts within:

- Nepalese community
- Somali community
- Black Afro Caribbean community
- Deaf community

In order to engage with those who do not take part in voluntary groups, we took part in several events and conducted activities such as:

- approaching individuals at an event celebrating International Older People's Day
- holding an information stall at a World Mental Health Day Event
- presenting at Woolwich Common Health day
- holding a pop up stall at Queen Elizabeth Hospital

## 5. Methodology

Healthwatch Greenwich was very conscious of the sensitive nature of the subject and the varying levels of abilities of participants and so adopted a number of methods to gather the information. The research involved a combination of semi-structured, one to one interviews (conducted face to face or on the phone), focus group discussions, and online surveys. All discussions were facilitated by a trained member of staff and effort was made to explain that all comments would be taken down anonymously and so allowed participants more freedom to express their honest opinions.

Of the 130 people, 46 responses came from one to one interviews, 41 responses came from focus group discussions, 36 responses were received from postal surveys and 7 were received from online surveys.

It was noted however that the responses from the interviews and focus groups provided richer data and gave a better sense of the service users and carers' stories as the semi-structured format made interactions more conversational without taking away the focus.

32% of service users who took part in this research are male, 68% are female. 10% of service users were aged 45-64, 21% are aged 65-74 and 68% are 75 years old and older. 73% are White British.

## 6. Findings

A total of 130 people took part in the research. This was made up of 61 people with dementia, 41 carers and 14 staff or volunteers and 14 'other'. This group 'other' will be explain further in the report (point 6.2.2).

### 6.1 What is good?

#### 6.1.1 Good experience of Memory Clinic

The majority of the service users and their carers interviewed at the Memory Clinic, and those who have stated they have used the Memory Clinic recently fed back good experiences of the service, describing it as helpful and informative. In fact, of all the participants who stated that they had enough information and support to make decisions about their care, 70% of people with dementia and 54% of carers identified Memory Clinic as the source of the information. Of all the services, the Memory Clinic was where the highest number of participants claimed they received useful information.

#### 6.1.2 Service users enjoy GAD Let's Not Forget Club

Every participant Healthwatch Greenwich interviewed who access the GAD Let's Not Forget Club fed back positive experiences of the service. Participants found it a good place to make friends and take part in activities;

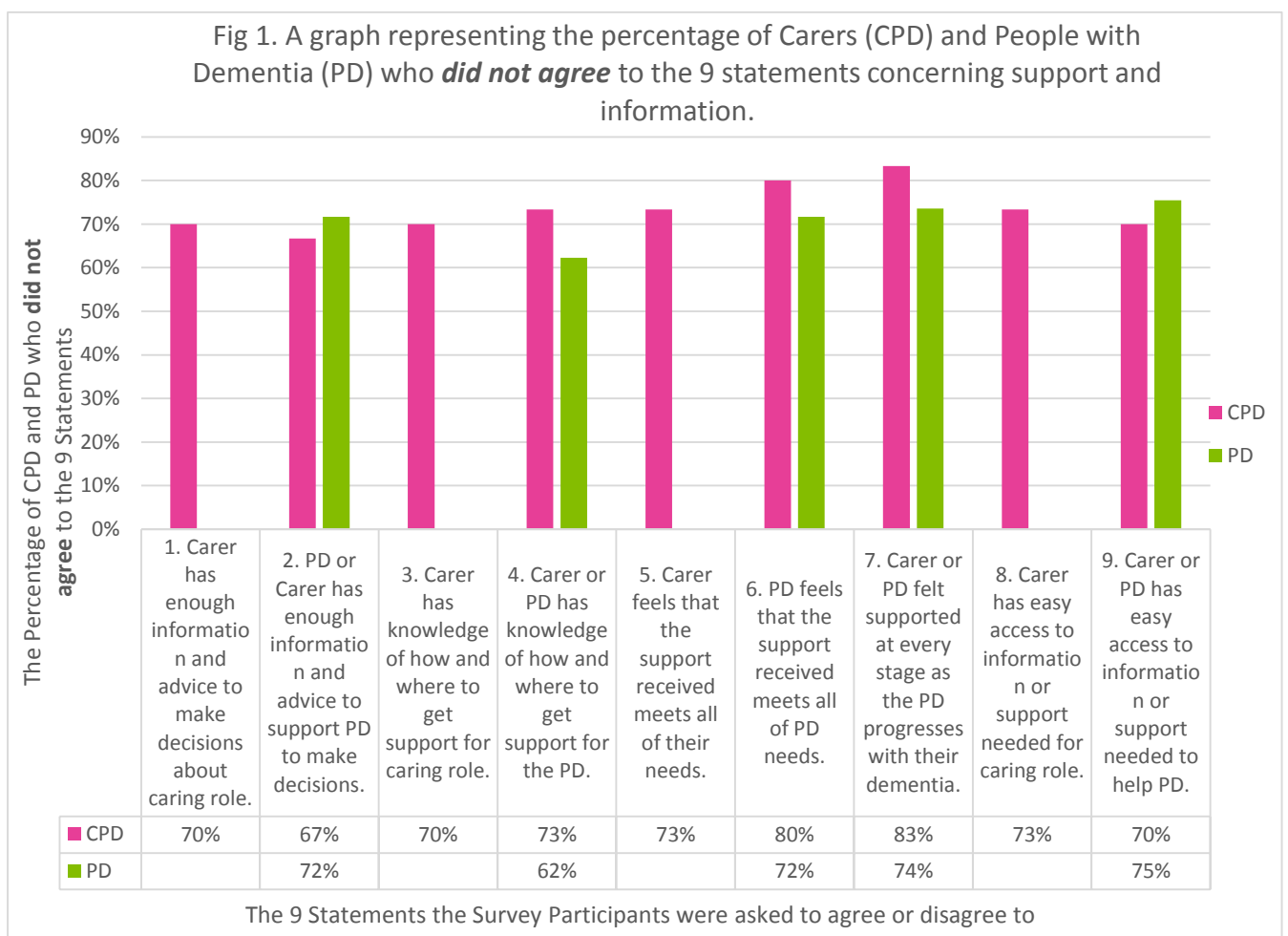
*“I attend this group every week and it’s a very good place to come to. Everyone is so friendly and helpful in lots of ways. We do lots of things every week and meet new people. I wish there were more places like this.”*

Both service users and carers felt that there should be more social groups like the Let’s Not Forget Club as it has helped improve their mental wellbeing and increase their physical activity.

## 6.2 What is bad?

### 6.2.1 Lack of information

The most pertinent issue raised from our engagement was the distinct lack of information. The majority of service users and their carers involved in the research did not agree that they had enough information to manage their care or had enough knowledge about support available as their dementia progresses.



This table (Fig.1) shows that the majority of the people with dementia (72% - 44 people) and carers of people with dementia (67%- 28 people) interviewed, did not feel that they had enough information and advice to make decision for themselves and for the cared for, leaving them with a sense of helplessness;

*“When the dementia got worse, we had to call an independent charity helpline as we did not know what to do or how to cope”*

Carers particularly indicated that they did not feel confident in their caring role and at least 20% of carers explicitly asked for a tool kit or guide on how dementia can affect the person they care for and how best to care for them. This was supported by staff and volunteers who participated in the research who expressed a need for training and support for carers to be more informed and fit for their caring role.

### 6.2.2 Lack of awareness - not getting diagnosed

Of the 61 participants with dementia, 14 people had not been formally diagnosed with dementia but displayed signs of dementia reporting to having regular problems with finding the correct words to say, misplacing things often, forgetting some important appointments, irregular speech pattern (unable to hold a linear or steady sequence of events when describing events or recalling stories) which sometimes resulted with irritation, a much better memory of things that happened many years ago in the past as opposed to things that happened very recently, and other such symptoms.

This group of participants came from the Nepalese community and explained that they believed the symptoms outlined above were a 'normal part of the ageing' and so would not seek medical advice for it.

*“Memory loss is normal for an old person like me. I wouldn’t bother a doctor about that.”*

The Nepalese participants felt reluctant to go to their GP with mental health issues and would only discuss physical symptoms.

This fact was further emphasised when engaging with the Somali community. After extensive engagement with the Somali community, Healthwatch Greenwich facilitated discussion with 14 Somali elders. This is the group classed as 'other'. The outstanding feedback received from the group was;

*“We don’t have dementia in the Somali Community”*

Members of the Somali community did not recognise dementia as a medical condition and insisted that memory loss is a normal part of old age, no matter how severe. Because of this fact, members of the community would not seek medical help for signs of memory loss and would care for their older generation within the community.

## 6.3 What can be improved?

### 6.3.1 GP identification of dementia signs and care

Amongst the participants, there was a suggestion that GPs should receive more training to enable them to identify early signs of dementia. One participant claimed;

*“I did not feel my GP knew or understood dementia”*

A small number of participants felt that things had deteriorated dramatically before any support was provided;

*“My husband’s memory and general cognitive and behavioural condition was going steadily worse but it was not until he completely failed his memory test at the GP’s that he was referral to the Memory Clinic. I feel we did not get much support until then”*

Participants expressed a view that GPs may not be fully equipped to make an early assessment for dementia as questions are a “blunt tool” and suggested that GPs should be trained to recognise people skilled in ‘hiding’ their condition.

### 6.3.2 Follow up - continued care

As identified in the Fig 1, 74% of people with dementia 83% of carers interviewed did not agree that they felt supported at every stage of the dementia's progress. As one participant explained;

*“Help should not stop at the doctor's door”*

A number of people with dementia and carers expressed concern for their future and how they will cope with the dementia and expressed a need for ongoing support and regular check-ups so that they could have the chance to feedback and get some reassurance. One participant stated;

*“I would like some follow up. I haven't seen anyone in months. I feel abandoned”*

Participants have suggested that a doctor (perhaps GP) could check on physical health as well as cognitive ability on a regular basis so that the person wellbeing as a whole could be reviewed.

### 6.3.3 Better transport service

A number of respondents felt that transport services such as dial-a-ride could be improved as it does not currently provide a reliable and consistent service. The problem with transport was also cited as a barrier to accessing services;

*“We are registered to use the memory clinic but we hardly use it because it is so difficult to get there. We don't have a car and taxis are so expensive”*

and

*“I used to take my wife singing but can't do it anymore because of travel difficulties”*

It is evident that there is a demand for improved transport service as carers felt that travelling with a person with dementia is a costly and difficult task which public transport in general are not good for and so assistance is needed.

One participant also suggested that transport service provide more of a role in assisting service users into and out of the car. However as service users are not able to travel without a chaperone, this particular participant deemed it of no use to them.

### 6.3.4 Sharing information between services

Of the 14 participants who were staff and volunteers (former or current), the main suggestion raised was for there to be better communication streams between services and particularly with GPs. Many participants did not feel that there was good integration between the services available to people with dementia and their carers and suggested that:

*“There is a need for regular networking meeting, emails, groups or newsletters. Need to remove the fear of 'sharing clients and carers' and an agreement from clients and carers that their data can be shared at referral”*

Services working together would improve the care pathway for people with dementia as it would allow for identification of care needs and avoid service users 'slipping through the net'.

### 6.3.5 Ensure all service users feel they are treated with dignity and respect

Of all the responses that answered the question: 'Do you feel you have been treated with dignity and respect?' 72% answered yes, 19% answered no and 6% answered sometimes. Healthwatch Greenwich is pleased that the majority felt



that they have been treated with dignity and respect, however would like service providers ensure that all service users feel this way.

The majority of those who expressed that they did not feel that they were treated with dignity or respect came from BME communities;

*“Not speaking English makes me feel invisible”*

BME participants felt that they more work could be done with GP in particular to recognise that

## 6.4 Gaps in service

### 6.4.1 No dedicated service for people with young onset dementia

Healthwatch Greenwich was tasked to identify and engage with people with young onset dementia and was pleased to reach four people aged between 45-64 years old with a diagnosis of dementia. In our scoping exercise, identifying opportunities to engage with people with young onset dementia highlighted a gap in service provision as there was no service specifically dedicated to them. A group for young onset dementia is provided by Alzheimer’s Society in the borough of Bexley but there is no equivalent in Greenwich. This gap in service was also identified by a carer of a person with young onset dementia;

*“The best thing would be if there were groups of similar people to my husband (who is 64) for him to join regularly in the week for a few hours so he can have a break for a few hours and I can have a break from care.*

*[I would like] more stimulation and variety for my husband as he himself has said that he is bored at home”*

Provision of a service for people with young onset dementia would hence provide both the social aspect for the people with dementia and respite for their carers.

### 6.4.1 No provision of service specifically for BME service users

Emphasising the issues raised by the Nepalese engagement, Healthwatch Greenwich received several comments that there were no services available to them as they did not speak English;

*“I am a Black African man and I feel that there is no help available to me and my community as they [service providers] don’t speak my language. I feel out of place and that unless I speak English, there is no support for me”*

25% of service users and carers interviewed felt that the language barrier was the main reason they did not access services and therefore did not feel supported in managing their care.

Some participants noted that they would request for interpreters but one was not always available. Furthermore, due to a lack of English and also partly due to illiteracy, some participants found no use in translated information provided online and in publications such as flyers or information packs. As a result participants feel isolated from and marginalised by the services.

### 6.4.2 More support for carers

As already stated earlier in the report carers has expressed a need for support in their caring role. As well as a carer’s tool kit, around 32% of carers have explicitly requested for respite or some such similar services. Of the carers, around 40% are not aware of any respite services available or how to access them. Carers have emphasised that their caring role puts a strain on them emotionally and physically;

*“I am the sole carer for my mother who has dementia and psychosis. It is a 24 hour, 7 day a week responsibility. It’s really hard for me and I feel awful that my mother has to take medication which keeps her quiet and subdued during the day”*

Carers have expressed difficulty watching their loved ones’ dementia progress and not recognising the person they are becoming. Because of this, some carers have said they feel lonely but have not sought help as there is a sense of guilt, shame and worry in admitting the difficulties they are having in their caring role. It is evident that support for the wellbeing of carers is essential to ensure that they can continue to fulfil their caring role.

## **7. Conclusion**

By engaging with a diverse population, people with dementia, carers, staff and volunteers, this research has provided a valuable insight into the views and experiences of dementia support services in Greenwich. Positive feedback has been received about particular services and a wealth of ideas have been generated on how to improve the care and support for people with dementia and their carers.

One of the significant issues raised in the research is that participants feel that there is lack of information about available support services and a lack of awareness about dementia in general. Because of this, many participants do not feel supported in the management of their dementia or the dementia of the person they care for. Due to a lack of awareness, many who may need it are not getting a diagnosis or receiving further help.

The engagement conducted with a number of groups has highlighted the need for services to be tailored to their particular needs. Certain BME groups, those with young onset dementia and carers have all specifically asked for support where they feel it is missing. Particular request have been made for support groups targeted to BME groups and people with young onset dementia, and more support and respite provided to carers to help them in their caring role.

Healthwatch Greenwich suggests that further effort is made to involve service users and carers in the design of future services to tailor them to best suits their needs.

## **8. Next steps**

This report was presented to the Dementia Implementation Group on 9<sup>th</sup> December 2015 to highlight the areas for service change. The Dementia Implementation Group is made up of both commissioners and providers of dementia services in Greenwich who work together to improve services for the service user, their families and carers. The report was positively received and a commitment was made to use the findings of this report to inform the Greenwich Dementia Strategy and the service specification for the Greenwich Dementia Support Services.

Healthwatch Greenwich has a role to influence change and will join the next meeting of the Dementia Implementation Group on 10<sup>th</sup> February 2016 to agree actions following the publication of the report.

Healthwatch Greenwich will endeavour to promote the findings widely and to feedback specifically to all research participants in order to show the value of their input and to demonstrate that their contribution has led to agreed actions.

## **9. Acknowledgements**

Healthwatch Greenwich would like to thank all the service users and their carers who took part in this research. We would also like to thank our partners within the voluntary and statutory sector for their help and support in completing this research.