



London Borough of Merton: Community Dementia Services Public Engagement Report, 2021/22

Published: February 2022

Contents

1	Introduction.....	3
2	Executive Summary and Recommendations	4
3	Methods.....	7
4	Results.....	8
5	Discussion	20
6	Conclusion	25
7	Acknowledgements	25
8	Appendices	26

1 Introduction

- 1.1. The London Borough of Merton commissions Alzheimer's Society Merton to provide community dementia services at the Dementia Hub, based in Mitcham. The initial contractual period is ending at the end of September 2021. The current contract allows for the service to be extended for the next 2 years, until end of September 2023. As part of this extension, Merton Council are looking to develop a community based model where some services are provided closer to home, in addition to services which will continue to be provided at the Dementia Hub.
- 1.2. The aim of the community-based dementia services model remains to support people living with dementia and their carers, throughout their dementia journey and to help them to live independently for longer. The model will align with the latest guidance, policy and best practice. The community-based model will make use of facilities and services across the borough, as well as develop the online community dementia services offer.
- 1.3. We can work towards this by harnessing existing community assets and services such as libraries, health and social care services and engaging the wider dementia friendly community, including faith and voluntary sector groups. We can also encourage voluntary sector partners to use their own networks to leverage the importance of dementia friendly organisations and dementia inclusive activities within the borough.
- 1.4. Alzheimer's Society Merton, via the Merton Dementia Hub, provides local services to people living with dementia, carers and families. They have a team of dementia advisers who can support and advise service users, and anyone else who might want to find out more, about information pre-diagnosis and beyond a dementia diagnosis. The team accept referrals from health and social care professionals and self-referrals. They provide a range of services and activities, some of which include planning for the future, financial and legal issues, a carers support group and Singing for the Brain sessions.
- 1.5. The Merton Dementia Action Alliance (MDAA) is a group of local organisations who have pledged to take action on dementia and, in doing so, improve the lives of people living with dementia, their carers, families and wider networks in the borough. It has been running since 2014, was refreshed in 2017 and in June 2018, the MDAA was awarded with 'Working Towards a Dementia Friendly Community' status, in recognition of the work done by members. Between April 2020 and March 2021, MDAA activities were paused to reflect the increased demand and pressure on voluntary and community organisations due to the COVID-19 pandemic during this time. As of April 2021 the MDAA had 134 members. It will be important to engage with and work alongside the MDAA as part of the community dementia services approach.
- 1.6. As part of the process of agreeing the contract extension, the London Borough of Merton undertook engagement activities to better understand people's perceptions of community dementia services. The results of the

engagement and the corresponding recommendations can be found in this report and were used to enhance the service specification that forms a key element of the contract.

2 Executive Summary and Recommendations

2.1. Findings

2.2. The results of the engagement sessions and the online survey found that respondents were in favour of dementia services proposed in the community dementia services model.

2.3. The six community dementia services (see the list below), all received positive feedback in the engagement. The majority of respondents indicated a strong level of agreement, or a high level of importance for, many of these services proposed both in the online survey and engagement activities. Within these service strands, there were activities that were ranked as more important than others. For example, peer support services in local areas of Merton were voted as more important than online peer support groups. Further information of this can be found in the results section. The six community dementia service areas proposed are:

- Information, advice and education
- Wellbeing assessment and support planning
- Peer support
- Dementia friendly communities co-ordination
- Volunteer support
- Activities

2.3.1 Some key findings included:

2.4. Lack of service awareness

2.4.1 Many respondents, such as carers and the voluntary sector, wanted to know more about what community dementia services were available in the borough.

2.5. Connected services

2.5.1 Preference for a single point of contact to help signpost services and seek advice from.

2.6. Dementia Friendly Communities (DFC)

2.6.1 Many respondents stated the importance of dementia friendly communities and dementia awareness within the general public, public services, such as healthcare and commercial services, including banks and shops.

2.7. Accessing services

- 2.7.1 Many respondents experienced barriers to accessing dementia services. These included: transport, support needed to attend services, IT, the need for respite care and knowledge of what services existed.
- 2.7.2 Many respondents wanted to access services locally and face-to-face. These included the 6 community dementia services mentioned above in section 2.4.
- 2.8. **Inclusive services**
- 2.8.1 Respondents highlighted the need for services to be inclusive. For example, for services to be available in other languages, such as Tamil and for services to better include those with additional health needs, such as people with a learning disability, autism and hearing impairments.
- 2.9. **Face-to-face contact (services)**
- 2.9.1 Some respondents indicated a preference for accessing services face-to-face, including a preference for local opportunities to socialise, including outdoor activities. Some respondents also stated a lack of confidence/know-how in using communication platforms, such as Zoom.
- 2.10. **Digital Services**
- 2.10.1 The majority of respondents felt they had the confidence, equipment and provisions to access dementia services online. However, a lower proportion of respondents felt that they were 'able to' or 'wanted to' access services online, or that they would benefit from support to access digital services.
- 2.10.2 However, local research on the impact of COVID-19 on people living with, or affected by dementia in Merton, conducted last year found digital exclusion was an issue.
- 2.11. **COVID-19**
- 2.11.1 When considering potential service changes as a result of COVID-19, respondents placed more importance on accessing services in their local area of Merton and outdoors/in public spaces.
- 2.12. **Recommendations**
- Based on the headline findings from the engagement work, this report makes a series of recommendations for community dementia services in Merton as follows.
- It is recommended that:
1. Whilst keeping the Hub as a service base at which a range of activities will continue to be offered, partners proceed with the implementation of service adaptations to allow community dementia services to be more accessible in local areas of Merton.

2. The Dementia Action Alliance and other partners proceed with the development and provision of the six community dementia services areas as outlined below.
 - a) **Information, advice and education:** work to increase awareness of services available in Merton to residents and advice / support agencies. Make these services available locally to residents and organisations across the borough.
 - b) **Wellbeing Support Services:** continue to provide wellbeing support services that offer support to people living with a dementia diagnosis and their friends, family and carers dementia. Provide courses that include support tips to use in day-to-day life and support to promote physical and mental wellbeing.
 - c) **Peer support groups:** build on existing networks, promote and/or establish these in local areas of Merton. Work with voluntary sector partners and libraries to help provide services. Peer support should be available face-to-face and online, for people living with a dementia diagnosis and their friends, family and carers.
 - d) **Volunteer support services:** continue to develop and provide volunteer support services across the borough.
 - e) **Dementia Friendly Communities:** continue work to build dementia friendly communities with the Merton Dementia Action Alliance. Work will involve outreach to new community organisations and as well as strengthening links with existing DAA members, including health and social care services.
 - f) **Community based activities:** Provide activities that take place outdoors (where appropriate) and face-to-face, in local communities in Merton. Partnership working to help offer dementia friendly activities will be important to provide a range of activities across the borough.
3. We continue to strengthen partnership working - promote better connections, integrated services (including provision of local activities) and referrals between Alzheimer's Society and different partners, including the voluntary sector and healthcare sector, in Merton.
4. Wherever in their dementia journey, we ensure that people have the ability to access face-to-face contact/services. Additional provisions, such as home visits, are arranged when needed, especially if individuals are no longer able to access community services.
5. The Dementia Action Alliance in partnership with Alzheimer's Society deliver an awareness campaign including signposting of services that are available in the borough for people living with a dementia diagnosis and family members, including those that care for them. Information on what services are available should be communicated to all partners,

including healthcare, social care, housing and voluntary sector services, and service users. This should be complemented by strong information, advice and education services.

6. Community dementia services in Merton should strive for inclusivity, including provisions made for different communities in Merton. This should include ethnic minority groups, and individuals with additional health needs, including people with learning disabilities.

3 Methods

- 3.1. There were two engagement meetings, facilitated by Council and Alzheimer's Society, that took place via Zoom on the 6th and 14th of July 2021 for people living with a dementia diagnosis and their friends, family and carers.
- 3.2. An online engagement survey was developed and published via the council's consultation database, where stakeholders had the opportunity to input their views on the proposed approach to community-based services. The survey ran from 26th of July until the 24th of August 2021.
- 3.3. The timeframe was such to allow for time to analyse results, establish key findings and implement modifications to the extended community dementia services model specification prior to its renewal at the end of September 2021.
- 3.4. Upon analysis of the survey results, it was found that whilst there was a strong response from carers, less than 5 people living with dementia completed the survey. A further round of engagement was undertaken, where 30 paper surveys were sent to people living with dementia. At a later date, these results will be incorporated into the main findings of the engagement. These findings (as well as the findings from the engagement events) will also feed into the community dementia services model in the first 3-4 months of the varied contract.
- 3.5. **Promotion of survey**
 - 3.5.1 The online dementia survey was promoted via email to a range of networks in Merton. These included: Merton Council departments, Alzheimer's Society Merton, Voluntary and Community Sector, Healthcare sector, Merton Dementia Action Alliance members, among others. Some organisations promoted the survey via social media. Where appropriate, email recipients were asked to circulate the survey to those people living with, or affected, by dementia in Merton, to help increase the reach of those responding to the survey.
- 3.6. **Analysis method**
 - 3.6.1 The two engagement sessions had approximately 30 people attend and contribute their perspectives over the two sessions. The online survey received 106 responses.

- 3.6.2 There were twenty questions in the survey, of which 6 were dedicated to demographic questions to help better understand the background of the participants. There were also some free text questions, to allow respondents to further contribute their opinions and experience.
- 3.6.3 All responses of the free text box were examined together and thematic analysis conducted. Key words or phrases were brought together into themes, where appropriate. These themes were examined in relation to the tick-box online survey questions and engagement session findings, to form recommendations.

4 Results

- 4.1. The online survey was broadly divided into two sections. One section asked about respondent's characteristics, the other focussed on community-based dementia services and other related questions. As no questions were mandatory, not all questions were completed by all respondents. Where possible, tables and graphs reference the number of respondents who answered a particular question. Please note, for categories where the number of respondents is less than 5, the number is suppressed and replaced with <5. Where percentages are provided, these may not add up to 100% due to rounding.

4.2. Respondent Characteristics

- 4.2.1 The following summarises the respondent characteristics of those who completed the online survey part of the engagement, not the engagement sessions, where these characteristics were not recorded. Table 1 provides the result breakdown for respondent characteristics questions.

4.3. Type of participant

- 4.3.1 All 106 survey participants responded to this question. The largest group of respondents were carers for people living with dementia (33%), followed by the voluntary and community sector (20%), then person affected by dementia e.g. family member (17%), comprising 70% of survey respondents. The remaining 30% was divided between the remaining categories. Due to small numbers, the categories of person living with dementia, local authority professional and 'Prefer not to say' have been combined into the 'Other' category.

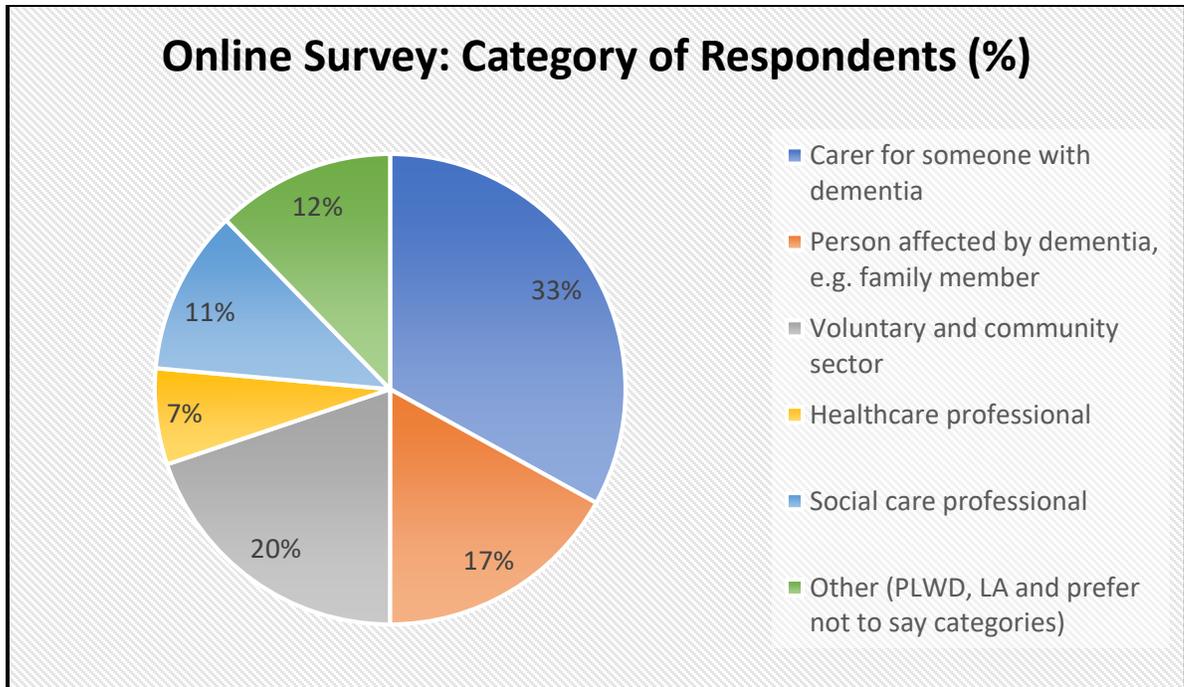


Figure 1: The breakdown of category of respondents who answered the online dementia survey

4.4. **Gender**

4.4.1 The majority of participants who completed the survey identified as female – 58 respondents.

4.5. **Living set-up**

4.5.1 When respondents were asked about their living set-up, of those who answered the questions, the majority of respondents stated they lived with a partner or with family. A smaller number of respondents identified as living alone.

4.6. **Age**

4.6.1 The highest proportion of respondents were aged between 55-64 years old. There were very few respondents below the age of 44 and above the age of 85.

4.7. **Ethnicity**

4.7.1 Many of the participants identified themselves as White British, White Other (White Irish, White Eastern European, White Other) or preferred not to say. The remaining respondents identified as belonging to other ethnic groups.

4.8. **Cross-tabulation of results**

4.8.1 Of carers and people affected by dementia, there was almost three times as many female respondents as male. Furthermore, nearly two-thirds of carers

and over one-third of people affected by dementia were between the ages of 55-74.

Table 1: Results of the participant characteristic questions in the online dementia survey.

Category	Number of respondents
<i>Gender</i>	
Female	58
Male	17
Other	-
Prefer not to say	<5*
<i>Living Set-up</i>	
Alone/single household	9
With family	25
With a carer	<5*
With a partner	30
Care/residential home	-
Prefer not to say	9
Other	5
<i>Age</i>	
under 18 years	-
18-24	-
25-34	<5*
35-44	<5*
45-54	12
55-64	21
65-74	19
75-84	7
85+	<5*
Prefer not to say	8
<i>Ethnicity</i>	
White British	46
White Other (White Irish, White Eastern European, White Other)	11
Black (Black British, Black Caribbean, Black African)	5

Category	Number of respondents
Mixed (Mixed White & Caribbean, Mixed White and African, Mixed White and Asian, Mixed Other)	<5*
Asian (British Asian, Indian, Bangladeshi, Pakistani, Tamil, Chinese, Korean, Asian Other)	<5*
Other	<5*
Prefer not to say	12

*Numbers below 5 are suppressed and replaced with <5

4.9. **Area of Residence**

4.9.1 For Motspur Park, Pollard’s Hill and Colliers Wood, there were less than 5 respondents in each category. Therefore, these numbers are suppressed and combined with the ‘Prefer not to say’ category into ‘Other’. Together, this makes up 30% of responses. After this, Morden (20%), Wimbledon (19%), Mitcham (15%) and Raynes Park (15%), accounted for the place of residence for 69% of participants. In total, 79 participants answered this question.

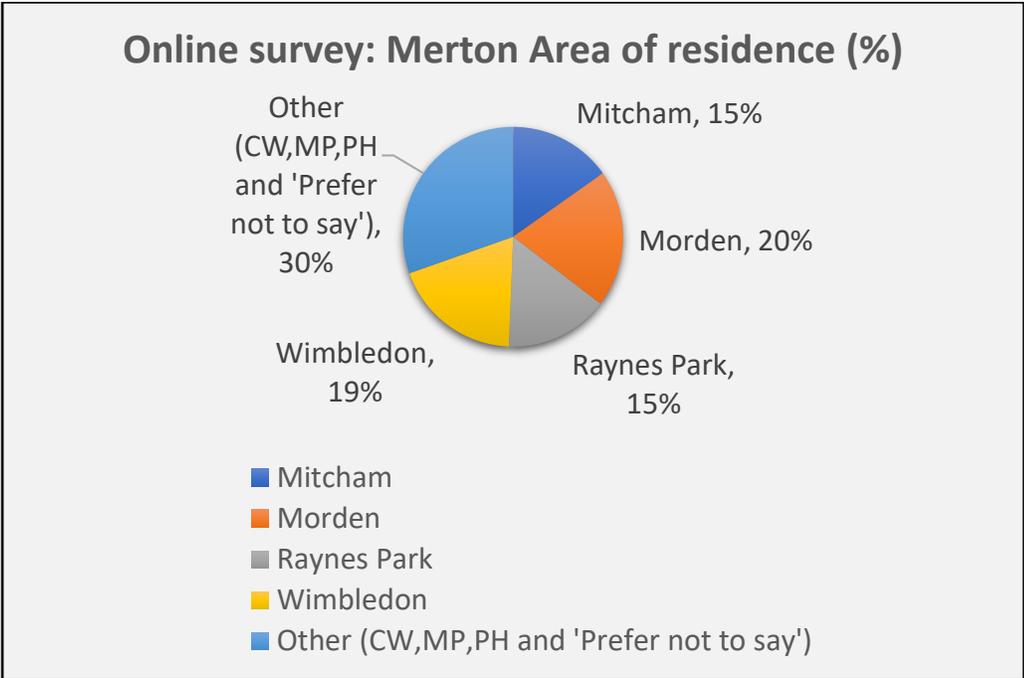


Figure 2: The breakdown of the online dementia survey respondents by Merton area of residence.

4.10. **Type of community services**

4.11. The contract with Alzheimer’s Society includes the provision of the following service areas:

- Information, advice and education
- Wellbeing assessment and support planning
- Peer support
- Dementia friendly communities co-ordination
- Volunteer support
- Activities

4.12. To better understand the engagement participant’s opinion on these service areas, the survey asked a number of questions aiming to ascertain the relative importance of these services to survey respondents. Where appropriate, the questions asked are summarised in the results section of the report. To see the full list of questions asked, see Appendix A.

4.13. **Information, advice, education**

4.13.1 Participants were able to choose up to three information, advice and education services that were most important to them. The highest ranked services were those offering support services available to people affected by dementia, such as health and social care services, or educational courses (see Table 2).

Table 2: The results of the information, advice, education service question in the online survey

Information, advice, education services	Number of Respondents (96)
Information and advice on dementia/carer support services and groups in Merton	66
Information and advice on health and social care services relating to dementia support in Merton	57
Short courses to support people living with dementia and their carers	39
Information and advice on dementia after recent diagnosis	31
Information and advice on planning for the future	30
Information and advice on benefits and entitlements	26
Prefer not to say	5
Other	<5

4.14. **Wellbeing support services**

4.14.1 Participants were asked about the relative importance of wellbeing support services for a person living with dementia (Table 3), and for a person affected by dementia (Table 4).

4.14.2 Support with developing plans for the future was considered least important both for people living with, and affected by, dementia. However, practical tips and support to use in daily life for both types of participants scored highly across both wellbeing questions.

Table 3: The results of the ranked importance of wellbeing services for people living with dementia.

Wellbeing Support Services for people living with dementia	Very important	Important	Less important	Not important	Prefer not to say
Support to access activities to promote their physical health and mental wellbeing	73	16	<5		<5
Support/practical tips to use in day-to-day life for people living with dementia	72	14	<5		<5
Support/practical tips to use in day-to-day life that would benefit a carer, friend or family member	69	16		<5	<5
Support with accessing social care services	67	14	<5		<5
Support with developing plans for the future	48	32	<5		<5

Table 4: The results of the ranked importance of wellbeing services for a carer, family member or friend providing support to a person living with dementia.

Wellbeing Support Services for people affected by dementia	Very important	Important	Less important	Not important	Prefer not to say
Support/practical tips to use in day-to-day life for carers, family or friends of people living with dementia	77	10	<5		<5
Support/practical tips to use in day-to-day life to help people living with dementia	73	12			<5
Support with accessing social care services	67	15	<5	<5	<5
Support to access activities to promote their physical health and mental wellbeing	64	19	<5		<5
Support with developing plans for the future	56	25	<5		<5

4.15. Peer Support

4.15.1 The survey found that the provision of peer support services in participant's local area of Merton was most important to them relative to other peer support services, such as online peer support groups (Table 5). Responses from free text boxes and the engagement sessions were also in favour of face-to-face support groups and wider activities.

Table 5: The results of the ranked importance of peer support services in the online survey.

Peer support service	Very important	Important	Less important	Not important	Prefer not to say
Peer support groups in your local area	53	31	<5	<5	<5
Drop-in peer support cafes	39	35	7	<5	<5
One-to-one peer support	36	29	12	<5	<5
Peer support groups across the borough	29	35	12	<5	<5
Online peer support groups	21	36	19	5	<5

4.16. Volunteer Support

4.16.1 Many volunteer support services were ranked important by the survey participants. The best ranked example of a volunteer support service was providing a volunteer to help a person living with dementia to get out in the community. Support to attend an activity group was also ranked as important, a finding that was reflected in some of the free text box comments.

Table 6: The results of the ranked importance of volunteer support services in the online survey

Volunteer Support Services	Very important	Important	Less important	Not important	Prefer not to say
Providing a volunteer to support a person living with dementia to get out and about (e.g., walks, visits to coffee shops)	65	15	<5		<5
Support to attend activity groups	54	19	<5	<5	<5
Help with shopping and errands	45	19	10	5	<5
Attend a peer support group together	42	26	8		<5
Travel to a face-to-face service together	39	24	10		<5
Keeping in touch over the phone	35	24	16	<5	<5
Help with learning to use IT devices/the internet	22	26	16	10	<5

4.17. **Dementia Friendly Communities**

4.17.1 The importance of dementia friendly communities was noted in the online survey in the free-text boxes and in the engagement sessions. There were many services which participants most wanted to see create or develop a dementia friendly environment, but local health and social care services was ranked most important.

Table 7: The results of the dementia friendly communities question in the online survey

Dementia Friendly Communities	Number of Respondents (89)
Local health and social care services	66
Local shops / banks / post offices	39
Transport services	32
Council services and locations such as libraries and parks	30
Community and leisure centres	30
Leisure activities in the local community	29
Local cafes/restaurants	24
Places of worship	<5
Prefer not to say	<5

4.18. **Community-based activities**

- 4.18.1 The survey asked which activities participants would most like to see in the community for people living with dementia (Table 8) and for carers, family members or friends providing support to a person living with dementia (Table 9).
- 4.18.2 Social groups were best ranked and sporting activities were worst ranked in both activity questions. Outdoor activities were better ranked for people living with dementia relative to people affected by dementia. Respondents ranked activities whereby support groups met in cafes or restaurants as more important for people affected by dementia.

Table 8: The results of the community-based activity for people living with dementia question in the online survey

Community-based activity for people living with dementia	Number of Respondents (86)
Local groups that provide a chance to meet friends and socialise	57
Local outdoor groups (such as gardening, walking, conservation)	43
Local wellbeing classes (such as mindfulness, choirs, book clubs, art classes)	42
Local physical exercise classes (such as yoga, chair-based exercise, dance, Tai Chi, aqua aerobics)	39
Local support groups that meet in cafes/restaurants	32
Local cultural events (such as talks, cinema, music)	21
Local sporting activities (such as tennis, table tennis, swimming, cycling, football)	<5
Prefer not to say	<5

Table 9: The results of the community-based activity carers, family members or friends providing support to a person living with dementia question in the online survey

Community-based activity for carers, family members or friends providing support to a person living with dementia	Number of Respondents (86)
Local groups that provide a chance to meet friends and socialise	52
Local support groups that meet in cafes/restaurants	49
Local physical exercise classes (such as yoga, chair-based exercise, dance, Tai Chi, aqua aerobics)	39
Local wellbeing classes (such as mindfulness, choirs, book clubs, art classes)	39
Local cultural events (such as talks, cinema, music)	27
Local outdoor groups (such as gardening, walking, conservation)	23
Local sporting activities (such as tennis, table tennis, swimming, cycling, football)	8
Prefer not to say	<5

4.19. **All services**

4.19.1 Three community services ranked very highly among survey respondents as services that would like to be able to access in their local area. These were wellbeing support services, community activities and information, advice and education.

Table 10: The results of the community-based dementia services question in the online survey

Community dementia services	Number of Respondents (85)
Ongoing support to improve your wellbeing	48
Community-based activities in partnership with other organisations	48
Information, advice and education	47
Dementia Friendly Communities	38
Peer support	28
Volunteer support	28
Prefer not to say	<5

4.20. **Impact of COVID-19**

4.20.1 Survey respondents were asked how, considering service adaptations as a result of COVID-19, they would like services to operate looking forward. The most highly ranked option was community dementia services based in local areas of Merton. However, online services had the weakest level of agreement. This finding was supported in qualitative engagement data, where the importance of face-to-face contact was frequently mentioned.

Table 11: The results of the relative agreement of COVID-19 community dementia services adaptations question in the online survey

COVID-19 service adaptations	Strongly agree	Agree	Disagree	Strongly disagree	Prefer not to say
I would like to see more community dementia services closer to where I live	48	33	<5		<5
I would like to see more community dementia services in open public spaces, such as peer support groups in the park/outdoor café	37	39	<5		<5
I would like to see an equal mix of services online and closer to where I live	26	28	16	7	5
I would like to see more community dementia services online	13	30	28	8	<5

4.21. **Digital Inclusion**

4.21.1 Respondents were asked about how they use community dementia services online in order to better understand what support provision may be needed to support this.

4.21.2 The majority of respondents, including carers and people affected by dementia, such as family members, stated that they had the equipment, internet connectivity, confidence and financial resources available to use IT devices and the internet to use dementia services. However, there was comparatively less agreement for the desire to use dementia services online, or that respondents felt they would benefit from accessing services in this way by carers and people affected by dementia. The survey also highlighted a smaller number who were digitally excluded and would need support to access online services.

Table 12: The results of the digital community dementia services question in the online survey

Online dementia services	Strongly agree	Agree	Disagree	Strongly disagree	Prefer not to say
I have the equipment to be able to access online dementia services	35	28	7	<5	7
I have good enough internet connectivity to access online dementia services	30	27	9	<5	7
I feel confident using IT devices to access online dementia resources	28	28	9	5	7
I can afford the initial and monthly costs needed to access the internet	26	26	9	<5	12
I am able to use dementia services online	23	29	11	5	9
I want to use dementia services online	12	16	26	10	12
I would benefit from some support to access online dementia services	10	15	27	11	11

4.22. **Barriers in accessing community dementia services, recommendations and further comments**

4.22.1 The survey asked three questions where a free-text box response was available.

4.22.2 Due to the number and length of responses, not all responses to these questions are included in section 4.23-4.25. A greater selection of responses to the three questions below are included in Appendix B.

4.23. **Barriers to community dementia services**

4.23.1 Survey respondents were asked about the barriers they face in using community dementia services. This question received 60 responses. Common emerging themes from responses included: service awareness, specifically a lack of awareness and knowledge of service provision and difficulties accessing services, including difficulties of travel or getting support to attend and difficulties with digital services. A selection of these responses can be found below:

- *“I think the barrier is awareness of services, but mainly lack of willingness to overcome the stigma of participation.”*

- *“Carers have difficulty attending social and local amenities due to their caring role and not being able to leave the cared for person.”*
- *“Do not use a computer or have transport or respite care”*
- *“Transport, local knowledge on accessible groups, respite, specialist knowledgeable carers for support.”*

4.24. **Other community dementia services**

4.24.1 Survey respondents were asked if there were any other community dementia services that they'd like to see in Merton. This question received 46 responses. Common emerging themes from responses included services related to information and advice and community activities. A selection of these responses can be found below:

- *“A list of dementia services which are available in Merton, to be provided to all Merton healthcare community services”*
- *“More befriending and volunteer home visiting services for Cared for person.”*
- *“More dementia hubs or places like that where people with dementia and their carers can visit. This can be for health, musical events or socialising in a relevant environment”*

4.25. **Further comments or recommendations**

4.25.1 Survey respondents were asked if they had any further comments or recommendations. A total of 38 responses were received for this question. Common themes from responses echoed many of those found in the previous free text questions, such as service awareness and difficulty in accessing services. Further comments addressed the importance of the dementia hub. A selection of these are included below:

- *“Meeting cafe at park or easy to park places”*
- *“Provide more community-base services rather than online ones.”*

5 **Discussion**

5.1. **Discussion**

5.1.1 The majority of participants were carers, or people living with a dementia diagnosis or their friends, family and carers, female, between the ages of 55-74 years, live with either a partner or family and identified themselves as 'White British'. These figures will be affected by wider groups that responded to the survey, such as social care workers and voluntary and community sector professionals. It is also important to note that some groups are over-represented when considering dementia prevalence. For example, the likelihood of developing dementia increases with age, with 7.1% of the

population over the age of 65 estimated to have dementia¹ and may in part explain the proportion of respondents above the age of 55 who completed the survey. Furthermore, the Dementia Statistics hub estimates 60-70% of carers for people living with dementia are women² and may in part explain the high proportion of carers and people affected with dementia that identified as female in the survey.

- 5.1.2 Respondents identifying as ‘White British’ in the survey were over-represented relative to the general Merton population, meaning fewer perspectives from other ethnic groups are present in the survey findings. Nationally, current estimates are that 3% of people living with dementia are from Black, Asian and Minority Ethnic communities, with this figure projected to double by 2026³. Research has also indicated these groups may face barriers accessing services. Therefore, it is important for community dementia services in Merton to continue to engage with these groups.
- 5.1.3 As a result, the survey findings may not be wholly representative of opinions of some Merton residents living and working in the borough. These groups may include: people living with dementia, men, younger carers, young people aged 24 years and below, adults below the age of 54 and above the age of 75, people who live alone and ethnic minority groups. For some questions, the categories available to them may have been overlapping and therefore may not wholly reflect the characteristics of the respondents. For example, someone could be a healthcare professional and a carer for someone with dementia in their personal life. Further work is needed to help better understand the perspectives of those groups underrepresented in the findings of the engagement. This could include expanding and diversifying the reach of networks in the borough that the council uses (see section 5.1.4), and better understanding the barriers that some groups, such as people living with dementia, may have in completing engagement surveys like this. This work will be picked up by the DAA as a priority piece over the next 12 months.
- 5.1.4 As far as the results show, the opinions and experiences of residents living in Pollard’s Hill, Colliers Wood and Motspur Park may not reflect those of people living in areas of borough who completed the survey. One possible explanation could be that residents from these areas did complete the survey, but didn’t disclose their location and therefore may make up a proportion of the respondents who preferred not to say, or selected a different location to the one they live in. Other possible explanations include the Merton network used to promote the survey didn’t reach these communities, or that more

¹ Prince, M et al (2014) Dementia UK: Update Second Edition report produced by King’s College London and the London School of Economics for the Alzheimer’s Society, Available from:

<https://www.dementiastatistics.org/statistics/prevalence-by-age-in-the-uk/>

² Women and Dementia: A Marginalised Majority by Alzheimer’s Research UK, Available on:

<https://www.dementiastatistics.org/statistics/impact-on-carers/>

³ Alzheimer’s Society, Black, Asian and minority ethnic communities and dementia research, Alzheimer’s Society, Available from: <https://www.alzheimers.org.uk/for-researchers/black-asian-and-minority-ethnic-communities-and-dementia-research>

- needs to be done on improving engagement in community dementia services in these areas of Merton. Work is already being done that could help address this. The DAA aims for 2021/22 strive to further the reach of the DAA network including re-engaging and renewing pledges of DAA members, expanding the DAA membership and continuing outreach to ethnic minority organisations and residents across the borough.
- 5.1.5 The COVID-19 pandemic has meant that many people have been isolated or had reduced face-to-face contact with those outside their household. Therefore, it may not be surprising that ‘Information and advice on dementia/carer support services and groups in Merton’ was the best ranked response from the Information, advice and education services, as groups like these would provide an opportunity for social and face-to-face interaction. A national survey has found that 32% of carers don’t receive the amount of social contact as they would like⁴, and therefore it is important that support services in Merton are well signposted to these groups.
- 5.1.6 Community dementia services in local areas of Merton ranked well across different services areas. The example service of ‘peer support services in your local area’ was best ranked of the peer support services. This mirrored some of the findings in the COVID-19 question, where respondents wanted to be able to access services in their local area. Another finding from the barriers to local services question found that transport and support needed to attend services were common barriers to people accessing services.
- 5.1.7 Digital service options for community dementia services received a mixed response. For peer support groups, online peer support groups was least well-ranked. Furthermore, fewer respondents, including carers and people living with dementia, stated that they would benefit from online services or that they wanted to see community dementia services online – many of the respondents felt they had the financial means and knowledge to use digital. This may also indicate some digital ‘fatigue’ among respondents, perhaps due to the proliferation of online/digital contact throughout the COVID-19 pandemic.
- 5.1.8 ‘Assistance with IT devices and the internet’ was the least well-ranked volunteer support service. This may be because this was an online survey and therefore, respondents were already confident, or believe their service users to be confident, about using the internet. There were mixed perspectives about online support in the engagement forums and survey. Some responses thought online services secondary to face-to-face, others wanted a hybrid approach to services. However, it should be noted that in a survey conducted last year into the effects of the pandemic on Merton residents living with a dementia diagnosis and their friends, family and carers, digital exclusion was raised as an issue. Furthermore, the NHS Long Term Plan aims to provide better digital access to services and personal health

⁴ Personal Social Services Survey of Adult Carers in England, 2016-17; NHS Digital, Available from: <https://www.dementiastatistics.org/statistics/impact-on-carers/>

- information so that patients and their carers can better manage their health over the next 10 years⁵. The increasing emergence of online health services means that the importance of online community dementia services should not be overlooked and support provided to those who want it in terms of access and training. Looking forward, it will be important to balance the provision of face-to-face and online activities.
- 5.1.9 The importance of face-to-face contact was demonstrated in the community-based activities and the volunteer support services question results, where the best ranked activity for both people living with and affected by dementia was local social groups and support to attend activities in the community. This finding was reflected in the barriers to community dementia services question, a common response was that additional support was needed to attend services. This also relates to the importance of the new service model engaging with community groups so there is increased dementia inclusive offer of activities, nearer to people's homes.
- 5.1.10 The importance of dementia friendly environments and services was raised throughout the results of the online survey and in the engagement sessions. The online survey found that 'local health and social care services' and 'local shops/banks/post offices' were best ranked for respondents wanting these to improve their environment/service to make it more dementia friendly. It will be important to maintain and provide further engagement with these settings through the Merton Dementia Action Alliance (MDAA). By encouraging these services to become MDAA members and attend MDAA meetings this will help raise awareness of dementia and the difficulties people living with dementia and their carers/families may face when in the community and using services.
- 5.1.11 Other barriers to accessing community dementia services included a need for more inclusive services. For example, providing services for different communities in the borough, such as the Tamil community, or for people with complex health needs, such as a hearing impairment or learning disability. Community dementia services in Merton should reflect on their current service offer and look to make adaptations to help make their services inclusive to a range of groups.
- 5.1.12 The top three services, wellbeing support services, community-based activities and information, advice and education were all closely ranked. The importance of these services were reflected elsewhere in the engagement responses. For example, one of the key findings in the barriers to dementia services was a lack of awareness about what community dementia services already existed and how to access these, both for people affected by dementia and professionals.
- 5.1.13 As well as reflecting the importance of these services to the lives of people living with or affected by dementia, a transition to community dementia services will help Merton meet national legislation and guidance. The Care

⁵ NHS, The NHS Long Term Plan, January 2019, Available at: <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>

Act (2014) requires local authorities to help prevent and/or delay care needs increasing by providing high quality services, information and advice for carers⁶. Furthermore, a series of National Institute of Care Excellence (NICE) guidelines outline service qualities that complement a community dementia services approach. These include; the importance of integrated health and social care services and wider agencies in the care of people living with dementia and their carers (NICE-SCIE guidelines (CG42))⁷, person-centred care (NICE (NG97))⁸, and quality standards including supporting carers and wellbeing activities (NICE (QS 184))⁹. Expanding the services available in the community will help Merton adopt a proactive, preventative approach to tackling dementia and care needs in the borough. Furthermore, continuing to work with a range of organisations in the borough and clearly signposting services, will help to develop stronger relationships between services and the wider community.

5.2. Limitations

- 5.2.1 Participants across the engagement sessions and online survey are self-selecting and are influenced by the extent of the London Borough of Merton's and our partners existing network.
- 5.2.2 Although many participants answered the online survey, the data is less reliable when disaggregated into sub-groups or categories. Therefore, it is important not to overestimate the relationships between, for example, category of respondent and a particular sub-service. This is also why a further breakdown of responses relative to a particular sub-group, for example, type of respondent, is not provided. The participant characteristics in the engagement sessions were not recorded.
- 5.2.3 It is important to note that although we know the findings of the online survey, we don't know why people answered as they did. People's lives are complex and it important to consider the findings, both numerical and qualitative, with the engagement sessions and the wider academic literature and national evidence base.

⁶ Department of Health and Social Care (2016). *Care Act Factsheets*. [online] GOV.UK. Available at: <https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets> .

⁷ NICE, Dementia: supporting people with dementia and their carers in health and social care, NICE, 2006, Available from: <https://www.nice.org.uk/guidance/cg42>

⁸ NICE, Dementia: assessment, management and support for people living with dementia and their carers, 2018, Available from: <https://www.nice.org.uk/guidance/ng97>

⁹ NICE, Dementia, NICE, 2019, Available from: <https://www.nice.org.uk/guidance/qs184>

6 Conclusion

- 6.1. The results of the engagement activities, the engagement sessions and the online survey, showed that respondents were in favour of changes to services that aligned with the community-based dementia services model. Further engagement with people living with dementia will continue to better understand the experience of this group with community dementia services in Merton.
- 6.2. The recommendations resulting from the engagement will feed into the dementia services contract and help inform Alzheimer's Society service specification for operation of these services over the next 2 years.
- 6.3. As well as supporting people living with and affected by dementia, adopting a community-based dementia services model will help Merton meet legislation and best practice guidelines, including that of The Care Act and NICE guidelines.

7 Acknowledgements

- 7.1. Merton Council remains committed to working with Alzheimer's Society Merton to provide community dementia services. Merton Council have listened to the responses of the engagement and appreciate the time and contributions of those who responded to the engagement. Thank you to all those who help run community dementia services and their work to help make Merton a dementia friendly community.

8 Appendices

Appendix A: List of questions asked in the online survey.

- Please select the appropriate description that best describes you (type of respondent)
- Which information, advice and education services are most important to you?
- In your opinion, how important are these services in improving the wellbeing of a person living with dementia?
- In your opinion, how important are these services in improving the wellbeing of a carer, family member or friend providing support to a person living with dementia?
- In your opinion, how important are these peer support services to you?
- Which services would you most like to see create or further develop a dementia friendly environment?
- In your opinion, how important are dementia volunteer support services to you?
- Which activities would you most like to see in the community for people living with dementia?
- Which activities would you most like to see in the community for carers, family members or friends providing support to a person living with dementia?
- What community dementia services would you most like to be able to use and access in your local area?
- COVID-19 has transformed the way we offer services and how people in Merton engage with them – many services have moved online during this time. As well as making community dementia services accessible around the borough of Merton, we also need to consider how to implement services in the safest and most effective way for residents in light of COVID-19. When considering how our community dementia services may adapt over the next couple of years, which of the following statements do you agree with most?
- In light of changes to services as a result of COVID-19, some community dementia services moved online and for some people support is needed to access these services. We'd like to understand more about how you access services online and any support that you may need with this. Please tick options that apply to you.
- We'd be interested to hear about the barriers you face in using community dementia services. Please note, by community dementia services we do not mean GP diagnosis services or Adult Social Care services, but services such as information, advice and peer support. Please tell us what are the biggest barriers you face in using community dementia services in Merton?
- Are there any other community dementia services that you would like to see in Merton?

- Please let us know if you have any further comments or recommendations that you'd like us to know.
- How would you describe your gender?
- Which of the following best describes your living set-up?
- Which of the following age groups applies to you?
- What is your ethnic background?
- Which area of Merton do you live in or near?

Appendix B: Community dementia services engagement (free text responses)

We'd be interested to hear about the barriers you face in using community dementia services. Please note, by community dementia services we do not mean GP diagnosis services or Adult Social Care services, but services such as information, advice and peer support. **Please tell us what are the biggest barriers you face in using community dementia services in Merton?**

- "Barriers for me is the Lack of information and encouraging support to be a part of these groups."
- "I think the barrier is awareness of services, but mainly lack of willingness to overcome the stigma of participation."
- "Initially as a new Carer it was difficult to know who did what in terms of getting the help and advice."
- "Carers have difficulty attending social and local amenities due to their caring role and not being able to leave the cared for person."
- "Do not use a computer or have transport or respite care"
- "I am not very good on computers and find it hard to go onto zoom meetings that have been on during covid ."
- "I am totally reliant on my carer for my transport and access to all services...Other barriers are lack of toilets and seating in shops and town centres."
- "I struggle with the online services like the dementia hub support group as I don't find them as effective or comforting as in-person."
- "if I was to access the services for myself perhaps my deafness would be a barrier for access/communication"
- "Transport , local knowledge on accessible groups , respite, specialist knowledgeable carers for support."
- "Writing on behalf of members with Dementia or nearing that stage, there are not enough outlets close by to access information and advice. Transport not always the best way to access these outlets. Language a problem. Speak very little English. Also cultural misunderstandings crop up from time to time."

Are there any other community dementia services that you would like to see in Merton?

- "A 24 hour help line that is "local". Much more "education" about the disease for all including doctors, health professionals, social services. A join up with others in

the voluntary sector to try to make their services more inclusive for both sufferers and carers...An advice sheet as to exactly what is available in both the borough and possibly other nearby boroughs.”

- “A list of dementia services which are available in Merton, to be provided to all Merton healthcare community services”
- “A local dementia group closer to home than Mitcham for my mother to attend to meet other people”
- “Dementia friendly trained Tamil Volunteers...”
- “It would be good to just ring another carer with similar problems and just meet with our cared ones in a cafe, park etc so that I am not always alone with my Mum when we go out together.”
- “More befriending and volunteer home visiting services for Cared for person.”
- “More people coming out to visits at home . .some more community groups in the area and advice centres”
- “More dementia hubs or places like that where people with dementia and their carers can visit. This can be for health, musical events or socialising in a relevant environment”

Please let us know if you have any further comments or recommendations that you'd like us to know.

- “Current volunteer lead befriending services are very difficult to offer clients with moderate dementia as we are unable to offer volunteers the ongoing support and training to work with this client group. Further support and training for these volunteers would mean that they would be able to be offered this service which could give their carers the break that they may need and also the stimulation and activity that the client may need.”
- “IT devices to be either provided or accessible to dementia patients/carers with support/help/ training to enable access to online To help with costs to enable this”
- “Meeting cafe at park or easy to park places”
- “Provide more community-base services rather than online ones.”
- “Regular telephone contact with a named supporter. Yearly visit, preferably 6 monthly Drop in gp specialist center”