Living with Dementia in London 2023

April 2023

Care City

UCLPartners

NHS
London
Clinical Networks

Contents

Glossary

What is dementia?

Dementia is a term used to describe a range of cognitive and behavioural symptoms that can include memory loss, problems with reasoning and communication and change in personality, and that cause a reduction in a person's ability to carry out daily activities, such as shopping, washing, dressing and cooking. Dementia is a progressive condition, so the symptoms will gradually worsen. This progression will vary from person to person, and each will experience dementia differently – people may often have some of the same general symptoms, but the degree to which these affect each person will vary. The most common types of dementia are Alzheimer's disease, vascular dementia, mixed dementia, dementia with Lewy bodies and frontotemporal dementia (based on the Dementia Gateway, Social Care Institute for Excellence).

What is an ICS or ICB?

Clinical commissioning groups (CCGs) were clinically-led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area. At their peak, there were 211 CCGs. On 1 July 2022, Integrated Care Systems (ICSs) became legally established through the Health and Care Act 2022, and CCGs were closed down. Integrating health and care is about removing traditional barriers between services so people can seamlessly access the support and care they need from the NHS and social care services.

Integrated Care Boards (ICB)

The Integrated Care Board holds responsibility for planning NHS services, including those previously designed by clinical commissioning groups (CCGs). As well as chairs and chief executives, board members include 'partner' members drawn from local authorities, NHS trusts/foundation trusts and primary care. The ICB should ensure that services are in place to deliver the Integrated Care Board strategy developed with partnerships.

Integrated Care System (ICS)

This system brings together the health and care organisations in a particular local area to work together more closely. There are 42 ICSs across England, and they were formally established as legal entities in July 2022. Each Integrated Care system is responsible for planning health and care services in its area. Each one comprises an Integrated Care Board and an Integrated Care Partnership, which work in tandem to meet the needs of their population.

Other terms

Carer

We use this term for unpaid people who support a person with a health condition. This carer is often a family member or friend of the person.

Care Worker

We use this term for people paid by a social care provider or local authority to support a person with a health condition.

Executive Summary

Dementia has been the leading cause of death in the UK[1] and has been so since 2016. It is becoming more common and is affecting significant numbers of younger people. Estimations show that social care costs will triple by 2040[2]. Dementia affects a person's memory, function, and sense of identity. It attacks the very things that make us who we are. It exacts a toll not just on the person living with dementia but also their carers and family.

This evaluation of dementia services in London revealed a fragmented and unsatisfactory experience for the almost 73,000 people in London with dementia and their carers. While pockets of good practice were identified, they were often overwhelmed by demand and a lack of provision in neighbouring boroughs. Those living with dementia often felt "ignored" and "disrespected". At the same time, carers struggled with the emotional and physical impact of caring for someone with dementia and the administrative burden of an uncoordinated health and social care system.

Although they had received a diagnosis of dementia, more than three-quarters of people (77.4%) were unfamiliar with national dementia guidance. Nine out of ten carers (93.8%) were not offered a coping strategies intervention after their loved one was diagnosed. Despite London's multicultural makeup, we did not find a single person who had been provided information in a language other than English.

Many were concerned about carer burnout. They felt the need for therapy to help those living with dementia and their carers cope as the condition progresses. The dementia pathway was often unfavourably compared to other health conditions. People feel that GPs and social services are "unreachable" and "unsympathetic". Systemic issues were also identified, such as a lack of good leadership within health and social care settings, few agreements between health and care providers to share necessary information, and inadequate staff training.

> **Despite all the problems people living with dementia face, what we found they wanted was realistic, practical and achievable.**

There is a need for better coordination between health and social care services for people living with dementia. Participants in the evaluation noted that health and social care providers were hard to make contact with and seemed to work in silos, with few data sharing protocols or inadequate training even for staff dedicated to supporting people living with dementia. However, the evaluation also identified pockets of good practice and highlighted the importance of listening to the voices of those affected by dementia to inform future service provision.

Despite all the problems people living with dementia face, what we found they wanted was realistic, practical and achievable. People living with dementia want to live as independently as possible in their own homes. They would like annual health checks, a personalised plan with guidance in their language, and someone they can call for advice. By responding to this demand at a London-wide and Integrated Care Board level, it should be possible to improve the lives of people living with dementia and their carers significantly.

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[1] **ONS Data**

[2] **Sustaining community-based interventions for people affected by dementia long term: the SCI-Dem realist review**

About Care City

Care City is an innovation centre for healthy ageing and regeneration. Our mission is a happier, healthier older age for East Londoners. We pursue this mission by working as an innovation partner to East London's health and care system. We do research, innovation and development work of local benefit and national significance. Care City was commissioned by NHS England (London) Dementia Clinical Network and worked in partnership with UCLPartners on the research and development of this report.

About London Dementia Clinical Network

The NHS England (London) Dementia Clinical Network (LDCN) brings together clinicians, commissioners, people living with dementia and their carers to support improvements in dementia services, so that people living with dementia receive an effective and timely diagnosis and evidence -based treatment and care.

About UCLPartners

UCLPartners is a health innovation partnership. Their mission is to help five million people from North London to the Essex coast live longer, healthier lives. They solve the biggest health challenges through research and innovation, speeding up the delivery of solutions that improve health and care.

Methodology

Aims

The London Dementia Clinical Network (LDCN) received funding from the London Health and Care Partnership 2021-2022 to develop an ICS commissioning framework for post-diagnostic care for people living with dementia. The work is being carried out in four phases:

1. Map post-diagnosis dementia care across London (**Appendix A**)
2. Reflections from people living dementia, family, carers and healthcare professions to identify gaps and best practice (described in this report).
3. Develop guidance for a best-practice dementia care pathway
4. Run a pilot of the pathway.

Approach

The evaluation of current service provision started in April 2022. Initially the evaluation took covered just North East London from June 2022 to July 2022. Refinements and the Topic Guide for workshops and interviews were updated (**Appendix C**). A London-wide evaluation (**Appendix D**) of the health care experience of people living with dementia took place from August 2022 to December 2022.

Group sessions were arranged in each London ICS area for individual interviews or discussion focus groups. Interviews were also conducted with individuals who responded to our flyer (**Appendix E**). Capacity to consent, GDPR and dementia-friendly interview processes were observed throughout the evaluation. We would have expected higher response levels, but numerous focus groups had to be cancelled due to staff having coronavirus, transportation strikes, the state funeral of the Queen and venues shutting during the summer heatwave.

Figure 1: Responses

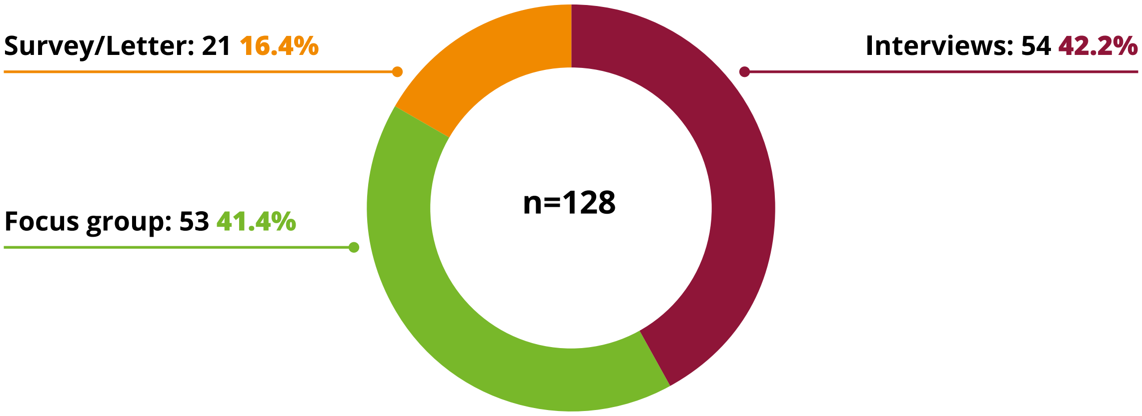
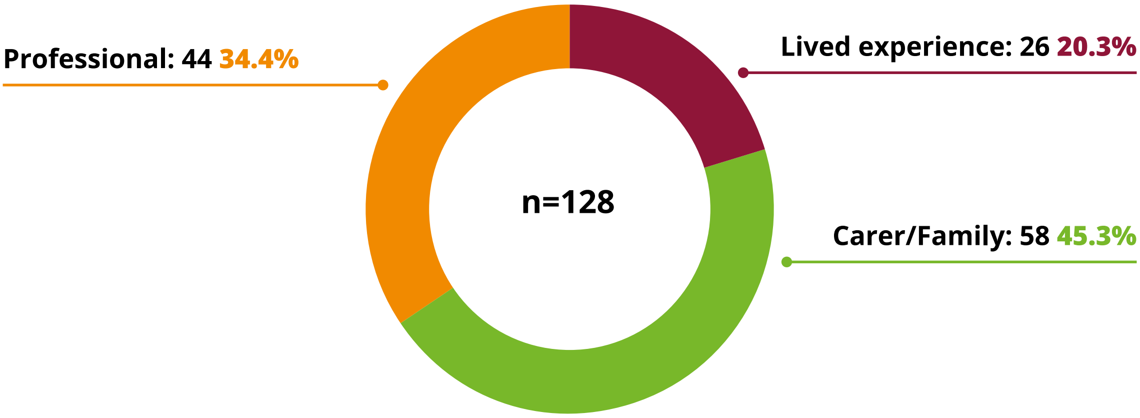
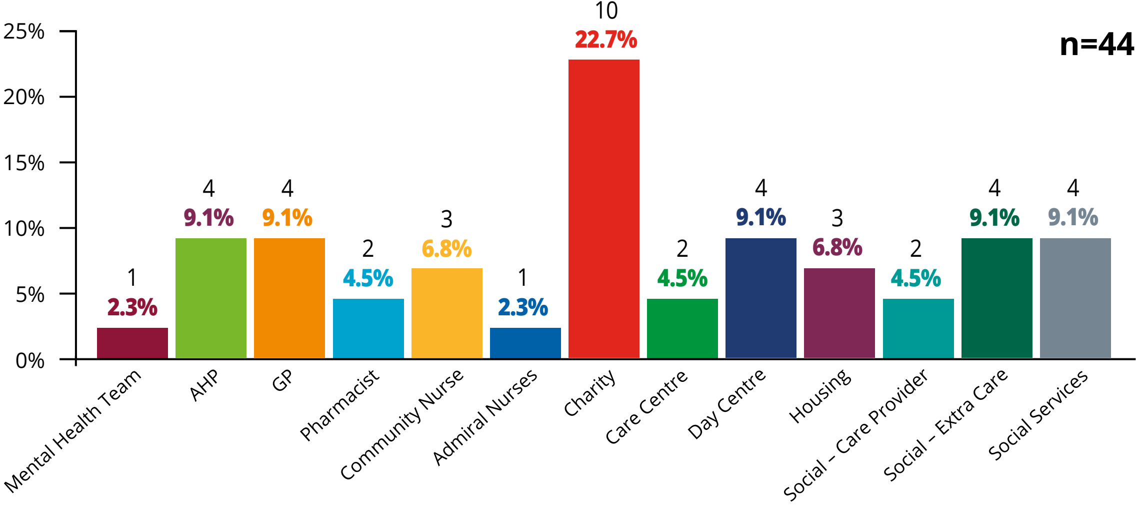


Figure 2: Relationship



Efforts were made to match the participant demographics (**Appendix B**) to the London demographics based on Office of National Statistics (ONS) data. 66% of particants were non-white British. 52% identified as female, 45% identified as male. Speakers of 17 languages other than English participated.

Figure 3: Professionals' field of expertise



Evaluation

Each sentence in the interviews were organised into themes. Focus group notes and survey responses were then added to the thematic headings. A summary of the thematic review has been provided in this report.

A review of the summary was completed in December 2022 with a focus group of carers and professionals. This resulted in clarification to the section 'What does good look like in London 2023?'

Those involved with collecting comments found it to have an emotional impact. Please consider this before viewing this material. Quotes recorded do not necessarily reflect the opinions or values of those carrying out this evaluation.

Positive Experiences of Living with Dementia in London

> ***People living with dementia and their family and carers appreciate the hard work done by experienced individuals or teams who want to make a difference. Carer's centres and charities help connect peers and provide a supportive network to resolve issues. People appreciated having support within their own homes and in their language. People felt secure when taught more about dementia, their rights, and options for supporting people living with dementia.***

Personal connections

Personal connections are the most valued part of the pathway. The primary connection for most people is between the person living with dementia and their family or carer. They said that the connection between themselves and their carer played "a more significant role" with dementia than it did with other health conditions they had.

Despite frustration with systems and processes, those living with dementia and their carers appreciate the individual professionals who actively support them. They appreciate care workers, GPs, and social workers who have experience with dementia care.

Valued organisations and teams

Peer support

Many people living with dementia spoke of their appreciation for peer support groups and the connections they make there. Family members and carers also greatly appreciated these groups, especially carer's centres. These centres provide signposting, emotional support, and practical educational sessions.

Many appreciate peer sessions as they say they are filled with "good humour" and "fun", even when discussing topics that some consider taboo, such as end-of-life. Even after their caring role ends, people still go to these groups as they have created friendships and receive emotional support. Some sessions also provide a break for carers from being solely supportive of the person they are caring for.

NHS

Occupational therapists, physiotherapists, and community treatment teams were singled out as providing the most significant practical help for those living with dementia. People also value the accessibility of these teams once they have been referred.

Professionals highlighted the organisations they value the most, such as local dementia hubs and day centres and dedicated dementia health teams. These represent a bank of knowledge and resources that are especially helpful to professionals dealing with rare or complex situations.

Community

Although not available in every part of London, Admiral nurses[3] (specialist dementia nurses) held the role most commented on for the depth of their experience in helping families, carers and professionals. People also listed the organisations that helped them, either in their dementia journey or professionally. The most commented on was the Alzheimer's Society, with Age UK and Dementia UK also highly recommended. These organisations typically provide peer support sessions, activities, advice, and information.

Valued approaches and ways of working

People value having their health reviews in their homes, as unfamiliar locations can be unsettling for many people living with dementia. This was also preferred as it did not involve travel or waiting rooms, which some found challenging. Others noted that those whose first language is not English appreciate having someone speak to them in their language. These approaches result in lower agitation for the person living with dementia.

Medical professionals valued systems that provided them with a brief patient background, such as hospital passports and integrated electronic patient record systems (EPRS).

Other interventions were highlighted as beneficial for people living with dementia. For example, many people involved with cognitive stimulation sessions feel these have benefits. Others really appreciate social prescribing.

Valued education

Many family members of those living with dementia, their carers and health and care professionals noted that they benefited from educational sessions or formal training in dementia. Staff reported that it not only makes them more knowledgeable about dementia but also helps them to be more "empathetic" and "considerate". Staff also commented that it had "improved their resilience in the workplace".

> ***I feel that the training I have received has given me some essential skills and a refreshed understanding of how to support individuals living with dementia.***
> Day Centre professional

Most of the people we spoke to are familiar with the concept of Power of Attorney. They have found this valuable in supporting a person living with dementia. Legal advice about end-of-life and finances was also considered helpful. Advance care plans, advance statements and advance directives were also crucial to those who knew about them; however, we found that fewer people were aware of them.

Commentary for commissioners

> ***People said they need spaces and opportunities to speak with people in similar situations. It is essential for people to be heard and know they are not alone. Traditionally this was done using day centres and carer centres, but these are being phased out. Commissioners need to consider how they can meet this need creatively.***

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[3] **Dementia UK – What is an Admiral nurse?**

Where People Turn for Advice in Times of Need

Information and advice

Several people commented that they usually use the Internet to find an answer to a question before going to other people. This channel is not a universally used source due to the digital divide (the gulf between those who have access and skills to use computers and the internet and those who do not); however, it is becoming more popular.

Some living with dementia and their family or carers contact their dementia support group or carers centre for advice.

GPs told us they ask the memory assessment service, a specialist service where people with memory loss can be assessed and diagnosed, for advice.

Most other health professionals and professionals from social care, housing and other providers told us they usually consult with others in their organisation for guidance.

Housing providers, especially those who provide housing for people aged 55+, noted they have unique issues with contacting health services. Housing for people aged 55+ often has staff on site; however, these are housing professionals, not healthcare professionals. If housing staff do not get a timely response from normal health advice channels, they feel pressured into contacting emergency services to mitigate risk, thereby burdening emergency services. Housing providers told us this is due to a need for more training in dementia, the healthcare ways of working and risk management. These issues are not just limited to health; residents are at times also being deprived of liberty without authorisation.

When facing challenges

The GP of the person living with dementia is the first point of contact for post-diagnostic support in the vast majority of cases.

After GPs, there was a smaller and broader mix of responses. Some go to the memory assessment service because they associate that clinic with expertise in dementia. People also contact social services, Admiral nurses, the community care team or their housing provider if they have a representative on-site – such as with housing for people aged 55+. Overall, people go to those they trust, or have resolved previous issues.

"At Crisis"

During a "crisis", most family members, carers and care workers contact emergency services[4]. Others turn to their GP, social services, or the community care team (if contact has already been established) in times of crisis.

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[4] This was also highlighted in the recent report *Providing viable dementia care services in NEL*. There is a cohort, identified by ambulance crews, that is struggling with dementia, not engaging with medical services, and has no social care coordination for a variety of reasons. Ambulance crews know that such people need support but are unsure who can help. It was noted that a local carers centre had provided promotional material for their services to these crews.

Commentary for commissioners

> ***Regardless of the appropriateness of the channel people use, ensuring that those at the end of these channels have access to the correct information or can signpost is critical.***
>
> ***It is, therefore, essential to ensure GPs and emergency services are knowledgeable and up-to-date with the pathway and have the necessary information to signpost people to the support they need. This highlights the importance of making sure existing directories of service include what dementia support is currently available locally.***

What are the Challenges for Londoners with Dementia?

Challenges for those living with dementia

> ***People living with dementia often said they feel "ignored" and "disrespected". To cope with and manage their condition, those living with dementia often create rigid routines. Their families were worried about them when they lived alone as they were concerned about what they thought of as risky behaviour, or that they could become victims of abuse.***
>
> ***People struggle with the impact of being informed about a diagnosis of dementia. It was felt that this within itself was a "traumatic" experience. It often takes people months to know the questions they want to ask after receiving a diagnosis.***

Those living with dementia feel they are not "heard" and are often "disrespected". Others had heard from people living with dementia about similar feelings of being unheard and ignored.

Some living with dementia use routine to combat their sense of loss of control. For them, it is crucial that they maintain a sense of control. Processes that do not allow those living with dementia to have control or don't work with their schedules increase their distress.

Dementia is not always a person's only condition. Some people living with dementia felt that mental health professionals were more willing to be flexible and make adjustments to their medical appointments.

Families, carers and professionals are concerned when someone living with dementia is living alone. They are concerned that the person living with dementia might lack insight into their condition and neglect tasks such as eating or sleeping. Many are concerned about the person living with dementia being at higher risk of abuse, such as financial abuse or discrimination.

Carers often know the triggers for what can make the person living with dementia distressed and techiques to minimise this for the individual. They want to be used as a source of information for care providers and to be involved in developing care plans.

Debbie’s story

> “ I’m Debbie. I am a mother. I have a nice partner, I worked in the City for quite a long time, I had a really good career… So I was a money broker in the City and I moved to a few different companies, but because my big client was Barclays, I could do what I wanted.
>
> But then I went through one stage where I was losing things all the time.
>
> The memory clinic was a nightmare. It was as if I was talking to the blinds because no one was listening. I don’t get upset easily but this woman, she literally made me cry.
>
> My husband was frustrated because she was talking to him and asked him the questions. She directed all the conversation to my husband. It was as if I wasn’t there. My other half said ”Come, we’re going”.

Challenges for those living with young onset dementia

It was noted by many that the support needs for people living with young-onset dementia differ. Some healthcare professionals reported seeing an increase in those with young-onset dementia. People living with young onset dementia are more likely to struggle to get a diagnosis. This “struggle” makes some people living with young-onset dementia feel “anxiety and depression” and does not stop following diagnosis. This is why some said they lacked trust in the health service.

Many feel the interventions and support are aimed at older people and are not suitable for them. They also want to have more physically active interventions than just traditional psychosocial support.

People living with young-onset dementia wanted to highlight how losing a job due to dementia at working age might have a more significant impact than developed it when after retirement. For example, people with young-onset dementia may have more financial dependents.

Family and carers often have a dual caring role for elderly parents and the person with young onset dementia. There is also an emotional toll on the young children of people with young onset dementia who can be of school age or younger.

> **“** ***... a wife that’s just had a baby, and then the husband’s been diagnosed [with young onset dementia]...***
>
> Person living with dementia at focus group

Challenges with the digital-first approach

Some people living with dementia told us they wanted to access health services digitally. However, the ‘digital-first approach’ taken as the primary way to access or use their services is causing concern.

For some, it is an issue with not having devices that allow them access to the internet, often due to cost. Although it was noted that this was less of an issue since a surge of such devices became popular during the coronavirus pandemic lockdowns.

For others, it is a skills issue, lacking the ability to use smartphones, tablets or remote communication software. Without a clear alternative way to engage with services or support, some people living with dementia said they struggled.

Challenges for the families and carers

> ***Carers struggle with the emotional impact of dementia and the physical toll of supporting someone whose has needs 24/7. Carers feel this isolates them and significantly impacts their family life, as well as their finances, housing and employment. They struggle to cope with the administrative load.***
>
> ***Many are concerned about carer burnout. Carers struggle to cope with managing dementia, and they need support to continue in the role. Carers want help with the administrative burden of an uncoordinated and antiquated healthcare system. Both those living with dementia and their carers need therapy to help them transition to cope with the demands of dementia.***

Family members and carers told us it is hard to find relevant, personalised information on dementia. They are either overloaded with generic information and fail to find what they are looking for or struggle to find anything about their situation.

They also struggle to absorb information at the point of diagnosis. Even if they are prepared for the diagnosis, they are hit emotionally with the weight and reality of it. Carers told us it took them a long time to process the diagnosis and months to be emotionally prepared to absorb information.

The caring role has a significant impact on the person delivering it. One aspect is the emotional toil of caring for someone with dementia. Healthcare professionals felt that carers need more support with this. For example, dementia can often affect a person's sleep patterns so the caring role can become an ongoing challenge without sufficient sleep. Others struggle with behaviour that may be challenging, such as physical or verbal abuse or demonstrating repetitive behaviour or communication. Carers are often described as "exhausted" or "at breaking point".

Carers can feel they are failing when the person living with dementia's condition deteriorates.

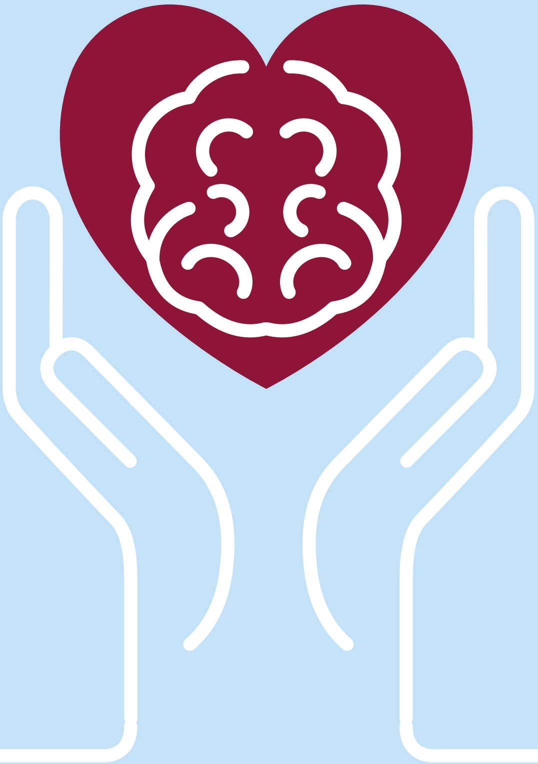
> ***We've had a few carers that actually deteriorated in their own mental health and wellbeing due to that carer responsibility. And in fact, we've had a couple recently that even contemplate suicide. Not only for them but for the person that they were caring for.***
>
> Care Centre professional

Dementia has a significant impact on family life. People living with dementia may forget their partners and object to their presence. Those caring for elderly parents with dementia who do not live with them can spend much time away from other members of their families. Should the person living with dementia move in with their family, this also impacts the family dynamic. Even relatively straightforward tasks such as managing household pets can become an issue.

Professionals felt that carers only ask for support when they reach burnout or crisis point. Many reported a struggle to engage with social services. Social services can respond, but responses take time, and social worker caseloads are high. It would be easier for carers to engage with social services before an issue gets to a crisis. However, demand for social services is so high that it seems to many that social services only can respond to crisis cases.

Shona's story[5]

> *Today was a hard day. My husband Derek passed away this morning. Once they took his body away, I was at home alone, for the first time in a long time. I kept thinking, 'what am I going to do now?' 'How will I carry on?' I am 72 and my life has revolved around caring for him for the past six years.*
>
> *I suddenly remembered that I had arranged to attend this focus group and I felt I owed it to my late husband to tell his story.*
>
> *When Derek first started losing his way on the way back from the shops, I started to get worried. Our GP thought it was depression and did not look into it as he said there was no treatment for it anyway. I kept going back and eventually our GP did a referral to the memory clinic for assessment.*
>
> *Then we were left really a bit on our own, sort of like, oh, he was diagnosed with dementia and that was it. Being married to someone living with dementia, it's like... was like... living with a stranger. Derek was unable to dress himself or to shower. He was not able to comprehend that he was no longer able to work. It was hard.*
>
> *I came here today, on the day my husband died, as I want to see change, I had to come. If I don't help people who are trying to make things better then I'm part of the problem, not the solution, and I don't want that to happen.*



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[5] Names in this account have been changed. Statements have been reconstructed from notes.

Despite this, most family members and carers don't want the person living with dementia to move from the family home. They worry about the person becoming "institutionalised" and are concerned about what they perceive as "poor-quality" care compared to the care they can provide. They are also concerned about "overmedication" in health and care facilities.

Some find assimilating their relatives back into the family home after receiving respite care at a residential care home "taxing" and "demanding". Families and carers are also very concerned about leaving the person with dementia alone. The pandemic prevented many from seeing their families in person and exacerbated the problem of isolation.

People feel isolated once they have a caring role. They struggle to keep in contact with friends as they are so busy. Others struggle to communicate well with people who do not have the same experiences of caring for someone with dementia. Some carers said this made them hide away from their friends. It is felt this is why peer support organisations such as carer's centres are so valued.

It was not uncommon for carers to be in their 70s or 80s with their own health problems. Some people struggle to be a carer for their adult children living with dementia.

The caring role massively disrupts a person's employment. Many feel they must be with the person living with dementia "round the clock" to care for them properly. Some try to work from home but struggle with this. Some worry that this disruption to their work will mean losing their jobs and homes.

> ***Social services were trying to say to my husband, will you take on [the person with dementia's] financial affairs?... And he said no... we've tried to get carers in for her. She's accused them of stealing, of putting poison in her drink. He's a finance person. If he got accused of stealing from her, that could be his job.***
> Carer

Carers may also have their own health problems or care for more than one person. Speaking to people, this was a frequent occurrence, with many reporting depression but also conditions such as their own dementia. When this happens, they must juggle the health appointments for more than one person. The reported stress levels in dealing with administration increase exponentially as the carer supports more people.

It was noted that a few carers could benefit from additional education in the basics of dementia. Some feel dementia only affects memory, and some professionals noted how some carers do not know how to communicate effectively with the person living with dementia.

We asked families and carers what their main concern is for the future in supporting the person living with dementia. Carers are concerned about the person living with dementia developing incontinence, being unable to carry out personal care, and exhibiting threatening behaviour.

Carers report that the situation can be difficult if the person living with dementia lacks "awareness of their condition". Carers often spot an internal logic behind a person with dementia's seemingly inappropriate actions.

> ***Plus [the person living with dementia and has incontinence] simply will not drink because if she drinks, she has to go to the toilet.***
> Carer

In fact, many carers feel that managing the behaviour of a person living with dementia is a significant challenge. Some carers are deeply upset by a perceived lack of empathy; others worry about the person being physically or verbally abusive. Carers report being unable to leave their homes because of the threat of violence or having the person living with dementia follow the family around continually.

Although we met several male carers, it was indicated by some carers that caring is seen as the “women’s role” in some communities.

> ***It’s a women’s issue, women are the carers, and they talk about women still having their lives, and really they’re being held back.***
>
> Carer

> ***The issues of the caring role holding women back from work and impacting their mental health is widely reported on. We recommend that dedicated follow-up research is conducted to understand the scale of this issue for women living in London.***

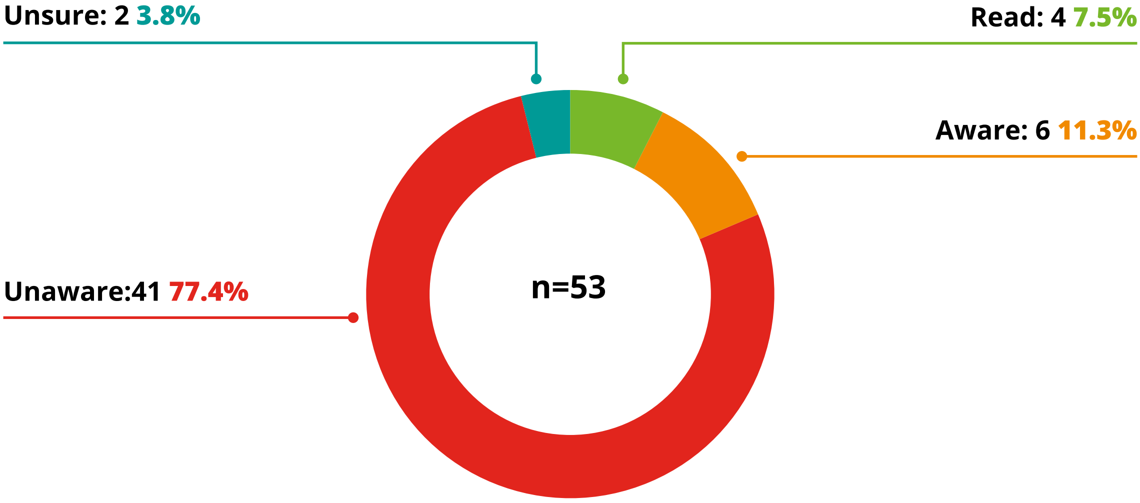
Health and social care issues

Navigating health, social care and community systems

> ***The dementia pathway was consistently unfavourably compared with the offer for other health conditions, especially cancer. People are "upset" that a degenerative, life-long condition with no cure that significantly impacts a person's identity and life prospects gets less support than a health condition that is often treatable. People feel that GPs and social services are "unreachable" and "unsympathetic." Many struggle to navigate the health and social care system, especially those not born in the UK or whose first language is not English.***

We found that 77.4% of those living with dementia, their family or their carers did not know about the NICE dementia guideline.

Figure 4: Awareness of NICE dementia guidance



The impact of diagnosis

Many are concerned about the time it takes to get a referral to the memory assessment service. Professionals felt that people generally do not understand how long it can take to get an accurate diagnosis. This resulted in frustration, and people told us this frustration made it harder to absorb information when receiving a diagnosis.

After getting a diagnosis, people said they are left with a feeling of uncertainty that they feel is disproportionate to that following the diagnosis of other long-term health conditions.

Family and carers are concerned that, without education and guidance relevant to their specific circumstances, they could be supporting the person with dementia in an ineffective way, which could have a negative effect. They are unclear about whom to go to for support.

> ***I was left all on my own, and I had no idea how to cope with this. I had no idea how… how this is going to play out? So there's no sympathy, no help or guide or anything, you know, for you to know what to do.***
> Person living with dementia

> ***The uncertainty is so difficult to live with, isn't it? It's the uncertainty of what's going to happen next. I've been left with a lot of uncertainty, and I'm having to question myself a lot… if someone had a different disease or different illness, they probably wouldn't have all this doubt.***
> Person living with dementia

There is a consistent and strong sense that those living with dementia are abandoned.

> ***Post-diagnosis is a desert. No oasis in sight.***
> Carer

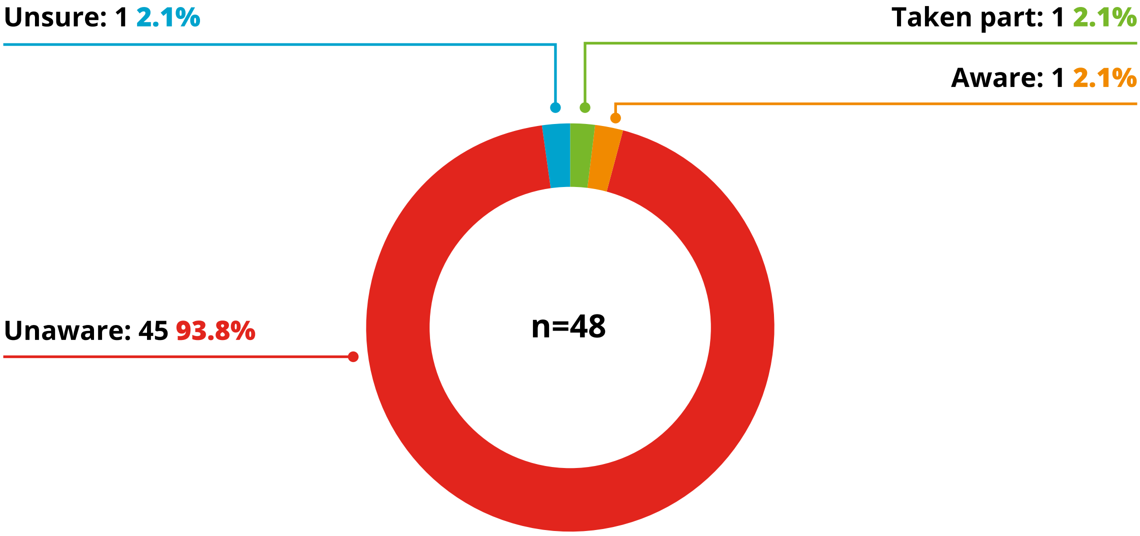
> ***I had yesterday [a visit] with a family, someone with a really lovely person who hasn't seen any psychogeriatrician or geriatrician or anybody for five years. So she had her diagnosis, I think, six years ago. She hasn't seen anyone. She's definitely had a deterioration.***
> Healthcare professional

Many are also concerned about the emotional toll of a diagnosis of dementia, even when it's expected. It can be "traumatising" to receive the diagnosis itself. But people also struggle with the awareness of the loss of identity, transition from their previous way of life, and losing control or independence.

> ***Having that loss of control all… can quite often lead to a very negative reaction, you know, feeling that there's a loss of control. Awareness of that loss of control.***
> Carer

Those offered post-diagnostic six-week interventions felt these were insufficient. Most people we spoke to said they were not offered this at all. 93.8% of the people we talked to who have dementia or are family or carers said they were unaware of the STrAtegies for RelaTives (START) intervention or alternatives. Those who had it said they wanted it for longer.

Figure 5: Awareness of STrAtegies for RelaTives (START) intervention



Dementia health and social care offer

The dementia pathway was consistently unfavourably compared with the offer for other health conditions, especially cancer. People are “upset” that a degenerative, life-long condition with no cure that significantly impacts a person’s identity and life prospects gets less support than a health condition that is often treatable.

> ***When my partner had cancer, the GP involved me, and Macmillan [nurses] were brought in. They did an assessment and gave medication and relief of pain, and that was coordinated. It was peaceful. They offered me a room to stay in there for a week. Imagine if they did any of that for dementia.***
> Person living with dementia during focus group

The loss of support services such as day centres has affected many. They would like to attend their local day centre but find that most only support those with lower levels of need, with incontinence being the most common threshold. Those still open centres feel they are not providing the service they want and would like to engage in more activities in the community.

> ***We need a Dementia pack, like a school’s pack, with risk assessments and maps for us to arrange visits outside the day centre.***
> Day centre professional

The pandemic has been blamed for reducing the amount of social care provision, with many social interventions moving online. This has diminished attendance, which is struggling to recover now that the risk from the pandemic has reduced. People told us that they are often told that services used to be available before the pandemic but are now no longer available.

> ***Lots of people said, “Oh, well, before COVID, we used to do this, and we used to do that, but now we don’t.”***
> Carer

Many see residential care homes as a natural pathway of dementia care and cannot conceive alternatives.

Perceived poor quality

> ***Systemic issues highlighted included “a lack of good leadership” within health and social care settings, with a sense that departments are more focused on their budget than on supporting the person in need. Patient record systems and IT infrastructure are “hard to manage” and actively cause “stress” and “pressure” on those who use them. There are few data-sharing protocols, so people must repeat their situation constantly. People also have to wait weeks or months to get their medication changed.***
>
> ***Health and care staff need better training and increased awareness. Staff struggle to know what to do regarding assessments, ongoing support and end-of-life care. When situations become challenging, care providers withdraw services, placing increased pressure on carers leaving some to ask, “If the professionals don’t know what to do, how do they expect us to know how to manage?” People are also concerned about the pressures on healthcare professionals, with some facing burnout.***

Those living with dementia and their family and carers feel that healthcare staff do not treat them with dignity.

> ***Being a clinician makes you knowledgeable. It doesn't make you experienced. I live with the condition 24 hours a day. I know me.***
> Person living with dementia

Family and carers feel they are "sidelined" or "ignored" when being seen by healthcare professionals. Carers feel "frustrated" as a person living with dementia is often very good at giving a falsely positive view on how they are managing or lack insight into their condition during assessments. Carers feel they can provide an objective account but are often "ignored."

Memory assessment services

There is a perception that since people are sent to a memory assessment service for diagnosis, the clinic must be responsible for managing dementia. People are then frustrated that the clinic does not provide ongoing support. GPs report they also find it difficult to get advice from the clinics.

There are reports of people living with dementia failing to attend memory assessment service and being discharged for failing to show up. Many are also frustrated that the diagnosis goes only to the person with dementia and their GP and does not include the carer.

Primary care

By far, the most frequently raised issue is a lack of access to and a perceived disinterest from their GP. This frustration is unsurprising as they are the primary point of contact and gatekeeper for referrals to the rest of the NHS. Since the pandemic, access to GP services has been limited, with increased use of electronic systems to triage patients before they can speak to a GP. However, people also commented that their GP seemed "uninterested" at the point of consultation, and people left their appointment feeling discouraged. GPs told us they felt GPs failed when they "failed to show compassion".

Another concern from those living with dementia was that GPs do not have the capacity to support people at home. Carers also felt there was inconsistency between GPs.

End-of-life support

There were a few accounts of poor quality support and a lack of dignity at the end of life. Families and healthcare professionals felt that too many are dying alone at home. Carers said often the experience of end-of-life is that there is less focus on the individual and more on "arguments" with the healthcare bureaucracy.

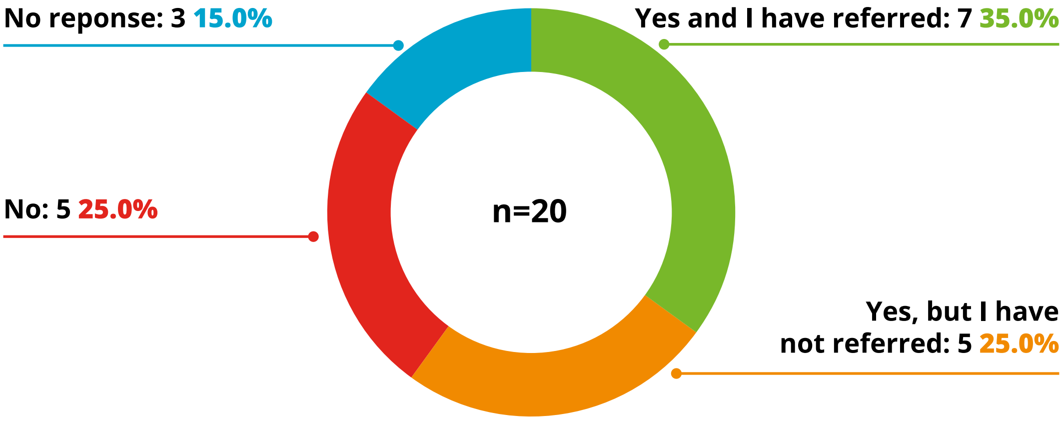
Carers struggle to get information about advance directives, advance statements, DNAR education and end-of-life decisions.

In recruitment and training

Medical professionals told us they feel the NHS needs more leadership training with a greater focus on emotional intelligence. Without this, teams' enthusiasm for innovative ways of working or practice refinement is sapped away. Morale is driven more by job satisfaction rather than galvanised by leadership.

Some medical and social care professionals said their colleagues are unaware of dementia guidance, and it is felt that recommended guidelines are not being followed. Others are unaware of common social care or community support interventions. For example, some GPs we spoke to were unfamiliar with the term social prescribing. We asked professionals working with people living with dementia, 'Are there social prescribers/link workers in your area, and have you ever referred?' 25% responded, 'No.'

Figure 6: Are there social prescribers/link workers in your area, and have you ever referred?



Those living with dementia and their families and carers were also concerned that health professionals lacked experience. Some said they felt they were educating care staff on how best to support those living with dementia.

Pharmacists felt that there was "a battle" between clinical staff and pharmacy, with clinical staff afraid that pharmacists' only goal was to reduce medication usage. They hoped that there could be great discourse between themselves and clinical staff.

It was also noted that it is hard to retain experienced staff. Some felt let down by the systems in place and move on to other teams, and others leave the sector entirely.

Day and carer centre managers told us they "struggle" to stay open and have to rely more on volunteer staff. Their wishlist includes providing training for these volunteers.

When making health assessments

Social workers told us they feel there is an inconsistency in the quality of care assessments by health staff.

> ***We'll get a lovely three page written assessment of what that person's cognitive issues are and abilities. And it might then say you need an OT assessment. You should do this. You should do that. And I've also seen terrible ones where they say, "Within a year, you will need residential care, and this person shouldn't be left unattended."***
>
> Social worker

Many are concerned that people living with dementia are not supported properly by health professionals. People feel that doctors are overreaching their authority.

> *I know what NICE is, yeah. I researched it online because I wanted to know what she, what she could have… And I was told by the doctors, "That's a load of rubbish… [the] regulations we can accept or reject… we make the decisions. NICE tell us what we could do, but we don't have to… I make the decisions, not NICE."*
>
> Carer

Private medical treatment

Some told us they had obtained private medical consultations. They noted that there is not a marked improvement in the quality of care with private health staff.

Social Services

Similarly to GPs, people are critical of social services. The role of social services as the first point of contact and gatekeepers to social care provision means that there is a focus on their role. Some feel that social workers and social care providers are "disinterested" in them and take a long time to process assessments.

Londoners could not help but notice the dramatically different levels of support from one Local Authority to the next. They also noted the inconsistency of care provider support. Londoners wanted a London-wide dementia offer that is consistent across borough boundaries.

A number of the people we spoke to said that the social care offer they were given does not meet the needs of the person living with dementia. Poor quality or a lack of social support puts pressure on NHS services. People get to crises quicker and use emergency services more frequently. The perception of "poor quality" means people want to avoid interacting with social services. Carers who receive social services support also noted that the adaptations to their home to make movement safer are "unsuitable."

Carers also feel that there is a lack of consistency among social workers and that, often, they are "excluded" from decision-making processes.

People are also concerned about how someone living alone will cope with just a domiciliary care package commissioned by social services. This is especially concerning if the person is incontinent, with the potential that people will be alone for hours until the next care visit.

One of the reasons why people are frustrated about domiciliary care may be the lack of understanding about funding thresholds. Traditionally in London, people can get up to four visits from domiciliary care services a day before social services feel it is more economical to move a person into a residential care home.

Professionals and carers feel social workers are "not trained sufficiently." Social workers must communicate more with experienced professionals in certain areas, such as hoarding, to manage behaviours appropriately. Current approaches to managing behaviours are often "traumatic" for the person.

Care providers

A common concern among families and carers is that care providers struggle to manage people living with dementia. Training and parallel planning would better support and reduce risks. Occupational therapists are more knowledgeable about techniques to get the person living with dementia to engage and reduce anxiety.

> ***She was just shouting at the carer, "Get out, get out, get out!" … [The care] company phoned my brother… "[The] carer has said that your mum's just shouting at us to get out… we're just letting you know the carer is going to be leaving." So my brother… got there as fast as he could. My mum was outside the back door. She'd fallen. She was laying in a pool of blood, and she broke her hip. She'd been there for the best part of 45 minutes. And if he hadn't have come home and got the ambulance when he did, she would have blacked out and died. She lost between four and five pints of blood.***
>
> Carer

There were numerous comments on the perceived "poor quality" of domiciliary care workers. People are concerned about inconsistent arrivals, a lack of training, insufficient time commissioned, task-focused engagement, and an over-reliance on agency staff.

People want commissioners to realise that person-centred care is time-consuming. Getting consent to do personal care can take the time allotted for the whole care session.

Family and carers noted that, at times, the relationship between the person living with dementia and the domiciliary care worker broke down. They said that care workers are not prepared to manage "challenging behaviour." Some care workers are "afraid of safeguarding" issues and would instead not work with a person than risk having a safeguarding issue raised about them.

The family and carers we spoke to are extremely concerned about the quality of care when a person is not being cared for within their own home. We had accounts of carers being given respite support. At the same time, the person living with dementia was placed temporarily in a residential care home, but the person's condition worsened while they were there.

People feel residential care homes represent "poor quality" care, mainly due to low staffing levels, and those living there have a "low quality of life". It is also felt that there is little support for people who don't speak English.

> ***My mother-in-law gets up at night. She struggles with incontinence and wanders all throughout the night. So I get very little sleep. My wife works at the hospital. During the COVID outbreak she had to sleep at the hospital as it was too risky for her to come home. I didn't sleep for a year. I had to look after my grandson during the day. I was offered a week's respite, but each time my mother-in-law came back from respite, her incontinence was so much worse that it wasn't worth it. This is what we have to choose, sleep or poor care.***
>
> Carer

> ***Within a week of moving into the care home, she had developed sores. She was not able to clean herself after using the bathroom, and no one noticed.***
>
> Carer

> ***During the pandemic, it was horrendous. She was isolated in her room in the care home. They wouldn't put on the TV channels or radio stations in her language. They didn't have WiFi. She had a phone, but needed staff to support her to use it, so she didn't.***
> Family member

Many people living with dementia don't want to move from the family home.

Other professional teams told us that they find care workers to be "unresponsive" to efforts at communication.

Challenges for health professionals

Many people, including those living with dementia and their family and carers, are concerned about NHS staff wellbeing. They worry about the stress and burnout of NHS staff. NHS staff said they don't always feel empowered to speak up about issues and feel like they're always in crisis mode.

> ***I think every day is a grind. First off, on the amount that they need to do working such long hours. I think if we could in some way make that a bit easier to give people the headspace to think about why they're doing what they're doing.***
> Healthcare professional

Health professionals told us they struggle to get the information they need. They want systems that will help them to access community notes. They also struggle to know what local community groups there are. Some professionals told us they struggle to navigate NHS pathways.

Challenges with medication

Pharmacists and carers are concerned that pharmacy processes delayed changes to treatment. Pharmacists told us that waiting for letters from clinical staff to be authorised results in some patients "waiting weeks" for medication changes.

Carers are highly concerned with ensuring that the person living with dementia is given the right medication. We were given accounts of how medications were prescribed without considering the person's other health conditions. Most feel this is a system issue and that GPs and prescribers should have warning flags on the EPRS that automatically question such decisions.

Pharmacists and carers are concerned about overmedication of the person living with dementia. People commented on the number of tablets, the concern over sedation, and the lack of information they get about the effectiveness or appropriateness of medication.

Some feel that the level of support in social care is as good as expected and is connected to the current economic situation:

> ***People don't care about older people: "You had it good in the '70s and '80s, house prices were good, you have to put up with what you got."***
> Family member

Health systems and procedures

Challenges with increased administration

Many people living with dementia and their family or carers told us their struggle with keeping on top of medical appointments. For a significant proportion, a dementia diagnosis is made when they are in hospital following an incident or crisis. Recovery appointments for the reason the person was brought into the hospital can be hard to manage, along with any other health issue appointments a person has. Those who support people living with dementia said they often struggle to find hospital letters.

Repetition

Those living with dementia and their family and carers are tired of repeating themselves to health and social professionals. They report being asked to provide a medical history at each appointment. Those living with dementia find it hard to do this. Family and carers are confused about the purpose of taking the history and feel that EPRS should negate the need for this.

Health professionals can increase their empathy for family and carers by considering that repeating their medical history is not only required in that particular health setting. It's part of a family or carer's daily experience for any appointments they have.

IT systems

Medical professionals told us they want one unified EPRS to share information with social services and care providers. This would not only help with integration but could help improve the speed of finding out about their patients. Some are concerned that EPRS systems are not currently used to their full potential. These systems can be "hard to access" and "time-consuming." This is not necessarily a new problem; staff noted that some medical professionals also felt the same about paper records and did not take sufficient time to review them before seeing a patient.

Those living with dementia feel that NHS booking systems were "antiquated." We reached out to a few of the EPRS software developers, including The Access Group, which provides many EPRS to medical trusts in London. We did not get a response.

> ***I spent an hour on the phone to the hospital and when they finally speak to you… 'you are number one in the queue' then they hang up. It happens all the time, it's so frustrating. Why can't I just email?***
>
> Person living with dementia

However, in speaking to several providers of social care electronic customer record systems, we got an insight into software developers' challenges. It was noted that as social care is run commercially by thousands of different organisations, providers do not have unified electronic customer record systems. Some providers still hold their data on paper records. Unpaid carers also often keep their own records and insights into a person's condition, also usually paper records. So there is often little way to share information, should the carer wish to.

Software developers told us that social care contracts are often run with little profit margins. In London, this is often well below[6] the Homecare Association's (formerly

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[6] **'Providing a viable domiciliary care sector in 2021 – Care City**

United Kingdom Homecare Association, UK) 'Minimum Price for Homecare' rate[7]. Developers say they have little financial incentive to enter the market to develop social care systems, let alone creating a system for carers, which would be less of a business-to-business model and more direct sales to the public, who also commonly have the least resources to pay for such a system.

Data sharing issues

Community organisations, housing and care providers labelled the NHS as "unresponsive." There is a concern that despite all the efforts made over the last few years, few health and social care providers have protocols to share information. Health professionals are nervous about sharing data and often use GDPR as a rationale. A lack of information sharing was felt to be a "deliberate cost-saving" tactic to get social care providers to take on contracts with people who needed more help than was outlined in a referral. In response, social services said that this situation was actually down to high workloads.

Budgetary issues

People often report that health and social services teams seem more focused on "protecting their team's budget than supporting the person living with dementia."

> ***There will always be people who argue, 'Who's going to pay for this?' I'm like, 'It's the same money.' … all these professionals in all these meetings for six weeks… We're debating that it's all taxpayer's money, and again by being in all different silos and everyone protecting theirs, then it just feels a little bit mad.***
>
> Carer

Examples of this issue are highlighted by the many cases repeatedly passed back and forth between health and social care teams. Many feel that those living with dementia, their family or carers do not need to know of the battles over responsibility and budget. Many are confused why mental health teams and social services are debating whether the person should fall under the purview of their team.

Across the board, there is a feeling that NHS services are "short-staffed" and "under-resourced." There is a particular concern for nursing staff. When asked what people would like to see changed, most said that increasing the dementia services budget is high on their list. People are also concerned about the reduction in social care provision.

Professionals are conflicted over whether resources should be focused on "enlarging the workforce" or "increasing professional acumen." Most professionals voted to have a balance.

Challenges with peer support

Many people are unaware of community support organisations such as a carers centre. Others cannot access them due to work commitments. There is a contingent who feel that group or peer support is unappealing. Others find that those living with dementia might not be welcome or may not enjoy such settings.

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[7] **Home Care Association 2022/23 minimum price**

Housing, financial and legal challenges

> ***Without proper management, dementia can also lead to homelessness. Many struggle with debt and financial issues, often worsened by symptoms occurring prior to diagnosis. Others struggle to navigate the complex legal situation for people when they lose mental capacity. Housing providers want to be included in the dementia pathway, especially as some care and support providers feel "disconnected" from health services.***

Housing

Some housing providers have 'care and support' services or housing for people aged 55+. They have a contractual duty of care agreement with the local authorities, so some have on-site interventions and activities for those with dementia. Housing providers noted "surprise" that health providers did not consider or include them in dementia strategy.

Even if a service does not have dementia specific provisions, many housing providers want to know which tenants have dementia to aid in fire evacuation planning and help manage tenant complaints. Staff report that they are "worried" about supporting those living independently with dementia, especially at night. Some people living with dementia have been left homeless because they cannot manage their tenancy.

Many housing providers feel they are being asked to provide support beyond the remit of a landlord. They reach out to the health service but need the correct communication channels for meaningful engagement. It is often felt that social services do not share the complete account of a person's care needs to get them into comparatively low-cost/low-support housing. Services with a member of housing staff available for half a day a week are classified as having 'support', so confusion from healthcare professionals and the public means that expectations are not being met concerning support for those with higher needs.

Financial

Those living with dementia and their family or carers are typically struggling financially. They have also been disproportionately affected by the "cost of living crisis[8]." People struggle to cover the cost of care, mortgage repayments and household bills when the person living with dementia stops working due to their condition, a particular issue for those with young onset dementia.

Many homeowners are 'asset rich, cash poor': they may own their home but do not have the resources to maintain it or provide for their needs. Others have struggled with financial difficulties that families have said the person living with dementia wouldn't have gotten into before dementia. There were reports of people giving money away, being victims of scams, or having poor impulse control, leaving them destitute and homeless.

> ***So basically, he was getting these letters, spot fines, not paying them, and I found he'd got about, God knows, thousands of pounds worth of unpaid fines.***
> Family member

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[8] **Carers UK – Heading for Crisis: caught between caring and rising costs**

Many day and carers centres are struggling financially and some have closed down. These services were traditionally funded through the local authority; however, with cutbacks, few local authorities fund such services. The costs mean that those operating them have a skeleton staff, cannot afford training and cannot provide transport.

Legal

Many people we spoke to know about Power of Attorney and advocate for its use. However, this knowledge is not universal. Several people explained that institutions such as banks and some social care professionals sometimes need help understanding the Power of Attorney role.

Few carers and professionals fully know the Deprivation of Liberty Safeguards (DoLS) implications. This is especially true regarding monitoring people without their consent or detaining people without authorisation from the courts or local authority. Housing staff said people needed help understanding the difference between housing for people aged 55+ and residential homes.

Language and culture

> ***People felt that services were not person-centred and that provisions for people living with dementia are often only in English and not culturally informed.***

Carers of people living with dementia who don't speak English as a first language are concerned that the person living with dementia will revert to only speaking in their first language, which their relatives and carers may not speak.

Many struggle to understand the UK social care model, as it differs from other countries.

We struggled to get responses from language/culture-specific dementia groups and found that many of those who did speak to us attended English-speaking dementia groups. Those we talked to told us they were only ever offered guidance in English.

LBGTQIA+

> ***LBGTQIA+ people often lived with abuse from care workers.***

We had several services respond to us and say that they were unable to support our evaluation at this time. The LBGTQIA+ groups told us this was due to a lack of relevant staff or current service delivery pressures. We did get some comments from individuals about their experiences.

It was reported that compassionate support is lacking and verbal abuse or homophobic remarks were even expected from social care providers. Residential care homes in particular were seen as "difficult places to live" for the LBGTQIA+ community and to combat this specific LBGTQIA+ residential care homes are now being set up.

It was also reported by carers that they found it difficult at times to know how to support LBGTQIA+ loved ones with dementia. They reported that some with dementia might feel they were living back in a time when they felt they had to hide their feelings causing distress. Others noted that a person's sexual identity might be more fluid and carers were uncertain if they should be trying to re-enforce an identity a person had before dementia or not interfere, despite the impact it would have on existing relationships.

What Does Good Look Like For London in 2023?

People wanted a definition to what they should expect from health and social care. They wanted these services to work together to make live easier, and not to create additional burden.

London offer

People want a consistent London dementia offer that includes a comprehensive review by a healthcare professional six months after diagnosis, ongoing yearly reviews with a named contact and access to advice from professionals with dementia expertise between reviews.

The mission of this offer is for people with dementia to live as independently as possible in their own home.

Carers wanted representation on Integrated Care Boards

People want a bespoke offer for those living with young-onset dementia.

Dementia review

Frequency

People want an in-person at-home review six months after diagnosis, as it can be difficult to process information at the point of diagnosis. An annual review with a dementia specialist keyworker would follow this.

Review

This review should include:

- A separate preliminary interview with family or carers, which could be done remotely
- Discussion of any concerns for the person living with dementia and their carer
- Medication review
- Vision and hearing checks
- Signposting – so people are aware of carers centres and other local support services
- Advance care plans or statements
- Parallel planning (planning for clearly needed contingencies, such as carer absence)

Reviewer

The review would be carried out by a healthcare professional, such as a nurse or allied health professional. It was felt that this reviewer would be experienced with dementia and able to work within the health service to manage any referral issues that would need to take place. This was preferable to a dementia navigator, who it was viewed as focusing more on signposting. If a dementia navigator is available then there would be benefits to them working in partnership with the healthcare professional.

It is felt that this service should focus on continuity over accessibility and that this would facilitate a close, long-term working relationship with their reviewer. This was a top priority for the vast majority of people who responded to this evaluation.

Output

The output of this review would be a care plan that can be shared with other professionals to reduce people having to repeat themselves. The care plan should clearly outline the subtype of dementia and would contain personalised information. It would be a place to store letters from all professionals about dementia. This pack should be available in the most common languages spoken in London.

The review's goal would be to ensure that the person living with dementia can live as independently as possible within their own home. Referrals for care packages, social services, housing or adaptations would be agreed upon and followed up either by the professional carrying out the review or the family/carer, depending on the wishes of the family/carer.

Feedback

Areas of concern would be communicated to professionals in training sessions.

Advice line

People want a telephone advice line about dementia staffed with medical health and social care professionals. This would be a place where family/carers or professionals could ask for advice, or ask to be signposted. Advice could be provided on matters such matters as finances and housing. This service would have a focus on accessibility over continuity and would be used when people have immediate concerns.

Additional interventions

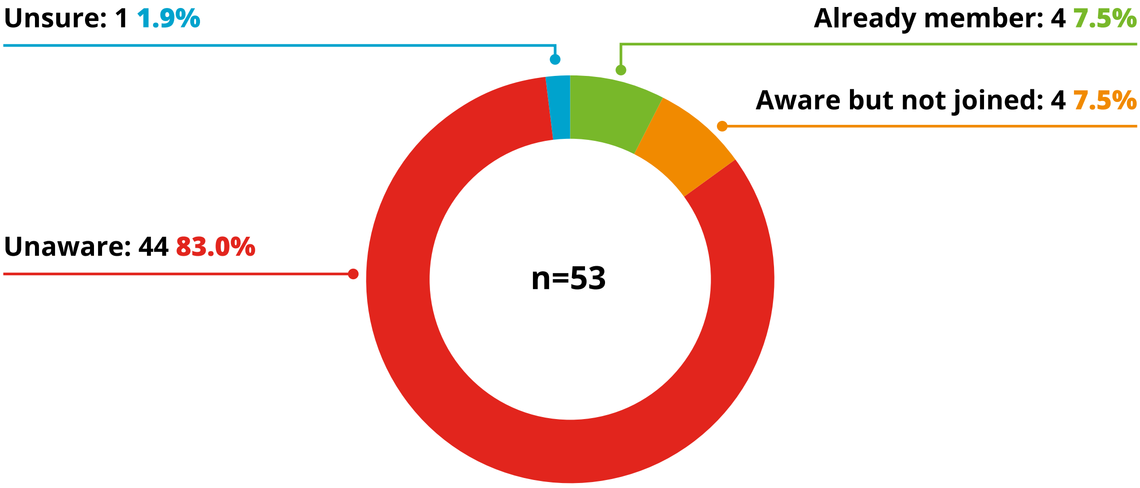
Administrative support

People want support to manage the heavy administrative workload that comes with having reduced capacity or being a carer. This was one of the most frequent comments we received. People either want the amount of administration to be reduced or for someone else to do the majority of the administration.

Involvement with research

Those we spoke to want to be more involved. 83% of those living with dementia, their family or carers are unaware of **Join Dementia Research** run by run by the National Institute for Health and Care Research (NIHR) and partners.

Figure 7: Awareness of 'Join dementia research'



Those who do know about it are frustrated that they haven't been invited to participate in research yet.

Therapy and training

People see a need for those who have a diagnosis of dementia and their carers to have counselling support after diagnosis with the goal of transitioning to a new way of life, coping with grief, and building resilience. Such therapy should also be available at other transition points, such as when a carer stops or is due to stop their caring role.

Respite and social interventions

People want meaningful respite. This is hard to manage as carers report that they find the person living with dementia is often in a worse state following respite. People want social prescribing.

People want social interventions that dignify them, are person-centred and culturally appropriate in the language they understand. This can reduce isolation.

People want day centres to support people with low to high dementia needs, including incontinence issues. People want transportation to be available.

People want a dedicated offer for people with Young Onset Dementia with interventions that provide health benefits and cognitive stimulation.

Housing providers for people aged 55+ that run social interventions want to include more local people in their sessions.

Self-management and improved NHS IT systems

People want training in self-management of dementia. They want carer systems that allow them to record their experiences and communicate with community teams.

They want modern NHS appointment booking systems that allow them to make and cancel appointments and access their records. They want EPRS to be designed to visually show things with clear flags for health conditions and reduce the need for patients to repeat themselves.

People want communication channels to send their thanks and appreciation to professionals.

Professionals want accessible channels to find up-to-date information on local social and community provisions.

Conclusion

Commentary

Expectations are realistic and proportionate

The additional support that people wanted did not cover all the challenges they faced. People knew that resources are limited, and they wanted to be able to look after themselves or keep care within the family for as long as possible. People understood the focus was on prevention and ways of keeping the person away from expensive social care and decreasing engagement with NHS frontline services.

Comparing the dementia offer

Comparing the NHS offer for learning disabilities (LD) to the offer for dementia, we note some inconsistencies:

Learning Disabilities	Dementia
The **NHS website** outlines the offer: *"It is important that everyone over the age of 14 who is on their doctor's learning disability register has an annual health check."*	The **NHS website** outlines that people with dementia should: *"Apply for a needs assessment from the adult social services department of your local council."*
There are 1.1 million adults with a learning disability in the UK[9].	There are 944,000 people with dementia in the UK[10].
"We do not always know why a person has a learning disability. Sometimes it is because a person's brain development is affected, either before they are born, during their birth or in early childhood."[11]	*"Dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of brain functioning."*[12]
Life expectancy of people with a learning disability is 66 years[13].	The life expectancy[14] of those with: • Alzheimer's disease – 8 to 10 years • Vascular dementia – 5 years • Dementia with Lewy bodies – 6 years • Frontotemporal dementia – 6 to 8 years

People with LD get an annual health check, whereas people with dementia do not. People want this to be addressed and feel it will provide a yearly safety net to catch concerns at an early stage.

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[9] **Mencap – Research and statistics 2022**

[11] **NHS condition information**

[13] **NHS Digital 2020**

[10] **Dementia Statistics 2022**

[12] **NHS condition information**

[14] **Alzheimer's Society guidance**

Recommendations

Much of the feedback we gathered validates what we expected to hear. People said they were tired of being asked what the problems were and now want to see a focus on delivering the interventions they have been requesting for years. As stated in the methodology section, this report is the second stage of a four-part project. Following this, the London Dementia Clinical Network (LDCN) will pilot a framework that addresses the primary goal of health checks and reviews delivered by a keyworker. The results will be published and shared in 2023.

1. **We recommend that London ICBs review the findings of this evaluation and implement the LDCN framework once available.**

The evaluation has collected a large amount of information. People living with dementia and their families and carers have suggested what they would like to help and support them in the section **What does good look like for London in 2023?** However, each of the comments generated from this report could potentially result individual improvement project. Questions have been raised and solutions could be provided by health and social care organisations working more cohesively. For example, how can people in financial crisis prior to receiving a diagnosis be supported if they didnt have the mental capacity to manage finances? Which organisations could help with answering that question?

2. **We recommend ICBs review the section What does good look like for London in 2023? and consider the proposals made.**
3. **We recommend that all those responsible for commissioning and running memory assessment service, GPs, social services, and care providers to read the report and review the section Health and social care issues and consider how they might work remove the challenges highlighted.**

We have seen that health and care services are not addressing the current needs of people living with dementia in London. For various reasons, there seems to be apathy about supporting dementia.

There is a real opportunity for a Londonwide offer to stop the inconsistency across borough boundaries and create a new dementia offer for Londoners.

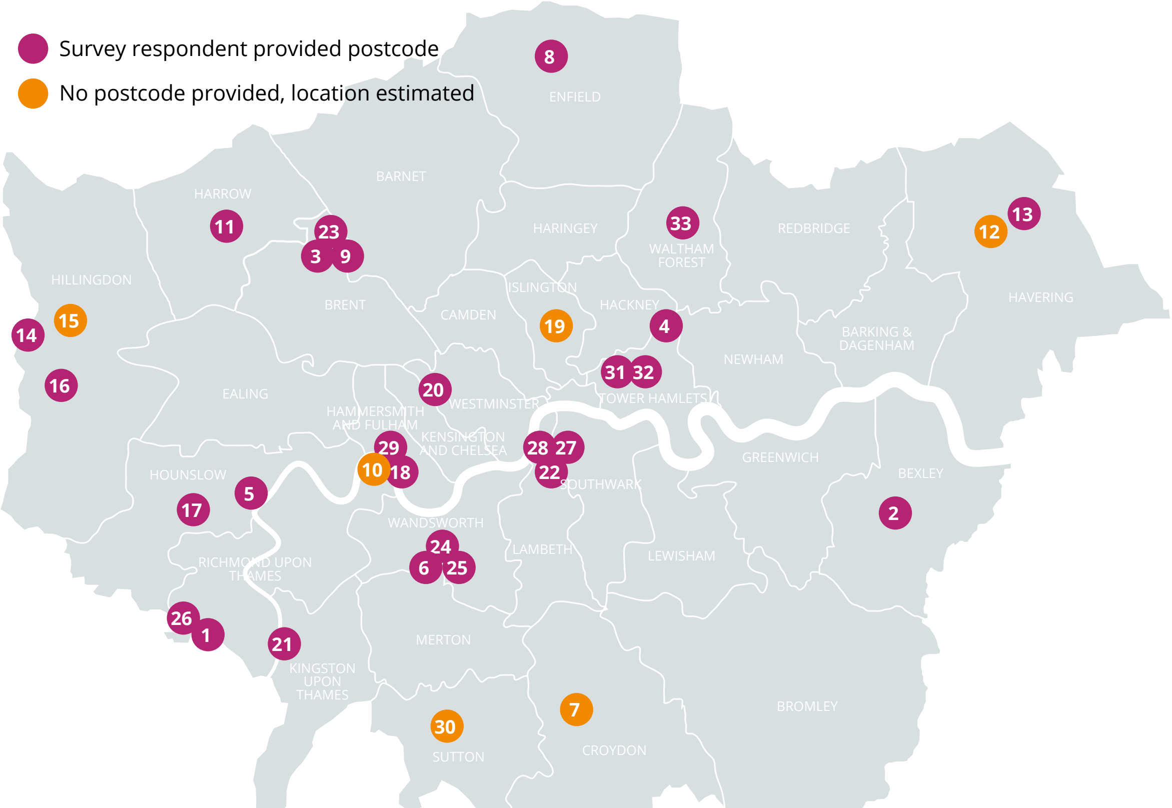
Appendix A: Dementia Service Mapping

The LDCN mapped post-diagnosis dementia care across London, completing the first stage of the aims. While they retain the mapping results, they have shared some highlights to include in this report.

Headline

81% reported No to the question ‘Does our service keep patients on caseload for life?’.

Figure 8: London dementia service locations (based on responses to June 2022 questionnaire)



1. Alzheimer’s Society Richmond CILS Dementia Support Service
2. Bexley Dementia Connect
3. Brent Memory Service
4. City & Hackney Dementia Service
5. Cognitive Impairment and Dementia Service
6. Community Dementia Support Service
7. Croydon Dementia Advisors Service
8. Enfield Memory Service
9. Hammersmith and Fulham
10. Hammersmith & Fulham Dementia Support
11. Harrow Memory Assessment Service
12. Havering CRIsP and LWWD
13. Havering Dementia Advice Service – NEL
14. Hillingdon Carers Support
15. Hillingdon DA
16. Hillingdon Memory service
17. Hounslow Community Dementia Hub
18. Imperial Service
19. Islington Groups - NCL
20. Kensington Chelsea and Westminster Memory Service
21. Kingston Dementia Support Service
22. Lambeth Dementia Support Service
23. Memory Clinic
24. Memory Wandsworth Dementia Support
25. Richmond Dementia Adviser
26. Richmond Young Onset Dementia Support
27. Southwark Dementia Support Service
28. Southwark Dementia Adviser Service
29. St Vincents Day Centre
30. Sutton Dementia Advice and Support Service
31. Tower Hamlets Dementia Advice Service
32. Tower Hamlets Inclusion Service
33. Waltham Forest Dementia Advice Service – NEL

Figure 9: Support service keyworker provider

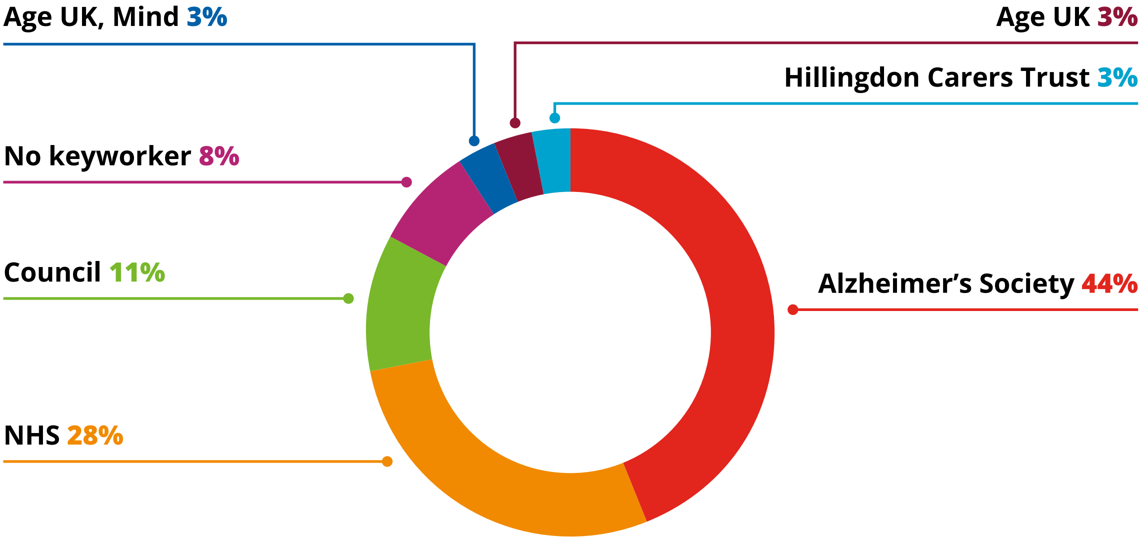
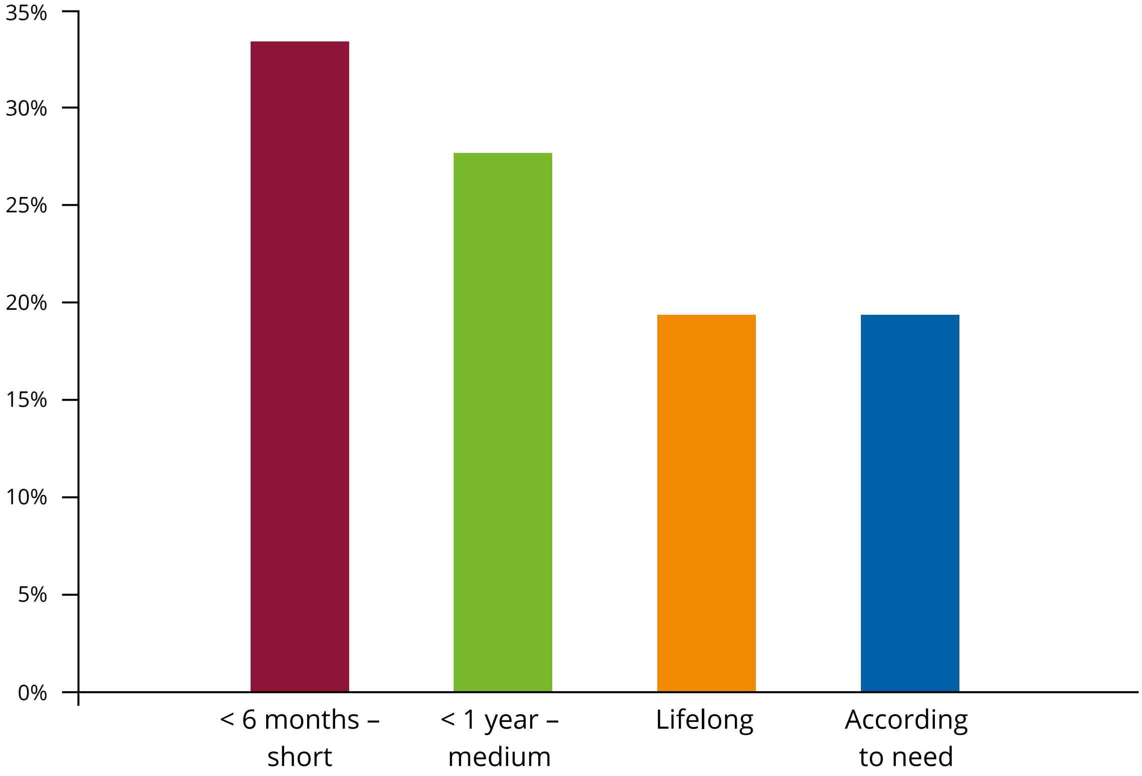


Figure 10: Level of support post-diagnosis



Appendix B: Demographic Breakdown Of Respondents

Figure 11: ICS level responses for this project

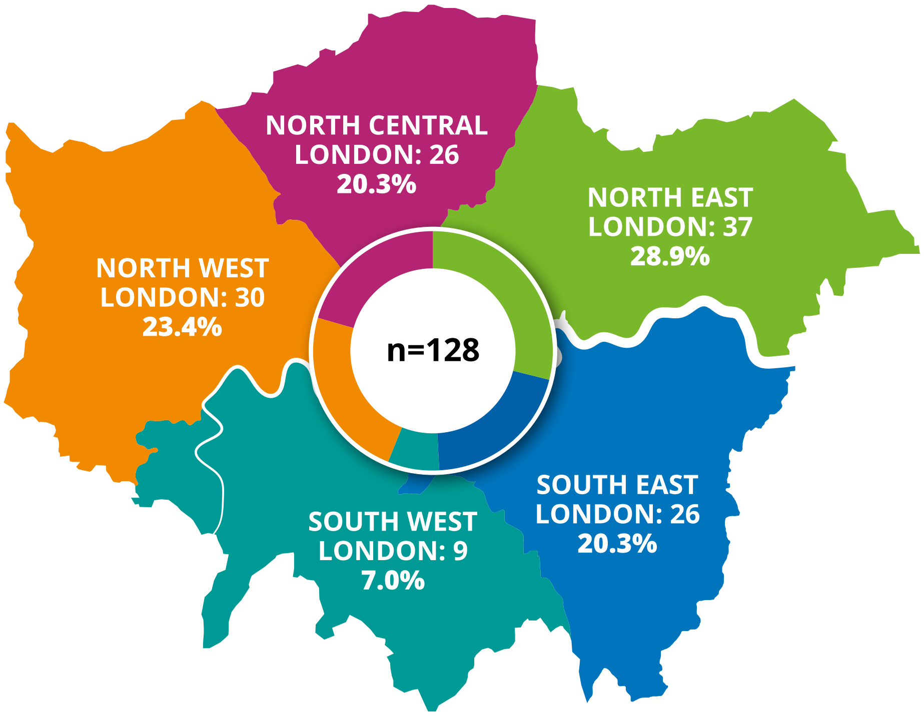


Figure 12: Borough level responses for this project

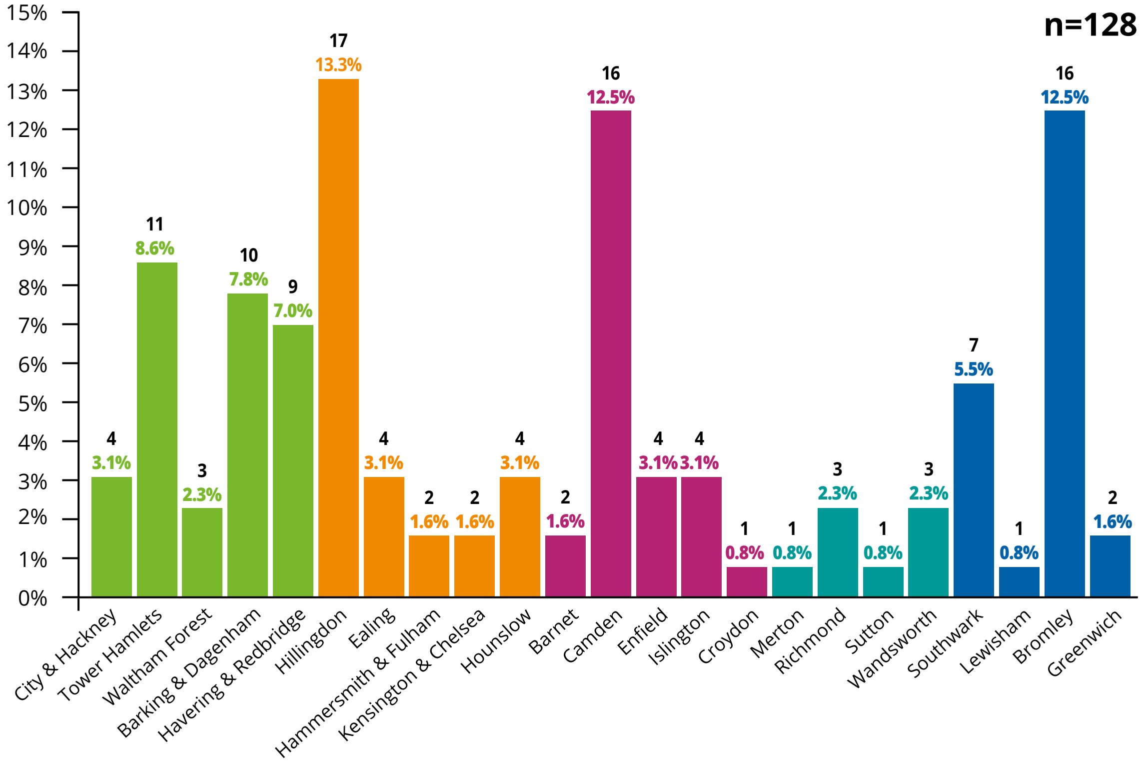


Figure 13: Dementia subtype of person living with dementia who responded to our evaluation

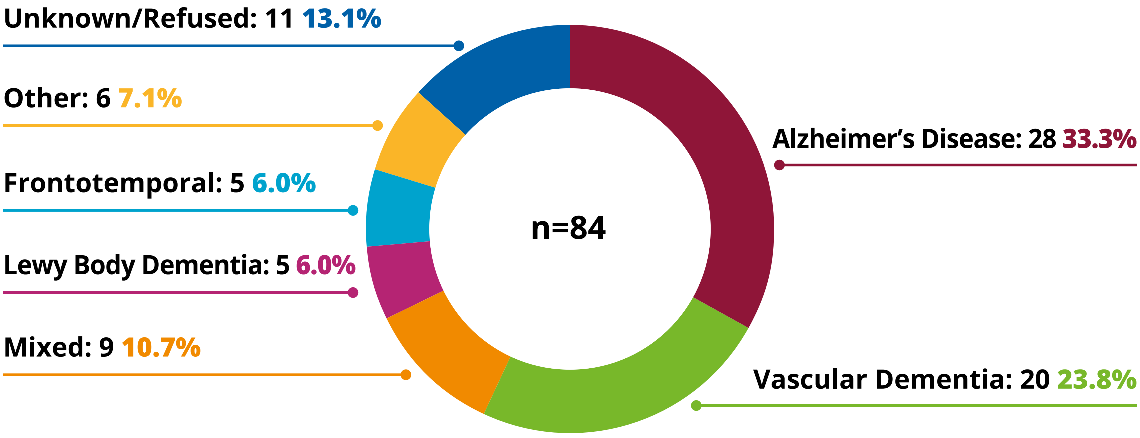


Figure 14: Gender of person living with dementia who responded to our evaluation (ONS categories)

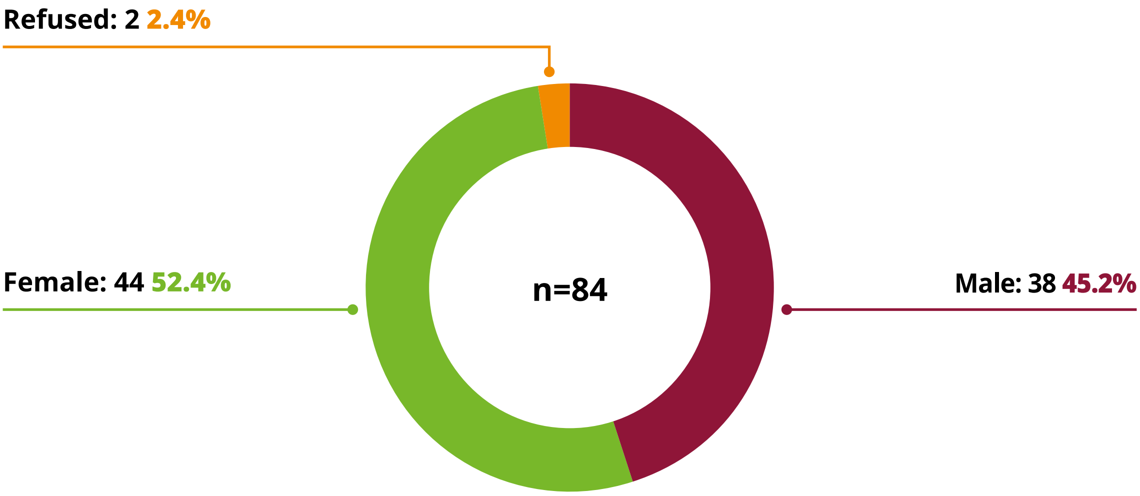


Figure 15: Age of person living with dementia who responded to our evaluation

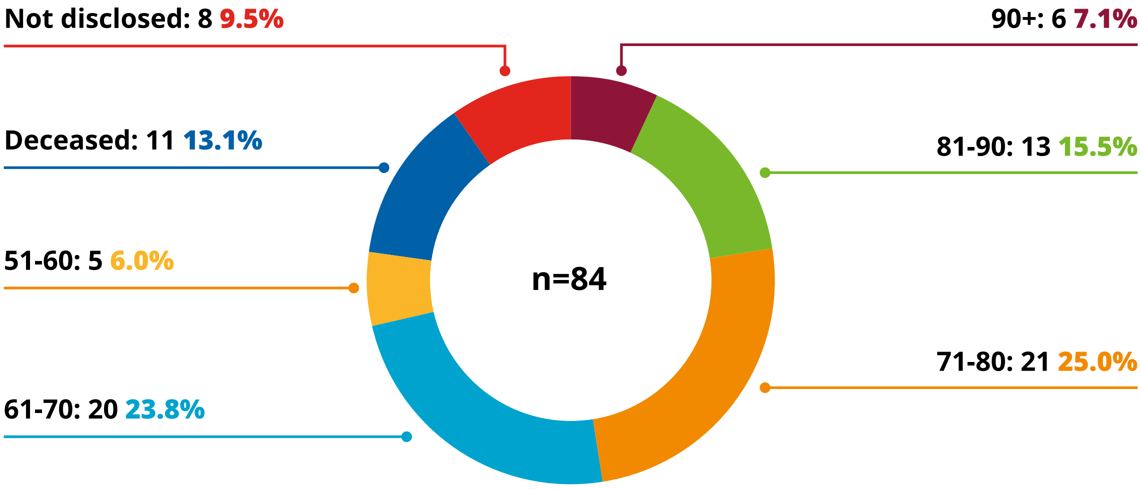


Figure 16: First Language of person living with dementia who responded to our evaluation

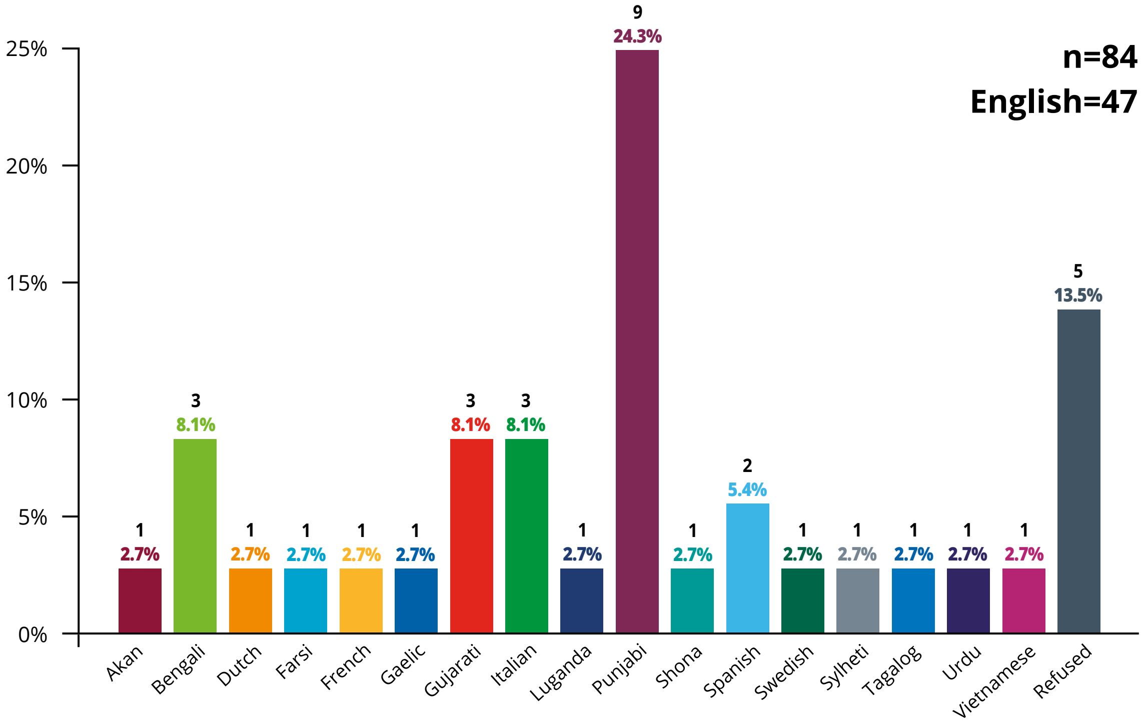


Figure 17: Sexuality of person living with dementia who responded to our evaluation (ONS categories)

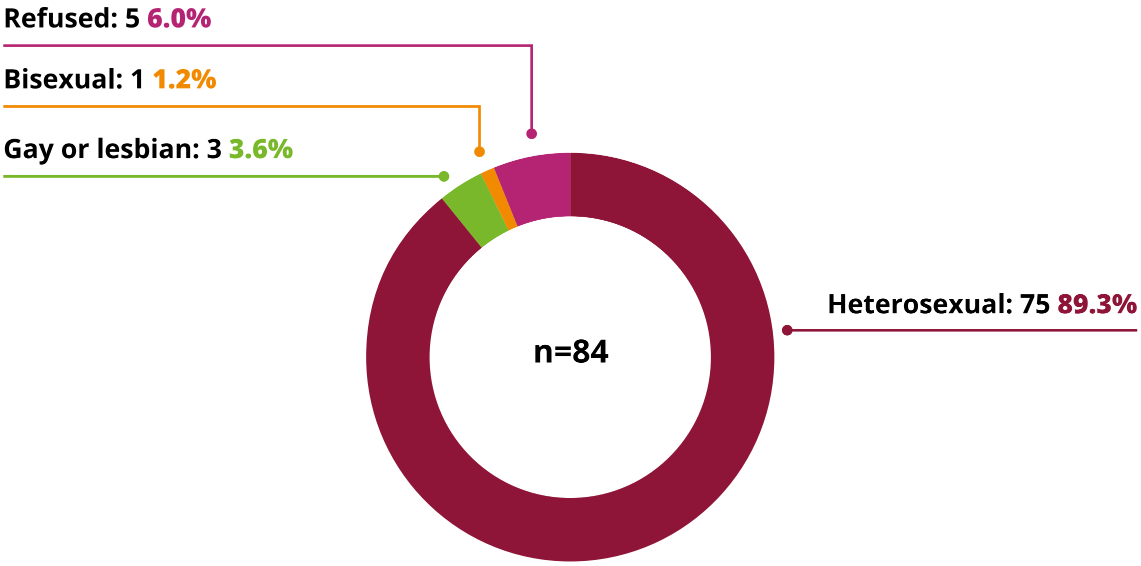


Figure 18: Sexuality of people living in London (for comparison) 2019 ONS data

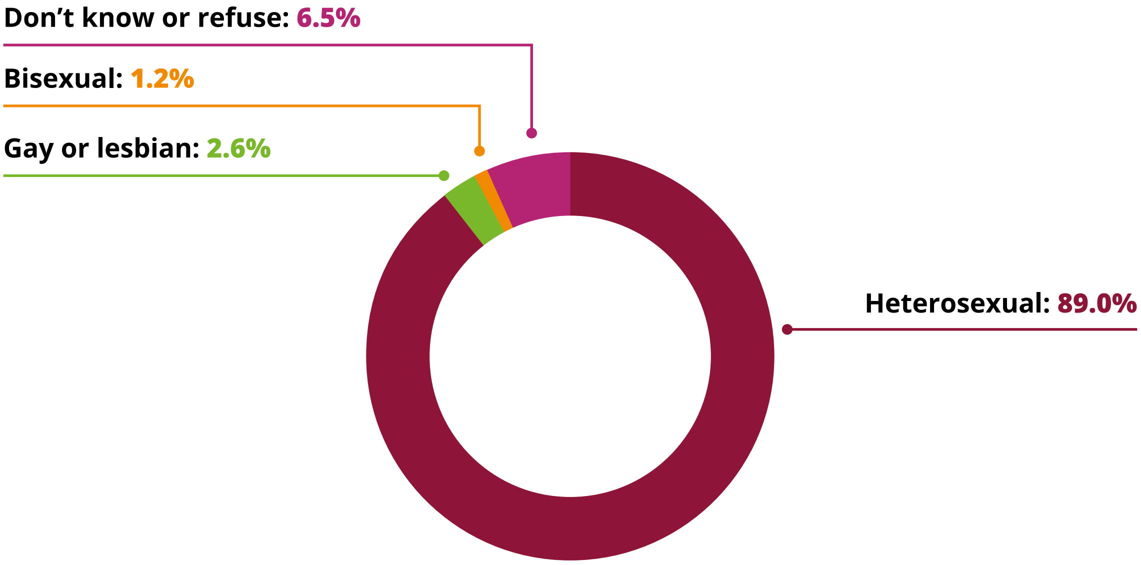


Figure 19: Ethnicity of person living with dementia who responded to our evaluation (ONS categories)

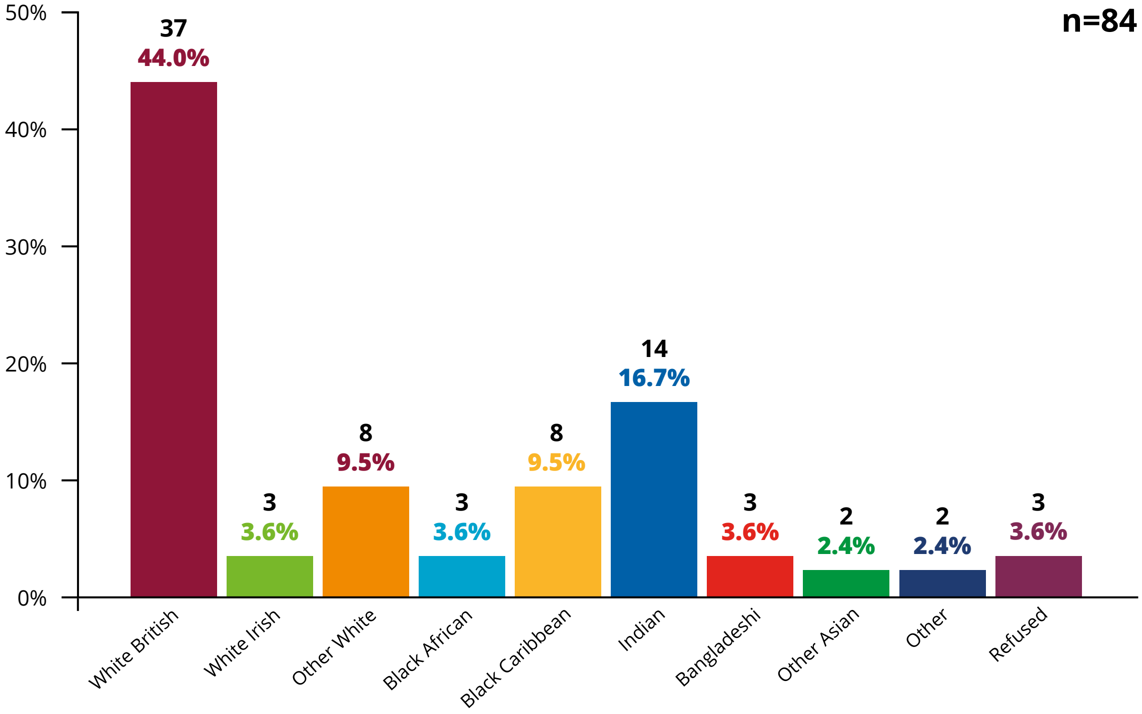
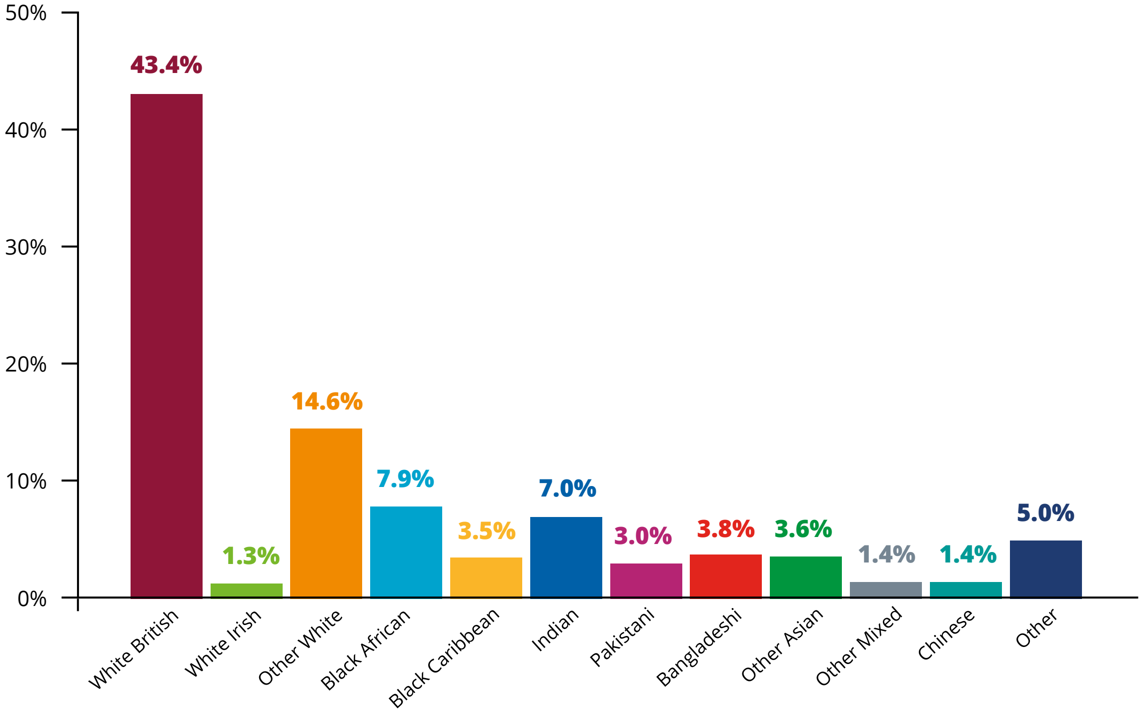


Figure 20: Ethnicity of people living in London (for Comparison) 2019 ONS data



Appendix C: Topic Guide

Introduction

The London Dementia Clinical Network is developing a commissioning framework for post-diagnostic support of people living with dementia. This is a funded project through the Office of Health Inequalities and Disparity. The work is being completed in collaboration with Care City and University College London Partners. Care City, a non-profit Community Interest Company, has a mission to create a happier, healthier older age Londoners and have asked to help gather views and information to shape the framework.

We want to speak to those who have a diagnosis of dementia, their family and carers as well as health and social care professionals who provide services used by people living with dementia to better understand the gaps of provision. To do this we are arranging a series of interviews and focus groups throughout 2022 to collect your views.

If you would be interested in talking more about this or sharing your views please contact…

Semi-structured interviews for people with lived experience/carers

Scheduler

5-10 minutes to schedule an interview and gather demographic information. Usually done remotely. Demographics of a person with lived experience (could be established during scheduling of interview). Quantitative data to ensure we are reaching a mix of experience.

Script

Hi, thanks for contacting us. My name's (say name) and I'm a Project Support Officer at Care City. We really appreciate your interest in taking part in our service evaluation. I'd like to start by telling you a little bit about the project.

The person leading this project is our colleague Ben Williams and he's conducting interviews with people who are living with dementia, as well as with carers, family members and professionals. If you agree to an interview to tell him about your experience of dementia support, it will probably take about half an hour, and my job today is to answer any questions you have, ask you a few preliminary questions and then to book you an appointment for your interview with Ben.

(Start interview, or answer questions)

Question: What is the project for?

We're asking questions about your experiences of the support you received or didn't receive after you/your relative/your contact received their diagnosis, in order to find out what additional support could be provided in order to improve your experience. At the moment we're at the investigation stage of the project, collecting people's views about the current level of dementia support, and after that we're hoping to develop a pilot project designed around the results of the feedback.

1. **Preferred name**
   - Free text
2. **Phone number**
   - Free text
3. **Email**
   - Free text
4. **ICS location/Borough**
   - North East London ICS
     - City and Hackney
     - Newham
     - Tower Hamlets
     - Waltham Forest
     - Barking and Dagenham
     - Havering and Redbridge
   - North West London ICS
     - Hillingdon
     - Harrow
     - Brent
     - Ealing
     - Hammersmith and Fulham
     - Kensington and Chelsea
     - City of Westminster
     - Hounslow
   - North Central London ICS
     - Barnet
     - Camden
     - Enfield
     - Haringey
     - Islington
   - South West London ICS
     - Croydon
     - Kingston
     - Merton
     - Richmond
     - Sutton
     - Wandsworth
   - South East London ICS
     - Lambeth
     - Southwark
     - Lewisham
     - Bexley
     - Bromley
     - Greenwich
5. **Are you?**
   - A Person living with dementia
   - A carer or family member of someone living with dementia
   - A professional who works with people living with dementia
6. **Dementia subtype**
   - Alzheimer's Disease
   - Vascular Dementia
   - Dementia With Lewy Bodies (DLB)
   - Parkinson's Disease Dementia
   - Frontotemporal Dementia (FTD)
   - Other
   - Don't know or refuse

7. **Gender of person living with dementia (not for Professional)**
   - Male
   - Female
   - Other
   - Don't know or refuse
8. **Age of person living with dementia (not for Professional)**
   - 90+
   - 81-90
   - 71-80
   - 61-70
   - 51-60
   - Under 50
   - Deceased
   - Don't know or refuse
9. **Sexuality of person living with dementia (not for Professional) (based on ONS breakdown)**
   - Heterosexual or straight
   - Gay or lesbian
   - Bisexual
   - Other
   - Don't know or refuse
10. **Ethnicity of person living with dementia (not for Professional) (based on ONS breakdown)**
    - White British
    - White Irish
    - White Gypsy/Irish Traveller
    - Other White
    - Black African
    - Black Caribbean
    - Other Black
    - Indian
    - Pakistani
    - Bangladeshi
    - Other Asian
    - White & Asian
    - White & Black Caribbean
    - White & Black African
    - Other Mixed
    - Chinese
    - Arab
    - Other
    - Don't know or refuse
11. **First language of person living with dementia (not for Professional)**
    - English
    - Other (please specify)
12. **Confidence level using an electronic device with support?**
    - Independant
    - Needs support
13. **Preference**
    - Phone Interview
    - Video call interview
    - Face to Face
14. **Date of Interview**
    - Date
15. **Time of interview**
    - Time
16. **Consent to store their information**
    - Date
17. **How long ago were you/ they diagnosed?**
    - Free text

Scheduler will then book the appointment into the Interviewer's calendar using ID number from GDPR compliant contact record spreadsheet. They will record that appointment has been added on the spreadsheet. Spreadsheet will be deleted at the end of the project.

Interviews with person living with dementia/ carer/family member

Interview

Estimate 20-45 minutes. These interviews will help gather data and adapt the focus group sessions to the wishes of those with lived experience. In-person or remotely. Quantitative and qualitative data from a person with lived experience or their carer.

1. **What surprised you/them the most about dementia after being diagnosed?**
   - Free text
2. **What would you tell someone else who has been diagnosed with dementia?**
   - Free text
3. **What services have been the most useful help to you since the diagnosis?**
   - Free text
4. **Who do you go to when things go wrong?**
   - Free text
5. **What needs to happen to support people after they are diagnosed?**
   - Free text
6. **Do you use any of the following services:**
   - Admiral nurses
   - Carers centre
   - Social prescribers
   - Dementia/Memory Cafe
   - Yes/No/Never heard of them
7. **Who would you go to for advice about dementia? (prompts are not part of the question)**
   - Friends and family
   - Medical services (GP/Memory clinic)
   - Charity (Alzheimer's Society/ Dementia UK/Age UK etc)
   - Carers centre
   - Community group (please specify)
   - Housing association
   - Other (please specify)
8. **What was the biggest support to you as your loved one moved into a terminal phase of dementia? (if person with dementia has died)**
   - Free text
9. **What did you feel was lacking from a support perspective in the final year of life? (If person with dementia has died)**
   - Free text
10. **What has been your experience of Advanced Care Planning?**
    - Free text
11. **Have you discussed Advanced Care Planning or Power of Attorney?**
    - Free text
12. **Tell me about your concerns, if any, about how your dementia will progress?**
    - Free text

13. **We are planning on gathering services for people living with dementia to ask questions about support after the diagnosis. What would you ask them? If you were to meet with the people who build services for people with dementia, what support services do you think they should have, and why?**
    - Free text

14. **Can we talk to you again, if we have some additional questions?**
    - Yes
    - No

15. **Are you aware of the NICE dementia guidelines?**
    - Yes
    - No
    - Comment

16. **Are you aware of 'join dementia research'?**
    - Yes
    - No
    - Comment

17. **Awareness of STrAtegies for RelaTives (START) intervention**
    - Yes
    - No
    - Comment

Interviews with professionals

1. **What do you feel would help you be better equipped to support people living with dementia as part of your role?**
    - Free text
2. **Do you feel part of a wider team in terms of accessing help to support people with dementia? Support could mean timely access to expertise/more intensive support/sharing resources**
    - Free text
3. **Do you know who to contact for help?**
    - Free text
4. **Are there social prescribers/link workers in your area, and have you ever referred?**
    - Free text
5. **Are there systems to share patient information in an easy way with dementia services?**
    - Free text
6. **What has been most helpful to you (in your professional role) when it comes to providing support for people with dementia and their families?**
    - Free text
7. **What are your views on accessibility vs continuity? ie duty social worker (immediate response) verses continuity of care (slower response)**
    - Free text
8. **Where do you feel the balance is, should our limited resources be spent increasing the amount of health care support staff (regardless of qualifications) or increasing the professional acumen of existing staff (despite their limited availability)?**
    - Free text
9. **What does good look like for support services for those living with dementia?**
    - Free text
10. **What does crisis breakdown in support services for those living with dementia look like?**
    - Free text
11. **If you were to change one thing around support services what would it be?**
    - Free text

Appendix D: Detailed Methodology

A Google search using the word 'dementia' + borough was completed for each London borough. The first 50 results for each borough were checked for contact information. Each contact identified was emailed a copy of our flyer inviting people to participate (Appendix D) and asked to disseminate it to their staff and contacts. Each organisation contacted was sent the flyer three times throughout the evaluation period.

A secondary search using **www.nhs.uk/service-search/find-a-gp** was completed to find GP services in each borough. Each service with current contact information was emailed, contacted by phone, and then emailed again. Some GPs requested that we provide our questions via a survey made using SurveyMonkey and distributed with the email and flyer.

A third search involved using the word 'dementia London' + language and was completed for each of the top ten languages spoken in London other than English. The first 50 results for each of the ten languages were checked for contact information. Another search took place, this time for 'London' + language using the same ten languages. Each contact identified was emailed a copy of our flyer (**Appendix E**) translated into their language and asked to disseminate it to their staff and contacts. This request was repeated later in the service evaluation period. Some contacts included local community radio groups who we asked to share our study with their listeners.

Social media, such as Facebook and Twitter, were used to convey the flyer in all 11 languages in which it was available. The project team's professional contacts were also asked for comments and to disseminate our flyer.

Organisations that we approached for comment and to disseminate information about our project:

Care Providers (54)

1. Abbcross Nursing Home
2. Abbeleigh House Care Home
3. Abbeyfield East London Extra Care Society
4. Abbey Care Complex
5. Acorn Lodge Care Centre
6. Albany Nursing Home
7. Alexander Court Care Home
8. Arran Manor Care Home
9. Ashling House Care Home
10. Aspen Court Care Home
11. Aspray House Care Home
12. Auriel Lodge Care Home
13. Barchester Westgate House Care Home
14. Barleycroft Care Home
15. Beaumont Court Care Home
16. Beech Court Care Centre
17. Beis Pinchos Care Home
18. Bennett Lodge Care Home
19. Bennetts Castle Care Home
20. Bless Support Group
21. Chaseview Care Home
22. Cherry Orchard Care Home
23. Chestnut Court Care Home
24. Clover Cottage Care Home
25. Cranham Court Care Home
26. Derham House Care Home
27. Dothan House Care Home
28. Ebury Court Care Home
29. Emerson Court Care Home

30. Faringdon Lodge Care Home
31. Folkestone Nursing Home
32. Freshfields Care Home
34. Hawthorn Green Residential and Nursing Home
35. Home Instead
36. Jewish Care
37. Kallar Lodge Residential Care Home
38. Little Gaynes Care Home
39. Lodge Group Care
40. Manor Farm Care Home
41. Mary Seacole Nursing Home
42. Meadowbanks Residential Care Home
43. Moreland House Care Home
44. Park View Care Home
45. Priory Residential Home
46. Ravenscourt Nursing Home
47. Revitalise Jubilee Lodge
48. Sahara Parkside Care Home
49. Springfield Care Centre
50. St Ives Lodge Care Home
51. Sundial Community Centre
52. The Spinney Care Home
53. Three Willows Care Home
54. Wellesley Lodge (Dementia specialists)

Health Providers (126)

1. Abbey GP Medical Centre
2. The Acorn Group Practice
3. Albany Practice
4. Amwell Group Practice
5. Argyle Surgery
6. Argyle Health Isleworth
7. Argyle Health Group
8. Balham Park Surgery
9. Balaam Street Practice
10. The Barkantine Practice
11. The Barnabas Medical Centre
12. Bec Family Practice
13. Bedford Hill Family Practice
14. The Belgravia Surgery
15. Birchdale Road Medical Centre
16. Blackheath Standard Pms
17. The Bloomsbury Surgery
18. Blue Wing Family Doctor Unit
19. The Bradbury Center
20. Brentford Family Practice
21. Brixton Hill Group Practice
22. Brunswick Medical Centre
23. Burnt Ash Surgery
24. Chestnut Practice
25. Churchill Medical Centre
26. Crawley Road Medical Centre
27. Danebury Avenue Surgery
28. Deptford Surgery
29. Dr Ghufoor
30. Dr Marilyn Graham
31. E16 Health
32. Ealing Park Health Centre
33. East Ham Dementia centre
34. Edith Cavell Surgery
35. Enderley Road Medical Centre
36. Essex House Surgery
37. Essex Lodge
38. The Exchange Surgery
39. Fair Hill Medical Practice
40. Falmouth Road Group Practice
41. Figges Marsh Surgery
42. Firstcare Practice
43. Fitzrovia Medical Centre
44. Francis Road Medical Centre
45. Grafton Medical Partners
46. Grays Inn Road Medical Practice
47. Grove Medical Centre
48. Grove Park Surgery
49. GP Direct
50. Headstone Lane Medical Centre
51. Hounslow Family Practice
52. Dr John Segarajasinghe
53. The Doctor Hickey Surgery
54. King Edwards GP Medical Centre
55. Kingfisher Medical Centre
56. King’s College Health Centre
57. Kings Cross Surgery
58. Kingston Health Centre
59. Kiyani Medical Practice
60. Knights Hill Surgery
61. Lancelot Medical Centre
62. Lees Place Medical Centre
63. Lewisham Medical Centre
64. Liberty Bridge Road Practice
65. Lime Tree Surgery
66. Manor Place Surgery (Nexus Health Group)

67. The Mayfair Medical Centre
68. Macmillan Way Surgery
69. Merchant Street Practice
70. Nelson Medical Practice
71. New Cross Health Centre
72. Newham Transitional Practice
73. Newham Medical Centre
74. The Nightingale Practice
75. The Northwick Surgery
76. The Old Dairy Health Centre
77. Open Door Surgery
78. The Paradise Road Practice
79. Parkshot Medical Practice
80. Pimlico Health At The Marven Surgery
81. Plashet Road Medical Centre
82. Primary Care Pharmacists Association
83. Premier Medical Centre
84. Preston Road Surgery
85. Prentis Medical Centre
86. Primecare Pms
87. The Queens Road Partnership
88. Queens Road Surgery
89. Richmond Community Healthcare Team
90. Richmond Lock Surgery
91. Ripple Road GP Surgery
92. Roserton Street Surgery
93. The Rowans Surgery
94. Royal Hospital Chelsea
95. Savita Medical Centre
96. The Shaftesbury Medical Centre
97. Sheen Surgery
98. Silverlock Medical Centre
99. Simpson House Medical Centre
100. Sms Medical Practice
101. Soho Square General Practice
102. Soho Centre For Health And Care
103. Staines Road Medical Centre
104. Streatham Park Surgery
105. Streatham Common Group Practice
106. Streatham High Practice
107. Streatfield Health Centre
108. St Peter’s Medical Centre
109. Student Medical Centre
110. Surrey Docks Health Centre
111. Thames View GP Medical Centre
112. Thurleigh Road Practice
113. Tooting South Medical Centre
114. Thornbury Road Centre For Health
115. Tulasi GP Medical Centre
116. Twickenham Park Surgery
117. Upper Tooting Road Medical Centre
118. The Vauxhall Surgery
119. Victoria GP Medical Centre
120. The Vicarage Lane Surgery
121. Wandsworth Older People’s Mental Health Team
122. Waterloo Health Centre
123. White House GP Surgery
124. The White House Surgery
125. Wide Way Surgery
126. Woodlands Health Centre

Community/Charity organisations (109)

1. The Advocacy Project
2. Age UK – Bromley and Greenwich
3. Age UK – Croydon
4. Age UK – East London
5. Age UK – Kensington & Chelsea
6. Age UK – Merton
7. Age UK – Redbridge Advice Centre for Older People
8. Age UK – Richmond
9. Age UK – Waltham Forest
10. Age UK – Wandsworth
11. Ageing Well
12. Alzheimer’s Society – City & Hackney
13. Alzheimer’s Society – Croydon
14. Alzheimer’s Society – Enfield, Haringey, Barnet
15. Alzheimer’s Society – Hammersmith & Fulham
16. Alzheimer’s Society – Havering
17. Alzheimer’s Society – Hillingdon & Harrow
18. Alzheimer’s Society – Hounslow & Ealing
19. Alzheimer’s Society – Islington
20. Alzheimer’s Society – Merton Dementia Hub
21. Alzheimer’s Society – Waltham Forest
22. Alzheimer’s Society Wandsworth
23. Alzheimer’s Society – Redbridge
24. Alzheimer’s Society – Tower Hamlets
25. Arts for Dementia
26. Ashford Place Dementia Cafe
27. BLG Dementia Mind
28. Brent Carers’ Centre
29. Cambridge House (Advocacy)
30. Camden Carers Centre
31. Camden Crossroads
32. Carers Centre Tower Hamlets
33. Carers FIRST – Waltham Forest
34. Carers of Barking & Dagenham
35. Carers Support Merton
36. Carers Trust – Havering & Redbridge
37. The City Connections Service
38. City and Hackney Carers Centre
39. City Mission Dementia Project
40. Community Service Volunteers – Retired & Senior Volunteer Programme
41. CrossRoads
42. The Dance Studio
43. Dementia Advice Early Intervention Service
44. Dementia and me
45. Dementia Concern
46. Dementia Concern – Ealing
47. Dementia Support – Streatham
48. The Dennis Centre – Jewish Community Centre
49. Driving Miss Daisy Harefield
50. Ealing Carers Centre
51. End of Life Doula UK
52. Enfield Carers Centre
53. Forget me not club
54. Frog Life
55. Gujarati Arya Association London
56. Gurkhas Support group
57. Hammersmith & Fulham Dementia Action Alliance
58. Harrow Association of Disabled People
59. Harrow Carers
60. Havering Carers Hub

61. Havering Dementia Action Alliance
62. HealthWatch Newham (Advocacy)
64. Hoarding UK
65. HUBB advocacy
66. Islington Carers Centre
67. Jewish Care
68. Lavender Hope CIC – Tulse Hill
69. LinkAge Southwark
70. Love to Move – Croydon
71. Mael Gael
72. Magnolia Club
73. Mama Low's Kitchen (Sound Minds)
74. Memory Lane Club
75. Mind Bromley, Lewisham, Greenwich
76. Mind in Harrow
77. Mind in Tower Hamlets & Newham (Advocacy service)
78. Money and Pensions Service
79. Museum of London
80. National Academy of Social Prescribing
81. Newham Carers Network
82. Open Age
83. Opening Doors London
84. POhWER (Advocacy)
85. Ramblers
86. Redbridge Carers Support Service
87. Redbridge CVS
88. Redbridge Dementia Befriending Service
89. Redbridge Respite Care Association
90. Richmond Carers Centre
91. Roma support group
92. Share & Care Homeshare
93. South Mitcham Community Association
94. Spear Homeless Charity
95. Spires Homeless Centre
96. Staywell Dementia Support
97. St Mungo's Homeless Charity
98. Sutton Carers Centre
99. Tapestry
100. Tennyson Grange Care Home (offers Dementia care)
101. Third Age Trust
102. Together UK
103. Tooting Neighbourhood Centre
104. Voiceability Advocacy
105. Wandsworth Asian Women's Association
106. Wandsworth Carers Centre
107. Waltham Forest Dementia Hub
108. Wimbledon Park Bowls Club
109. Women & Health – Caring and Talking Together

Housing Providers (8)

1. Guinness Housing Association
2. Housing 21 Housing Association
3. Notting Hill Genesis Housing Association
4. Origin Housing Association
5. Peabody Housing Association
6. Places for People Housing Provider
7. Transform Housing & Support
8. West Kent Housing Association

Care Technology Provider (4)

1. Access Group
2. After Cloud
3. Birdie Home Care Software
4. Vine health

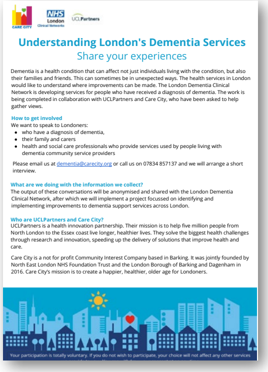
Flyers about this project were translated (by human translators) into the top ten most common language spoken in London (excluding English) and then sent to the boroughs with the largest populations of those speakers:

1. **Polish**
    a. Polish Social and Cultural Association, Hammersmith
    b. Parafia Devonia – Polish Catholic Mission, Islington
    c. Polish Ealing Community Facebook, Ealing
2. **French**
    a. The Third Age Trust, French conversation, Hammersmith
    b. French African Welfare Association (FAWA), Lambeth, Southwark, Croydon, Kensington & Chelsea, Hammersmith & Fulham, Westminster
    c. London French Meetup, City of London
3. **Turkish**
    a. IMEC Turkish Women's group, Islington
    b. Haricare, Haringey
    c. Enfield Turkish Cypriot Association, Enfield
    d. Hackney Cypriot Association, Hackney
4. **Punjabi**
    a. Network of Sikh Organisations
    b. Bexley Sikh Seva, Bexley
    c. Barking Gurudwara, Barking
    d. Panjabi Centre Radio Broadcaster, Ealing
5. **Bengali**
    a. St Peter's Bengali Association, Tower Hamlets
    b. Jeyes Community Centre, Newham
6. **Urdu**
    a. Network of Sikh Organisations
    b. Henna, Asian Women's group, Camden
    c. Panjabi Centre Radio Broadcaster, Ealing
7. **Tamil**
    a. The Tamil Welfare Association, Barking
    b. Tamil Association of Brent, Brent
    c. Tamil Community Centre, Hillingdon
8. **Spanish**
    a. Latin American House, Camden
    b. British Spanish Society, Westminster
9. **Gujarati**
    a. Redbridge Gujarati Welfare Association, Redbridge
    b. The London Hindu Gujarati Network Facebook group
    c. Gujarati Arya Association London, Harrow
10. **Lithuanian**
    a. Lithuanian City of London Facebook Club, City of London
    b. British-Lithuanian Society, Wandsworth

Organisations who provided us with comments via focus groups and service visits:

- Young Onset Dementia Activists Group – Mind Bromley, Lewisham, Greenwich
- Carers of Barking & Dagenham
- Camden Carers
- Alzhiemer's Society
- Notting Hill Genesis Housing Association
- Peabody Housing Association
- West Kent Housing Association

Appendix E: Service Evaluation Flyers



Understanding London's Dementia Services

Share your experiences

Dementia is a health condition that can affect not just individuals living with the condition, but also their families and friends. This can sometimes be in unexpected ways. The health services in London would like to understand where improvements can be made. The London Dementia Clinical Network is developing services for people who have received a diagnosis of dementia. The work is being completed in collaboration with UCLPartners and Care City, who have been asked to help gather views.

How to get involved

We want to speak to Londoners:

- who have a diagnosis of dementia,
- their family and carers
- health and social care professionals who provide services used by people living with dementia community service providers

Please email us at dementia@carecity.org or call us on 07834 857137 and we will arrange a short interview.

What are we doing with the information we collect?

The output of these conversations will be anonymised and shared with the London Dementia Clinical Network, after which we will implement a project focussed on identifying and implementing improvements to dementia support services across London.

Who are UCLPartners and Care City?

UCLPartners is a health innovation partnership. Their mission is to help five million people from North London to the Essex coast live longer, healthier lives. They solve the biggest health challenges through research and innovation, speeding up the delivery of solutions that improve health and care.

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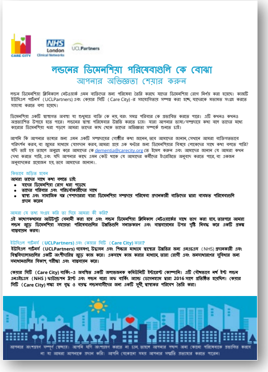
English



Bengali

Comprendre les Services en matière de Démence de Londres Partagez vos expériences

Le Réseau Clinique de la Démence de Londres développe des services pour les personnes ayant reçu un diagnostic de démence. Ce travail est effectué en collaboration avec UCLPartners et Care City, à qui il a été demandé d'aider à recueillir des avis.

La démence est un problème de santé qui peut affecter non seulement des individus, mais aussi des familles entières. Cela peut parfois se produire de manières inattendues. Les services de santé de Londres aimeraient s'améliorer. Nous souhaiterions entendre des personnes parlant votre langue/de votre communauté à propos de leurs expériences lorsque quelqu'un a reçu un diagnostic de démence.

Connaissez-vous un groupe communautaire de votre langue auquel nous pourrions rendre visite en personne, ou joindre via zoom, et où nous pourrions parler à des gens sur ce sujet de la démence durant environ une heure ? Si c'est le cas, envoyez-nous, s'il-vous-plait, un e-mail à dementia@carecity.org et faites-nous savoir quand nous pourrions organiser un rendez-vous, et si vous avez quelqu'un qui pourrait traduire en anglais à notre équipe, ou si un interprète serait nécessaire.

Comment s'impliquer

Nous voulons parler à :

- ceux qui ont reçu un diagnostic de démence,
- leur famille et les personnes assurant leurs soins
- les professionnels de la santé et des services sociaux qui fournissent des services utilisés par des personnes vivant avec une démence
- des fournisseurs de services communautaires

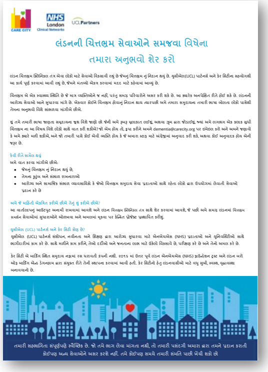
Qu'allons-nous faire avec les informations que nous recueillons ?

Le résultat de ces conversations sera anonymisé et partagé avec le Réseau Clinique de la Démence de Londres, après quoi, nous allons mettre en œuvre un projet centré sur l'identification et l'implantation d'améliorations des services de soutien de la démence dans toute la ville de Londres.

Qui sont UCLPartners et Care City ?

UCLPartners travaille par le biais d'un partenariat de fournisseurs du NHS et d'universités afin d'améliorer la santé à travers la recherche, l'innovation et l'éducation. En travaillant ensemble, ils développent, testent et mettent en œuvre des solutions au bénéfice des patients et du public.
Care City est une société d'intérêt communautaire sans but lucratif basée à Barking. Elle a été fondée conjointement par la North East London NHS Foundation Trust et le London Borough of Barking and Dagenham en 2016. La mission de Care City est de créer un âge avancé plus heureux et en meilleure santé pour les Londoniens.

French



Gujarati

Londono demencijos paslaugų supratimas

Pasidalykite savo patirtimi

Londono demencijos klinikinis tinklas (angl. *London Dementia Clinical Network*) teikia paslaugas žmonėms, kuriems diagnozuota demencija. Darbas atliekamas bendradarbiaujant su „UCLPartners" ir „Care City", kurių buvo paprašyta padėti surinkti nuomones.

Demencija yra sveikatos būklė, kuri gali paveikti ne tik atskirus asmenis, bet ir ištisas šeimas. Kartais tai gali vykti netikėtais būdais. Sveikatos priežiūros paslaugos Londone norėtų patobulinti savo darbą. Norėtume išgirsti žmonių, kalbančių jūsų kalba ir (arba) bendruomenės atstovų nuomonę apie jų patirtį, kai asmeniui diagnozuojama demencija.

Ar žinote savo kalbos bendruomenės grupę, kurioje galėtume apsilankyti asmeniškai arba prisijungti prie jos per „Zoom" nuotolinę platformą ir maždaug valandą pasikalbėti su žmonėmis šia demencijos tema? Jei taip, rašykite mums el. paštu dementia@carecity.org ir praneškite, kada galėtume susitikti, ir ar turite žmogų, kuris galėtų išversti mūsų darbuotojams į anglų kalbą, arba pasakykite, ar reikalingas vertėjas.

Kaip dalyvauti

Norime pasikalbėti su:

- tais asmenimis, kuriems diagnozuota demencija;
- jų šeimos nariais ir globėjais;
- sveikatos priežiūros ir socialinės rūpybos specialistais, teikiančiais paslaugas, kuriomis naudojasi demencija sergantys ir su bendruomenės paslaugų teikėjais gyvenantys asmenys.

Ką darome su surinkta informacija?

Šių pokalbių rezultatai bus anonimizuoti ir perduoti Londono demencijos klinikiniam tinklui, o po to įgyvendinsime projektą, kurio tikslas – nustatyti ir įgyvendinti pagalbos sergantiesiems demencija paslaugų patobulinimus visame Londone.

Kas yra „UCLPartners" ir „Care City"?

„UCLPartners" dirba Nacionalinės sveikatos priežiūros tarnybos (angl. *NHS*) paslaugų teikėjų ir universitetų partnerystėje, siekdami pagerinti sveikatą per mokslinius tyrimus, inovacijas ir švietimą. Bendradarbiaudami jie kuria, išbando ir įgyvendina pacientams ir visuomenei naudingus sprendimus.

„Care City" yra pelno nesiekianti bendruomenės interesų bendrovė, įsikūrusi Barkinge. 2016 m. jį kartu įkūrė Šiaurės Rytų Londono NHS fondas „North East London NHS Foundation Trust" ir Londono Barkingo ir Dagenhamo rajonas. „Care City" misija – užtikrinti laimingesnį ir sveikesnį vyresnio amžiaus londoniečių gyvenimą.

Jūsų dalyvavimas yra visiškai savanoriškas. Jei nepageidaujate dalyvauti, jūsų pasirinkimas neturės įtakos jokioms kitoms jums teikiamoms paslaugoms. Savo sutikimą galite atšaukti bet kuriuo metu

Lithuanian

Przedstawienie usług dla osób chorych na demencję w Londynie

Podziel się swoimi doświadczeniami

London Dementia Clinical Network opracowuje usługi dla osób, u których zdiagnozowano demencję. Prace są realizowane we współpracy z UCLPartners i Care City, które zostały poproszone o pomoc w zbieraniu opinii.

Demencja to choroba, która może dotyczyć nie tylko pojedynczych osób, ale całych rodzin. Czasami może to nastąpić w nieoczekiwany sposób. Służba zdrowia w Londynie chciałaby się udoskonalić. Chcielibyśmy usłyszeć od ludzi, którzy mówią w Państwa języku/Państwa społeczności o ich doświadczeniach z diagnozą demencji.

Czy znają Państwo grupę społeczności mówiącą w Państwa języku, z którą możemy się spotkać osobiście lub za pomocą aplikacji Zoom, aby porozmawiać na temat demencji przez około godzinę? Jeśli tak, prosimy o kontakt z nami poprzez adres e-mail dementia@carecity.org I poinformowanie nas o tym, kiedy możemy zaplanować takie spotkanie i czy mają Państwo dostępną osobę, która tłumaczyłaby na język angielski dla naszego personelu lub czy potrzebny byłby tłumacz.

Jak mogą się Państwo zaangażować

Chcemy porozmawiać z:

- osobami, u których zdiagnozowano demencję,
- ich rodzinami i opiekunami
- pracownikami służby zdrowia i opieki społecznej, którzy świadczą usługi, z których korzystają osoby chore na demencję

Co robimy z informacjami, które zbieramy?

Wyniki tych rozmów zostaną zanonimizowane i udostępnione London Dementia Clinical Network, po czym zrealizujemy projekt skoncentrowany na identyfikacji i wdrażaniu ulepszeń usług wsparcia osób chorych na demencję w całym Londynie.

Kim są UCLPartners i Care City?

UCLPartners działają w ramach partnerstwa dostawców NHS i uniwersytetów w celu poprawy zdrowia poprzez badania, innowacje i edukację. Współpracując, opracowują, testują i wdrażają rozwiązania z korzyścią dla pacjentów i społeczeństwa.

Care City jest organizacją non-profit działającą w interesie społeczności (ang. *Community Interest Company*) z siedzibą w Barking. Została założona wspólnie przez North East London NHS Foundation Trust i London Borough of Barking and Dagenham w 2016 roku. Misją Care City jest stworzenie szczęśliwszego, zdrowszego i dłuższego życia dla mieszkańców Londynu.

Państwa udział jest całkowicie dobrowolny. Jeśli nie chcą Państwo uczestniczyć w tym projekcie, nie wpłynie to na żadne inne usługi, które Państwu świadczymy. Zgodę na udział mogą Państwo wycofać w dowolnym momencie.

Polish

Punjabi

Servicios de apoyo a la demencia de Londres

Comparte tus experiencias

La London Dementia Clinical Network está desarrollando una serie de servicios para las personas diagnosticadas con demencia. Esta labor recibe la colaboración de UCLPartners y Care City, a quienes les hemos pedido ayuda para tener más visibilidad.

La demencia es un trastorno de la salud que puede afectar no solo a una persona en particular, sino a familias enteras. Puede ocurrir de maneras inesperadas. Los servicios sanitarios de Londres quieren mejorar. Nos gustaría que personas de tu comunidad o que hablen tu mismo idioma compartieran su experiencia tras recibir un diagnóstico de demencia.

¿Conoces alguna comunidad de personas que hablen tu idioma con las que podríamos reunirnos en persona o vía zoom para hablar de la demencia durante una hora? Si es así, por favor, envíanos un correo electrónico a dementia@carecity.org y dinos cuándo podríamos vernos. Avísanos también si hay alguien que pueda traducir a inglés para nuestros trabajadores o si será necesario un intérprete.

Cómo formar parte

Queremos hablar con:

- aquellos que han sido diagnosticados con demencia
- sus familiares y cuidadores
- profesionales sanitarios y sociales cuyos servicios benefician a las personas con demencia
- proveedores de servicios a la comunidad

¿Qué hacemos con la información que recopilamos?

Estas conversaciones serán anónimas. Compartiremos el resultado con la London Dementia Clinical Network para, más tarde, implementar un proyecto centrado en identificar y poner en marcha mejoras en los servicios de apoyo a la demencia de Londres.

¿Quiénes son UCLPartners y Care City?

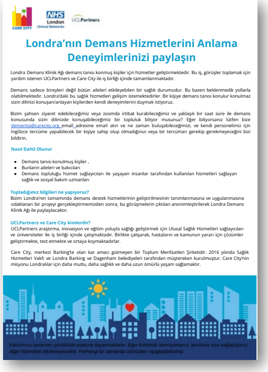
UCLPartners trabajan junto con universidades y profesionales del NHS para mejorar la salud a través de la investigación, la innovación y la educación. Esta colaboración hace posible que puedan desarrollar, probar e implementar soluciones que beneficien a los pacientes y al público en general.

Care City es una empresa de interés comunitario sin ánimo de lucro con sede en Barking. Fue fundada conjuntamente por la North East London NHS Foundation y el distrito de Barking y Dagenham en 2016. La misión de Care City es que los londinenses tengan una tercera edad más feliz y saludable.

Tu participación es completamente voluntaria. Si eliges no participar, ninguno de los demás servicios que te ofrecemos se verá afectado por tu decisión. Puedes retirar tu consentimiento en cualquier momento.

Spanish

Tamil



Londra'nın Demans Hizmetlerini Anlama Deneyimlerinizi paylaşın

Londra Demans Klinik Ağı demans tanısı konmuş kişiler için hizmetler geliştirmektedir. Bu iş, görüşler toplamak için yardım istenen UCLPartners ve Care City ile iş birliği içinde tamamlanmaktadır.

Demans sadece bireyleri değil bütün aileleri etkileyebilen bir sağlık durumudur. Bu bazen beklenmedik yollarla olabilmektedir. Londra'daki bu sağlık hizmetleri gelişim istemektedirler. Bir kişiye demans tanısı konulur konulmaz sizin dilinizi konuşan/anlayan kişilerden kendi deneyimlerini duymak istiyoruz.

Bizim şahsen ziyaret edebileceğimiz veya zoomda irtibat kurabileceğimiz ve yaklaşık bir saat süre ile demans konusunda sizin dilinizde konuşabileceğimiz bir topluluk biliyor musunuz? Eğer biliyorsanız lütfen bize dementia@carecity.org email adresine email atın ve ne zaman buluşabileceğimizi, ve kendi personelimiz için İngilizce tercüme yapabilecek bir kişiye sahip olup olmadığınızı veya bir tercüman gerekip gerekmeyeceğini bizi bildirin.

Nasıl Dahil Olunur

- Demans tanısı konulmuş kişiler ,
- Bunların aileleri ve bakıcıları
- Demans topluluğu hizmet sağlayıcıları ile yaşayan insanlar tarafından kullanılan hizmetleri sağlayan sağlık ve sosyal bakım uzmanları

Topladığımız bilgileri ne yapıyoruz?

Bizim Londra'nın tamamında demans destek hizmetlerinin geliştirilmesinin tanımlanmasına ve uygulanmasına odaklanan bir projeyi gerçekleştirmemizden sonra, bu görüşmelerin çıktıları anonimleştirilerek Londra Demans Klinik Ağı ile paylaşılacaktır.

UCLPartners ve Care City kimlerdir?

UCLPartners araştırma, inovasyon ve eğitim yoluyla sağlığı geliştirmek için Ulusal Sağlık Hizmetleri sağlayıcıları ve üniversiteler ile iş birliği içinde çalışmaktadır. Birlikte çalışarak, hastaların ve kamunun yararı için çözümler geliştirmekte, test etmekte ve ortaya koymaktadırlar.

Care City, merkezi Barking'te olan kar amacı gütmeyen bir Toplum Menfaatleri Şirketidir. 2016 yılında Sağlık Hizmetleri Vakfı ve Londra Barking ve Dagenham belediyeleri tarafından müştereken kurulmuştur. Care City'nin misyonu Londralılar için daha mutlu, daha sağlıklı ve daha uzun ömürlü yaşam sağlamaktır.

Katılımınız tamamen gönüllülük esasına dayanmaktadır. Eğer Katılmak istemiyorsanız, tercihiniz size sağladığımız diğer hizmetleri etkilemeyecektir. Herhangi bir zamanda izninizden vazgeçebilirsiniz.

Turkish

Urdu

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লন্ডনের ডিমেনশিয়া পরিষেবাগুলি কে বোঝা

আপনার অভিজ্ঞতা শেয়ার করুন

লন্ডন ডিমেনশিয়া ক্লিনিক্যাল নেটওয়ার্ক এমন ব্যক্তিদের জন্য পরিষেবা তৈরি করছে যাদের ডিমেনশিয়া রোগ নির্ণয় করা হয়েছে। কাজটি ইউসিএল পার্টনার্স (UCLPartners) এবং কেয়ার সিটি (Care City) -র সহযোগিতায় সম্পন্ন করা হচ্ছে, যাদেরকে মতামত সংগ্রহ করতে সাহায্য করতে বলা হয়েছে।

ডিমেনশিয়া একটি স্বাস্থ্যগত অবস্থা যা শুধুমাত্র ব্যক্তি কে নয়, বরং সমগ্র পরিবার কে প্রভাবিত করতে পারে। এটি কখনও কখনও অপ্রত্যাশিত উপায়ে হতে পারে। লন্ডনের স্বাস্থ্য পরিষেবার উন্নতি করতে চায়। যারা আপনার ভাষা/সম্প্রদায়ে কথা বলে তাদের মধ্যে কারোর ডিমেনশিয়া ধরা পড়লে আমরা তাদের কাছ থেকে তাদের অভিজ্ঞতা সম্পর্কে শুনতে চাই।

আপনি কি আপনার ভাষার জন্য এমন একটি সম্প্রদায়ের গোষ্ঠীর কথা জানেন, তবে আমাদের জানান, সেখানে আমরা ব্যক্তিগতভাবে পরিদর্শন করব, বা জুমের মাধ্যমে যোগদান করব, আমরা প্রায় এক ঘন্টার জন্য ডিমেনশিয়ার বিষয়ে লোকেদের সাথে কথা বলতে পারি? যদি তাই হয় তাহলে অনুগ্রহ করে আমাদের কে dementia@carecity.org তে ইমেল করুন এবং আমাদের জানান যে আমরা কখন দেখা করতে পারি, এবং যদি আপনার কাছে এমন কেউ থাকে যে আমাদের কর্মীদের ইংরেজিতে অনুবাদ করতে পারে, বা একজন অনুবাদকের প্রয়োজন হয়, তবে আমাদের জানান।.

কিভাবে জড়িত হবেন

আমরা তাদের সাথে কথা বলতে চাই:

- **যাদের ডিমেনশিয়া রোগ ধরা পড়েছে**
- **তাদের পরিবার এবং পরিচর্যাকারীদের সাথে**
- **স্বাস্থ্য এবং সামাজিক যত্ন পেশাদাররা যারা ডিমেনশিয়া সম্প্রদায় পরিষেবা প্রদানকারী ব্যক্তিদের দ্বারা ব্যবহৃত পরিষেবাগুলি প্রদান করেন**

আমরা যে তথ্য সংগ্রহ করি তা দিয়ে আমরা কী করি?

এই কথোপকথনের আউটপুট বেনামী করা হবে এবং লন্ডন ডিমেনশিয়া ক্লিনিকাল নেটওয়ার্কের সাথে ভাগ করা হবে, তারপরে আমরা লন্ডন জুড়ে ডিমেনশিয়া সহায়তা পরিষেবাগুলির উন্নতিগুলি সনাক্তকরণ এবং বাস্তবায়নের উপর দৃষ্টি নিবদ্ধ করে একটি প্রকল্প বাস্তবায়ন করব।

ইউসিএল পার্টনার্স (**UCLPartners**) এবং কেয়ার সিটি (**Care City**) কারা?

ইউসিএল পার্টনার্স (UCLPartners) গবেষণা, উদ্ভাবন এবং শিক্ষার মাধ্যমে স্বাস্থ্যের উন্নতির জন্য এনএচএস (NHS) **প্রদানকারী এবং বিশ্ববিদ্যালয়গুলির একটি অংশীদারিত্ব জুড়ে কাজ করে। একসাথে কাজ করার মাধ্যমে, তারা রোগী এবং জনসাধারণের সুবিধার জন্য সমাধানগুলির বিকাশ, পরীক্ষা এবং বাস্তবায়ন করে।**

কেয়ার সিটি (Care City) বার্কিং-এ অবস্থিত একটি অলাভজনক কমিউনিটি ইন্টারেস্ট কোম্পানি। এটি যৌথভাবে নর্থ ইস্ট লন্ডন এনএইচএস (NHS) ফাউন্ডেশন ট্রাস্ট এবং লন্ডন বরো অফ বার্কিং অ্যান্ড ডেগেনহ্যাম দ্বারা 2016 সালে প্রতিষ্ঠিত হয়েছিল। কেয়ার সিটি (Care City) লক্ষ্য হল বৃদ্ধ ও বয়স্ক লন্ডনবাসীদের জন্য একটি সুখী, স্বাস্থ্যকর পরিবেশ তৈরি করা।

আপনার অংশগ্রহণ সম্পূর্ণ স্বেচ্ছায়। আপনি যদি অংশগ্রহণ করতে না চান, তাহলে আপনার পছন্দ অন্য কোনো পরিষেবাকে প্রভাবিত করবে না যা আমরা আপনাকে প্রদান করি। আপনি যেকোনো সময় আপনার সম্মতি প্রত্যাহার করতে পারেন।

Comprendre les Services en matière de Démence de Londres Partagez vos expériences

Le Réseau Clinique de la Démence de Londres développe des services pour les personnes ayant reçu un diagnostic de démence. Ce travail est effectué en collaboration avec UCLPartners et Care City, à qui il a été demandé d'aider à recueillir des avis.

La démence est un problème de santé qui peut affecter non seulement des individus, mais aussi des familles entières. Cela peut parfois se produire de manières inattendues. Les services de santé de Londres aimeraient s'améliorer. Nous souhaiterions entendre des personnes parlant votre langue/de votre communauté à propos de leurs expériences lorsque quelqu'un a reçu un diagnostic de démence.

Connaissez-vous un groupe communautaire de votre langue auquel nous pourrions rendre visite en personne, ou joindre via zoom, et où nous pourrions parler à des gens sur ce sujet de la démence durant environ une heure ? Si c'est le cas, envoyez-nous, s'il-vous-plait, un e-mail à dementia@carecity.org et faites-nous savoir quand nous pourrions organiser un rendez-vous, et si vous avez quelqu'un qui pourrait traduire en anglais à notre équipe, ou si un interprète serait nécessaire.

Comment s'impliquer

Nous voulons parler à :

- ceux qui ont reçu un diagnostic de démence,
- leur famille et les personnes assurant leurs soins
- les professionnels de la santé et des services sociaux qui fournissent des services utilisés par des personnes vivant avec une démence
- des fournisseurs de services communautaires

Qu'allons-nous faire avec les informations que nous recueillons ?

Le résultat de ces conversations sera anonymisé et partagé avec le Réseau Clinique de la Démence de Londres, après quoi, nous allons mettre en œuvre un projet centré sur l'identification et l'implantation d'améliorations des services de soutien de la démence dans toute la ville de Londres.

Qui sont UCLPartners et Care City ?

UCLPartners travaille par le biais d'un partenariat de fournisseurs du NHS et d'universités afin d'améliorer la santé à travers la recherche, l'innovation et l'éducation. En travaillant ensemble, ils développent, testent et mettent en œuvre des solutions au bénéfice des patients et du public.

Care City est une société d'intérêt communautaire sans but lucratif basée à Barking. Elle a été fondée conjointement par la North East London NHS Foundation Trust et le London Borough of Barking and Dagenham en 2016. La mission de Care City est de créer un âge avancé plus heureux et en meilleure santé pour les Londoniens.

CARE CITY NHS London Clinical Networks UCLPartners

લંડનની ચિત્તભ્રમ સેવાઓને સમજવા વિષેના

તમારા અનુભવો શેર કરો

લંડન ચિત્તભ્રમ ક્લિનિકલ તંત્ર એવા લોકો માટે સેવાઓ વિકસાવી રહ્યું છે જેમનું ચિત્તભ્રમ નું નિદાન થયું છે. યુસીએલ(UCL) પાર્ટનર્સ અને કેર સિટીના સહયોગથી આ કાર્ય પૂર્ણ કરવામાં આવી રહ્યું છે, જેમને મંતવ્યો એકત્ર કરવામાં મદદ માટે કહેવામાં આવ્યું છે.

ચિત્તભ્રમ એ એક સ્વાસ્થ્ય સ્થિતિ છે જે માત્ર વ્યક્તિઓને જ નહીં, પરંતુ સમગ્ર પરિવારોને અસર કરી શકે છે. આ ક્યારેક અનપેક્ષિત રીતે હોઈ શકે છે. લંડનની આરોગ્ય સેવાઓ આને સુધારવા માંગે છે. એકવાર કોઈને ચિત્તભ્રમ હોવાનું નિદાન થાય ત્યારપછી અમે તમારા સમુદાયના તમારી ભાષા બોલતા લોકો પાસેથી તેમના અનુભવો વિશે સાંભળવા માંગીએ છીએ.

શું તમે તમારી ભાષા જાણતા સમુદાયના જૂથ વિશે જાણો છો જેની અમે રૂબરૂ મુલાકાત લઈશું, અથવા ઝૂમ દ્વારા જોડાઈશું, જ્યાં અમે લગભગ એક કલાક સુધી ચિત્તભ્રમ ના આ વિષય વિશે લોકો સાથે વાત કરી શકીએ? જો એમ હોય તો, કૃપા કરીને અમને dementia@carecity.org પર ઇમેઇલ કરો અને અમને જણાવો કે અમે ક્યારે મળી શકીએ, અને જો તમારી પાસે કોઈ એવી વ્યક્તિ હોય કે જે અમારા સ્ટાફ માટે અંગ્રેજીમાં અનુવાદ કરી શકે, અથવા કોઈ અનુવાદક હોય એની જરૂર છે.

કેવી રીતે સામેલ થવું

અમે વાત કરવા માંગીએ છીએ:

- જેમનું ચિત્તભ્રમ નું નિદાન થયું છે,
- તેમના કુટુંબ અને સંભાળ રાખનારાઓ
- આરોગ્ય અને સામાજિક સંભાળ વ્યાવસાયિકો કે જેઓ ચિત્તભ્રમ સમુદાય સેવા પ્રદાતાઓ સાથે રહેતા લોકો દ્વારા ઉપયોગમાં લેવાતી સેવાઓ પ્રદાન કરે છે

અમે જે માહિતી એકત્રિત કરીએ છીએ તેનું શું કરીએ છીએ?

આ વાર્તાલાપનું આઉટપુટ અનામી રાખવામાં આવશે અને લંડન ચિત્તભ્રમ ક્લિનિકલ તંત્ર સાથે શેર કરવામાં આવશે, જે પછી અમે સમગ્ર લંડનમાં ચિત્તભ્રમ સમર્થન સેવાઓમાં સુધારાઓને ઓળખવા અને અમલમાં મૂકવા પર કેન્દ્રિત પ્રોજેક્ટ પ્રસ્થાપિત કરીશું.

યુસીએલ (UCL) પાર્ટનર્સ અને કેર સિટી કોણ છે?

યુસીએલ (UCL) પાર્ટનર્સ સંશોધન, નવીનતા અને શિક્ષણ દ્વારા આરોગ્ય સુધારવા માટે એનએચએસ (NHS) પ્રદાતાઓ અને યુનિવર્સિટીઓ સાથે ભાગીદારીમાં કામ કરે છે. સાથે મળીને કામ કરીને, તેઓ દર્દીઓ અને જનતાના લાભ માટે ઉકેલો વિકસાવે છે, પરીક્ષણ કરે છે અને તેનો અમલ કરે છે.

કેર સિટી એ બાર્કિંગ સ્થિત સમુદાય નફામાં રસ ધરાવતી કંપની નથી. ૨૦૧૬ માં ઉત્તર પૂર્વ લંડન એનએચએસ (NHS) ફાઉન્ડેશન ટ્રસ્ટ અને લંડન બરો ઓફ બાર્કિંગ એન્ડ ડેગનહામ દ્વારા સંયુક્ત રીતે તેની સ્થાપના કરવામાં આવી હતી. કેર સિટીનો હેતુ લંડનવાસીઓ માટે વધુ સુખી, સ્વસ્થ, વૃદ્ધાવસ્થા બનાવવાનો છે.

તમારી સહભાગિતા સંપૂર્ણપણે સ્વૈચ્છિક છે. જો તમે ભાગ લેવા માંગતા નથી, તો તમારી પસંદગી અમારા દ્વારા તમને પ્રદાન કરાતી કોઈપણ અન્ય સેવાઓને અસર કરશે નહીં. તમે કોઈપણ સમયે તમારી સંમતિ પાછી ખેંચી શકો છો

Londono demencijos paslaugų supratimas

Pasidalykite savo patirtimi

Londono demencijos klinikinis tinklas (angl. *London Dementia Clinical Network*) teikia paslaugas žmonėms, kuriems diagnozuota demencija. Darbas atliekamas bendradarbiaujant su „UCLPartners“ ir „Care City“, kurių buvo paprašyta padėti surinkti nuomones.

Demencija yra sveikatos būklė, kuri gali paveikti ne tik atskirus asmenis, bet ir ištisas šeimas. Kartais tai gali vykti netikėtais būdais. Sveikatos priežiūros paslaugos Londone norėtų patobulinti savo darbą. Norėtume išgirsti žmonių, kalbančių jūsų kalba ir (arba) bendruomenės atstovų nuomonę apie jų patirtį, kai asmeniui diagnozuojama demencija.

Ar žinote savo kalbos bendruomenės grupę, kurioje galėtume apsilankyti asmeniškai arba prisijungti prie jos per „Zoom“ nuotolinę platformą ir maždaug valandą pasikalbėti su žmonėmis šia demencijos tema? Jei taip, rašykite mums el. paštu dementia@carecity.org ir praneškite, kada galėtume susitikti, ir ar turite žmogų, kuris galėtų išversti mūsų darbuotojams į anglų kalbą, arba pasakykite, ar reikalingas vertėjas.

Kaip dalyvauti

Norime pasikalbėti su:

- tais asmenimis, kuriems diagnozuota demencija;
- jų šeimos nariais ir globėjais;
- sveikatos priežiūros ir socialinės rūpybos specialistais, teikiančiais paslaugas, kuriomis naudojasi demencija sergantys ir su bendruomenės paslaugų teikėjais gyvenantys asmenys.

Ką darome su surinkta informacija?

Šių pokalbių rezultatai bus anonimizuoti ir perduoti Londono demencijos klinikiniam tinklui, o po to įgyvendinsime projektą, kurio tikslas – nustatyti ir įgyvendinti pagalbos sergantiesiems demencija paslaugų patobulinimus visame Londone.

Kas yra „UCLPartners“ ir „Care City“?

„UCLPartners“ dirba Nacionalinės sveikatos priežiūros tarnybos (angl. *NHS*) paslaugų teikėjų ir universitetų partnerystėje, siekdami pagerinti sveikatą per mokslinius tyrimus, inovacijas ir švietimą. Bendradarbiaudami jie kuria, išbando ir įgyvendina pacientams ir visuomenei naudingus sprendimus.

„Care City“ yra pelno nesiekianti bendruomenės interesų bendrovė, įsikūrusi Barkinge. 2016 m. ją kartu įkūrė Šiaurės Rytų Londono NHS fondas „North East London NHS Foundation Trust“ ir Londono Barkingo ir Dagenhamo rajonas. „Care City“ misija – užtikrinti laimingesnį ir sveikesnį vyresnio amžiaus londoniečių gyvenimą.

Jūsų dalyvavimas yra visiškai savanoriškas. Jei nepageidaujate dalyvauti, jūsų pasirinkimas neturės įtakos jokioms kitoms jums teikiamoms paslaugoms. Savo sutikimą galite atšaukti bet kuriuo metu

Przedstawienie usług dla osób chorych na demencję w Londynie

Podziel się swoimi doświadczeniami

London Dementia Clinical Network opracowuje usługi dla osób, u których zdiagnozowano demencję. Prace są realizowane we współpracy z UCLPartners i Care City, które zostały poproszone o pomoc w zbieraniu opinii.

Demencja to choroba, która może dotyczyć nie tylko pojedynczych osób, ale całych rodzin. Czasami może to nastąpić w nieoczekiwany sposób. Służba zdrowia w Londynie chciałaby się udoskonalić. Chcielibyśmy usłyszeć od ludzi, którzy mówią w Państwa języku/Państwa społeczności o ich doświadczeniach z diagnozą demencji.

Czy znają Państwo grupę społeczności mówiącą w Państwa języku, z którą możemy się spotkać osobiście lub za pomocą aplikacji Zoom, aby porozmawiać na temat demencji przez około godzinę? Jeśli tak, prosimy o kontakt z nami poprzez adres e-mail dementia@carecity.org I poinformowanie nas o tym, kiedy możemy zaplanować takie spotkanie i czy mają Państwo dostępną osobę, która tłumaczyłaby na język angielski dla naszego personelu lub czy potrzebny byłby tłumacz.

Jak mogą się Państwo zaangażować

Chcemy porozmawiać z:

- osobami, u których zdiagnozowano demencję,
- ich rodzinami i opiekunami
- pracownikami służby zdrowia i opieki społecznej, którzy świadczą usługi, z których korzystają osoby chore na demencję

Co robimy z informacjami, które zbieramy?

Wyniki tych rozmów zostaną zanonimizowane i udostępnione London Dementia Clinical Network, po czym zrealizujemy projekt skoncentrowany na identyfikacji i wdrażaniu ulepszeń usług wsparcia osób chorych na demencję w całym Londynie.

Kim są UCLPartners i Care City?

UCLPartners działają w ramach partnerstwa dostawców NHS i uniwersytetów w celu poprawy zdrowia poprzez badania, innowacje i edukację. Współpracując, opracowują, testują i wdrażają rozwiązania z korzyścią dla pacjentów i społeczeństwa.

Care City jest organizacją non-profit działającą w interesie społeczności (ang. *Community Interest Company*) z siedzibą w Barking. Została założona wspólnie przez North East London NHS Foundation Trust i London Borough of Barking and Dagenham w 2016 roku. Misją Care City jest stworzenie szczęśliwszego, zdrowszego i dłuższego życia dla mieszkańców Londynu.

Państwa udział jest całkowicie dobrowolny. Jeśli nie chcą Państwo uczestniczyć w tym projekcie, nie wpłynie to na żadne inne usługi, które Państwu świadczymy. Zgodę na udział mogą Państwo wycofać w dowolnym momencie.

لندن دیاں سروسز برائے عتاہٹ(ڈیمینشیا) دی سمجھ

اپنے تجربیاں دا اشتراک کرو

لندن ڈیمینشیا کلینیکل نیٹ ورک اوہناں لوکاں لئی سروسز نُوں فروغ دے رہیا اے جیناں وچ عتاہٹ (ڈیمینشیا) دی تشخیص ہوئی اے۔ ایہہ کم UCLPartners اتے Care City دے سانجھے تعاون نال مکمل کیتا جا رہیا اے، جیناں توں آراء جمع کرن وچ مدد کرن دی درخواست کیتی گئی اے۔

عتاہٹ صحت دا اک مرض اے جیہڑا بس افراد نوں ای نہیں، سگوں پورے ٹبراں نوں متاثر کر سکدا اے۔ کدی کدار ایہہ غیر متوقع طریقیاں نال وارد ہو سکدا اے۔ لندن دیاں صحت دیاں سروسز (اینوں) بہتر بنان دیاں خواہشمند نیں۔ کسے بندے وچ عتاہٹ دی تشخیص ہون تے اسی تہاڈی زبان بولن آلے لوکیں/کمیونٹی توں اوہناں دے تجربیاں بارے جاننا چاہواں گے۔

کیی تہانوں اپنی زبان بارے کسے انج دے کمیونٹی گروپ دا پتا اے جینوں اسی بالمشافہ مل سکدے آں، یا zoom راہیں شمولیت کر سکدے آں، جتھے اسی لگ بھگ اک گھنٹہ عتاہٹ دے ایس موضوع بارے گل کر سکدے آں؟ جے انج اے تے میربانی کر کے سانوں dementia@carecity.org تے ای میل کرو اتے اسی کدوں مل سکدے آں، اتے جے تہاڈے کول کوئی بندہ موجود ہووے جیہڑا ساڈے عملے نوں انگریزی وچ ترجمہ کر کے دس سکے، یا جے ترجمان دی لوڑ ہووے تے ایس بارے سانوں دسو۔

ایدے وچ شامل کینج ہونا اے۔

اسی گل بات کرنا چاہندے آں:

- اوہ لوکیں جیناں وچ عتاہٹ دی تشخیص ہوئی اے،
- اوہناں دے ٹبر اتے نگہداشت کار
- صحت اتے سماجی نگہداشت دے ماہر جیہڑے عتاہٹ دی کمیونٹی دے سروس فراہم کاراں دے نال رہن آلے لوکاں ولوں ورتیاں جان آلیاں سروسز فراہم کردے نیں۔

اسی جیہڑی جانکاری جمع کردے آں اوہدے نال اسی کیی کر رہے آں؟

اوہناں ساریاں گلاں باتاں نوں گمنام بنایا جاوے گا اتے لندن ڈیمینشیا کلینیکل نیٹ ورک دے نال اشتراک کیتا جاوے گا، جیدے بعد اسی اک پراجیکٹ دا اطلاق کراں گے جیدی توجہ دا مرکز پورے لندن وچ عتاہٹ دیاں معاونتی سروسز لئی بہتریاں دی شناخت اتے اوہناں دا اطلاق کرنا ہووے گا۔

UCLPartners اتے Care City کون نیں؟

UCLPartners تحقیق، جدت اتے تعلیم راہیں صحت نوں بہتر بنان لئی NHS فراہم کاراں اتے یونیورسٹیز دے نال شراکت داری وچ کم کردے نیں۔ اکٹھیاں کم کر کے، اوہ مریضاں اتے عوام دے فائدیاں لئی حل بناندے، ٹیسٹ اتے لاگو کردے نیں۔

بارکنگ وچ موجود Care City غیر منافع بخش کمیونٹی دے فیدے دی کمپنی اے۔ ایس دی بنیاد مشترکہ طور تے شمال مشرقی لندن NHS فاؤنڈیشن ٹرسٹ اتے لندن بورو بارکنگ اتے ڈیگنہیم ولوں 2016 وچ رکھی گئی۔ Care City دا مشن لندن دے واسیاں لئی خوشگوار، صحت مند، بہتی عمر دی فضا تخلیق کرنا اے۔

تہاڈی شرکت مکمل طور تے رضاکارانہ اے۔ جے تسی شرکت دے خواہشمند نہیں او، تے تہاڈا انتخاب تہانوں ساڈے ولوں دتیاں جان آلیاں ہور سروسز نوں متاثر نہیں کرے گا۔ تسی کسے ویلے وی اپنی رضامندی توں دستبردار ہو سکدے او۔

Servicios de apoyo a la demencia de Londres

Comparte tus experiencias

La London Dementia Clinical Network está desarrollando una serie de servicios para las personas diagnosticadas con demencia. Esta labor recibe la colaboración de UCLPartners y Care City, a quienes les hemos pedido ayuda para tener más visibilidad.

La demencia es un trastorno de la salud que puede afectar no solo a una persona en particular, sino a familias enteras. Puede ocurrir de maneras inesperadas. Los servicios sanitarios de Londres quieren mejorar. Nos gustaría que personas de tu comunidad o que hablen tu mismo idioma compartieran su experiencia tras recibir un diagnóstico de demencia.

¿Conoces alguna comunidad de personas que hablen tu idioma con las que podríamos reunirnos en persona o vía zoom para hablar de la demencia durante una hora? Si es así, por favor, envíanos un correo electrónico a dementia@carecity.org y dinos cuándo podríamos vernos. Avísanos también si hay alguien que pueda traducir a inglés para nuestros trabajadores o si será necesario un intérprete.

Cómo formar parte

Queremos hablar con:

- aquellos que han sido diagnosticados con demencia
- sus familiares y cuidadores
- profesionales sanitarios y sociales cuyos servicios benefician a las personas con demencia
- proveedores de servicios a la comunidad

¿Qué hacemos con la información que recopilamos?

Estas conversaciones serán anónimas. Compartiremos el resultado con la London Dementia Clinical Network para, más tarde, implementar un proyecto centrado en identificar y poner en marcha mejoras en los servicios de apoyo a la demencia de Londres.

¿Quiénes son UCLPartners y Care City?

UCLPartners trabajan junto con universidades y profesionales del NHS para mejorar la salud a través de la investigación, la innovación y la educación. Esta colaboración hace posible que puedan desarrollar, probar e implementar soluciones que beneficien a los pacientes y al público en general.

Care City es una empresa de interés comunitario sin ánimo de lucro con sede en Barking. Fue fundada conjuntamente por la North East London NHS Foundation y el distrito de Barking y Dagenham en 2016. La misión de Care City es que los londinenses tengan una tercera edad más feliz y saludable.

Tu participación es completamente voluntaria. Si eliges no participar, ninguno de los demás servicios que te ofrecemos se verá afectado por tu decisión. Puedes retirar tu consentimiento en cualquier momento.

லண்டனின் டிமென்ஷியா சேவைகளைப் புரிந்துகொள்தல்

உங்கள் அனுபவங்களைப் பகிர்ந்துகொள்ளுங்கள்

லண்டன் டிமென்ஷியா கிளினிக்கல் நெட்வொர்க்கானது டிமென்ஷியா நோய் கண்டறியப்பட்டவர்களுக்கு உதவும் வகையில் சேவைகளை உருவாக்கி வருகிறது. UCLPartners மற்றும் Care City ஆகியவற்றின் ஒத்துழைப்புடன் பணிகள் நிறைவடையப்பட்டு வருகின்றன, அவர்கள் கருத்துகளைச் சேகரிக்க உதவுமாறு கேட்டுக் கொள்ளப்பட்டுள்ளனர்.

டிமென்ஷியா என்பது தனிநபரின் ஆரோக்கியத்தைப் பாதிப்பது மட்டுமல்லாமல், முழு குடும்பத்தையும் பாதிக்கும் ஒரு நிலையாகும். இது சில சமயங்களில் எதிர்பாராத விதமாக இருக்கலாம். லண்டனில் சுகாதார சேவைகள் மேம்படுத்தப்பட வேண்டும். ஒருவருக்கு டிமென்ஷியா இருப்பது கண்டறியப்பட்டவுடன், உங்கள் மொழிப் பேசுபவர்களிடமிருந்து /சமூகத்தைச் சார்ந்தவர்களிடமிருந்து அவர்களின் அனுபவங்களைப் பற்றி கேட்க விரும்புகிறோம்.

உங்கள் மொழிப் பேசும் சமூகக் குழுவை நீங்கள் அறிவீர்களா, நாங்கள் நேரிலோ அல்லது zoom மூலமாகவோ சந்தித்து, இந்த டிமென்ஷியா தலைப்பைப் பற்றி ஒரு மணிநேரம் பேசலாமா? அப்படியானால், தயவுசெய்து dementia@carecity.org இல் எங்களுக்கு மின்னஞ்சல் அனுப்பவும், மேலும், நாம் எப்போது சந்திக்கலாம் என்பது பற்றியும், எங்கள் ஊழியர்களுக்குப் புரியும்படி ஆங்கிலத்தில் மொழிபெயர்ப்பவர் உங்களிடம் இருந்தால் அல்லது மொழிபெயர்ப்பாளர் தேவை என்பது பற்றியும் எங்களுக்குத் தெரியப்படுத்தவும்.

எப்படி பங்கேற்பது

நாங்கள் பேச விரும்புபவர்கள்:

- டிமென்ஷியா நோய் கண்பறியப்பட்டவர்கள்,
- அவர்களின் குடும்பம் மற்றும் அவர்களை பராமரிப்பவர்கள்
- டிமென்ஷியா சமூக சேவை வழங்குநர்களுடன் வாழும் மக்கள் பயன்படுத்தும் சேவைகளை வழங்கும் சுகாதார மற்றும் சமூக பராமரிப்பு நிபுணர்கள்

நாங்கள் சேகரிக்கும் தகவலை என்ன செய்கிறோம்?

இந்த உரையாடல்களின் வெளியீடு அநாமதேயமாக, லண்டன் டிமென்ஷியா கிளினிக்கல் நெட்வொர்க்குடன் பகிரப்படும், அதன் பிறகு லண்டன் முழுவதும் டிமென்ஷியா ஆதரவு சேவைகளை அடையாளம் கண்டு, செயல்படுத்துவதில் கவனம் செலுத்தும் திட்டத்தை செயல்படுத்துவோம்.

Londra’nın Demans Hizmetlerini Anlama

Deneyimlerinizi paylaşın

Londra Demans Klinik Ağı demans tanısı konmuş kişiler için hizmetler geliştirmektedir. Bu iş, görüşler toplamak için yardım istenen UCLPartners ve Care City ile iş birliği içinde tamamlanmaktadır.

Demans sadece bireyleri değil bütün aileleri etkileyebilen bir sağlık durumudur. Bu bazen beklenmedik yollarla olabilmektedir. Londra’daki bu sağlık hizmetleri gelişim istemektedirler. Bir kişiye demans tanısı konulur konulmaz sizin dilinizi konuşan/anlayan kişilerden kendi deneyimlerini duymak istiyoruz.

Bizim şahsen ziyaret edebileceğimiz veya zoomda irtibat kurabileceğimiz ve yaklaşık bir saat süre ile demans konusunda sizin dilinizde konuşabileceğimiz bir topluluk biliyor musunuz? Eğer biliyorsanız lütfen bize dementia@carecity.org email adresine email atın ve ne zaman buluşabileceğimizi, ve kendi personelimiz için İngilizce tercüme yapabilecek bir kişiye sahip olup olmadığınızı veya bir tercüman gerekip gerekmeyeceğini bizi bildirin.

Nasıl Dahil Olunur

- Demans tanısı konulmuş kişiler ,
- Bunların aileleri ve bakıcıları
- Demans topluluğu hizmet sağlayıcıları ile yaşayan insanlar tarafından kullanılan hizmetleri sağlayan sağlık ve sosyal bakım uzmanları

Topladığımız bilgileri ne yapıyoruz?

Bizim Londra’nın tamamında demans destek hizmetlerinin geliştirilmesinin tanımlanmasına ve uygulanmasına odaklanan bir projeyi gerçekleştirmemizden sonra, bu görüşmelerin çıktıları anonimleştirilerek Londra Demans Klinik Ağı ile paylaşılacaktır.

UCLPartners ve Care City kimlerdir?

UCLPartners araştırma, inovasyon ve eğitim yoluyla sağlığı geliştirmek için Ulusal Sağlık Hizmetleri sağlayıcıları ve üniversiteler ile iş birliği içinde çalışmaktadır. Birlikte çalışarak, hastaların ve kamunun yararı için çözümler geliştirmekte, test etmekte ve ortaya koymaktadırlar.

Care City, merkezi Barking’te olan kar amacı gütmeyen bir Toplum Menfaatleri Şirketidir. 2016 yılında Sağlık Hizmetleri Vakfı ve Londra Barking ve Dagenham belediyeleri tarafından müştereken kurulmuştur. Care City’nin misyonu Londralılar için daha mutlu, daha sağlıklı ve daha uzun ömürlü yaşam sağlamaktır.

Katılımınız tamamen gönüllülük esasına dayanmaktadır. Eğer Katılmak istemiyorsanız, tercihiniz size sağladığımız diğer hizmetleri etkilemeyecektir. Herhangi bir zamanda izninizden vazgeçebilirsiniz.

لندن کی ڈیمنشیا سروسز کو سمجھنا

اپنے تجربات شیئر کریں

لندن ڈیمینشیا کلینکل نیٹ ورک ان لوگوں کے لیے خدمات تیار کر رہا ہے جن کو ڈیمنشیا کی تشخیص ہوئی ہے۔ یہ کام یو سی ایل پارٹنرز اور کیئر سٹی کے اشتراک سے مکمل کیا جا رہا ہے، جن سے آراء جمع کرنے میں مدد کرنے کو کہا گیا ہے۔

ڈیمنشیا ایک صحت کی حالت ہے جو نہ صرف افراد بلکہ پورے خاندان کو متاثر کر سکتی ہے۔ یہ کبھی کبھی غیر متوقع طریقوں سے بھی ہو سکتا ہے۔ لندن میں صحت کی خدمات صورتحال کو بہتر کرنا چاہیں گی۔ اگر آپ کی کمیونٹی میں آپ کی زبان بولنے والے لوگوں میں کسی کو ڈیمنشیا کی تشخیص ہوتی ہے تو ہم ان کے تجربات کے بارے میں سننا چاہیں گے۔

کیا آپ اپنی زبان بولنے والی کمیونٹی کے کسی گروپ کے بارے میں جانتے ہیں جس کو ہم ذاتی طورملیں، یا زوم کے ذریعے شامل ہوں، جہاں ہم ڈیمنشیا کے اس موضوع پر لوگوں سے تقریباً ایک گھنٹے تک بات کر سکیں؟ اگر ایسا ہے تو براہ کرم ہمیں نیچے دئیے ہوئے ایڈریس پر ای میل کریں اور ہمیں بتائیں کہ ہم کب مل سکتے ہیں، اور کیا آپ کے پاس کوئی ایسا شخص ہے جو ہمارے عملے کے لیے انگریزی میں ترجمہ کر سکے، یا کیا کسی مترجم کی ضرورت ہے۔
dementia@carecity.org

شامل ہونے کا طریقہ

ہم ان سے بات کرنا چاہتے ہیں:

- جن کو ڈیمنشیا کی تشخیص ہوئی ہے
- ان کے خاندان اور دیکھ بھال کرنے والے
- صحت اور سماجی نگہداشت کے پیشہ ور افراد جو ڈیمنشیا کمیونٹی سروس پرووائیڈرز کے ساتھ رہنے والے لوگوں کے ذریعہ استعمال کی جانے والی خدمات فراہم کرتے ہیں

ہم ان معلومات کے ساتھ کیا کر رہے ہیں جو ہم جمع کرتے ہیں؟

اس گفتگو سے حاصل ہونے والی معلومات کو گمنام رکھا جائے گا اور لندن ڈیمینشیا کلینیکل نیٹ ورک کے ساتھ شیئر کیا جائے گا، جس کے بعد ہم پورے لندن میں ڈیمینشیا سپورٹ سروسز میں بہتری کی نشاندہی کرنے اور ان پر عمل درآمد پر توجہ مرکوز کرنے والے پراجیکٹ کو نافذ کریں گے۔

یو سی ایل پارٹنرز اور کیئر سٹی کون ہیں؟

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Ben is an experienced project lead managing complex, cross-partnership programmes and projects in the health and social care industry. He has expertise in dementia, older people's housing, mental capacity, safeguarding and care standards. He does public speaking arrangements on dementia.

Ben joined Care City in 2019 and has worked on managing health innovation integration for social care, the NHS, local authorities and Integrated Care Boards.

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