

Health & Wellbeing Board

Supplementary Agenda

Tuesday 21 September 2021 at 6.00 pm
Online

MEMBERSHIP

Councillor Ben Coleman - Cabinet Member for Health and Adult Social Care (Chair)
Vanessa Andreae - H&F Clinical Commissioning Group (Vice-Chair)
Dr James Cavanagh - Chair of the Governing Body, H&F Clinical Commissioning Group
Councillor Adam Connell - Cabinet Member for Public Services Reform
Councillor Larry Culhane - Cabinet Member for Children and Education
Philippa Johnson - Central London Community Healthcare NHS Trust
Dr Nicola Lang - Director of Public Health
Jacqui McShannon - Director of Children's Services, H&F
Lisa Redfern – Strategic Director of Social Care, H&F
Sue Roostan – Borough Director, H&F Clinical Commissioning Group
Glendine Shepherd – Assistant Director of Housing Management, H&F
Sue Spiller – Chief Executive Officer, SOBUS
DI Luxan Thuraiatnasingam – Metropolitan Police
Carleen Duffy – Healthwatch H&F Manager

Nominated Deputy Members

Councillor Patricia Quigley – Assistant to the Cabinet Member Health and Adult Social Care
Councillor Lucy Richardson, Chair, Health, Inclusion and Social Care Policy and Accountability Committee
Nadia Taylor, H&F, Healthwatch Representative

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Health & Wellbeing Board

Supplementary Agenda

Item

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7. DRAFT DEMENTIA STRATEGY

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For the Board to consider the borough's Draft Dementia Strategy which has been prepared with community input and the support of the Dementia Action Alliance.

London Borough of Hammersmith & Fulham

Report to: Health & Wellbeing Board

Date: 21/09/2021

Subject: Draft Hammersmith and Fulham Dementia Strategy 2021 - 2024

Report of Stuart Downey (Chair) and Peggy Coles (Coordinator), Hammersmith and Fulham Dementia Action Alliance (DAA), Kate Sergeant (Local Services Manager) Hammersmith and Fulham Alzheimer's Society and Lisa Redfern, Strategic Director of Social Care and co-chair of Hammersmith and Fulham Integrated Care Partnership (ICP)

Summary

1. The Hammersmith and Fulham Dementia Strategy sets out how significant improvements can be made to the planning, commissioning, delivery, and review of local services so that people living with dementia and their families are better supported.
2. The Hammersmith and Fulham Dementia Strategy Task and Finish Group (DSTFG) initially convened in March 2020 as a group of stakeholders concerned about the impact of Covid-19 lockdown restrictions on elderly residents with cognitive issues.
3. The group began by identifying the key issues in the borough's Dementia Care Pathway and focusing on the sufficiency and quality of local services with the aim of ensuring the best quality of life for people living with dementia, their carers and families.
4. The DSTFG have actively engaged with the new H&F Integrated Care Partnership (ICP) and respective Frailty and Mental Health Campaigns, to ensure the Dementia Strategy is aligned to existing workstreams, avoids duplication and to consider how best to implement the Dementia Strategy recommendations. The Dementia Strategy will be signed off at the ICP Board on 20th September 2021
5. Key to the implementation of the Dementia Strategy will be co-production with residents living with dementia, their families and carers.

Recommendations

1. That the Health and Wellbeing Board endorses the co-produced Hammersmith and Fulham Dementia Strategy between the local Council, the local NHS, the voluntary sector, our residents and businesses.
2. That the Health and Wellbeing Board supports the proposed establishment of the Dementia Partnership Board, with representation from the local Council, the local NHS, the voluntary sector, our residents and businesses to oversee the implementation of the Dementia Strategy, aligned to the work of the ICP.

Wards Affected: All

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DEMENTIA STRATEGY FOR HAMMERSMITH AND FULHAM

2021 – 2024



All Ability Cycling Hub on Fridays – For Brian, CIC with Bikeworks

Living Well

I am always touched by incredible gestures of humanity
frequent acts of kindness
no matter whether it's shady or sunny
achieving little goals day by day
making sure I take time to smell the roses
feel the glow on my body
being believed and supported
the difference between listening, and hearing
fight ignorance, have patience, remove burden.

Be the best ally possible:
love what is; stand up for empathy

Excerpt from 'Living Well' – poem co-produced with H&F residents for Dementia Action Week 2021 - Dan Simpson, Poet in residence, Imperial College London

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1. Foreword

Dementia affects more and more people each year. Many of us already have experienced the impact that dementia can have on people we know and on our families.

This co-produced Hammersmith and Fulham Dementia Strategy reflects the views and experiences of people living with dementia and their carers, and those of the public, private, voluntary and community sector services supporting them (our 'dementia community').

Priorities identified by our dementia community include a range of dementia specific and dementia inclusive activities that give choice and control, reduce social isolation, and promote equality: clear accessible information about how to get services and support and for the borough to become a Dementia Friendly Community.

In order to respond to the priorities identified, it is imperative that Health and Social Care, in partnership with other services, have a clear strategy to support people living with dementia and their carers, now and in the future. The new H&F Integrated Care Partnership (ICP) provides the framework, overarching governance and accountability for the Council and the NHS to collaborate with the local community to make this happen. We are encouraged that that the additional needs of people living with dementia and their families are informing the work across the ICP Campaigns.

Co-production will be at the core of the work of the proposed Dementia Partnership Board, which, we anticipate, will have oversight of implementation of the recommendations contained within this strategy.

We would like to thank all those individuals, groups and organisations who have given their views and helped to shape this strategy, and particularly those represented on the Dementia Strategy Task and Finish Group.



Stuart Downey – Chair of H&F Dementia Action Alliance (DAA) and Partner - TWM Solicitors)

2. Executive Summary

This is Hammersmith and Fulham's first Dementia Strategy. It was co-produced with people with dementia, their families and carers and identifies the improvements needed to the services and support they receive. Dementia is a disability and hence we have aligned our co-production to the H&F Council's Disabled People's Commission 2018.

The aim of the strategy is to address the additional needs of the dementia community and the gaps, sufficiency, affordability, and quality of services as identified by our residents with dementia and their families, carers and the services supporting them.

The Dementia Task and Finish Group has gathered quantitative data available on dementia locally, regionally, and nationally, undertaken surveys with residents with dementia, their carers and families, stakeholders, and businesses, and reviewed where we are now and how we need to improve services and support in Hammersmith and Fulham to become a Dementia Friendly Community.

We have set out key recommendations which will inform the work of our proposed new Dementia Partnership Board to develop an implementation plan and have oversight of progress in improving the wellbeing of our Hammersmith and Fulham dementia community.

Our data, surveys and co-production identified eleven local priorities:

1. Early and accurate diagnosis within clearly understood timeframes
2. Clear and accessible information about how to get services and support
3. People affected by dementia must be treated with dignity and respect and be offered opportunities for good quality of life throughout their condition
4. Good availability and choice of day services, short breaks and overnight respite to support people with dementia, their families and carers
5. Multi-disciplinary coordination between services, with improved communication and cooperation between services and with people with dementia, their carers and families
6. Continuation of support and care for people with dementia, their carers and families, including the sensitive planning and provision of end-of-life care
7. Services must meet the real, as opposed to assumed, needs of people with dementia and their carers and families
8. A network of peer-led support groups across H&F for the recently diagnosed, for families and carers, for people who have been living with dementia and for carers living with bereavement
9. A range of dementia-specific and dementia-inclusive activities that give choice and control, reduce social isolation, and promote equality
10. Ensure that the health and social care workforce meets core competencies around dementia and that family carers are offered training to meet their needs
11. Hammersmith and Fulham to be a Dementia Friendly Community.

These priorities in turn informed our nine recommendations:

1. That a **Dementia Partnership Board** be established to oversee an implementation plan, with representation from the NHS, H&F Council, the Voluntary and Community Sector and people with dementia, their carers and families.
2. That the Dementia Partnership Board **co-produces** services and support for people with dementia and their carers from all our diverse communities, including those who are Black, Asian and minority ethnic, in order to tackle systemic barriers to early diagnosis and the accessibility and adequacy of services.
3. That the Dementia Partnership Board prioritises improving the **Dementia Diagnosis Rate** for Hammersmith and Fulham, working closely with GP surgeries, Primary Care Networks, the Older Peoples Mental Health Service (OPMHS) and all professionals and front-line staff in the NHS, Social Care and the voluntary and community sector.
4. That the Dementia Partnership Board establishes a **Data Working Group** to understand better the profile of the residents on the Dementia Register, the changing demographics of Hammersmith and Fulham and the diagnosis patterns across GP surgeries.
5. That the Dementia Partnership Board develops a **Dementia Communications Plan** which includes a printed Dementia Guide and online local services and support. This will include training for staff and volunteers to signpost and refer to services, developing the confidence and practice of the network of professionals, carers and volunteers working with people with dementia.
6. That the Dementia Partnership Board **reviews and develops the dementia pathway**, that is the continuation of support and care for people with dementia and their families, including end-of-life care. A key focus will be creating a range of dementia-specific and inclusive activities that give residents choice and control.
7. That the Dementia Partnership Board promotes **multi-disciplinary practice** and keyworkers to support people with dementia and their carers at the earliest opportunity to ensure their issues do not escalate, with a specific focus on residents aged over 65 living alone.
8. That the Dementia Partnership Board co-produces a **Dementia Workforce Development Strategy**, which establishes core competencies including empathy and compassion.
9. That Hammersmith and Fulham progress towards becoming a '**Dementia Friendly Community**', encouraging local statutory and voluntary organisations and businesses to improve the health and wellbeing of people with dementia and their families.

3. Introduction

This strategy sets out how significant improvements can be made to the planning, commissioning, delivery and review of local services so that people with dementia and their families are better supported. Our hope is that it will prove to be an important milestone in improving services for residents with dementia and their family and carers in Hammersmith and Fulham.

The H&F Dementia Strategy Task and Finish Group (DSTFG) initially convened in March 2020 as a group of stakeholders concerned about the impact of Covid-19 lockdown restrictions on elderly residents with cognitive issues.

The DSTFG has representation from H&F Dementia Action Alliance (DAA), the Alzheimer's Society, For Brian CIC, Carers Network, Nubian Life, Elgin Day Centre, the Older People's Mental Health Service (OPMHS) Clinic, the GP Federation and with support from H&F Adult Social Care.

The group began by identifying the key issues in the borough's Dementia Care Pathway and focusing on the sufficiency and quality of local services with the aim of ensuring the best quality of life for people with dementia, their carers and families.

The active engagement of the new H&F Integrated Care Partnership (ICP), which brings together the Council and NHS, will be essential to achieving the strategy's aims, working with local dementia partners. We much appreciate the support we have had from H&F Council, H&F Clinical Commissioning Group and the ICP to date.

4. Some facts about Dementia

The Alzheimer Research UK's Dementia Attitude Monitor has revealed that more than half of the UK public (52%) know someone who has been diagnosed with a form of dementia, typically a family member such as a grandparent (15%) or parent (11%).

Dementia cannot be viewed singularly as a mental health issue. It is a disability and one typically with multiple comorbidities impacting on the additional needs of the person with dementia, their families and carers.

The word 'dementia' describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. A person with dementia may also experience changes in their mood or behaviour, with greater sensitivity to noise and visual misperceptions, hallucinations, and delusions.

Dementia is caused when the brain is damaged, such as by Alzheimer's disease or a series of strokes. Alzheimer's disease is the most common cause of dementia. Other common types of dementia are vascular dementia, mixed dementia, dementia with Lewy bodies and frontotemporal dementia.

Dementia is a long-term progressive condition. As such, it causes changes that are often small to start with, but which can become severe enough to affect daily life for someone

with dementia. This progression will vary from person to person and each will experience dementia in a different way.

People with mild dementia will be able to continue to live actively and independently, with minimal support and adjustments. People with moderate dementia will need more support with the tasks of daily living and social engagement. People with severe dementia will need full-time support, often including nursing care, for them and their families to live well.¹

Risk factors for dementia include:

- Ageing
- Gender (higher prevalence amongst women)
- Ethnicity (different ethnic communities experience dementia differently)
- Cardiovascular factors (Type 2 Diabetes, high blood pressure/cholesterol levels and obesity)
- Other medical conditions (e.g., Parkinson's, Multiple Sclerosis, HIV)
- People with Down's Syndrome and Learning Disabilities
- Genetics (for some young onset dementias)
- Medications that are high on anticholinergic activity
- Hearing loss, untreated depression, loneliness or social isolation, excessive alcohol misuse and a sedentary lifestyle

There is currently no cure for dementia. However, there is compelling evidence that a healthy lifestyle can help reduce an individual's risk of developing dementia by as much as 40%. It can also help prevent cardiovascular diseases such as stroke and heart attacks, which are themselves risk factors for vascular dementia.

4.1 The local picture in H&F

Before we know how best to offer treatment and support to people with dementia in Hammersmith and Fulham, we need to understand how many people in the borough have dementia, how severe it is and other factors which might lead us to tailor care to meet specific needs of our communities, such as ethnicity, where people live and whether they have people to care for them.

We set out some data below. While this is revealing, it is not sufficient and the picture it paints is partial due to a number of factors as below.

- The data is subject to different recording, categorisation and protocols.
- While we have some data about referrals to Older People's Mental Health Service (OPMHS), we lack data about those referred who received a diagnosis, how long the diagnosis took, how old these people are, what stage or subtype of dementia they have, where they live (for instance in a care home or independently) and in which ward or community they are active in H&F.
- Data on risk factors for dementia is skewed due to Babylon GP at Hand's

registrations from across London.

- We lack current data about the ethnicity and nationality of people with dementia who are registered with GPs in H&F.

Our recommendations address how data around dementia can be improved.

4.2. What the data for H&F tells us

As of July 2021, it is estimated that there are 1,337 Hammersmith & Fulham residents aged 65 years and over living with dementia². According to a report published by the Care Policy and Evaluation Centre (CPEC) at the London School of Economics and Political Science (LSE), it is estimated that the number of people estimated to have dementia in Hammersmith & Fulham is expected to rise by 42% to 1,900 people living with dementia in 2030³.

However, in H&F, as of July 2021, there are 770 people over the age of 65 with a recorded diagnosis of dementia (representing 3.5% of the total H&F population in the 65+ age group). This is the lowest number of people diagnosed with dementia so far this year in any London borough and also the second lowest recorded dementia prevalence of any London borough after Newham.

In Hammersmith & Fulham, the dementia diagnosis rate in the population over 65 years is 57.6% as of July 2021. It is lower than the national diagnosis target for dementia which is 66.7%. In order to reach the national target, Hammersmith & Fulham would need to diagnose 121 more people. This diagnosis rate is the second lowest of all London boroughs.

Dementia diagnosis in H&F is unacceptably low; local residents are not receiving equity of diagnosis as in other boroughs with Mental Health services provided by West London Mental Health Trust (the dementia diagnosis rate for Hounslow is 65% and for Ealing 68.7%)

In H&F, 36 people under 65 years have a recorded diagnosis of dementia and these 'Early Onset' cases of dementia account for 4.5% of all recorded dementia diagnoses. These residents require a different set of support interventions, with Care Plans reflecting that the person with dementia can also be employee, 'breadwinner' or parent or even carer for another family member.

Of the 1,337 estimated dementia population in H&F in 2020, 58.2% were estimated to have severe dementia, 27.3% moderate dementia, and 14.5% mild dementia. The sharpest increase is estimated to occur among those who are diagnosed as having severe dementia

² NHS Digital. Recorded Dementia Diagnoses July 2021. [Online]. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/july-2021>

³ Wittenberg, R.,. Available from: https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

By 2030, it is estimated that of those people living with dementia in H&F, 63.1% will have severe dementia, 23.9% will have moderate dementia and 12.8% will have mild dementia. As our population of older persons get older, so too will their dementia disease advance, requiring more costly care.

As of 2020, 32% of all H&F residents over 65 live alone, equating to 6744 residents. It is likely that many of these residents are at increased risk of getting dementia due to the effects of isolation. Even more critical, are the residents who have developed cognitive issues who may not be known to the Local Authority or to the NHS, and the Dementia Partnership Board must engage H&F Housing and Registered Social Landlords to coordinate support.

In H&F there is an unusually high recorded prevalence of dementia amongst Black, Asian and Minority Ethnic (BAME) communities. Nationally, these account for 3% of people with dementia, whilst in H&F in 2019, of those with a recorded dementia diagnosis who recorded ethnicity, 30% were from a Black Caribbean, Black African, Asian, and other ethnic backgrounds.

Everyone has a right to equity of diagnosis regardless of their local ward or GP and to the very best care and support. It is vital that dementia services in H&F become as accessible as possible by understanding the psychosocial dimensions and cultural factors specific to each community group.

There were 970 emergency admissions into hospital in 2019/2020 where dementia or Alzheimer's is mentioned in the diagnosis code. This equates to a rate of 4,893 dementia admissions per 100,000 population.

Further analysis of frequent users, some who live alone, will clarify residents with dementia for whom there may be more appropriate care. The Dementia Partnership Board will oversee the collaboration across Health, Social Care, and the Emergency Services.

Improving the quality of our data in all aspects of our forecasting, planning and delivery of dementia services and support is a key recommendation going forward and will be central to the work of the proposed Dementia Partnership Board. We know that this is a priority for West London Trust as part of their transformation of Older People's Mental Health Services.

5. Co-production

“Co-production (working together) means that Disabled residents and decision makers are working together in an active way to plan, design and review policy and services that affect our lives, to get rid of the barriers we face” – H&F Council's Independent Disabled People's Commission, November 2017

Using the Disabled People's Commission model of co-production and following the DEEP (Dementia Engagement and Empowerment Project, the network of Dementia Voices), we have developed our understanding of the experience of people with dementia, of their carers and families and of the people who support them through:

- Regular meetings of the Dementia Strategy Task and Finish Group

- Conversations with people with dementia and with their carers and families as to how they experience local services and support
- Four online surveys for people with dementia, carers, stakeholders and businesses to establish what works well locally, where there are gaps and what needs to be improved

Between November 2020 and March 2021, we utilised the Council's online survey software (Citizenspace) wherever possible to harness the views of all our H&F dementia community. As we realised this would not be accessible for many residents, H&F Dementia Action Alliance, Alzheimer's Society, For Brian CIC, Elgin Close Resource Centre and Carers Network also undertook face-to-face and phone conversations.

The surveys were communicated via our respective Dementia stakeholders, and for businesses via the Council's Economy Team business newsletter.

We received 135 responses in total:

- 52 responses from organisations and services supporting people with dementia and their carers/families
- 10 responses from business
- 28 from people with dementia
- 45 from carers.

H&F Dementia Action Alliance, Carers Network and H&F Council analysed the responses and captured the 11 highest scoring priorities identified by people with dementia, their carers and families and the people supporting them and local businesses. We have also begun to map the current services and support available in order to identify issues around eligibility, accessibility, and sufficiency. The survey and this work informed our recommendations below.

6. What people with dementia, their carers and families and local stakeholders told us were their priority issues to be addressed.

Priority 1: To obtain an early and accurate diagnosis within clearly understood timeframes

"Starting with a personalised dementia diagnosis – age and stage appropriate: we want person-centred care" – Person living with dementia

It needs to be clear to residents and to all professionals working with older people, as well as those under 65 with memory challenges, that it is important to diagnosis early to allow, for example, families to plan care, support, and finances, and to continue to manage symptoms in order to continue to live independently longer.

The existing system relies heavily on people self-identifying symptoms and presenting for medical diagnosis. This means that people who do not identify their symptoms at an early stage or those who do not wish to either receive a diagnosis or engage with statutory services, can miss out on vital support, information, and care planning.

Typically, the diagnosis process starts with a visit to the GP, who will do a preliminary assessment and organise necessary tests, followed by a referral to the Memory Clinic (aka Older Peoples Mental Health Service) to complete the diagnostic process.

As important, enabling a dialogue about people's concerns is part of developing a Dementia Friendly Community, providing the opportunity for people to enter a conversation, to ask questions and 'dip a toe in' without immediately initiating a diagnostic process.

Recommendations:

1.1 That we prioritise how we engage and co-produce dementia services with and for all our diverse communities, including those who are from Black, Asian and Minority Ethnic backgrounds, utilising our strong network of voluntary and community sector partners who have first-hand experience of systemic barriers to early diagnosis, of accessibility and adequacy of services and of engagement and trust in health and social care.

1.2 That we continue to work with H&F Dementia Action Alliance to improve community awareness and encourage open and ongoing discussions around cognitive decline, symptoms of dementia and changes in behaviour. It is essential that this engagement is authentic and inclusive, sensitive to the needs of all residents and delivered in a person-centred way.

1.3 That we educate the staff and volunteers in public and voluntary organisations and in the community (for example POPS Forum, Mutual Aid Groups, Libraries, Adult Education, and the Faith Forum) in order that they can recognise residents who might be experiencing cognitive difficulties, signpost them to services and support them in getting answers to their questions at the earliest opportunity

1.4 GPs are the 'front door' to the dementia care pathway and as such, must be part of Dementia Friendly Surgeries. We need to work with them to promote healthy living to mitigate the likelihood of getting dementia, identify dementia symptoms and share information with residents and their families about cognitive decline. Both culturally specific awareness and associated diagnostic tools will be key in building trust in the NHS.

1.5 That the Memory Clinic undertakes outreach with the community and with all of our dementia stakeholders to ensure that their service is widely promoted, understood and accessible to all the diverse communities of H&F and with a focus on increasing dementia diagnosis rates. Adult Social Care and NHS professionals must develop practice and policy around early identification of dementia and subsequent referrals to the Memory Clinic.

1.6 That the Dementia Partnership Board establishes a Data Working Group to focus on increasing dementia diagnosis rates in H&F through a better understanding of the profile of the residents on the Dementia Register, of the changing demographics of Hammersmith and Fulham and of diagnosis patterns across GP surgeries.

1.7 The Dementia Partnership Board will engage with the borough's Public Health team in reviewing the accessibility of services focused on preventing dementia to inform both future commissioning of services and to identify synergies with other Public Health priorities

Priority 2: Clear, accessible information about how to get services and support

“We want clear information about how to get help. Information must be available about services and how to find them. Printed materials are not always what’s needed, but if published, they should be clearly written, simple and accessible” – Carer of person living with dementia

Some information and advice around support and services for people with dementia and their carers and families is held on each dementia stakeholder’s website, this includes basic information about dementia services and provision is on the LBHF ‘Living Independently’ site. the Alzheimer’s Society is also a source of practical information for people with dementia, their carers and the community.

However, the borough lacks a local accessible Dementia Guide which captures the range of support available across the borough in order that all resources can easily be found, professionals can signpost with confidence and people with dementia and carers can be supported at each stage with care and compassion.

We need to build on existing innovative partnerships around digital inclusion to provide information and advice in different formats and languages and to support people with dementia, their carers, and families to be proficient in accessing the internet.

Recommendations.

2.1 That a Dementia Guide is co-produced with residents with dementia and their carers and families. The guide should include the NHS health check dementia leaflet and be available in different languages and accessible to all our communities. It should explain each stage of the Dementia care pathway starting with pre-diagnosis, and explain treatment interventions and emotional and practical support available, with access-to-assistive technology

2.2 That the Dementia Partnership Board co-produces a Communications Plan. This would acknowledge that whilst some residents will access websites and use social media, others will not use technology. Printed information will need to be in different formats and languages to be accessible to all residents, with a ‘drop-in’ offer where questions can be answered face-to-face, with signposting as necessary

2.3 That, aligned to the recommendations in the Hammersmith and Fulham Older Peoples Commission (March 2019), highlighting the importance of partnership with the H&F Council Housing Team, Sheltered Housing providers, Tenants and Residents Associations, Wardens and Careline, we disseminate information on dementia services and support to the thousands of older residents H&F Council supports and accommodates.

Priority 3: People affected by dementia must be treated with dignity and respect and be offered opportunities for good quality of life throughout their condition

*“We want people to realise there is a life still to be lived with a dementia diagnosis”
– Person living with dementia*

There is currently a limited offer of designated dementia activities commissioned by H&F Council or H&F CCG in the borough. We need to work together to ensure that we have sufficiency of the right kind of specialist services and support. Funding is required to produce a programme of activities which is both accessible and inclusive and which offers what is needed, even as the needs change over time.

All commissioned services must be inclusive to people of all cognitive abilities and from all our diverse communities, with support from staff who have participated in dementia awareness sessions.

Recommendations:

3.1 That the Dementia Partnership Board establishes governance which has co-production at its core so that people with dementia, their carers and families are equal and valued partners in the planning, delivery, and review of improvements to services and support for all stages of the dementia condition.

3.2 That the Dementia Partnership Board should promote care as being a cycle of support rather than something linear – every resident and carer’s experience is different but the need to have high quality services, with strong underpinning safeguarding practice is important for everyone.

3.3 That the Dementia Partnership Board works with commissioners across the NHS and H&F Council to ensure they can evidence that they are inclusive, accessible and have a dementia friendly workforce.

Priority 4: Availability and choice of day services, short breaks and overnight respite to support people with dementia and their families and carers

“We want respite services to fit the daily schedule of the person with dementia or when the family needs it – not the other way around” – Carer of person living with dementia

As well as sufficiency of specialist services, we need further to develop day services, short breaks and respite to be flexible and person-centred. A consistent theme in our surveys was that the council must consider the needs of the family as to the frequency, time and duration of social care: the care package and the continuity of staff.

Recommendations:

4.1 That a review of all specialist dementia support services is undertaken, alongside the mapping of those mainstream services currently supporting people with dementia, to address the issues raised by residents with dementia and their carers and families as part of co-producing the Dementia Strategy

4.2 That the funders and commissioners represented on the proposed Dementia Partnership Board consider the sufficiency, quality, affordability and breadth of the existing dementia services and opportunities to bring extra resource and capacity into H&F.

Priority 5: Multi-disciplinary coordination between services, with improved communication and cooperation between services and with people with dementia, their carers and families

“Having access to one point of contact, instead of having to go from one service/agency to another and having to keep repeating myself” – Carer of person living with dementia

Although there are a number of professionals working with people with dementia and their families/carers, services often work in silos and are uncoordinated, wasting time and causing stress, particularly for carers.

We need to establish the principles of multi-disciplinary working at the earliest opportunity in order to coordinate and streamline care, support and sharing of information for all residents with dementia and not just those in crisis.

Given the increased prevalence of dementia among people aged 65+, a large number of whom live alone, we also need multi-disciplinary practice to support those who may feel socially isolated and lonely. Our local data and intelligence tell us that some residents use the Police, Fire Service, A&E and Careline for non-crisis support when stronger multi-disciplinary working would ensure they received a person-centred response which mitigated against an escalation in their situation.

Recommendations:

5.1 That the multi-disciplinary working in Primary Care Networks (PCNs) is reflected in the planning and delivery of all support for those with dementia and for their carers and families, in particular for people with dementia living alone.

5.2 That the person with dementia, their family and carer are at the centre of the planning of care and support and that all support and all paperwork held by local services are co-produced to reflect that.

5.3 That services supporting people with dementia develop protocols which facilitate the appropriate sharing of data, minimise delays and avoid carers and families having to ‘tell the story’ over and over again.

Priority 6: Continuation of support and care for people with dementia, their carers and families, including the sensitive planning and provision for end-of-life care

“Post-diagnostic support should be continually available as and when we need it until end of life. GPs should be proactive in checking up. For example we want help to continue to be part of a group, so we want transport to get us where we want to go, with dementia friendly drivers” – Person living with dementia

There is currently no system in place to ensure that, at the time of diagnosis, people with dementia and their families are referred to a funded dementia service in H&F. After receiving a diagnosis (which is often a traumatic experience), some people never get around to registering with support services and lack the access to information and support throughout the dementia journey. Hence referral protocols and integration are required.

Added to this, the multi-disciplinary approach from diagnosis would inform better planning, support, and continuity with, ideally, one named professional (or key worker). This would enable families to build trust and confidence and enable professionals to plan care, respite and support effectively and efficiently.

Recommendations:

6.1 That the Dementia Care Plan and its vital role throughout the dementia pathway is clearly promoted and understood by the people with dementia, their carers and families and that sensitive management of end-of-life care is discussed and recorded at the earliest available opportunity and when people with dementia have mental capacity.

6.2 That post-diagnosis, a named worker is identified for continuity of support and to make a schedule of regular meetings between the GP and the person with dementia and their carers and family.

6.3 That in line with H&F Council’s vision for Independent Living, people diagnosed with dementia are given choice and control as to where they live and the nature of the support they get – for example, through active engagement by the Reablement Team, maximising digital technologies, and promotion of Personal Budgets – all documented within the annually reviewed Adult Social Care Plan.

Priority 7 - Services must meet the evidenced needs of people with dementia and their carers and families as opposed to assumed needs

“Services centred around us like a menu, ones that fit our needs rather than what others think we want” – Person living with dementia

It is critical that in addressing the needs of our diverse communities we focus our work on and with those groups of people who lack trust in statutory services, some of whom may have increased risk of developing dementia due to ethnicity, age, lifestyle factors, sexual orientation, gender, and existing medical conditions.

Our on-going co-production with people with dementia, their carers and families will build our awareness of the intersectionality of these communities and how we can build on what

services and support work well, and develop new services for those for whom existing ones are not a good fit.

Recommendations:

7.1 That the support offered to all who are referred to the Memory Clinic (OPMHS) is reviewed, acknowledging that support is not diagnosis dependent and those with Minor Cognitive Impairment should receive focused support from existing Dementia Link Workers in collaboration with dementia services.

7.2 That a referral protocol be established between the Alcohol Service and the OPMHS to support those at risk of getting alcohol-related dementia, building on the existing good practice protocol between the Learning Disability Team and the Memory Clinic.

7.3 That the Dementia Partnership Board works with expert bodies, such as the Social Care Institute for Excellence, when considering how best to support, for example, H&F's LGBT community and those with complex needs to access dementia services and support.

7.4 That the use of Advanced technologies, Assistive Technology and the range of equipment and adaptations is promoted to support independence and quality of life for people with dementia and their carers/families.

Priority 8: A network of peer-led support groups across H&F for the recently diagnosed, for families and carers, for people who have been living with dementia and for carers living with bereavement

"It was my dementia that I needed to understand. What better way to do that than with people who'd been through the same as me?" – Person living with dementia

It is widely understood that peer support groups improve wellbeing by providing both social and emotional support and practical advice

At each stage of the dementia pathway, there are new challenges for people with dementia and for their families and carers. Building on the services and support wrapped around the PCNs and existing dementia carer peer support groups, a variety of different peer support networks would help reduce isolation and loneliness, building a more resilient H&F dementia community.

Recommendations:

8.1 That the proposed Dementia Partnership Board explores funding opportunities and proposals to set up peer-led dementia support groups for all residents, including those recently diagnosed, as well as for families of people with dementia and for carers living with bereavement across Hammersmith and Fulham.

Priority 9: A range of dementia specific and dementia inclusive activities that give choice and control, reduce social isolation and promote equality

“Acknowledgement that medical information is only a small part of the picture. We want somewhere to go where we can be part of the community, where we feel we belong” – Person living with dementia

For people with dementia, their carers and families in H&F, getting out and about is a key ingredient in reducing their social isolation and maintaining their resilience.

Our surveys evidenced that:

- There is a need to offer a range of activities because not everyone likes to do the same thing
- It is important to minimise travel wherever possible, providing as much as possible within local areas in the borough and improving current transport arrangements
- People with cognitive challenges need a choice as they may prefer outdoor and physical activities in natural settings

Engaging in stimulating activities focused on shared group experiences is the cornerstone of social prescribing, improving wellbeing, reducing GP visits and delaying deterioration of health and risk of admission to care homes.

The commissioned ‘offer’ for dementia needs re-visiting to ensure organisations providing specialist support for people with dementia and their carers have a trained workforce and adequate funding and capacity to meet increased demand.

Recommendations:

9.1 That the proposed Dementia Partnership Board ensures (via self-referral or social prescribing link workers) a coordinated range of inclusive and accessible activities for people with cognitive impairment or a dementia diagnosis across the borough. This could include additional Memory Cafes in the north and south of the borough, an intergenerational dementia hub and a regular programme of outdoor and cultural activities, all increasing resident wellbeing and reducing patient medical visits

9.2 That H&F Council and CCG take a holistic approach in supporting people with dementia and their carers/families, acknowledging that being active, being creative and having a safe place to live are as important as receiving good quality health and social care.

Priority 10: To ensure that the health and social care workforce meet core competencies around dementia and family carers are offered training to meet their needs

“We need trained staff with lots of patience, who know the person” – Carer of person living with dementia

Over 50 comments from stakeholders highlighted the importance of staff and volunteers receiving training pertinent to their role in supporting people with dementia, their carers, and families.

Stakeholders emphasised that training and development was not one size fits all and that:

- There are core competencies when supporting people with dementia and their carers and families which everyone should have
- Co-production and co-delivery of training and developed activities should involve residents and the organisations closest to and most experienced in working with those communities (for example, H&F Dementia Action Alliance, For Brian CIC, Elgin Close Resource Centre, Nubian Life and Alzheimer's Society).

Recommendations:

10.1 That a Dementia Workforce Development Strategy is co-produced and delivered with residents with dementia, their carers, families and with stakeholders and businesses. This will be delivered in local areas, harnessing the expertise of Skills for Care and H&F GP Federation's Community Education Provider Networks.

10.2 That Dementia Friends awareness sessions will continue to be used to increase understanding of dementia across H&F

Priority 11: Hammersmith and Fulham to be a Dementia Friendly Community

"The biggest problem I encounter is other people, we need more knowledge" - "Be kind and smile. If we look confused or anxious, ask if we're ok or need help" – Person living with dementia

In order that H&F becomes a Dementia Friendly Community, it will require the engagement of dementia friends from across public services and local business, the voluntary and community sectors.

H&F Dementia Action Alliance is working to raise awareness and maximise the impact of local organisations, services and businesses to support the dementia community; this includes organising Dementia Action Week in May each year.

Local businesses have a role to play in building the foundations of a Dementia Friendly H&F, demonstrating social responsibility, understanding their customers, and ensuring that their workforce is inclusive of people with dementia and carers.

As of June 2021, Hammersmith and Fulham has registered over 700 new "dementia friends" on the national Alzheimer's Society Dementia Dashboard.

Recommendations:

11.1 That an application for H&F to receive Alzheimer's Society accreditation as a Dementia Friendly Community is progressed and approved

11.2 That best practice is celebrated in becoming a Dementia Friendly Community. One such example is the Herbert Protocol, a national scheme encouraging carers of any age to compile information in advance of a vulnerable person going missing (promoted by H&F DAA in partnership with the Metropolitan Police's Mental Health Team to "help everyone stay safe").

11.3 That LBHF and H&F DAA continue to encourage local statutory, voluntary and businesses to become Dementia Friendly organisations.

Dementia Report

Hammersmith & Fulham

September 2021

Prepared by Hammersmith & Fulham Council Business Intelligence to support the review by
the Hammersmith & Fulham Dementia Strategy Task & Finish Group

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ABBREVIATIONS

ASC	Adult Social Care
BAME	Black, Asian, and Minority Ethnic
CCG	Clinical Commissioning Group
CHD	Coronary Heart Disease
CPEC	Care Policy and Evaluation Centre
GP	General Practitioner
LBHF	London Borough of Hammersmith & Fulham
LSE	London School of Economics and Political Science
PHE	Public Health England
RBKC	Royal Borough of Kensington and Chelsea
WSIC	Whole System Integrated Care

1 DATA

1.1 WHAT DATA SOURCES WERE USED IN THIS REPORT?

This Dementia Report for Hammersmith & Fulham is mostly informed by three key data sources:

1. Public Health England's (PHE) Dementia Profile¹
2. Whole System Integrated Care (WSIC) Population Health Overview²
3. Adult Social Care (ASC), Hammersmith & Fulham Council

PHE obtains their data from various different sources, including Clinical Commissioning Groups (CCGs) and Local Authorities. The WSIC Population Health Overview collects data from General Practitioners (GPs) within Hammersmith & Fulham CCG. The ASC data is collected and recorded by Adult Social Care Social Workers who work for Hammersmith & Fulham Council.

It is important to note that various sources of published information do not reflect the full picture H&F, owing to the fact that the patient register for Babylon/GP at Hand (a GP practice in Hammersmith & Fulham CCG) includes a significant number of people who live outside of Hammersmith & Fulham.

¹ Public Health England. Dementia Profile. [Online]. Available from: <https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia/data>

² Whole Systems Integrated Care, North West London Collaboration of Clinical Commissioning Groups. Population Overview: Dementia. 2021.

2 BACKGROUND

2.1 WHAT IS DEMENTIA?

According to the Alzheimer's Society, Dementia describes a set of symptoms including **memory loss** and **difficulties with thinking, problem-solving or language**. A person with dementia may also **experience changes in mood and behaviour**. These changes often start as very small, but eventually become severe enough to affect daily life³.

There are several **different forms** of **dementia**. The **most common form** of dementia is **Alzheimer's disease** which accounts for 60-70% of all dementia cases. Other forms include vascular dementia, dementia with Lewy bodies, and frontotemporal dementia. Different forms of dementia can co-exist⁴.

2.2 WHAT CAUSES DEMENTIA?

Dementia is caused when the **brain is damaged** by diseases, such as **Alzheimer's disease** or a series of **strokes**.

The strongest known risk factor for dementia is **age** and dementia predominately affect older people. Other risk factors include **coronary heart disease, diabetes, hypertension, stroke, depression, lack of physical exercise, obesity, smoking and excessive alcohol consumption**. Therefore, a healthy lifestyle can help to reduce the risk of dementia³.

2.3 CAN YOU CURE DEMENTIA?

Currently there is **no cure** for dementia. However, much can be done to **support** and **improve the lives** of people with dementia and their carers and families.

2.4 WHO IS THE POPULATION UNDER SCRUTINY?

This report describes people with have clinically diagnosed dementia who are known to local GP practices and/or local adult social care service.

³ Alzheimer's Society. What is dementia?. [Online]. Available from: <https://www.alzheimers.org.uk/about-dementia/types-dementia/what-dementia>

⁴ World Health Organization. Dementia. [Online]. Available from: <https://www.who.int/news-room/fact-sheets/detail/dementia>

3 PREVALENCE

Summary

- 770 (3.5%) people over 65 years have recorded dementia in Hammersmith & Fulham
- This is the second lowest prevalence of recorded dementia of all London boroughs
- 36 (0.01%) people under 65 years have recorded dementia in Hammersmith & Fulham
- The low recorded prevalence of dementia in Hammersmith & Fulham may well reflect low diagnosis rates
- The estimated number of people with dementia in Hammersmith & Fulham is expected to rise from 1,337 in 2021 to 1,900 by 2030
- The sharpest increase is expected among people who have severe dementia

3.1 HOW MANY PEOPLE IN THE UK HAVE DEMENTIA?

It is estimated that there are currently **850,000 people** living with dementia in the **UK**. However, this number is expected to rise to **1.6 million people** in the **UK in 2040** due to accelerated population ageing⁵.

In England, as of July 2021, **423,817 people** above the age of 65 in England have a diagnosis of dementia. This equates to a prevalence of **4.0%** of the population over 65⁶.

3.2 HOW MANY PEOPLE IN HAMMERSMITH & FULHAM HAVE DEMENTIA?

Among people **aged 65 years and over**, **770** people were recorded as being diagnosed with dementia⁶. This equates to a prevalence of **3.5%** of the population over 65⁷. This is **the lowest number** of people with recorded dementia in any London borough, and **the second lowest recorded prevalence**, after Newham, of dementia among the population over 65 of any London boroughs (Figure 1). The **average prevalence** of dementia among people over 65 in **London** is **4.2%** and in **England** is **4.0%**⁶.

We stress the word 'recorded' because many cases of dementia go undiagnosed and the true number of people living with dementia is in excess of the 'recorded' diagnoses.

Among people **aged under 65 years**, dementia is less common. In Hammersmith & Fulham **36 people** under 65 years are recorded as having dementia⁷. This accounts for **4.5% of all recorded dementia cases** in Hammersmith & Fulham. This also equates to a recorded prevalence of **1.2 per 10,000** people under the age of 65 years having dementia. This is the **second lowest recorded prevalence**, after the Royal Borough of Kensington and Chelsea, of dementia in people under 65 years among all **London** boroughs. The **average recorded**

⁵ Alzheimer's Society. How many people have dementia and what is the cost of dementia care?. [Online]. Available from: <https://www.alzheimers.org.uk/about-us/policy-and-influencing/dementia-scale-impact-numbers>

⁶ NHS Digital. Recorded Dementia Diagnoses July 2021. [Online]. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/july-2021>

⁷ NHS digital. Recorded Dementia Diagnoses. [Online]. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses>

prevalence of dementia among people under 65 years in **London** is **2.2 per 10,000** people and in **England** is **3.1 per 10,000 people**⁸.

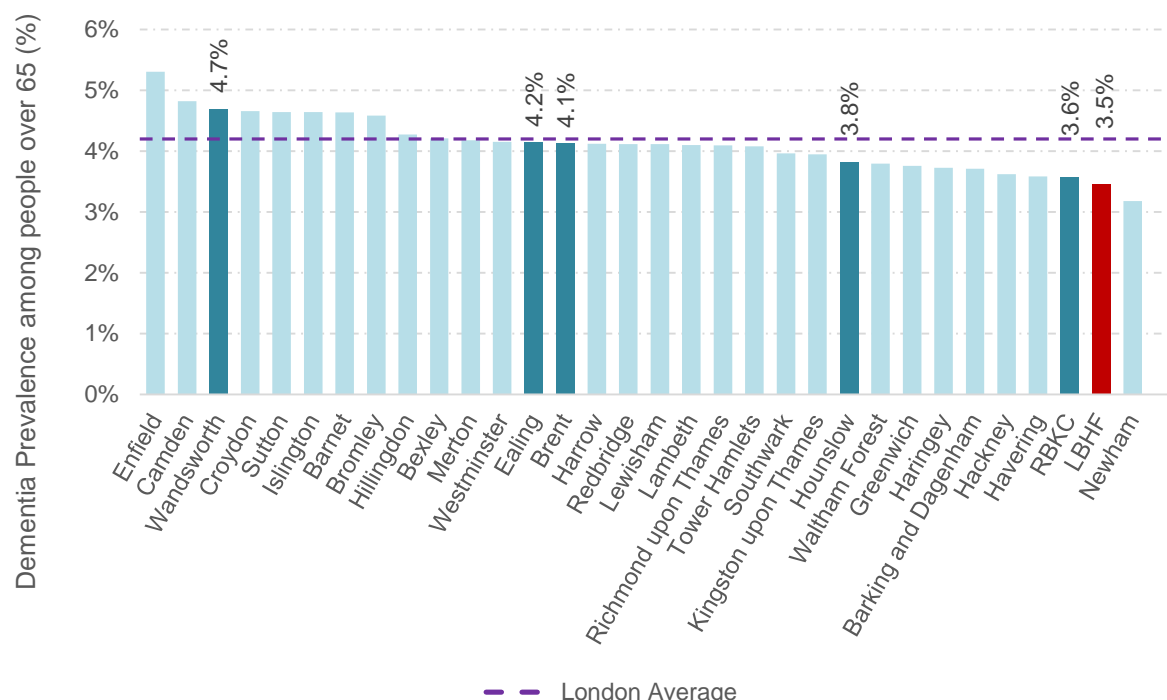


Figure 1: The Prevalence of Dementia Among People Aged Over 65 in Each London Borough. The London average recorded prevalence of 4.2% is marked. Hammersmith & Fulham has a recorded dementia prevalence of 3.5%, which is the second lowest recorded prevalence of dementia of all London boroughs.

3.3 HOW MANY PEOPLE ARE ESTIMATED TO ACTUALLY HAVE DEMENTIA IN HAMMERSMITH & FULHAM? AND WILL IT INCREASE?

As of July 2021, it is estimated that there are **1,337** Hammersmith & Fulham residents aged 65 years and over living with **dementia**⁹. Based on a prediction model for the UK as a whole, the number of people estimated to have dementia in Hammersmith & Fulham is expected to **rise** by **42% to 1,900 people** living with dementia in **2030**¹⁰.

The **estimated prevalence** of **dementia** in among people aged over 65 in Hammersmith and Fulham is, as of **2020**, **6.63%**. This prevalence is expected to **increase** to **7.33%** of the population over 65 in 2030. This is one of the **sharpest increases** in any London borough⁹. The increase is likely to occur due to an ageing population.

⁸ NHS digital. Recorded Dementia Diagnoses. [Online]. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses>

⁹ NHS Digital. Recorded Dementia Diagnoses July 2021. [Online]. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/july-2021>

¹⁰ Wittenberg, R, Hu, B, Barraza-Araiza, L, Rehill, A. Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040. Care Policy and Evaluation Centre, London School of Economics and Political Science. [Online] 2019. Available from: https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

Dementia can be split into 3 categories according to its symptoms: mild, moderate, and severe. Among the estimated dementia population in Hammersmith & Fulham in 2020, the **majority** of people with dementia have **severe dementia**; **58.2% (779/1,337)** of people have **severe** dementia, **27.3% (365/1,337)** of people have **moderate** dementia, and **14.4% (193/1,337)** of people have **mild** dementia¹¹.

The **sharpest increase** of cases is expected to occur among those who are diagnosed as having **severe dementia**. In Hammersmith & Fulham by **2030**, **63.1% (1,199/1,900)** of people will have **severe** dementia, **23.9% (455/1,900)** of people will have **moderate** dementia, and **12.8% (243/1,900)** of people will have mild dementia (Figure 2)¹¹.

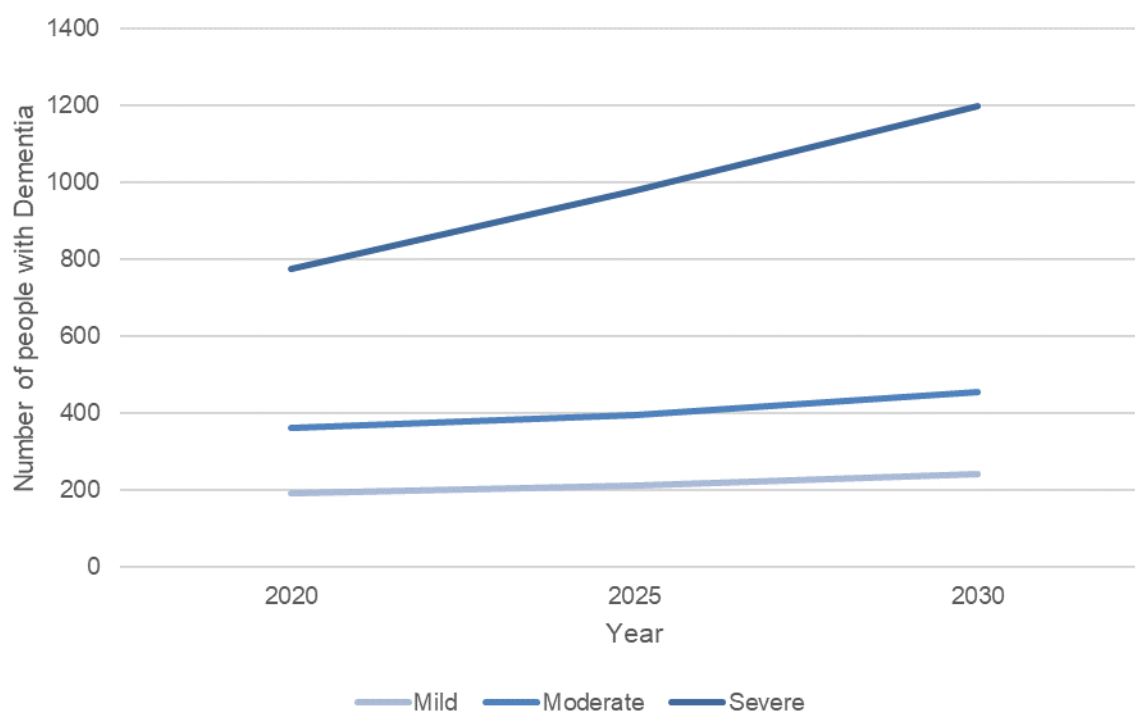


Figure 2: The Estimated Number of People with Severe, Moderate and Mild Dementia in Hammersmith and Fulham between 2020 and 2030. The sharpest increase is expected to occur to among those with severe dementia.

3.4 WHO HAS DEMENTIA IN HAMMERSMITH & FULHAM?

3.4.1 The Elderly

In 2021 over 90% of people who have dementia in Hammersmith & Fulham were over 65 years. As **age increases**, the **prevalence of dementia increases**. The **greatest proportion** of people with dementia are **over 80 years**; people over 80 years account for **64% (482/758)** of all recorded dementia cases in Hammersmith & Fulham (where exact age is known) (Figure 3)¹².

¹¹ Wittenberg, R, Hu, B, Barraza-Araiza, L, Rehill, A. Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040. Care Policy and Evaluation Centre, London School of Economics and Political Science. [Online] 2019. Available from: https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

¹² Whole Systems Integrated Care, North West London Collaboration of Clinical Commissioning Groups. Population Overview: Dementia. 2021

When we only focus on those people over 65 years; among these people **68%** (482/713) were **over 80 years** and **32%** (231/713) were aged between **65 and 79 years**¹³. This **contrasts** with the **age structure** of the over 65 years population in Hammersmith & Fulham; 25.4% are aged over 80, and 74.6% are aged between 65 and 79 years¹⁴. Therefore, the **risk** of having **dementia** is **6.1 times higher** among those who are **over 80 years**, compared to those aged between **65 and 79 years**.

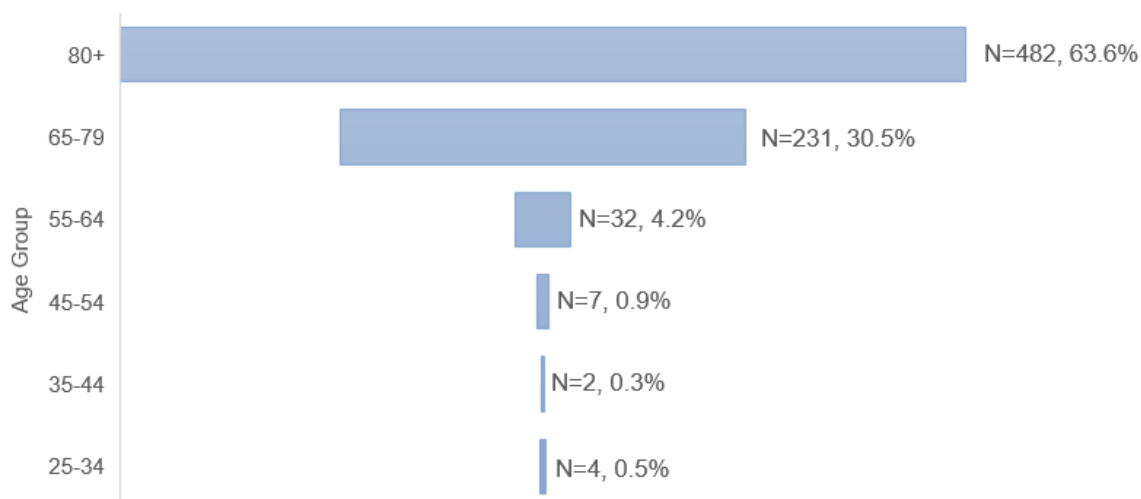


Figure 3: The age distribution of people with recorded dementia within Hammersmith & Fulham. The number of people within each age category, as well as the percentage of the total dementia population in Hammersmith & Fulham, is given for each age category.

3.4.2 Women

Our data tells us that **more women** than men have recorded **dementia** in Hammersmith & Fulham. In 2020 of those where gender is recorded, **61.9%** (469/758) of them are **female**, and **38.1%** (289/758) of them are **male**¹³. This aligns with **UK wide studies** which have found that **65%** of people living with dementia are **female**, and **35%** are **male**¹⁵. One of the main contributory factors for the higher prevalence of dementia among women is that women have a longer life expectancy.

Among both genders in Hammersmith & Fulham, the prevalence of dementia increases as age increases. Among **males 57.8%** (167/289) of all dementia cases occur in those aged **over 80 years**, and among **females 67.2%** (315/469) of dementia cases occur in those aged **over 80 years** (Figure 4). This could in part be explained by there being **more females than males over the age of 65** in Hammersmith & Fulham; **56.9%** of the population over 65 years in Hammersmith & Fulham are **female**, and **43.1%** are **male**. However, even after accounting for the differences in the number of females and males over 65 years, the **risk** of having **dementia** is **1.3 times higher** among **women** than among **men**. This aligns with

¹³ Whole Systems Integrated Care, North West London Collaboration of Clinical Commissioning Groups. Population Overview: Dementia. 2021

¹⁴ Office for National Statistics. Population Estimates. [Online]. Available from: <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates> .

¹⁵ Prince, M, Knapp, M, Guerchet, M, Mccrone, P, Prina, M. Dementia UK: Second edition – Overview. Alzheimer's Society. [Online] 2014. Available from: <http://alzheimers.org.uk/dementiauk>

studies which have found dementia to be more common among elderly females than among males¹⁶.

Among those who are **under 65** in Hammersmith & Fulham, however, the recorded **prevalence of dementia is similar in both genders**; **21 men** have dementia, and **19 females** have dementia¹⁷.

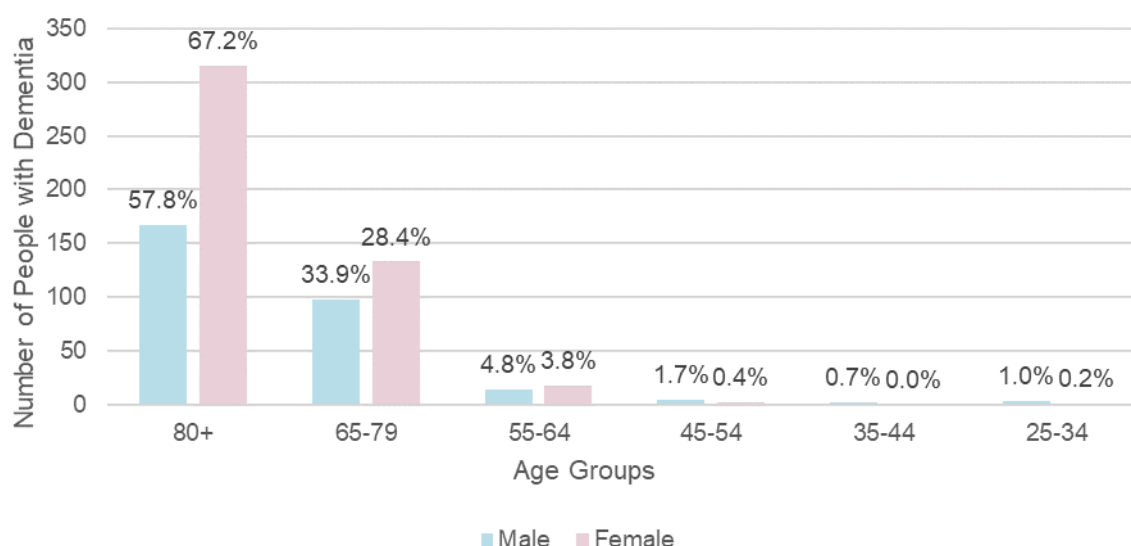


Figure 4: The recorded prevalence of dementia among certain age groups by gender. The number of people with dementia within each subgroup and the percentage of each gender within each age group is shown above.

3.4.3 Black, Asian, and Minority Ethnic

Black, Asian, and Minority Ethnic (BAME) patients in Hammersmith & Fulham have a **higher prevalence of dementia** than **White** patients. As of 2019, in Hammersmith & Fulham CCG, **64%** (549/863) patients with recorded dementia were of White ethnicity and **32%** (277/863) of patients were of a BAME ethnicity¹⁸. This is similar to the **ethnic structure** of the borough; in 2018, **65.7%** of the population was from a **White** ethnic background and **34.3%** were from a **BAME** ethnic background¹⁹. **Nationally** in the UK, **3%** of people with dementia are from **BAME** communities, therefore **Hammersmith & Fulham** has a **higher prevalence of dementia** among **BAME** communities.

According to Alzheimer's Research UK, one possible explanation for the high prevalence of dementia among BAME communities could be due to **cultural differences** in certain **screening tools** which are used to confirm a diagnosis of dementia in memory clinics. Efforts could be made to improve diagnosis among BAME communities by **standardising**

¹⁶ Corrada, M.M, Brookmeyer, R, Berlau, D, Paganini-hill, A, Kawas, C.H. Prevalence of dementia after age 90. Neurology. 2008;71(5): .

¹⁷ Whole Systems Integrated Care, North West London Collaboration of Clinical Commissioning Groups. Population Overview: Dementia. 2021.

¹⁸ Hammersmith & Fulham CCG. Dementia Profiling. 2019.

¹⁹ Office for National Statistics. Annual Population Survey. [Online]. Available from: <https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes/methodologies/annualpopulationsurveyapsqmi>

memory and **thinking tests**, modifying them to be **culturally appropriate** and **translating** tests into the person's primary language²⁰.

²⁰ Alzheimer's Research UK. What dementia means for ethnic minorities in the UK. [Online]. Available from: <https://www.alzheimersresearchuk.org/blog/what-dementia-means-for-ethnic-minorities-in-the-uk/>

4 PREVENTING WELL

Summary

- The risk of developing dementia can be reduced by having a healthy lifestyle

4.1 HOW CAN WE PREVENT DEMENTIA?

As mentioned in Section 2.2, there are various **risk factors** for dementia including:

- Coronary Heart Disease
- Diabetes
- Hypertension
- Stroke
- Depression
- Lack of physical exercise and Obesity
- Smoking
- Excessive alcohol consumption

Whilst dementia **cannot** be directly **prevented**, steps can be taken to **reduce** a person's **risk** of **developing dementia**. Certain risk factors can be avoided and/or minimised. Others are impossible to control. Overall, **managing conditions** such as **diabetes** and **high blood pressure**, having a **healthy diet**, **regular physical exercise**, and **avoiding smoking** and **excessive drinking** can all help to **reduce the risk** of developing **dementia**. The Alzheimer's Society suggests that a clear message of 'What is **good** for your **heart** is **good** for your **head**' is needed throughout preventative public health interventions and campaigns to improve public understanding of how people can reduce their risk of developing dementia²¹.

4.2 WHAT IS THE PREVALENCE OF RISK FACTORS IN HAMMERSMITH & FULHAM?

Hammersmith & Fulham has some of the **lowest occurrence of risk factors** in all of London, including prevalence of conditions such as Coronary Heart Disease, Diabetes, and strokes, and of unhealthy lifestyle activities such as smoking and excessive drinking. Furthermore, the **prevalence** of most of the **risk factors** for **dementia** have been **decreasing** in the population since 2012/2013, with the exception of, physical exercise, depression, and alcohol consumption.

4.2.1 Coronary Heart Disease

In Hammersmith & Fulham, as of 2019/20 **3,906** people have been diagnosed with **Coronary Heart Disease** (CHD), equating to **1.4%** of the population. This is the **second**

²¹ Alzheimer's society. Alzheimer's Society's view on public health, prevention and dementia. [Online]. Available from: <https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/public-health-prevention-dementia>

lowest prevalence of CHD in any **London Borough**. It is also **lower** than the **London prevalence of 1.9%** and less than **half the England prevalence of 3.1%**²².

4.2.2 Diabetes

Among adults in Hammersmith & Fulham, as of 2019/20 **9,692** were recorded as having diabetes, equating to **3.6%** of the adult population. This is the **second lowest prevalence** of diabetes in any **London Borough**. It is also **lower** than the **London prevalence of 6.8%** and **lower** than the **England prevalence of 7.1%**²².

4.2.3 Hypertension

As of 2019/2020, **22,746** people in Hammersmith & Fulham were recorded as having **hypertension**, equating to **7.5%** of the population. This is the **second lowest prevalence** of hypertension in any **London Borough**. It is also **lower** than the **London prevalence of 11.0%** and **lower** than the **England prevalence of 14.1%**²².

4.2.4 Stroke

In 2019/2020, **2,529** people in Hammersmith & Fulham had a **stroke**, equating to **0.8%** of the population. This is the **fourth lowest prevalence** of strokes in any **London Borough**. It is also **lower** than the **London prevalence of 1.1%** and **half the England prevalence of 1.8%**²².

4.2.5 Depression

Among adults in Hammersmith & Fulham in 2019/20, **17,575** were recorded as having depression, equating to **6.6%** of the adult population. This is the **6th lowest prevalence** of depression in any **London Borough**. It is also **lower** than the **London prevalence of 8.2%** and **lower** than the **England prevalence of 11.6%**²².

4.2.6 Lack of Physical Exercise and Obesity

Physical inactivity among adults is defined by engaging in less than 30 minutes of physical activity per week. In Hammersmith & Fulham as of 2019/20, **16.3%** of adults said that they were **physically inactive**. This is the **third lowest prevalence** of physical inactivity in any **London borough**. It is **lower** than both the **London prevalence of 23.8%** and the **England prevalence of 22.9%**²³.

The prevalence of adult obesity in Hammersmith & Fulham is relatively low. As of 2019/2020, **12,204** people in Hammersmith & Fulham were recorded as being **obese**, equating to **4.6%** of the population. This is the **second lowest prevalence** of obesity in any **London Borough**. It is also **lower** than the **London prevalence of 8.5%** and **less than half the England prevalence of 10.5%**²².

4.2.7 Smoking

The estimated number of **current smokers** among the adult population in Hammersmith & Fulham in 2019 is **15,305**, which equates to **10.3%** of the population. This is the **sixth lowest prevalence** of smoking in any **London Borough**. It is **lower** than the **London**

²² NHS digital. Quality and Outcomes Framework, 2019-20. [Online]. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data/2019-20>

²³ Sport England. Active Lives Adult Survey 2019/20 Report.

prevalence of **12.9%** and the **England** prevalence of **13.9%**²⁴. However, further **efforts** should be made to **reduce the prevalence of smoking** in Hammersmith & Fulham.

4.2.8 Excessive Alcohol Consumption

Excessive alcohol consumption often results in admission episodes for alcohol-related conditions, and admission rate is often used as a proxy indicator for alcohol consumption. In 2018/2019, there were **509 alcohol-related admissions** among 40-64-year-olds in Hammersmith & Fulham, which equates to **97.5 admissions per 10,000** 40-64-year-olds. This is the **2nd highest prevalence** of alcohol-related admission in any **London** Borough. It is **higher** than both the **London** prevalence of **77.3 admissions per 10,000** and the **England** prevalence of **92.9 admission per 10,000**²⁵. Further **efforts** should be made to **reduce excessive alcohol consumption** in Hammersmith & Fulham.

²⁴ Office for National Statistics. Adult Smoking Habits in the UK. [Online]. Available from: [tps://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bulletins/adultsmokinghabitsingreatbritain/2019](https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bulletins/adultsmokinghabitsingreatbritain/2019)

²⁵ Public Health England. Public Health Profiles. [Online]. Available from: <https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia/>

5 DIAGNOSING WELL

Summary

- In 2021, the diagnosis rate in Hammersmith and Fulham is 57.6%
- This is well below the *national diagnosis target of 66.7%*
- Between April 2019 and March 2021, 1,179 patients were referred to the Hammersmith & Fulham Cognitive Impairment and Dementia Service (OPMHS)
- The majority of patients who were referred were female

5.1 HOW DO YOU DIAGNOSE DEMENTIA?

A key step in **obtaining a dementia diagnosis** is to see a General Practitioner (GP). They will **ask** the resident about their **symptoms** and other aspects of their health. In order to rule out other causes of memory problems, the GP may perform a **physical examination** and organise a **blood test** and **urine test**. The GP will also give the resident a **memory** or **cognitive test**. If the GP is **unable to draw a conclusion** about the dementia diagnosis, for example if the **symptoms** are **mild**, then they might refer the resident to a **dementia specialist**, such as a psychiatrist, geriatrician, or neurologist. The specialist can then organise further tests including a **CT scan** or an **MRI scan** to determine the diagnosis²⁶.

5.2 HOW MANY PATIENTS ARE REFERRED INTO DIAGNOSIS SERVICES?

Between April 2019 and March 2021, a total of 1,179 patients were referred to Hammersmith & Fulham Cognitive Impairment and Dementia Service, to be assessed for concern over cognition and for a potential dementia diagnosis²⁷.

The average number of referrals per month is 49 and has remained relatively consistent between April 2019 and March 2021 (Figure 5)²⁷. However, the number of referrals decreased to 5 referrals in both April and May 2020, which coincides with the beginning of the COVID-19 pandemic in the UK.

²⁶ NHS. How to get a dementia diagnosis. [Online]. Available from: <https://www.nhs.uk/conditions/dementia/diagnosis/>

²⁷ West London NHS Trust. Hammersmith & Fulham Cognitive Impairment and Dementia Service. 2021.

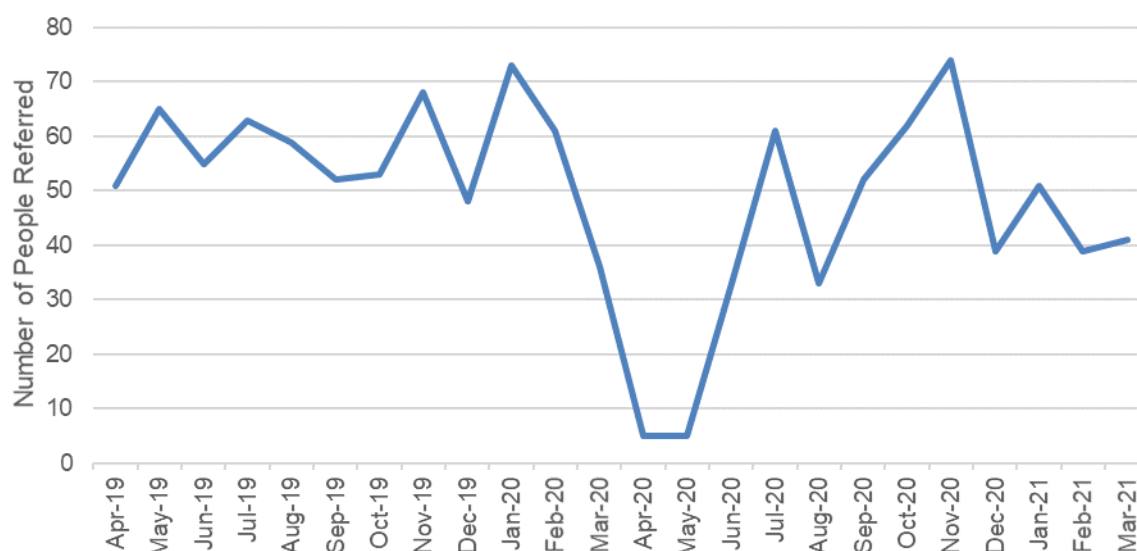


Figure 5: The number of patients referred to Hammersmith & Fulham Cognitive Impairment and Dementia Service, between April 2019 and March 2021.

The majority of patients referred were female; 62.5% (737/1,179) of patients were female, while 37.5% (442/1,179) of patients were male. The majority of patients referred were also over the age of 70; 82.4% (971/1,179) of patients referred were over 70, and of those people aged over 70 almost half (47.6%; 462/971) of them were aged between 80 and 89 years (Figure 6)²⁸.

²⁸ West London NHS Trust. Hammersmith & Fulham Cognitive Impairment and Dementia Service. 2021.

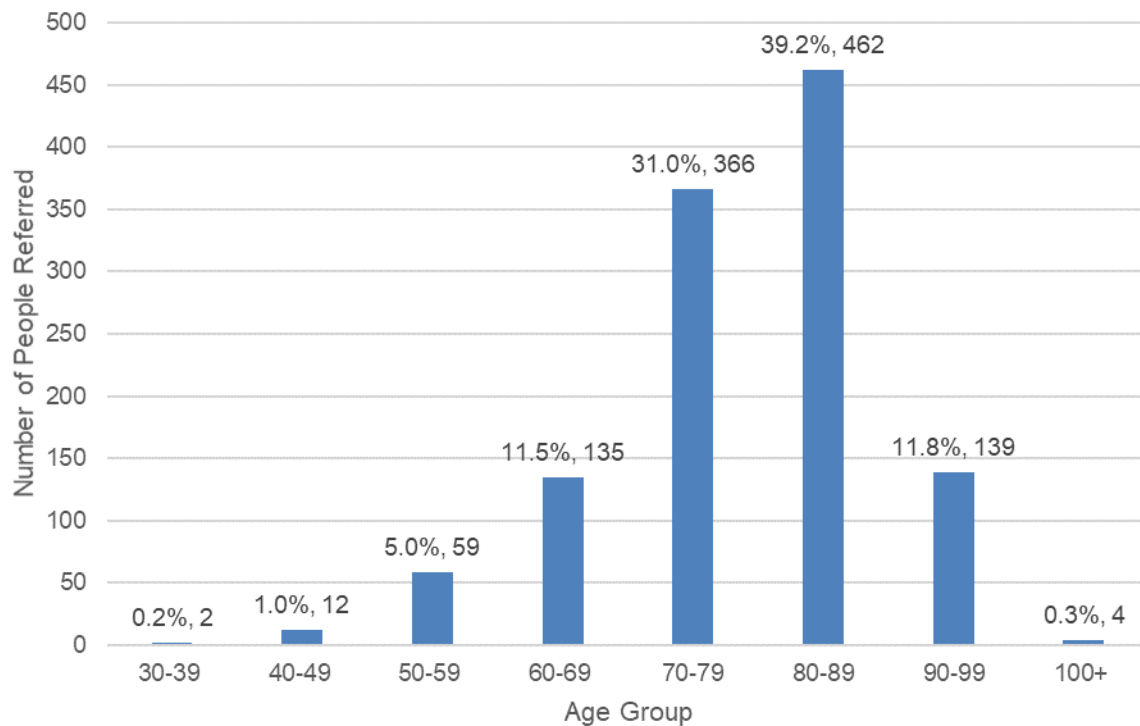


Figure 6: The Age Groups of residents Referred to Hammersmith & Fulham Cognitive Impairment and Dementia Service between April 2019 and March 2021.

In terms of ethnicity, the largest number of patients referred to Hammersmith & Fulham Cognitive Impairment and Dementia Service between April 2019 and March 2021 identified as British; 35.5% (419/1,179) of patients identified as being of British ethnicity. This was followed by patients who identified as being from any other White background, excluding British or Irish, (16.7%; 197/1,179) and patients who identified as being from a Caribbean background (8.5%; 100/1,179) (Figure 7)²⁸.

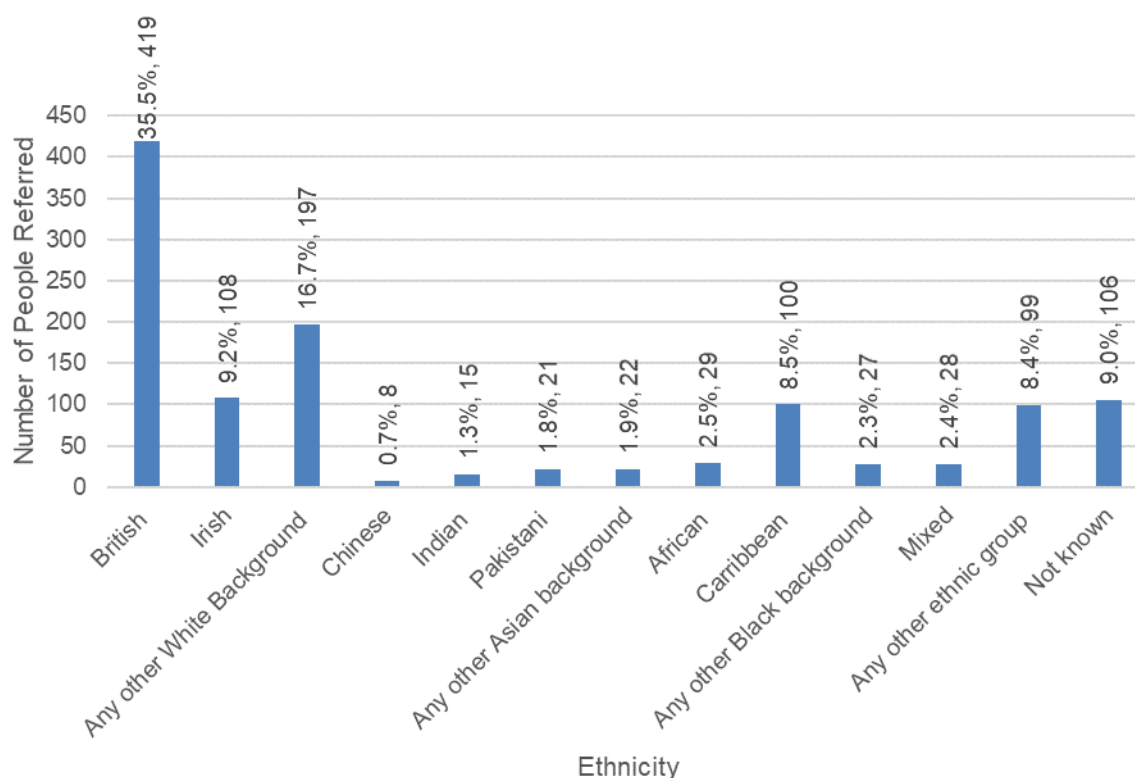


Figure 7: The number of patients referred to Hammersmith & Fulham Cognitive Impairment and Dementia Service between April 2019 and March 2021, by ethnicity.

5.3 HOW DOES HAMMERSMITH & FULHAM COMPARE IN TERMS OF DIAGNOSES RATES?

In Hammersmith & Fulham, the **dementia diagnosis rate** in the population over 65 years is **57.6%** as of July 2021. This is **lower** than both the **London** rate of **66.2%** and the **England** rate of **62.1%**²⁹. It is also **lower** than the **national diagnosis target** for dementia which is **66.7%**³⁰. In order **to reach the national target**, Hammersmith & Fulham would need to **diagnose 121 more people**. This diagnosis rate is the **second lowest** of all London boroughs.

²⁹ NHS Digital. Recorded Dementia Diagnoses July 2021. [Online]. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/july-2021>

³⁰ NHS digital. Dementia diagnosis rate and prescription of antipsychotic medication to people with dementia. [Online]. Available from: <https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/general-practice-data-hub/dementia-diagnosis-rate-and-prescription-of-antipsychotic-medication-to-people-with-dementia>

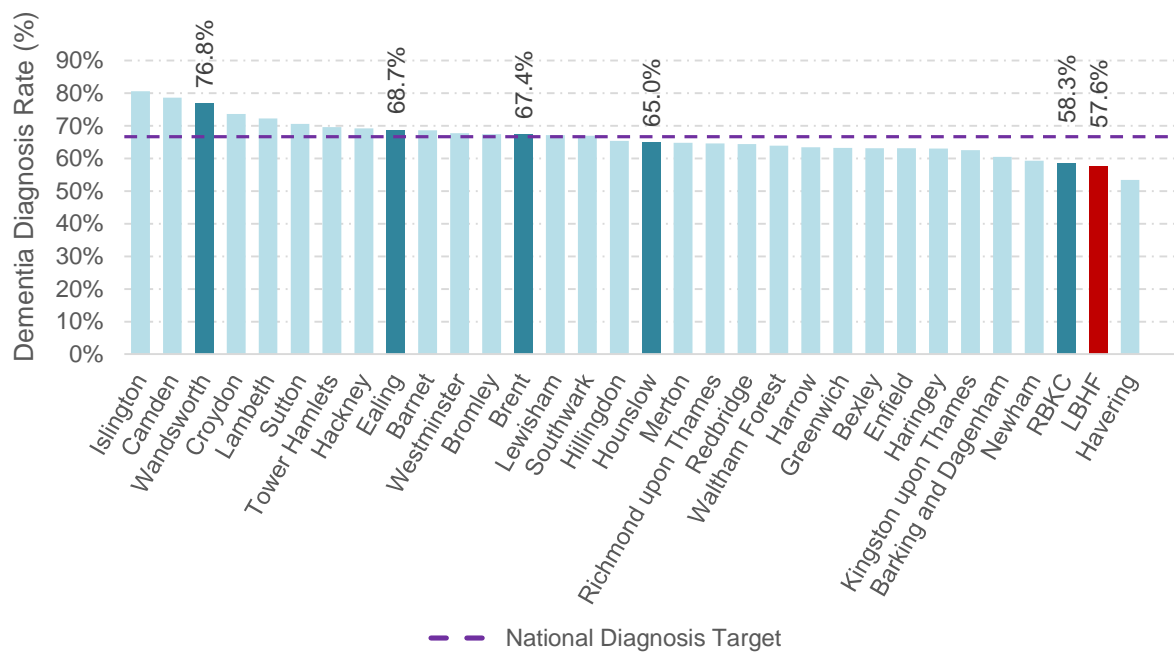


Figure 8: The Dementia Diagnosis Rates in Each London Borough. The national diagnosis rate target (66.7%) is marked. Hammersmith & Fulham has a diagnosis rate of 57.6%, which is 9.1% below the national diagnosis target.

6 LIVING WELL

Summary

- In 2019/2020, 71.5% of dementia plans were reviewed in a 12-month period
- This is lower than the London and England average
- In 2020, it is estimated that 6,744 residents over the age of 65 were living alone, and it was approximated that 435 residents with dementia were living alone
- Adequate social interactions and quality of life scores for carers in 2018/19 were below the London and England averages in Hammersmith & Fulham

6.1 HOW OFTEN ARE DEMENTIA PLANS REVIEWED?

Dementia Care Plans should be reviewed at least once a year by either a GP or a suitably qualified clinician in order to personalise dementia care and better support the needs of the resident and their carer. In 2019/2020, **71.5%** (629/880) of **dementia care plans** were **reviewed** in Hammersmith & Fulham. This is **below** the **London average** of **76.8%** and **below** the **England average** of **75.0%**³¹. In order to **meet the England average**, Hammersmith & Fulham would have to review the plans of **31 more people** with dementia.

6.2 HOW MANY PEOPLE LIVE ALONE?

As of 2020, it is estimated that 6,744 residents of Hammersmith & Fulham who are over the age of 65 years live alone, which equates to 32% (6,744/21,100) of the total population over 65 years old. This number is expected to increase to 11,943 by 2040 due to an ageing population³².

6.3 WHAT ABOUT THE QUALITY OF LIFE FOR CARERS OF PEOPLE WITH DEMENTIA?

To provide optimal care, the carers of people with dementia should also be supported and have a good quality of life. However, in 2018/19, **25.8%** (85/329) of **carers** in Hammersmith and Fulham reported having **as much social contact as they would like**, thereby implying that the other **74.2%** (244/329) of carers live in **social isolation**. This percentage of carers reporting adequate social contact in Hammersmith & Fulham is **lower** than both the London average of **33.2%** and **lower** than the **England average** of **32.5%**³³.

Similarly, when carers were asked to provide a score concerning their **quality of life**, with 0 indicating the lowest quality of life, and 12 indicating the highest quality of life, the average score for carers in Hammersmith and Fulham was **6.9**. This is **lower** than both the **London average** of **7.2** and the **England average** of **7.3**³³.

³¹ NHS digital. Quality and Outcomes Framework, 2019-20. [Online]. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data/2019-20>

³² Projecting Older People Population Information System. Living Alone. [Online]. Available from: <https://www.poppi.org.uk/>

³³ NHS Digital. Personal Social Services Survey of Adult Carers in England. [Online]. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers/england-2018-19>

Therefore, **efforts** should be made to **improve** the proportion of carers who have **adequate social contact** and to improve the **quality of carers lives** in Hammersmith & Fulham. This could be achieved through making carers aware of and offering them the opportunity for respite, education, training, emotional and psychological support.

7 SUPPORTING WELL

Summary

- In 2020 Adult Social Care documented providing support to up to 972 people with recorded dementia or difficulty with memory
- In 2020, there were 404 beds in care homes which are suitable for people with dementia, equating to 52.4 beds per 100 people with dementia
- In 2020, 97 (24.0%) beds were rated as good or outstanding
- This is below the national target of 75% of beds being rated as good or outstanding
- There were 970 emergency hospital admissions of residents with recorded dementia in 2019/20
- This is higher than the London and England average

7.1 HOW IS ADULT SOCIAL CARE INVOLVED?

Adult Social Care (ASC) provides support to many people with dementia. ASC data and NHS data are not formerly aligned and hence it is difficult to determine how many residents with a clinical diagnosis of dementia are supported by ASC. However, in 2020, **491 people** known to ASC have '**dementia**' cited in their case notes. A further **481 people** known to ASC have '**memory**', '**forget**' or '**remember**' mentioned in their case notes. *Therefore, it is estimated that 972 people known to ASC have dementia or symptoms of dementia*³⁴.

7.2 HOW MANY PEOPLE WITH DEMENTIA ARE IN CARE HOMES?

In 2019 there were **192 people** with dementia in **care homes** in Hammersmith & Fulham³⁵. This accounts for **23.8%** of the **dementia population** in Hammersmith & Fulham.

7.2.1 What is the capacity to house people with dementia in Care Homes?

It is estimated that **70% of people with dementia** may eventually **require long-term residential care**, therefore safe and high-quality care services should be available to people with dementia³⁶.

In Hammersmith & Fulham in 2020, there were **404 residential care and nursing home beds** which are **suitable** for people with **dementia**³⁷. This equates to **52.4 beds per 100 people with dementia**. However, it is **higher** than the **London average of 51.9 beds per 100 people with dementia** but is **lower** than the **England average of 75.3 beds per 100 people with dementia**. In order for Hammersmith & Fulham to **reach the England average**, Hammersmith & Fulham would **need to provide 176 more beds** which are suitable for people with dementia.

³⁴ Hammersmith and Fulham Council. Adult Social Care. 2020

³⁵ Hammersmith & Fulham CCG, Dementia Profiling. 2019.

³⁶ Alzheimer's Society. Fix Dementia Care NHS and care homes. 2016.

³⁷ Care Quality Commission. Care Directory. [Online]. Available from: <https://www.cqc.org.uk/files/cqc-care-directory-zip>

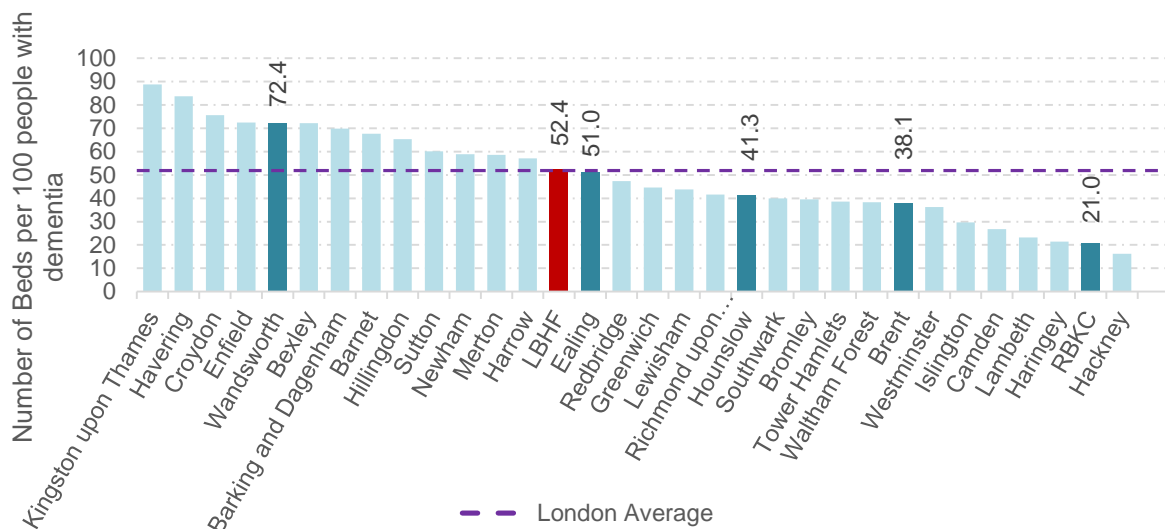


Figure 9: The Number of Beds in Residential Care and Nursing Homes per 100 People with Dementia in Each London Borough. The London average of 51.9 beds per 100 people with dementia is marked. Hammersmith & Fulham has 52.4 beds suitable for people with dementia per 100 people with dementia in the Borough. This equates to there being 404 residential care and nursing home beds which are suitable for people with dementia in the borough.

Out of the 404 residential care home and nursing home beds, **97 (24.0%)** are **rated as good or outstanding** by the Care Quality Commission in 2020 (Figure 10). This is the lowest proportion of beds rated as good or outstanding across all London Boroughs. This percentage is **lower** than the **London average of 73.2%**, and the **England Average of 74.1%**³⁸. In order to **reach the England average**, Hammersmith & Fulham would **need to provide an additional 144 beds of good or outstanding quality**.

This data in part reflects Hammersmith and Fulham provision requiring improvement and in part out of borough historical residential care homes requiring improvement.

³⁸ Care Quality Commission. Care Directory. [Online]. Available from: <https://www.cqc.org.uk/files/cqc-care-directory-zip>

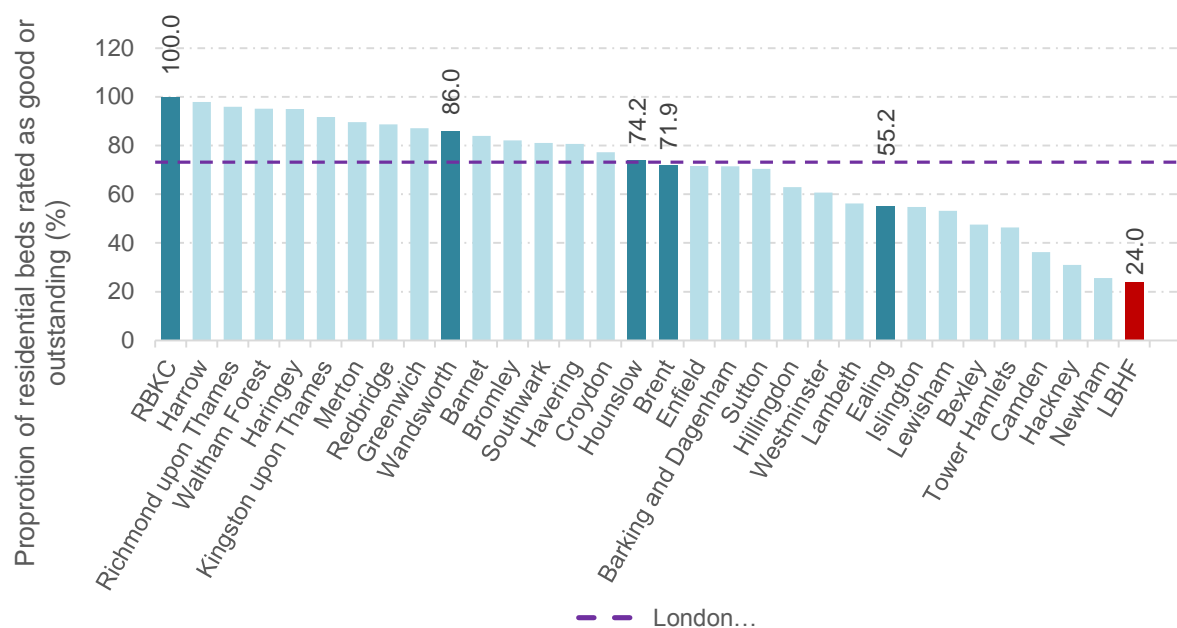


Figure 10: The Proportion of Beds in residential Care and Nursing Homes, which are Suitable for People with Dementia, and are Classified as Good or Outstanding. London average of 73.2% of beds being classified as good or outstanding is marked. Hammersmith & Fulham has 97 beds which are classified as good or outstanding, equating to 24.0% of all suitable beds.

7.3 HOW MANY PEOPLE WITH DEMENTIA ARE ADMITTED INTO HOSPITAL?

7.3.1 Emergency Hospital Admissions

There were **970 emergency admissions** into hospital in 2019/2020 where dementia or Alzheimer's is mentioned in the diagnosis code. This equates to a **rate** of **4,893** dementia admissions per 100,000 population. This is **higher** both the **London** rate of **4,013** per 100,000 and the **England** rate of **3,517** per 100,000. This emergency admission rate is also the **sixth highest** of all London Boroughs (Figure 11)³⁹. Further investigation is needed to understand the factors contributing to this rate of emergency hospital admissions.

³⁹ NHS digital. Hospital Episode Statistics. [Online]. Available from: <https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/hospital-episode-statistics> [Accessed 6 September 2021].

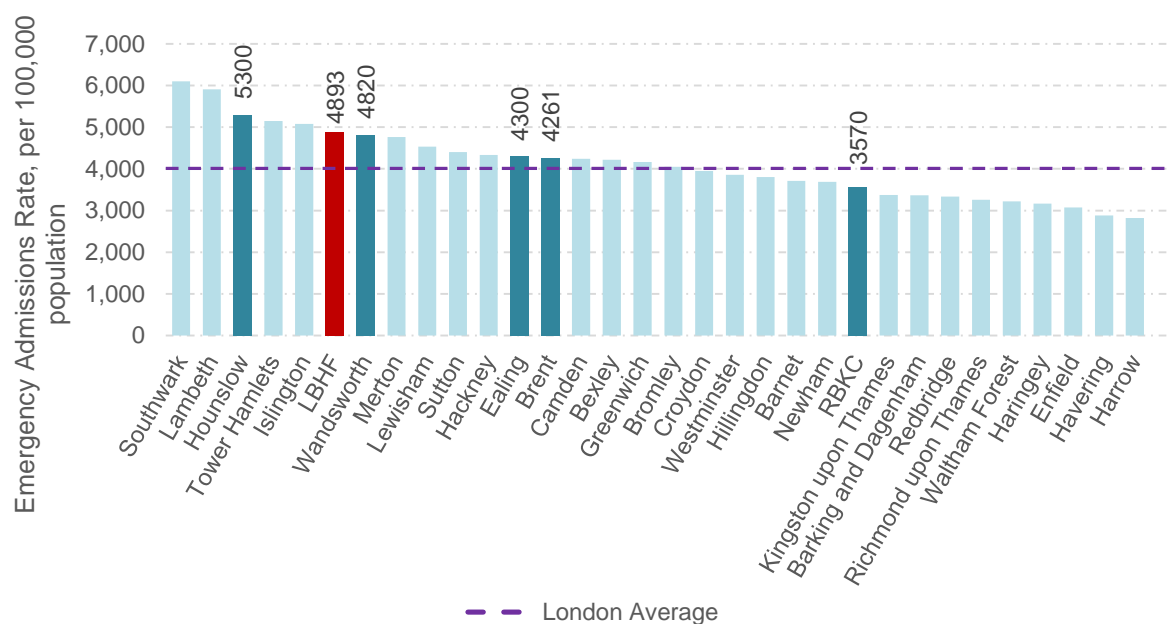


Figure 11: The Rate of Emergency Hospital Admissions Among People with Dementia per 100,000 Population in Each London Borough. The average London rate of 4,013 per 100,000 population is marked. Hammersmith & Fulham has a dementia emergency admission rate of 4,893 per 100,000 population, which is the sixth highest emergency admission rate in London.

8 DYING WELL

Summary

- In 2019, 124 residents with recorded dementia passed away, equating to a rate of 625 deaths per 100,000 population
- This is lower than the London average and the England average
- 61.3% (76/124) of residents with recorded dementia died in their 'usual place of residence'
- This is higher than the London average and lower than the national average
- The majority of residents with dementia passed away in care homes

8.1 HOW MANY PEOPLE DIE WITH DEMENTIA?

In 2019, 124 people with **dementia** in Hammersmith & Fulham **passed away**. This equates to a rate of **625 deaths per 100,000 population**. This is **lower** than the **London average of 722 deaths per 100,000 population**, and the **England average of 849 deaths per 100,000 population**⁴⁰. Further investigation is needed to determine any factors which could explain the death rate among people with dementia.

8.2 DO MOST PEOPLE WITH DEMENTIA DIE AT HOME?

To understand whether people with dementia die in their preferred place of death, the 'usual place of residence' is used as a proxy indicator for preferred place of death. Of the 124 people who died with dementia, **76 (61.3%)** of them **died** in their **usual place of residence** (Figure 12). This is **higher** than the **London average of 60.0%**, but **lower** than the **England average of 70.3%**⁴⁰. *Further investigation is required to determine how Hammersmith & Fulham can accommodate more people dying in their usual place of residence.*

Of the 124 people with dementia who passed away in 2019, **41.9% (52/124)** died at a **care home**, **37.9% (47/124)** of them died at **hospital** and **16.9% (27/124)** of them died at **home**⁴⁰ (Figure 12).

⁴⁰ Office for National Statistics. Deaths registered in England and Wales. [Online]. Available from: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/the21stcenturymortalityfilesdeathsdataset/current>

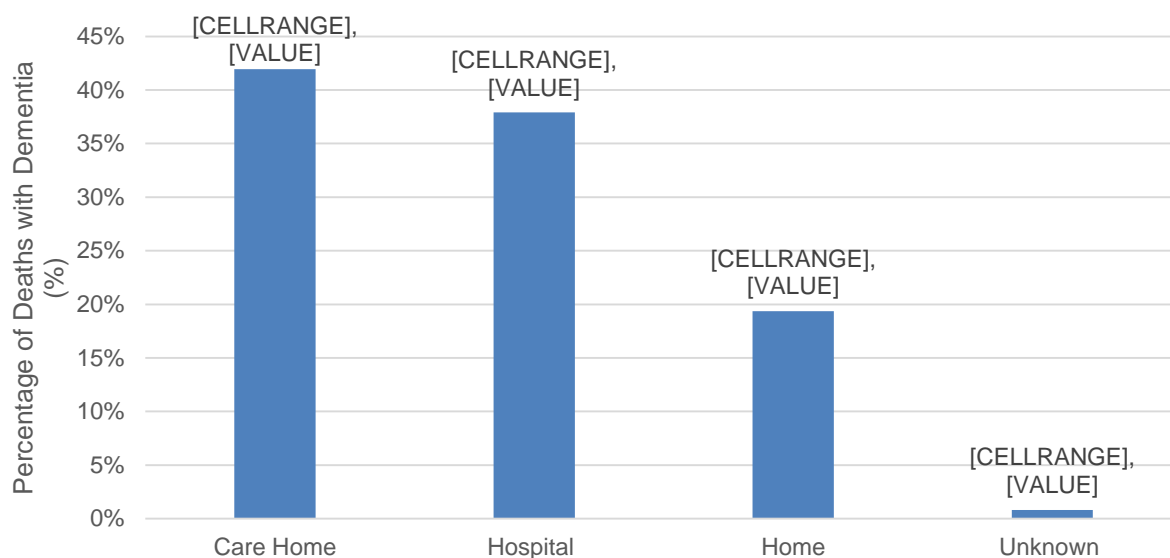


Figure 12: The Percentage of Total Deaths in each Location in Hammersmith & Fulham. The number of deaths in each location is also provided. This data is for 2019.

8.3 WHAT IMPACT HAS COVID-19 HAD?

The Covid-19 pandemic has had a significant impact on Hammersmith & Fulham residents, including residents with dementia. People with dementia are at a higher risk of getting severe Covid-19 illness, and Covid-19 has been showed to worsen dementia⁴¹. As of January 2021, 15% (57/388) of people who died from Covid-19 illness in Hammersmith & Fulham had dementia⁴².

⁴¹ Alzheimer's society. COVID-19 and dementia. [Online]. Available from: <https://www.alzheimers.org.uk/get-support/coronavirus/about-coronavirus>

⁴² West London Coroner Court – Hammersmith & Fulham. Coroner's Report. 2021.

H&F Dementia Strategy- Local Stakeholders Survey: Summary report

This report was created on Thursday 01 April 2021 at 14:09 and includes **52** responses.

The consultation ran from 10/02/2021 to 23/03/2021.

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Question 1: Your name

Name

There were **52** responses to this part of the question.

Question 2: Your (work) email address

email address

There were **52** responses to this part of the question.

Question 3: Your job title/role in the organisation

job title

There were 52 responses to this part of the question.

Question 4: Name of organisation

organisation name

There were 52 responses to this part of the question.

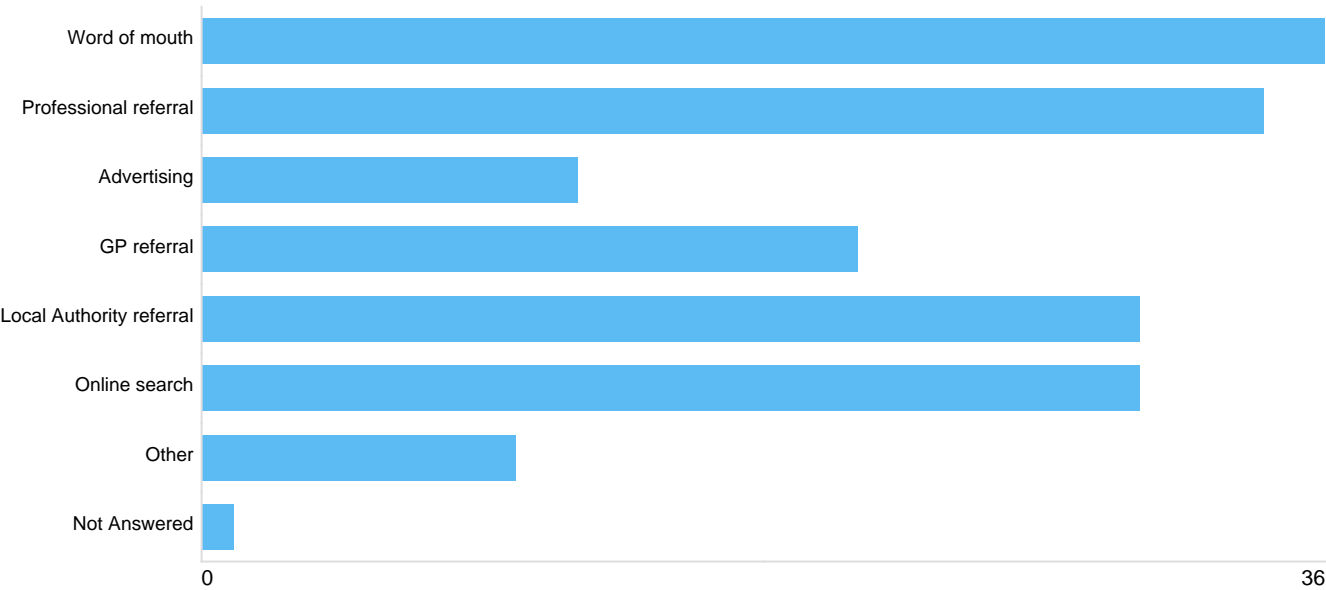
Question 5: Organisation address

organisation address

There were 51 responses to this part of the question.

Question 6: How do people usually find your organisation?

how organisation is found



Option	Total	Percent
Word of mouth	36	69.23%
Professional referral	34	65.38%
Advertising	12	23.08%
GP referral	21	40.38%
Local Authority referral	30	57.69%
Online search	30	57.69%
Other	10	19.23%
Not Answered	1	1.92%

If Other, please specify

There were 11 responses to this part of the question.

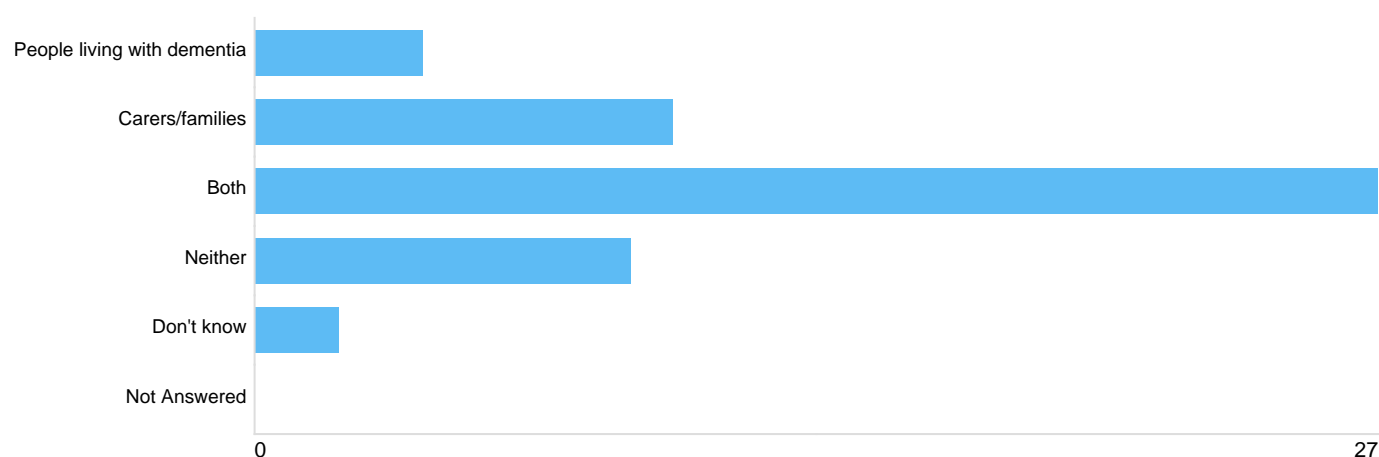
Question 7: What services/benefits does your organisation provide to the local community in Hammersmith & Fulham?

services/ benefits of organisation

There were 52 responses to this part of the question.

Question 8: Does your organisation work more with those living with dementia or their carers/families?

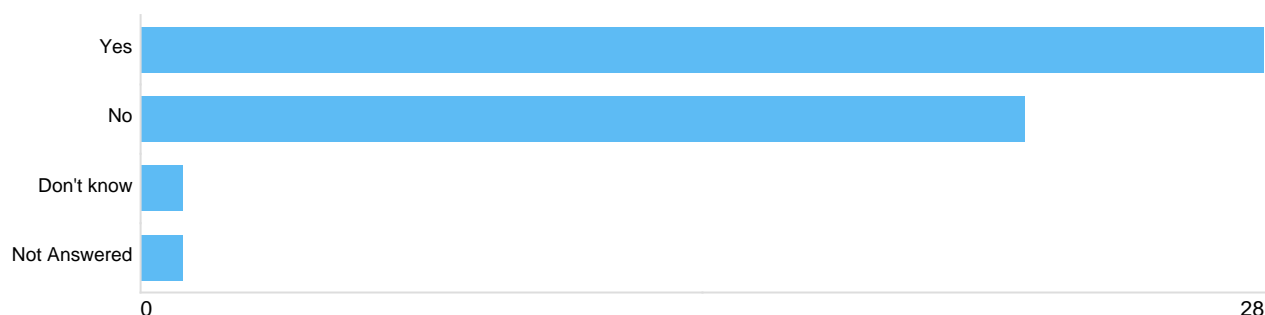
service user



Option	Total	Percent
People living with dementia	4	7.69%
Carers/families	10	19.23%
Both	27	51.92%
Neither	9	17.31%
Don't know	2	3.85%
Not Answered	0	0.00%

Question 9: Does your organisation run any services specifically for people living with dementia and/or their carers or families?

dementia-specific services



Option	Total	Percent
Yes	28	53.85%
No	22	42.31%
Don't know	1	1.92%
Not Answered	1	1.92%

Question 10: If you answered "Yes" to the previous question, please describe those services in as much detail as you can (e.g. prior to Covid, how many different people in the above groups you work with in a month, what services you provide for them)

Describe service

There were 30 responses to this part of the question.

Question 11: How has the coronavirus pandemic affected any dementia-specific services that you run?

C-19 affected services

There were 39 responses to this part of the question.

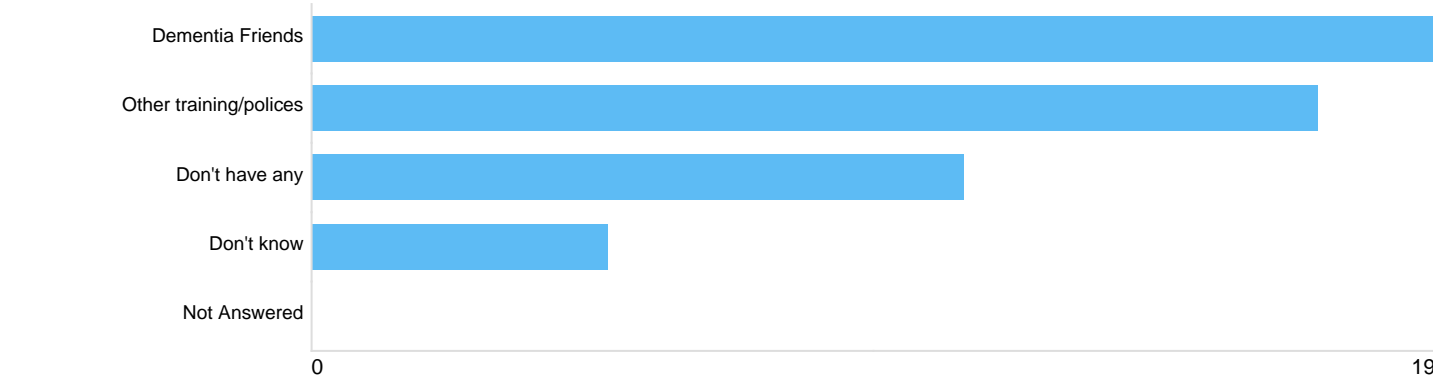
Question 12: Does your organisation signpost people with dementia or their carers/families to other organisations, and, if so, which?

signpost

There were 42 responses to this part of the question.

Question 13: Does your organisation have any dementia-awareness training/policies in place to support your staff and service users?

training policies



Option	Total	Percent
Dementia Friends	19	36.54%
Other training/policies	17	32.69%
Don't have any	11	21.15%
Don't know	5	9.62%
Not Answered	0	0.00%

If 'other training/policies' please specify

There were 19 responses to this part of the question.

Question 14: If your organisation has engaged with any people with dementia or their carers/families, can you describe any particular issues faced?

issues faced

There were 37 responses to this part of the question.

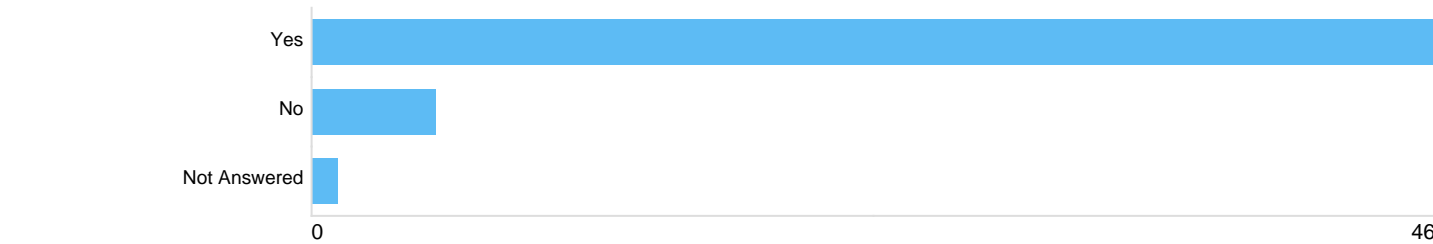
Question 15: How could we help your organisation better support people living with dementia and their carers/families?

e.g. training, information on what support services are available locally

There were 42 responses to this part of the question.

Question 16: Would you like to hear more about working with others to make our borough a Dementia-Friendly community? Please choose "Yes" if you are happy for us to store your details and contact you about this further.

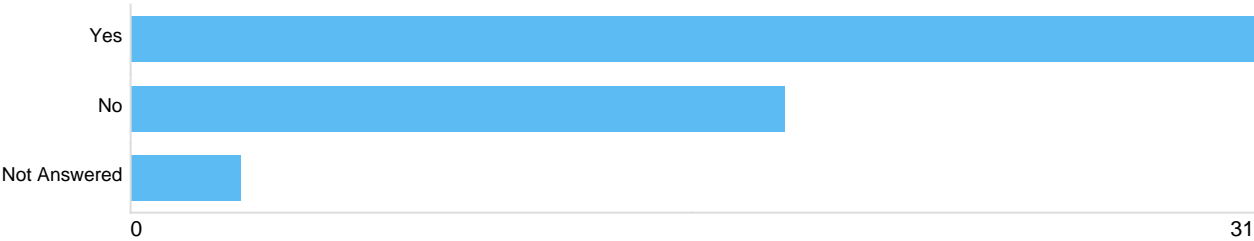
Storing details



Option	Total	Percent
Yes	46	88.46%
No	5	9.62%
Not Answered	1	1.92%

Question 17: Do you have a personal experience of dementia?

Do you have a personal experience of dementia?



Option	Total	Percent
Yes	31	59.62%
No	18	34.62%
Not Answered	3	5.77%

Please can you provide details

There were **27** responses to this part of the question.

H&F Dementia Strategy - People Living with Dementia: Summary report

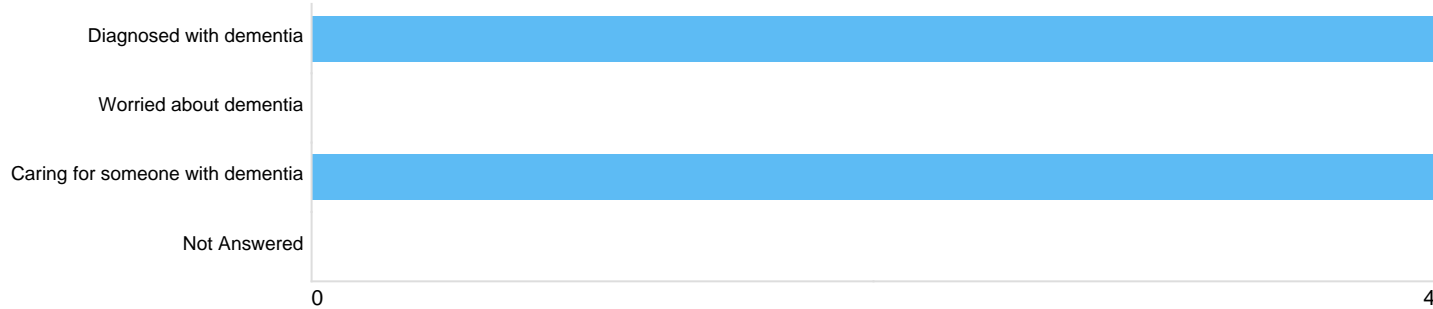
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The consultation ran from 10/02/2021 to 05/03/2021.

Contents

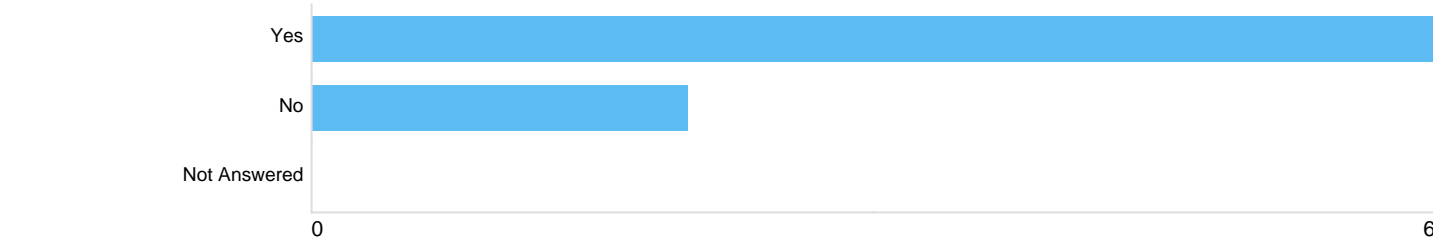
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obtaining care	6
If Other, please specify	6
Question 17: Would you like to comment about your experiences during Covid-19?	6
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Question 1: You are
who you are



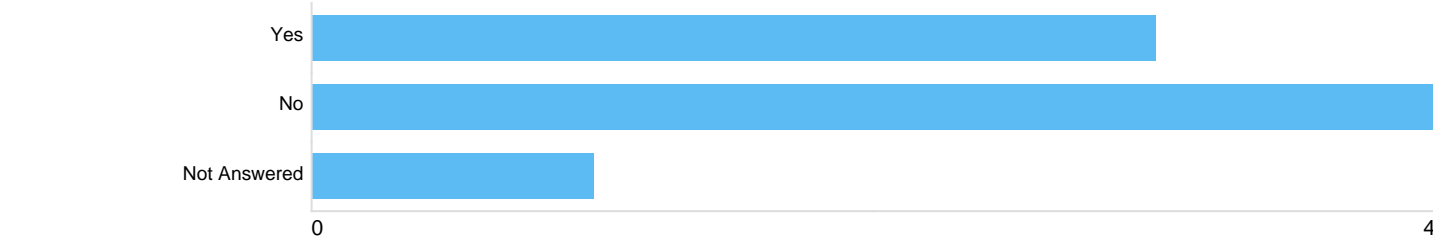
Option	Total	Percent
Diagnosed with dementia	4	50.00%
Worried about dementia	0	0.00%
Caring for someone with dementia	4	50.00%
Not Answered	0	0.00%

Question 2: Do you live in the London Borough of Hammersmith & Fulham?
where you live



Option	Total	Percent
Yes	6	75.00%
No	2	25.00%
Not Answered	0	0.00%

Question 3: Do you care for someone in the London Borough of Hammersmith & Fulham?
where you care for someone



Option	Total
Yes	3
No	4
Not Answered	1

Option	Total	Percent
Yes	3	37.50%
No	4	50.00%
Not Answered	1	12.50%

Question 4: Please leave an email address and choose "Yes" if you are happy for us to contact you in the future?

If yes, please type email address



Option	Total	Percent
Yes	1	12.50%
No	6	75.00%
Not Answered	1	12.50%

Email address

There were **5** responses to this part of the question.

Question 5: What would you say are the 3 most important things to include in a service for people living with dementia?

important things in a service

There were **8** responses to this part of the question.

Question 6: What works well for you?

what works well for you

There were **7** responses to this part of the question.

Question 7: What doesn't work well and needs to be improved?

what doesn't work well

There were **8** responses to this part of the question.

Question 8: What would make it easier to access services?

how can we make services easier to access?

There were **8** responses to this part of the question.

Question 9: What physical changes could be made in the community to make things easier for you?

physical access in the community

There were **7** responses to this part of the question.

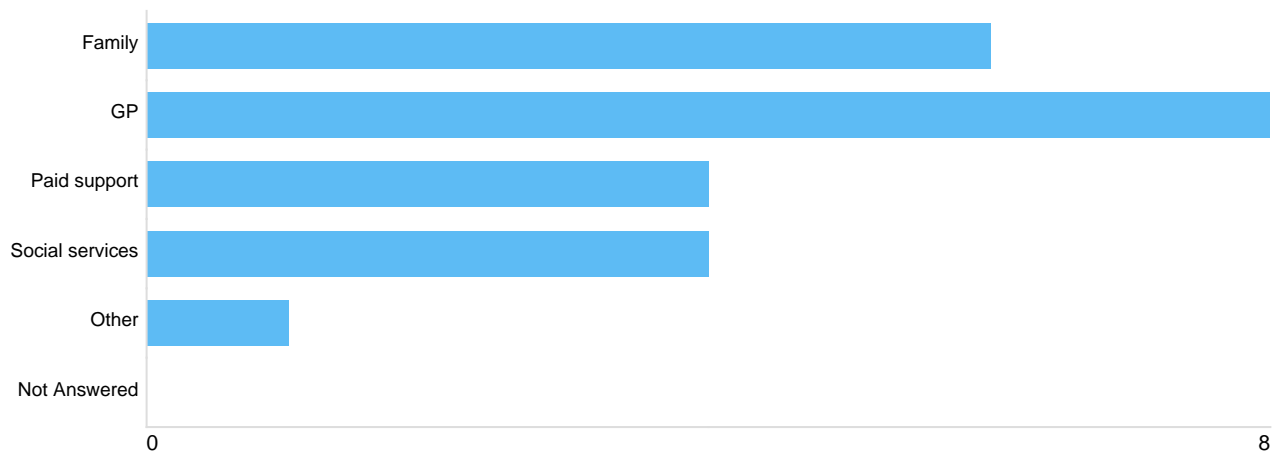
Question 10: How could people in the community make things easier for you (neighbours, shopkeepers, passers-by)?

how can the community help?

There were **6** responses to this part of the question.

Question 11: Who do you look to for support ?

support



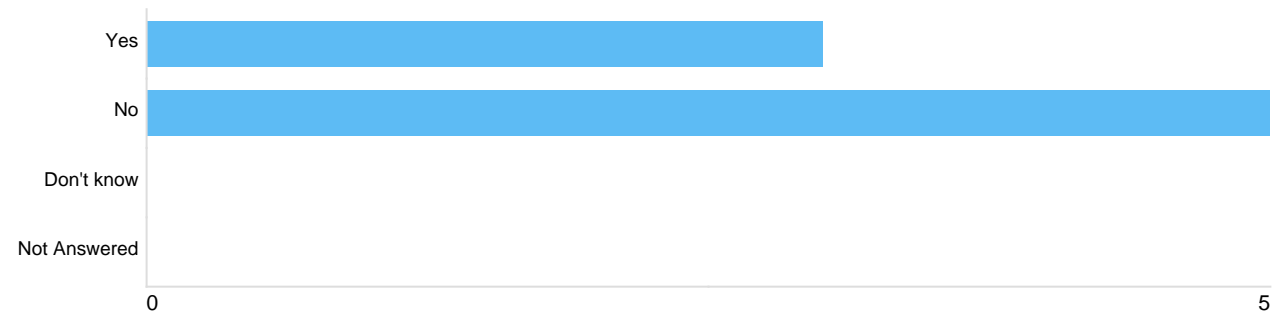
Option	Total	Percent
Family	6	75.00%
GP	8	100.00%
Paid support	4	50.00%
Social services	4	50.00%
Other	1	12.50%
Not Answered	0	0.00%

If Other, please specify

There were 2 responses to this part of the question.

Question 12: Are you self-funding?

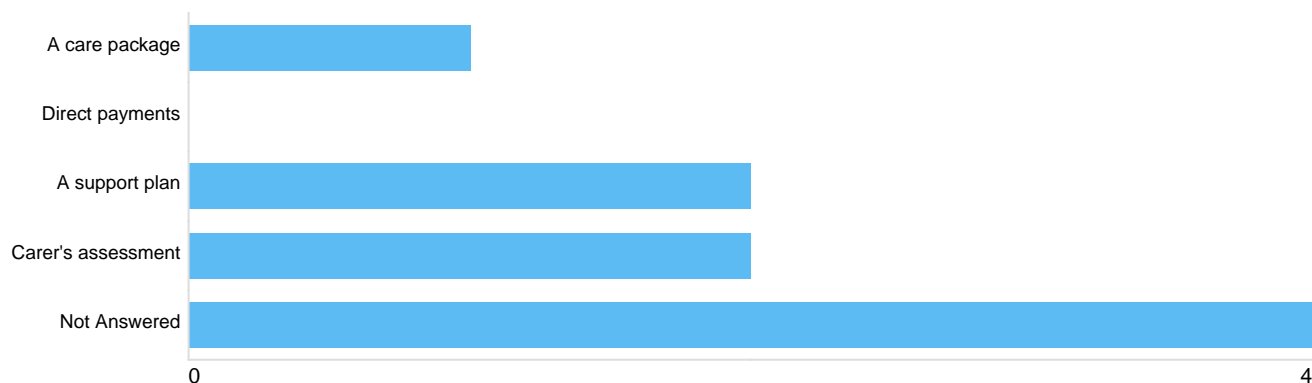
funding



Option	Total	Percent
Yes	3	37.50%
No	5	62.50%
Don't know	0	0.00%
Not Answered	0	0.00%

Question 13: Do you have any of the following?

plans/packages



Option	Total	Percent
A care package	1	12.50%
Direct payments	0	0.00%
A support plan	2	25.00%
Carer's assessment	2	25.00%
Not Answered	4	50.00%

Question 14: What is your experience of obtaining a diagnosis?

diagnosis experience



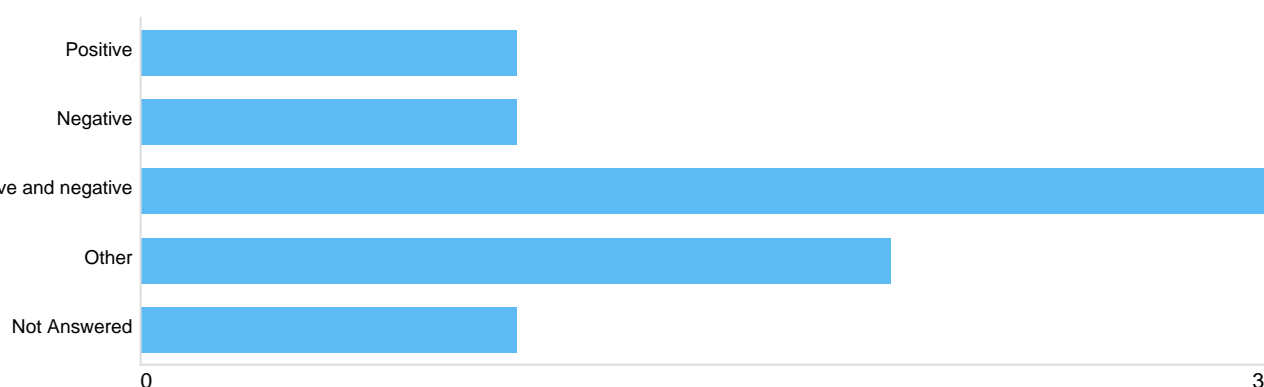
Option	Total	Percent
Positive	1	12.50%
Negative	0	0.00%
Mixture of positive and negative	1	12.50%
Other	6	75.00%
Not Answered	0	0.00%

If Other, please specify

There were 5 responses to this part of the question.

Question 15: What is your experience of obtaining support after diagnosis?

support post-diagnosis



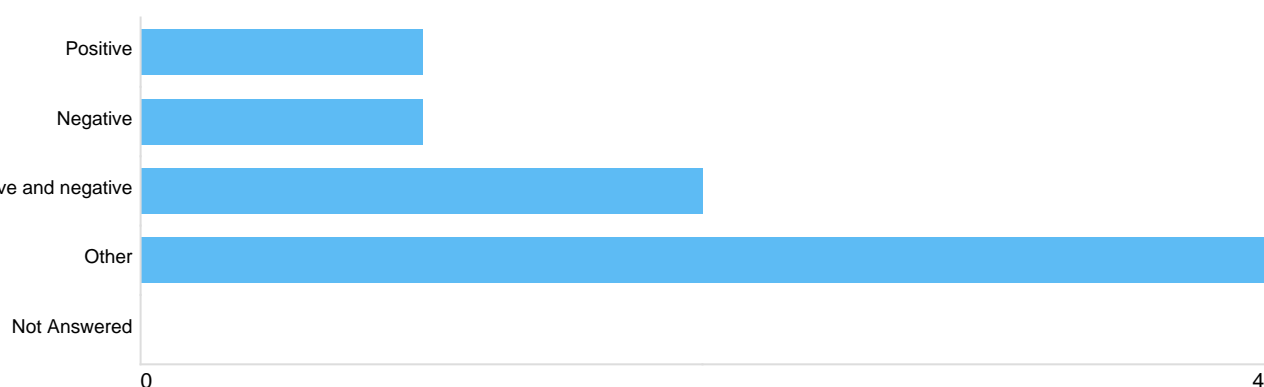
Option	Total	Percent
Positive	1	12.50%
Negative	1	12.50%
Mixture of positive and negative	3	37.50%
Other	2	25.00%
Not Answered	1	12.50%

If other, please specify

There were 2 responses to this part of the question.

Question 16: What is your experience of obtaining care?

obtaining care



Option	Total	Percent
Positive	1	12.50%
Negative	1	12.50%
Mixture of positive and negative	2	25.00%
Other	4	50.00%
Not Answered	0	0.00%

If Other, please specify

There were 4 responses to this part of the question.

Question 17: Would you like to comment about your experiences during Covid-19?

covid 19 experience

There were 3 responses to this part of the question.

H&F Dementia Strategy - Families/Carers of People Living with Dementia: Summary report

This report was created on Thursday 01 April 2021 at 14:03 and includes 45 responses.

The consultation ran from 10/02/2021 to 05/03/2021.

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Question 3: Do you care for someone in the London Borough of Hammersmith & Fulham?	2
where you care for someone	2
Question 4: Please leave an email address and choose "Yes" if you are happy for us to contact you in the future.	3
If yes, Please type your email address	3
If yes, please type email address	3
Question 5: What would you say are the 3 most important things to include in a service for carers of people with dementia?	3
service requirements	3
Question 6: What works well for you as a carer?	3
what works well	3
Question 7: What doesn't work well and needs to be improved as a carer	3
what doesn't work well	3
Question 8: What would make it easier to access services for carers or people with dementia?	3
access	3
Question 9: What physical changes could be made in the community to make things easier for you?	3
physical c hanges	3
Question 10: How could people in the community make things easier for you. e.g. neighbours, shopkeepers, passers-by?	3
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If Other, please specify	4
Question 12: Are you self-funding?	4
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Question 13: Do you have any of the following?	5
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Question 14: What is your experience of obtaining a diagnosis?	5
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If other, please specify	5
Question 15: What is your experience of obtaining support (starting after diagnosis)?	6
post-diagnosis support	6
If other, please specify	6
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direct payments	6
If Other, please specify	6
Question 17: Would you like to comment about your experiences during Covid-19?	6
covid 19 experience	6

Question 1: You are
who you are



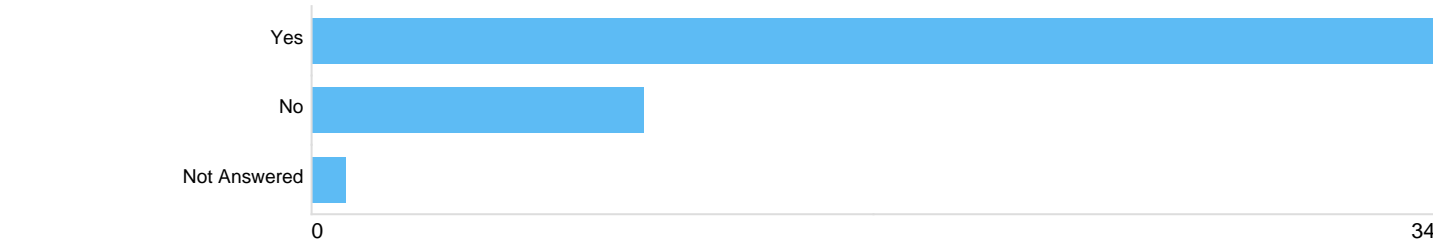
Option	Total	Percent
Diagnosed with dementia	0	0.00%
Worried about dementia	5	11.11%
Caring for someone living with dementia	38	84.44%
Not Answered	2	4.44%

If caring for someone with dementia, what year was the person who you care for diagnosed?

There were 39 responses to this part of the question.

Question 2: Do you live in the London Borough of Hammersmith & Fulham?

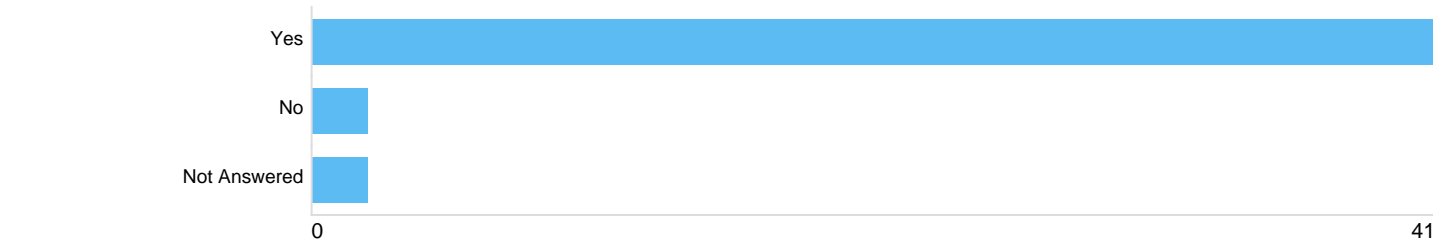
where you live



Option	Total	Percent
Yes	34	75.56%
No	10	22.22%
Not Answered	1	2.22%

Question 3: Do you care for someone in the London Borough of Hammersmith & Fulham?

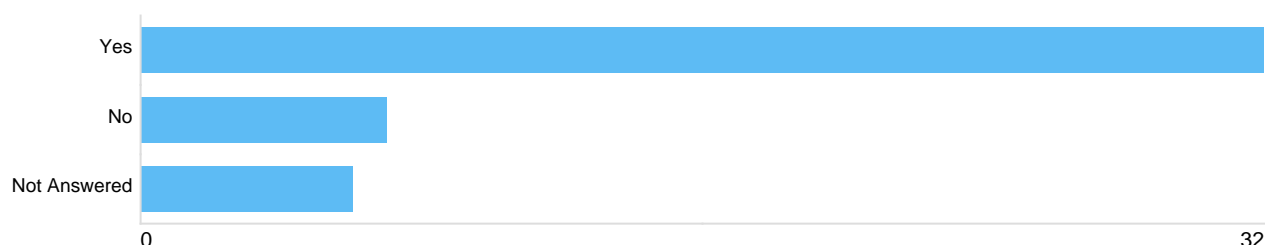
where you care for someone



Option	Total	Percent
Yes	41	91.11%
No	2	4.44%
Not Answered	2	4.44%

Question 4: Please leave an email address and choose "Yes" if you are happy for us to contact you in the future.

If yes, Please type your email address



Option	Total	Percent
Yes	32	71.11%
No	7	15.56%
Not Answered	6	13.33%

If yes, please type email address

There were **36** responses to this part of the question.

Question 5: What would you say are the 3 most important things to include in a service for carers of people with dementia?

service requirements

There were **44** responses to this part of the question.

Question 6: What works well for you as a carer?

what works well

There were **43** responses to this part of the question.

Question 7: What doesn't work well and needs to be improved as a carer

what doesn't work well

There were **42** responses to this part of the question.

Question 8: What would make it easier to access services for carers or people with dementia?

access

There were **42** responses to this part of the question.

Question 9: What physical changes could be made in the community to make things easier for you?

physical c hanges

There were **38** responses to this part of the question.

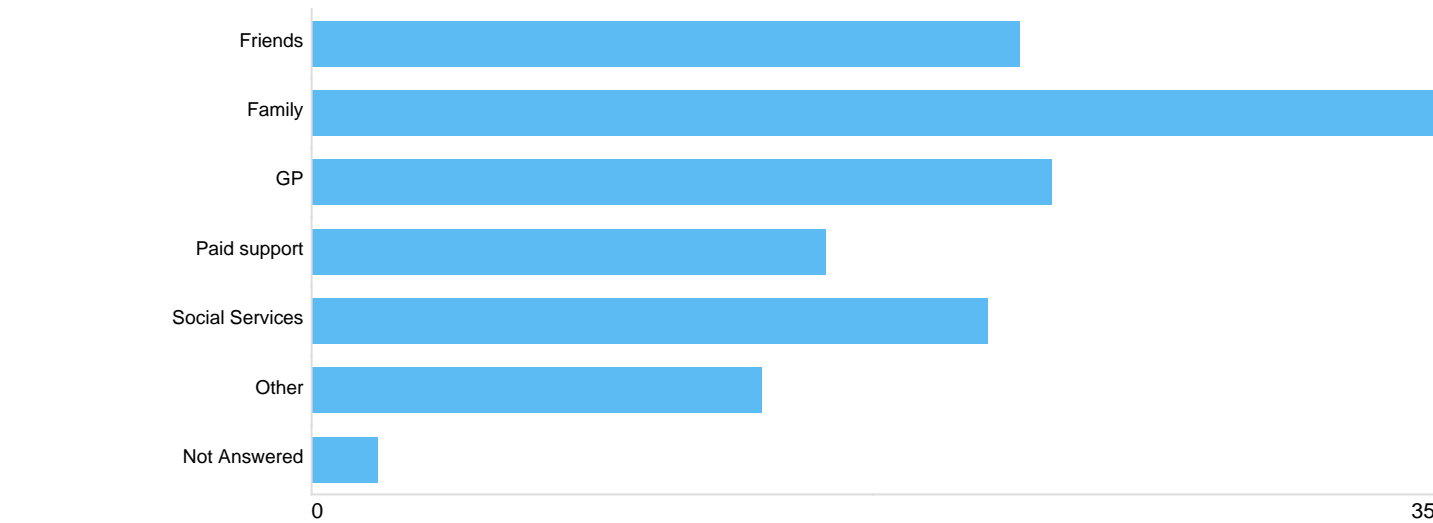
Question 10: How could people in the community make things easier for you. e.g. neighbours, shopkeepers, passers-by?

community

There were **37** responses to this part of the question.

Question 11: Who do you look to for support?

support



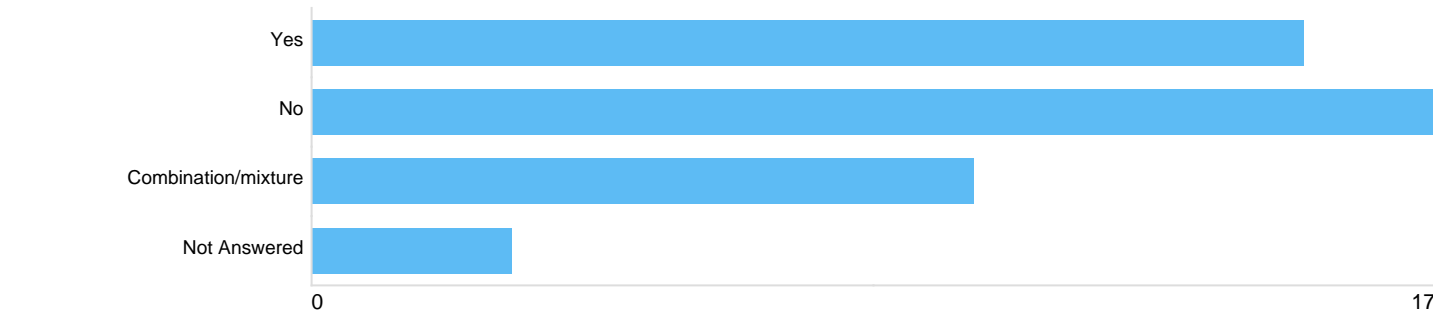
Option	Total	Percent
Friends	22	48.89%
Family	35	77.78%
GP	23	51.11%
Paid support	16	35.56%
Social Services	21	46.67%
Other	14	31.11%
Not Answered	2	4.44%

If Other, please specify

There were 16 responses to this part of the question.

Question 12: Are you self-funding?

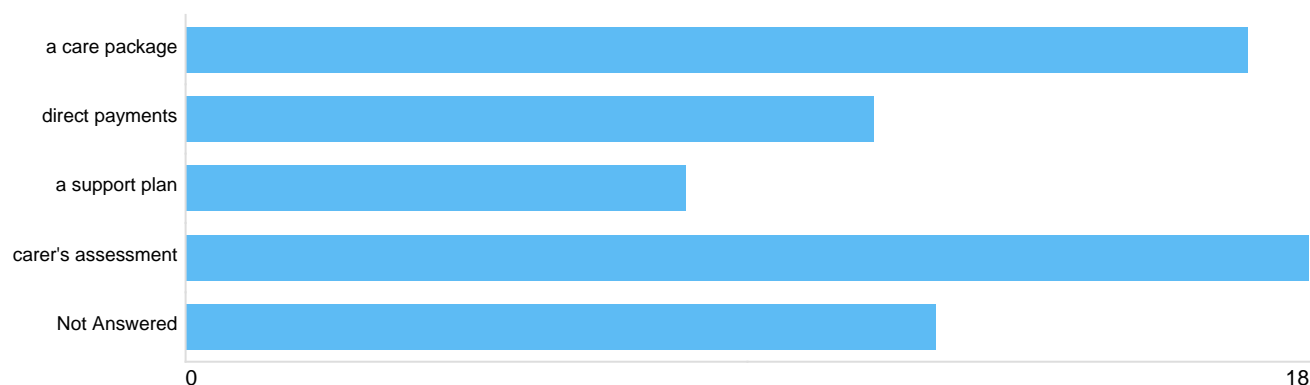
funding



Option	Total	Percent
Yes	15	33.33%
No	17	37.78%
Combination/mixture	10	22.22%
Not Answered	3	6.67%

Question 13: Do you have any of the following?

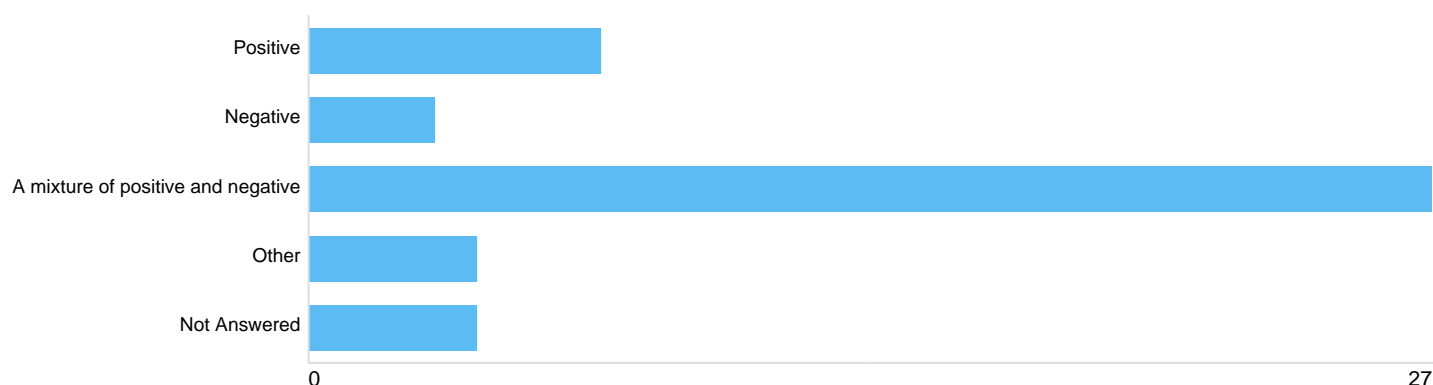
packages/plans



Option	Total	Percent
a care package	17	37.78%
direct payments	11	24.44%
a support plan	8	17.78%
carer's assessment	18	40.00%
Not Answered	12	26.67%

Question 14: What is your experience of obtaining a diagnosis?

diagnosis experience



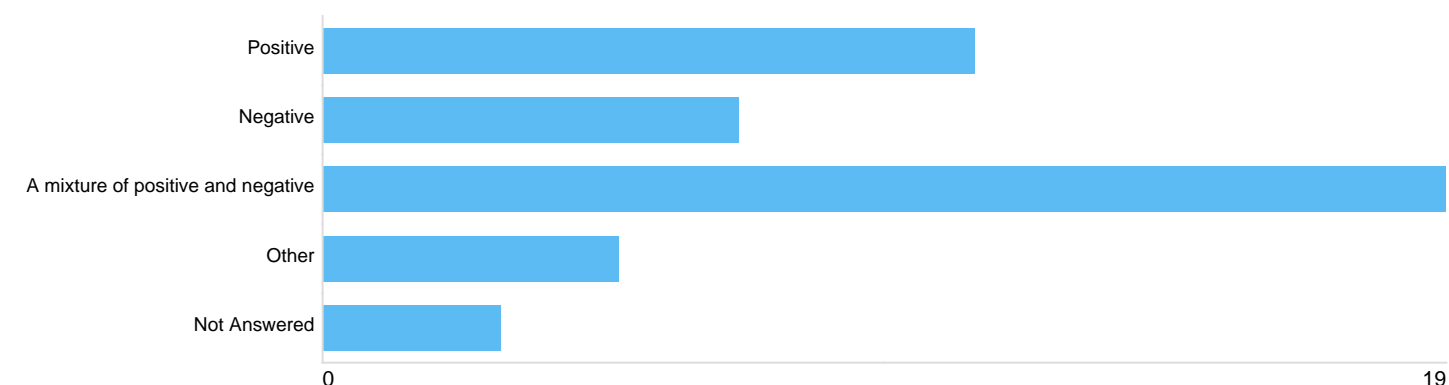
Option	Total	Percent
Positive	7	15.56%
Negative	3	6.67%
A mixture of positive and negative	27	60.00%
Other	4	8.89%
Not Answered	4	8.89%

If other, please specify

There were 5 responses to this part of the question.

Question 15: What is your experience of obtaining support (starting after diagnosis)?

post-diagnosis support



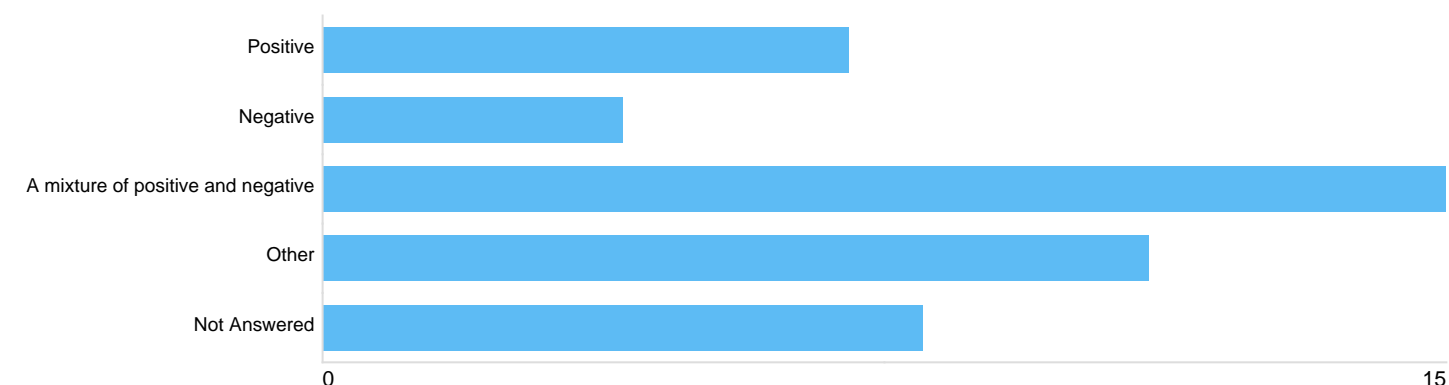
Option	Total	Percent
Positive	11	24.44%
Negative	7	15.56%
A mixture of positive and negative	19	42.22%
Other	5	11.11%
Not Answered	3	6.67%

If other, please specify

There were 6 responses to this part of the question.

Question 16: What is your experience of obtaining direct payments?

direct payments



Option	Total	Percent
Positive	7	15.56%
Negative	4	8.89%
A mixture of positive and negative	15	33.33%
Other	11	24.44%
Not Answered	8	17.78%

If Other, please specify

There were 17 responses to this part of the question.

Question 17: Would you like to comment about your experiences during Covid-19?

covid 19 experience

There were 39 responses to this part of the question.

H&F Dementia Strategy - Local Businesses Survey: Summary report

This report was created on Thursday 01 April 2021 at 14:09 and includes **10** responses.

The consultation ran from 10/02/2021 to 05/03/2021.

Contents

Question 1: Your name	1
Name	1
Question 2: Your work email address	1
email address	1
Question 3: Your job title/position in the business	1
job title	1
Question 4: Do you have a personal experience of dementia?	1
Please describe	1
Question 5: Please leave an email address and choose "Yes" if you are happy for us to contact you in the future.	2
Please leave an email address and choose "Yes" if you are happy for us to contact you in the future.	2
Email Address	2
Question 6: Name of business	2
Name of business	2
Question 7: Business address	2
business address	2
Question 8: What type of business are you?	2
e.g. retail	2
Question 9: Does your business have any dementia-awareness training/policies in place to support your staff and customers?	2
Training/policies	2
If 'other training/policies' please specify	2
Question 10: If your business has engaged with any people living with dementia or their carers/families, can you describe any particular issues faced?	3
issues faced	3
Question 11: How could we help your business better support people living with dementia and their carers/families?	3
e.g. training, information on what support services are available locally	3
Question 12: Would you like to hear more about working with others to make our borough a dementia-friendly community? Please choose "Yes" if you are happy for us to store your details and contact you about this further.	3
Storing details	3

Question 1: Your name

Name

There were **10** responses to this part of the question.

Question 2: Your work email address

email address

There were **10** responses to this part of the question.

Question 3: Your job title/position in the business

job title

There were **10** responses to this part of the question.

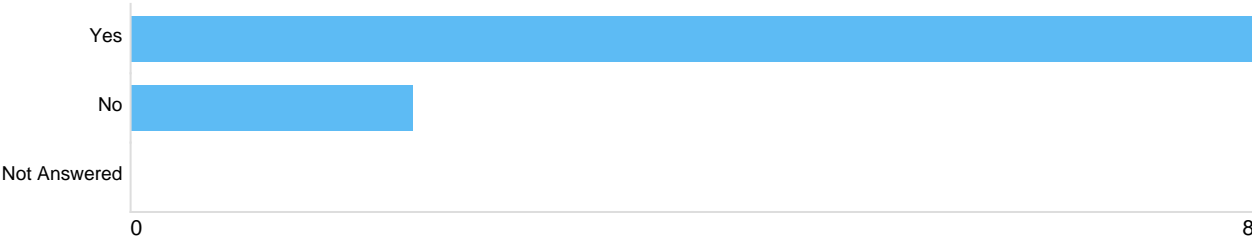
Question 4: Do you have a personal experience of dementia?

Please describe

There were **10** responses to this part of the question.

Question 5: Please leave an email address and choose "Yes" if you are happy for us to contact you in the future.

Please leave an email address and choose "Yes" if you are happy for us to contact you in the future.



Option	Total	Percent
Yes	8	80.00%
No	2	20.00%
Not Answered	0	0.00%

Email Address

There were 9 responses to this part of the question.

Question 6: Name of business

Name of business

There were 9 responses to this part of the question.

Question 7: Business address

business address

There were 9 responses to this part of the question.

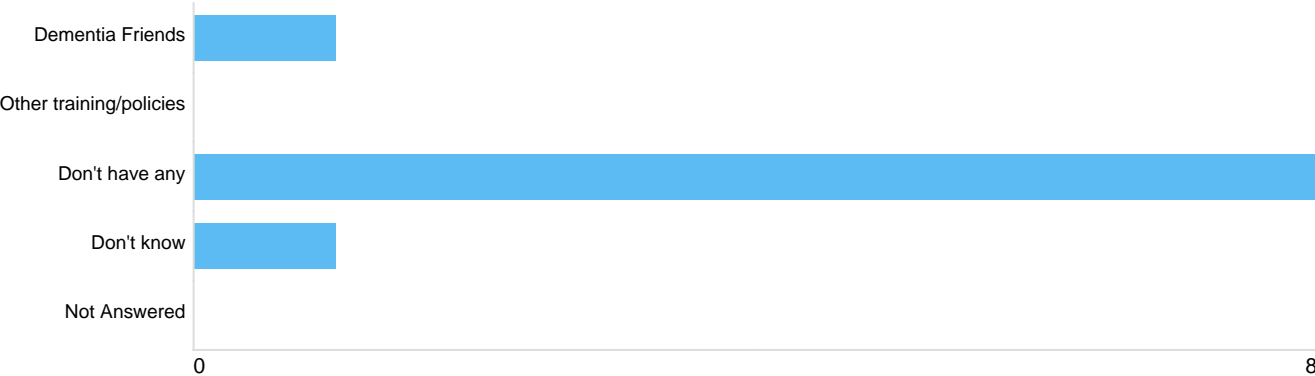
Question 8: What type of business are you?

e.g. retail

There were 9 responses to this part of the question.

Question 9: Does your business have any dementia-awareness training/policies in place to support your staff and customers?

Training/policies



Option	Total	Percent
Dementia Friends	1	10.00%
Other training/policies	0	0.00%
Don't have any	8	80.00%
Don't know	1	10.00%
Not Answered	0	0.00%

If 'other training/policies' please specify

There were 0 responses to this part of the question.

Question 10: If your business has engaged with any people living with dementia or their carers/families, can you describe any particular issues faced?

issues faced

There were 6 responses to this part of the question.

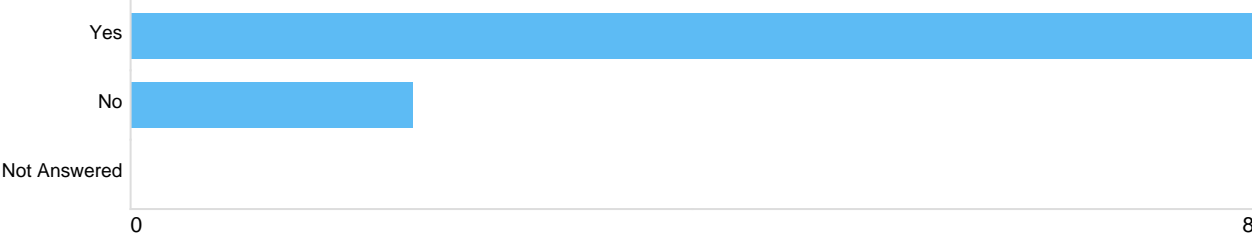
Question 11: How could we help your business better support people living with dementia and their carers/families?

e.g. training, information on what support services are available locally

There were 5 responses to this part of the question.

Question 12: Would you like to hear more about working with others to make our borough a dementia-friendly community? Please choose "Yes" if you are happy for us to store your details and contact you about this further.

Storing details



Option	Total	Percent
Yes	8	80.00%
No	2	20.00%
Not Answered	0	0.00%