# Compiled pre-publication results reporting from Get Real with Meeting Centres work packages 2-5

ISRCTN10332079

## Work Package 2

We spoke to a total of 77 people across three Meeting Centre case study sites in qualitative interviews and focus group discussions: 27 at the Herefordshire site, 21 at the Worcestershire site and 29 at the Powys MCs. The range of interviewees (attendees, family carers, staff, volunteers, trustees and external collaborators) was as planned, except at the Worcestershire MC where we did not manage to interview any family carers due to a lack of engagement of carers at this site during the data collection period, which was a notable finding in itself (see below). Table 1 shows the number of participants spoken to in each role.

**Table 1** Number and role of participants in interviews and focus groups (Total n=77)

| *Role in relation to MC* | *No. interviewed* | *No. taking part in focus groups* |
|---|---|---|
| **Attendees/Non-attendees living with dementia** | **14** | **4** |
| **Attendees/Non attendees supporting someone with dementia** | **6** | **7** |
| **MC staff & volunteers** | **16** | **1** |
| **MC trustees & governance** | **11** | **1** |
| **Professionals & other stakeholders external to MC** | **16** | **1** |

Interview and focus group discussions lasted between approximately 10 minutes and approximately 75 minutes, with the majority taking between 30 minutes and an hour. The content of the transcripts of these was organised under 20 identified themes from which a total of 94 CMOCs were developed, grouped under 7 broad, overlapping themes:

1. Referrals and pathway
2. Reaching people and membership
3. Carer engagement and benefit
4. Venue and location
5. External relationships and collaboration
6. Internal relationships and practices
7. Finances and funding

**CMOCs pertaining to *Referrals and the dementia care pathway***

| | |
|---|---|
| **Links and awareness in the health and social care system** | **CMOC 1:** If the referral pathway lacks clarity and consistency then people may not attend an MC because they do not receive clear, timely and adequate signposting and/or support. |
| | **CMOC 2:** If the dementia care pathway is complex with lots of different services and changing staff, then professionals within it may not refer to an MC as they may not hear about them or know if, how and when to refer (e.g. GPs) |
| | **CMOC 3:** If the ethos and target population of an MC is clear and well publicised across health and social care services then professionals are more likely to signpost as they will understand the purpose and potential benefits to the right people |
| | **CMOC 4:** If health and social care professionals and services can be helped to understand the benefits MCs can offer both to their service and their service users then they may become invested in referring to and supporting the MC as they will value it. |
| | **CMOC 5:** If an MC is overseen by a wider, umbrella organisation, then they can help get people in as they will have more resources and ways of interacting both with health and social care services and people affected by dementia. |
| | **CMOC 6:** If there is a linking service aware of MCs then MCs are more likely to get appropriate referrals as they are specifically focussed on and motivated to know about and fully understand what services like MCs are out there. |
| **Diagnosis issues** | **CMOC 7:** If people experience stigma, denial or lack of awareness about dementia then they may not seek a diagnosis nor attend an MC because they do not identify, or wish to be associated with dementia, or are unaware of the need for/existence of MCs. |
| | **CMOC 8:** If a person with dementia relies on driving to get about then they may not attend an MC because they are concerned that engaging with health, social care or support services regarding their condition may lead to losing their licence. |
| | **CMOC 9:** If a person lives in an isolated rural area then they may not be engaged with the healthcare pathway because accessing health services is difficult and not seen as essential unless urgent. |

| | |
|---|---|
| | **CMOC 10:** If a person with dementia does not have a diagnosis then they may not attend an MC because they may not have sought support in order to be aware of it, or if they are aware, may think it is not open to them. |
| | **CMOC 11:** If people do not get diagnosed until at a more advanced stage, then they may not come to an MC as their needs will be beyond what can be met there. |
| **Alternative support beyond MCs** | **CMOC 12:** If there is a lack of local provision for those with more advanced dementia to move on to then an older/more advanced dementia membership profile is more likely in the MC because staff will not want to stop supporting members who are no longer supposed to be appropriate for MC membership. |
| | **CMOC 13:** If there is a lack of local provision for those with more advanced dementia to move on to then members will not want to stop attending an MC though it struggles to meet their needs, because they will not have confidence they will find equivalent support elsewhere. |

**CMOCs pertaining to *Reaching people and membership***

| | |
|---|---|
| **Promotion** | **CMOC 14:** If MCs are not promoted widely with broadly inclusive and appealing materials then people may not attend because they find the promotional material off-putting or don't see it. |
| | **CMOC 15:** If MCs promote themselves via online media/social media that potential members or those supporting them use, then more people may be reached and access MCs because they will be able to discover and access information about MCs easily. |
| | **CMOC 16:** If a well-functioning MC has links/presence in the local community then they are more likely to attract members and funding because people will be recommend it through word of mouth. |
| | **CMOC 17:** If an MC has someone dedicated to public engagement and recruiting then they are more likely to recruit appropriate members as that person will have the time and motivation to reach the right people. |
| **Appropriateness and access** | **CMOC 18:** If an MC has an older/more advanced dementia membership profile then younger persons/those experiencing milder symptoms may not attend because they feel the MC is not for them and may not what to see what is in their future. |
| | **CMOC 19:** If a person is early in their dementia journey active and independent then they may not want to attend because they don't see the MC offer as relevant to them and their needs yet. |
| | **CMOC 20:** If people are not familiar with attending groups/community support then they may not attend an MC because they do not see it as being for them. |
| | **CMOC 21:** If a person is recently diagnosed with dementia then they may need time to adjust to and accept their diagnosis before being referred to an MC because diagnosis can be difficult to come to terms with. |
| | **CMOC 22:** If the transition into MC membership is supported or taster sessions are offered then people may be more likely to want to go/return to an MC because they will find it less daunting, less pressure and easier to adapt to the new setting/people. |
| | **CMOC 23:** If an MC only offers membership to people with a formal diagnosis then fewer people will come because many people living with dementia remain undiagnosed whether through delays or previous lack of engagement with healthcare services. |

| | |
|---|---|
| | **CMOC 24:** If MCs are not run and/or clearly promoted as intended or the MC offer is not understood then people may not attend or be referred because there is confusion or uncertainty about who the MC is for or what it offers or the MC offer does not appeal to/meet the needs of the people it is intended for. |
| | **CMOC 25:** If MC provision is not at the frequency people want then members may not attend as they will feel the support is not sufficient so not worthwhile or too demanding on their time. |
| | **CMOC 26:** If the costs involved in attending and accessing an MC (including transport) are high and value for money is not clear, then potential members may not attend because they are unable or unwilling to pay the involved costs. |
| | **CMOC 27:** If MCs support people to source and access funds to meet the costs involved in attendance where eligible then more people might be able to attend the MC because they can afford to. |
| | **CMOC 28:** If an MC does not maintain a diverse and inclusive membership profile then potential members may be deterred because they do not identify with the social group. |
| | **CMOC 29:** If a person living with dementia or their carer has challenges communicating in the language the MC uses, then they may not attend because of the language barrier. |
| **Social appeal, belonging and safety** | **CMOC 30:** If an MC has a reliably welcoming and stigma-less atmosphere then people are more likely to come and keep coming because they will feel safe, unjudged and supported. |
| | **CMOC 31:** If the social side of an MC is emphasised and encouraged then people will keep coming back because they will value the social opportunity and forge friendships and group cohesion. |
| **Range of activities** | **CMOC 32:** If activities are not varied and designed to appeal to a range of tastes and abilities then people will not come as they will feel the MC is not appropriate for them. |
| | **CMOC 33:** If activities focus on what people can do rather than what they can't then an MC may attract more members as they will find it empowering and helpful in maintaining skills. |
| **Food** | **CMOC 34:** If there are personnel and resources to devote to food then this may attract members as food activity is seen as valuable and enjoyable in multiple ways (nutritious meaningful activity social occasion). |
| | **CMOC 35:** If there are restrictions and limitations on resources and personnel then food may not be part of an MC's offer as it will be seen as too difficult labour intensive and interfering with delivering other activities. |

**CMOCs pertaining to *Carer benefit and engagement***

| | |
|---|---|
| **Carer benefit and engagement** | **CMOC 36:** If time and opportunity is made for carer peer support at the MC, then carers will be more likely to stay and engage because they will feel it may be of personal benefit to them to do so. |
| | **CMOC 37:** If the personal benefits to the carer of attending an MC along with the person they support are not made clear, then carers will tend to use the MC for respite only, as their need for respite will outweigh anything they see on offer. |
| | **CMOC 38:** If access to supporting services and information is offered at an MC then family carers are more likely to attend and engage as they will see clear benefits to them doing so. |

| | |
|---|---|
| | **CMOC 39:** If MC activities are flexible, supported and designed to include family carers, then carers may stay and engage because it is a beneficial way to spend time together with the person they support outside of the home without the pressure of being sole carer. |
| | **CMOC 40:** If carers have other responsibilities they may not attend as they feel they cannot afford the time or find it in their schedule. |

**CMOCs pertaining to *Venue and location***

| | |
|---|---|
| **Transport and rurality issues** | **CMOC 41:** If the MC catchment is a sparsely populated rural area support with transport will be important as potential members are more likely to have travel challenges. |
| | **CMOC 42:** If catchment covers multiple geographic areas with different identities people may not come to the MC as they will not see it as appropriate for them or think they are eligible. |
| | **CMOC 43:** If people are older and living with chronic health conditions then they may find getting to an MC challenging as they may be less able to drive or use public transport. |
| | **CMOC 44:** If people cannot get to the venue easily safely and cheaply then they will not attend the MC as they will feel getting there is too inconvenient or unsafe (especially if they do not have a person supporting them). |
| **Venue issues** | **CMOC 45:** If venue facilities are not appropriate for members' needs then people will not want to come along as it will not be comfortable or it will limit activities that might appeal to them. |
| | **CMOC 46:** If staff and members are restricted in what they can do with the space than an MC may be less appealing as members may feel less welcomed by the environment, with less ownership of it. |
| | **CMOC 47:** If use of a venue is not fixed, then this may discourage members to attend as they will find it confusing, disorientating or lack confidence in the MCs future. |
| | **CMOC 48:** If use of the venue is fixed and in the heart of a community, then people are more likely to know about the MC as it will have a visible, physical presence in the community. |
| | **CMOC 49:** If use of a venue is not fixed/exclusive then maintaining a fully functioning MC may be more difficult for staff and volunteers as they will have to bring and set up resources and negotiate with other users over competing uses (inc. storage if available). |
| | **CMOC 50:** If an MC is only one or two days a week then exclusive use of a venue is unlikely as this would be economically unviable. |
| | **CMOC 51:** If a venue is shared with other locally valued services, then it may be more attractive to people as a supportive community meeting multiple needs in multiple ways in a single location can develop. |
| | **CMOC 52:** If a venue owner gains non-monetary benefits from hosting an MC, then an MC is more likely to survive as they will be invested and want to help if there are any issues that threaten it from continuing to function well. |

**CMOCs pertaining to *External relationships and collaboration***

| | |
|---|---|
| **Community building** | **CMOC 53:** If an MC has a presence/connections in the community then it is more likely to be supported as it will raise the awareness of people in that community and act as a focus/hub for dementia-supportive activity. |

| | |
|---|---|
| | **CMOC 54:** If a community is closeknit then an MC is more likely to be successful because people will already be used to joining in to support group initiatives and each other. |
| **Partnerships and networks** | **CMOC 55:** If an MC can show local agencies, organisations and the community that it is a useful and reliable resource, then it is likely to be supported and promoted by them because it will be valued and trusted. |
| | **CMOC 56:** If an MC can develop and maintain strong partnerships and networks with local agencies and organisations then it is likely to attract more members, support and funding because it will become more known and visible to them. |
| | **CMOC 57:** If an MC does outreach activities with people and groups in the community then they are more likely to attract more members and support because the benefits of MCs will become more known and visible in the community. |
| | **CMOC 58:** If an MC has knowledge of and links with groups and individuals in the community then it is more likely to offer a variety of activities and services as it will be able to draw upon a wider pool of expertise and resources to contribute to the life of the centre. |
| **Organisational governance** | **CMOC 59:** If organisations at both local and regional level work together in a two tier system then MCs are more likely to sustain because they can pool different strengths, resources and reach. |
| | **CMOC 60:** If there is tension/competition between organisations then an MC is less likely to sustain as there will be a lack of collaboration and sharing to get things done. |
| | **CMOC 61:** If a large charity or authority takes over the running of an MC then they may be more likely to sustain as they will be able to call upon the existing infrastructure and resources of that charity. |
| | **CMOC 62:** If a large charity or authority takes over the running of an MC, then sustainability of the MC or its ethos may be threatened because the charity/authority's agenda will take precedence over it. |
| | **CMOC 63:** If a large charity or authority takes over the running of an MC they may struggle to make as good connections in the community as a grass roots group as they may be less embedded in it. |
| **Data collection and research involvement** | **CMOC 64:** If an MC is involved in research and/or collects performance and cost data then it increases its chances of sustaining as it will have some academic backing and evidence of its value to help get further support. |

**CMOCs pertaining to *Internal relationships and practices***

| | |
|---|---|
| **Trustee make-up** | **CMOC 65:** If trustees have relevant background skills and connections then an MC is more likely overcome threats to sustainability because they will know what to do and be able to use their contacts knowledge and experience to support the MC. |
| **Personnel recruitment and practice** | **CMOC 66:** If an MC has an experienced and highly motivated individual or individuals driving it then it is more likely to overcome threats to sustainability as they will go above and beyond and have the skills and connections to call upon to make it work. |
| | **CMOC 67:** If an MC is over-reliant on an individual or individuals then that may eventually threaten its sustainability as they may become overwhelmed or exhausted by the responsibility and burn out. |

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|---|---|
| | **CMOC 68:** If an MC expects volunteers to take on significant responsibilities and workloads in order to run then it may not sustain as they may find it too much to take on and commit to. |
| | **CMOC 69:** If an MC relies solely on volunteers with informal agreements to drive and run it then it may not sustain as those people may drop out as their circumstances change. |
| | **CMOC 70:** If staff do not have job security then an MC's provision may not be stable as it is less likely to be able to recruit and retain skilled an experienced people. |
| | **CMOC 71:** If a there is large organisation behind an MC, then staffing is likely to be more stable as they will have greater resources and more developed infrastructure to draw upon for recruiting and deploying staff and volunteers. |
| | **CMOC 72:** If MCs are widely geographically dispersed then sharing staff and volunteers may be difficult as they may not want to travel due to time cost and unfamiliarity with somewhere other than home. |
| | **CMOC 73:** If an MC is a friendly welcoming and flexible environment for volunteers then it is more likely to recruit and retain them because they will enjoy and benefit from their volunteer work. |
| | **CMOC 74:** If the community around an MC has people with personal experience of supporting people with dementia then this could be a good source of volunteers as they will understand the value of an MC and have relevant skills (e.g. friends and family of members people with a H&SC background). |
| | **CMOC 75:** If a person living with dementia has milder symptoms then they may take on a volunteering role within the MC as they may prefer to be more active engaged and empowered. |
| **Person-centred and ability focussed practice** | **CMOC 76:** If the structure of what happens at an MC is not flexible then the MC will struggle to deliver high quality person-centred provision because it will not be able to accommodate a range of needs and preferences. |
| | **CMOC 77:** If staff do not have enough time to consult with all members then an MC will struggle to deliver high quality person centred provision because it will not take account of and attend to each individual's needs and preferences. |
| **Mission drift** | **CMOC 78:** If staff or volunteers are not trained and working together in line with the ethos of an MC then the quality of experience for members may be poor as staff and volunteers may veer away from well-planned, well-delivered, respectful, person-centred practice. |
| | **CMOC 79:** If staff and volunteers at an MC do not all understand what MCs are trying to achieve or have a different agenda then an MC may suffer 'mission drift' and not sustain as originally intended because it will be pushed towards a different purpose or different practices. |
| | **CMOC 80:** If the health and social care pathway does not support what MCs are trying to achieve then an MC may suffer 'mission drift' and not sustain as originally intended because it will be pushed towards a different purpose or different practices. |
| | **CMOC 81:** If those holding the key resources needed to sustain MCs do not understand what MCs are trying to achieve or have a different agenda then an MC may suffer 'mission drift' and not sustain as originally intended because it will be pushed towards a different purpose or different practices. |

**CMOCs pertaining to *Finances and funding***

| | |
|---|---|
| **Meeting costs** | **CMOC 82:** If funds are significantly limited then an MC offer serving a variety of needs will not be sustainable, because a well-rounded holistic service for all is costly. |
| | **CMOC 83:** If an MC only has to run for one day a week or fortnight then it is more likely to be financially sustainable as costs are lower. |
| | **CMOC 84:** If an MC does not have any budget for external practitioners/activity facilitators then it may not recruit and retain as many members as it will struggle to offer a varied, appealing and high quality range of activities for a range of needs and preferences. |
| | **CMOC 85:** If an MC does not have sufficient members/attendance then it may not be able to keep running because it will not have enough income. |
| | **CMOC 86:** If the pricing structure is not clearly and carefully set together with members then an MC will have problems meeting costs as it may be too expensive to attract members or bring in too little to meet costs. |
| | **CMOC 87:** If a larger organisation takes over the running of multiple MCs then they may be more likely to sustain as there will be economics of scale and wider reach for fund raising. |
| **External funding** | **CMOC 88:** If membership fees are kept affordable then some external funding will be necessary to keep an MC going because what members are likely to be willing or able to pay is not likely to be enough to cover full costs. |
| | **CMOC 89:** If an MC has personnel dedicated to continually seeking and applying for external funding then it is more likely to sustain because new funding is always likely to be needed and obtaining it requires ongoing time and expertise. |
| | **CMOC 90:** If funders only support short-term or new projects, then MCs will struggle to become established long-term, as they will be unable to plan ahead with confidence or have time to learn how activity can be supported sustainably. |
| | **CMOC 91:** If local authorities and commissioning bodies do not see tackling social isolation as part of their remit then MCs will struggle to get substantial support from them because those bodies will not see MC's social model of support as a priority for their resources. |
| | **CMOC 92:** If MC members have mild to moderate dementia without acute care needs then MCs will struggle to get substantial support for them from local authorities as they are less likely to be seen as priority or qualify for specific LA/NHS support. |
| | **CMOC 93:** If funders mainly focus upon acute and clinical interventions then an MC may experience mission drift towards offering acute and clinical care because those running it may feel that is necessary to capture funding and resources to keep going. |
| | **CMOC 94:** If an MC has multiple and diverse income streams and pots then it is more likely to maintain some ongoing funding because smaller funding amounts are easier to capture costs can be met piecemeal and if one stream stops others will still be available. |

## Work Package 3

The DCE questionnaire underwent a difficult design process and significant revisions to what was outlined in the original protocol plan, as adapting this complex tool for an audience with cognitive impairment proved challenging. The questionnaire had to undergo various round of consultation and redesign, before finding a solution likely to work as intended. It was initially to be targeted towards both people living with dementia and those that support them but PPI consultation strongly suggested it would be too complex to be accessible to the majority of Meeting Centre attendees who are living with dementia, due to the cognitive load required to complete the questions, and may even cause stress and confusion for them. Due to the stipulations of a DCE, it was not possible to simplify the questionnaire further, hence the target demographic of the questionnaire was reconsidered as family/informal carers only, with additional focus groups with people living with dementia (n=12) at our 3 case study sites to triangulate. This, along with a challenging and disruptive landscape for our study sites during 2021 and into 2022, accounts for the delay to roll out and lower response rate than anticipated. Data collection was closed on 12 October 2022, at which point we had 121 responses. While this is well under our original stated target of 300 responses, it was enough to run a useful and informative analysis, cross referenced with “triangulation” focus group discussions, as well as results from WP2.

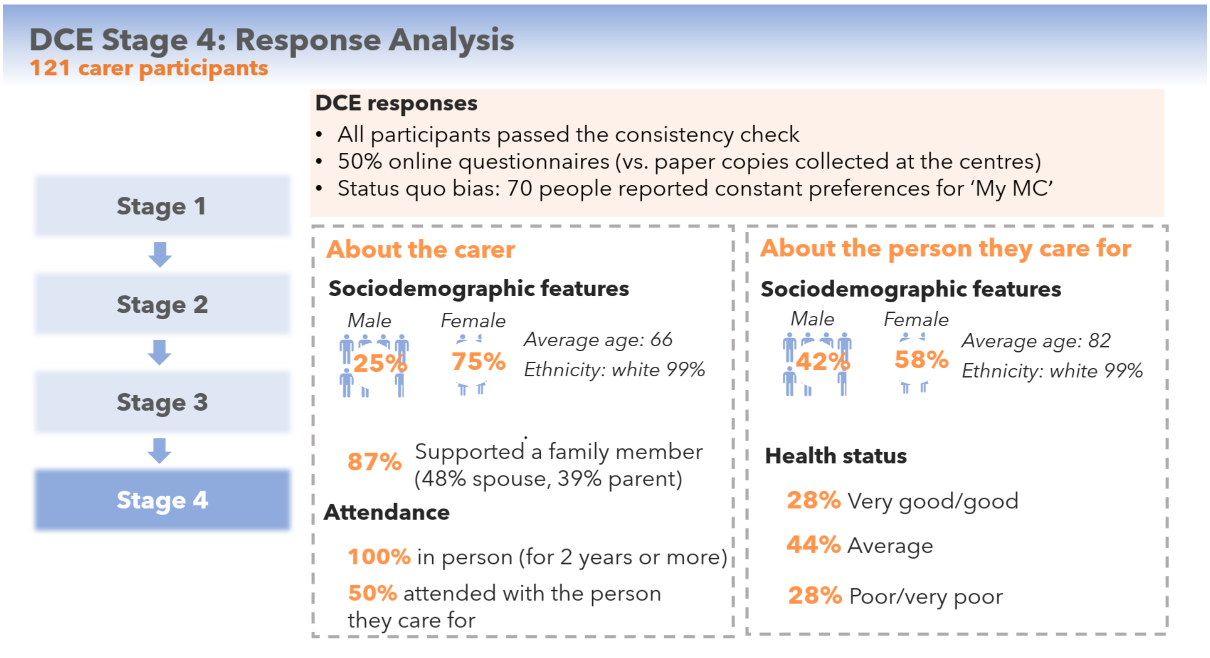
Key findings were that there was a strong preference for people to stay with their current MC offer, rather than change. However, overall, the preferred MC would have the following offer:

| | |
|---|---|
| Activities | A mix of brain-stimulating and physical activities, and useful information (as opposed to just one of those 3 elements) |
| Emotional Support | Opportunities to use and learn skills (as opposed to relaxation or peer support, or a mix of all 3 elements) |

|  |  |
|---|---|
| Social Opportunities | A mix of chatting with friends, meeting new people and doing activities (as opposed to just one of those 3 elements) |
| Attendance | Multiple times a week, with people able to go whenever they want, ideally for free |

The triangulation focus groups suggested:

|  |  |
|---|---|
| Activities | Brain-stimulating and physical activities were valued, information less so |
| Emotional Support | Skills and peer support were valued, but not relaxation |
| Social Opportunities | All were valued, with the view that these elements could not be distinguished |
| Attendance | Mixed response on whether people wanted to attend more or not; No strong opinions on availability to drop in, nor on cost |



## DCE Stage 4: Response Analysis

**121 carer participants**

Stage 1

Stage 2

Stage 3

Stage 4

**DCE responses**

- All participants passed the consistency check
- 50% online questionnaires (vs. paper copies collected at the centres)
- Status quo bias: 70 people reported constant preferences for 'My MC'

**About the carer**

**Sociodemographic features**

*Male* 25% *Female* 75%

*Average age: 66*

*Ethnicity: white 99%*

87% Supported a family member (48% spouse, 39% parent)

**Attendance**

100% in person (for 2 years or more)

50% attended with the person they care for

**About the person they care for**

**Sociodemographic features**

*Male* 42% *Female* 58%

*Average age: 82*

*Ethnicity: white 99%*

**Health status**

28% Very good/good

44% Average

28% Poor/very poor

## DCE Stage 4: Response Analysis

**Preferred model, most valued attributes, and their relative importance**

Stage 1

Stage 2

Stage 3

**Stage 4**

**MESSAGE 1:**
**Respondents do NOT value Online MCs.**

**MESSAGE 2:**
**They prefer 'My MC' to an alternative In person MC.**

**MESSAGE 3:**
**All service characteristics are valued apart from**

- **social opportunities** and
- **frequency of the meeting**.

**Those characteristics they valued were ranked:**

1. **Using their existing skills and learning new ones** (vs. equal mix of emotional support)
2. **Equal mix of emotional support** (vs mainly peer support)
3. **Equal mix of practical activity and support** (vs. either physical or brain stimulating activities)
4. **Don't have to book**
5. **Lower cost**

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## DCE Stage 4: Response Analysis

**Willingness to pay (WTP) – the maximum price a customer is willing to pay for a product or service**

**(NOT how much the customer should pay)**

Stage 1

Stage 2

Stage 3

**Stage 4**

**FOR EXAMPLE:**

**WTP for the preferred Meeting Centre:**

- **WTP £43 to stay with 'my Meeting Centre'** compared with shifting to alternative in person Meeting Centre **(everything else equal)**

**WTP for changes in emotional support:**

- **WTP £54** mainly a chance for people to use their existing skills and learn new ones (compared with receive a mix of relaxation, using/learning skills and peer support).
- **WTP £33** to receive a mix of relaxation, using/learning skills and peer support (compared with mainly an opportunity for people to talk with others, give and receive support).

# DCE Stage 4: Response Analysis

## Explicative factors for WTP

**MESSAGE 4: Factors that influence carers' choice: attendance modality, relationship with person they support, age and gender**

Stage 1

Stage 2

Stage 3

**Stage 4**

**Those carers that attend the Meeting Centre**

- Together with the person they support show a lower WTP for 'My MC' (compared with all the other carers).
- As a former carer prefer a shift from 'My MC' to an alternative in person MC (whereas the others prefer more the 'My MC').
- That are younger show a lower WTP for 'My MC' (compared with older carers).
- That are male show a higher WTP for 'My MC' (compared with female carers).

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# Comments

- DCE survey was well received by study participants.
- Response rate 30% of the total cohort of carers across the UK MCs.

**DCE analysis indicates:**

① Respondents do NOT value Online MCs.

② They prefer 'My MC' to alternative In person MC.

③ All service characteristics are valued apart from any type of social opportunities or frequency of the meeting.

Those characteristics they valued were ranked as it follows:
**1st:** Using their existing skills and learning new ones
**2nd:** Equal mix of emotional support
**3rd:** Equal mix of practical activity and support
**4th:** Don't have to book
**5th:** Lower costs

④ Factors that influence carers' choice: attendance modality, relationship with person they support, age and gender.

## Work Package 5

Publicly available local and national demographic data regarding Herefordshire and Worcestershire was compared with membership data recorded by the region's 13 MCs (See Demographic Report, attached). The following were identified as potential barriers to attendance of MCs:

- Diagnosis targets not being met
- Unavailability of both personal and public transport
- No MCs in many areas
- Isolation and other rural community challenges posing barriers to accessing health/social care support (including MCs)
- Cost of attending
- Stigma deterring both diagnosis and willingness to attend MCs

In addition, interviews were completed with 15 interviewees, including 6 non-attendees (people living with dementia and family carers), 7 MC staff and trustees, and 2 health and social care professionals, and a focus group was conducted with 6 potential referrers/health and social care professionals. As with WP2, this data was organised by theme and a Realist logic of analysis applied. 24 CMOC statements were generated, under 7 themes:

1. Unmet support needs
2. Costs
3. Health
4. Meeting Centres
5. Perceptions
6. Dementia pathway
7. Travel

Associated recommendations were made under the following headings: Meeting needs; Transforming perceptions; Improving inclusion and raising awareness; and Transforming practice. The CMOCs from WP2 and WP5 were compared and cross-referenced, showing a high degree of overlap.

Full WP5 reports are included below:

University of Worcester
Association for Dementia Studies

*University of Worcester*
*School of Allied Health and Community*
*Henwick Grove, Worcester, WR2 6AJ*
*www.worcester.ac.uk/dementia*

# Get Real with Meeting Centres

## Demographic Profile

### Herefordshire & Worcestershire Meeting Centres

### Report

January 2023

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## Table of Contents

# Demographic Summary

The following tables present the key demographic statistics from this report, based on publicly available local and national data and membership data recorded by Herefordshire and Worcestershire (H&W) Meeting Centres (MCs).

## Dementia and Ageing in Herefordshire & Worcestershire

| | | |
|---|---|---|
| Nearly a quarter of the population are estimated to be aged 65+ | 12,346 people aged 65+ are estimated to be living with dementia | 6,424 people aged 65+ have a formal diagnosis: 52% of estimated figures |
| 167 people aged <65 are living with a dementia diagnosis | H&W ICB has the lowest diagnosis rate in England of just 52% | 75,123 people aged 65+ are estimated to live rurally |
| Estimates suggest that there 2,586 people diagnosed with dementia aged 65+ living rurally | In Herefordshire, 53% of people aged 65+ who live alone, live rurally; more than double the figure for England | Estimates suggest that around over 5k households aged 65+ that include a person with dementia do not have a car or van |
| 2% of the population are Polish | The proportion of people who identify as 'White: Gypsy or Irish Traveller' is double that of England | More than two-thirds of residents identify as Christian, with the second largest religions being Buddhist and Hindu |
| It is estimated that 1,865 people aged 65+ are lesbian, gay bisexual or other | | Estimates suggest that eight people with dementia are either homeless or at risk of homelessness |

## Meeting Centres in Herefordshire and Worcestershire

| | | |
|---|---|---|
| Only 2-3% of people estimated to be experiencing the mild-moderate stages of dementia are recorded as currently attending an MC | There are approximately 122 current MC members | MCs are reaching people living in 79% of HR and WR outward postcode areas |
| More than three-quarters of current recorded members have attended for a year or less | More than two-thirds of ceased memberships recorded lasted a year or less | The most common reasons for membership ending are a move to residential care or passing away |

| | | |
|---|---|---|
| The majority of members were in their 80s at the time of joining | Female members outnumber male members at a lower rate than indicated by diagnosis rate for England | No recorded male members joined an MC under the age of 65 |
| 98% of members and 100% of carers identify their ethnicity as ‘White’ | Two-thirds of members live with a spouse or partner | 21% of members live alone; 16 fewer than expected |
| Most referral/signposting is via healthcare professionals | As for the UK, the three most common dementia types are Alzheimer’s, vascular and mixed dementias | 38% of members joined two years or more following diagnosis |
| 23 of 28 carers were aged 65+ at the time of joining | | The majority of MC family carers are spouses or partners. Wives are the largest group, followed by husbands then daughters |

# Background

This report forms part of the Get Real with Meeting Centres research project investigating the factors and issues involved in the long-term sustainability of MCs for people affected by dementia. Early indications from the Get Real with Meeting Centres project show that those who attend three case study sites located in Herefordshire, Powys and Worcestershire are only a fraction of those diagnosed with dementia in each locality, highlighting a need to expand the existing aims and objectives to include the following:

**Aims**

1. To understand who the MCs are reaching, appealing to and helping, and who they are not.
2. To provide a clear indication on the equality of access to support and where new strategies and further work needs to be focused to ensure that the needs of the whole community are met in the post-diagnostic phase in dementia.

**Objectives**

1. To determine whether those who attend MCs are representative of the local diagnosed population.

2. To identify if there are any particular barriers for people who do not attend or are not being reached (e.g. from certain demographics or with certain personal circumstances).

This report compares the profile of people who access MCs with the demographic profile of those diagnosed with dementia and older people in the communities around each MC. As there is a lack of detailed demographic data available for relevant populations in Powys, this report focusses on H&W MCs as a 'microsite'. This focus has enabled a more in-depth exploration of the barriers to attendance and draws on the existing local networks and connections of the Association for Dementia Studies research team. In conjunction with interviews conducted with people affected by dementia who do not attend H&W MCs and other stakeholders, including health and social care professionals and MC staff, this report forms a basis for developing recommendations for tackling disparities.

The following table shows the 13 MCs operating in Herefordshire and Worcestershire, their dates of opening and the dates data collection began at each MC[1]. Redditch MC provides membership for people living with younger onset dementia specifically. Those that list 'NA' have not provided data to date:

| MCs | Opened | Data from | MCS | Opened | Data from |
|---|---|---|---|---|---|
| Leominster | Feb 2016 | May 2019 | Evesham | Jul 2021 | July 2021 |
| Ross | Mar 2017 | NA | Worcester 2 | Jan 2022 | Jan 2022 |
| Hereford Veterans | Aug 2021 | NA | Kidderminster | Feb 2022 | Mar 2022 |
| Droitwich | Sep 2015 | Jan 2018 | Stourport | Mar 2022 | Apr 2022 |
| Malvern Link | Jun 2021 | Sept 2021 | Bromsgrove | July 2022 | Aug 2022 |
| Malvern Hills | Jun 2021 | Sept 2021 | Redditch | July 2022 | Aug 2022 |
| Worcester 1 | Jun 2021 | Sept 2021 | | | |

In July 2022, the single Clinical Commissioning Group (CCG) covering the counties of H&W was replaced by an Integrated Care Board (ICB). The NHS digital data for this ICB offers an overview of dementia diagnoses figures and related demographics for patients in H&W. Given that some published datasets only offer figures by ICB and country, such as dementia diagnoses by ethnicity and age (NHS Digital, 2022b; NHS Digital, 2022c), these are the figures used for comparisons with MC data for the purposes of this report.

According to the 2021 Census there are 186,513 people aged 65+ living in H&W, which is nearly a quarter (24%) of the population (ONS, 2022c). This proportion is slightly higher than the 18% for England as a whole (ONS, 2022b) and is expected to

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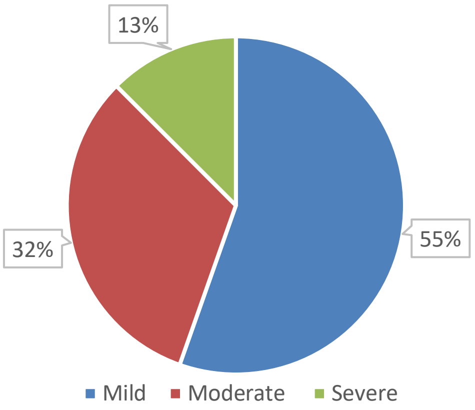
[1] Data includes members currently attending who joined prior to the start date of data collection.

continue to increase (Herefordshire Council, 2019; Worcestershire County Council, 2022a). Of this population, there are estimated to be 12,346 people living with dementia, with only 6,424 (52%) having a formal diagnosis (NHS Digital, 2022a). There are an additional 167 people living with a diagnosis aged <65 (NHS Digital, 2022b)[2]. Of those with a diagnosis, the estimated figures of those living with mild, moderate and severe dementia, based on UK statistics from the Alzheimer's Society (2014) can be estimated as mild 3,651 (55%), moderate 2,116 (32%) and severe 824 (13)%:



H&W ICB has the lowest diagnosis rate of ICBs in England of just 52% (NHS Digital, 2022a); well below the target agreed by NHS England of two-thirds (Department of Health, 2016).

# Demographic Landscape

This section of the report presents the latest demographic data available from across H&W MCs[3]. These data are contextualised within the local and national demographic landscape to highlight potential barriers to attendance for potential members. At the time of writing this report, full results from the Census 2021 data on ethnicity, rurality, household vehicles and unpaid care were awaiting release and so Census 2011 data were utilised.

## Meeting Centre Membership

For the sake of clarity, distinction is drawn between people with dementia attending MCs as 'members' and family members who care for them as 'carers'.

Only 11 of the 13 H&W MCs participated in data collection, and the data for some are incomplete, so the total numbers of current members and carers across all MCs

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[2] No NHS data is available on the number of people estimated to be living with dementia under the age of 65

[3] Last data collection point 14th October 2022

is not known (see Appendix for MC data overview). It is likely that the number is higher than that recorded and is likely to be increasing, as nine of the MCs are newly established within the past two years.

The following table shows the number of recorded members per H&W MC since data collection began, along with the date collection of data started:

| **Herefordshire** | | | **Worcestershire** | | | |
|---|---|---|---|---|---|---|
| Leominster MC | Ross MC | Hereford Veterans MC | Droitwich MC | Malvern Link MC | Malvern Hills MC | Worcester 1 MC |
| May 2019 | NA | NA | Jan 2018 | Sept 2021 | Sept 2021 | Sept 2021 |
| 71 | 0 | 0 | 88 | 32 | 9 | 13 |
| **Worcestershire** | | | | | | |
| Evesham MC | Worcester 2 MC | Kidderminster MC | Stourport MC | Bromsgrove MC | Redditch MC | |
| July 2021 | Jan 2022 | Mar 2022 | Apr 2022 | Aug 2022 | Aug 2022 | |
| 22 | 6 | 6 | 5 | 2 | 3 | |

The total number of recorded members who have attended H&W MCs since data collection began is 257. Of these, 122 are recorded as current members, which accounts for 2% of the population diagnosed with dementia in H&W ICB estimated to be experiencing the mild-moderate stages [4] (NHS Digital, 2022b; Alzheimer's Society, 2014), as indicated for MC membership (University of Worcester, 2022). However, there are 48 members whose attendance status is unknown, which, when added to the number of current members, takes the population percentage up to 3%. It is likely that the number with an unknown status also includes members who no longer attend, so the 87 ceased memberships recorded is also likely to be a higher figure.

The total number of recorded carers since data collection began is 123, with 28 of these recorded as current and 58 as having an unknow membership status. Further research into post diagnostic dementia support and services could offer an indication of whether member and carer figures are typical for local uptake and shed light on the similarities and differences between barriers to attendance and access.

Of the total 257 recorded members, 137 (53%) have a joining date recorded between 2016-2022. Since the easing of COVID-19 pandemic restrictions and the opening of nine new MCs between 2021-22, 102 new memberships have been recorded across all H&W MCs:

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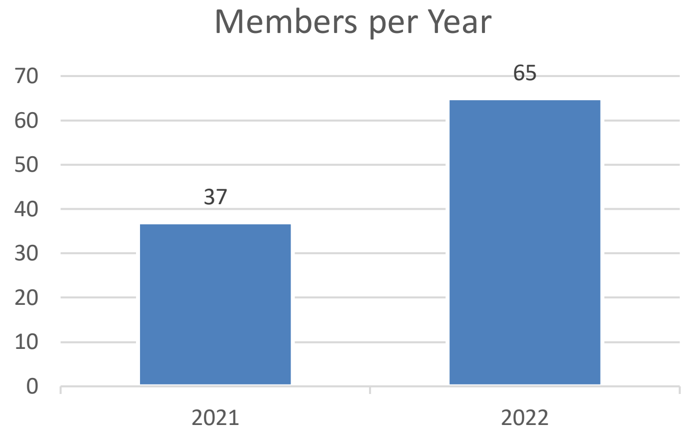
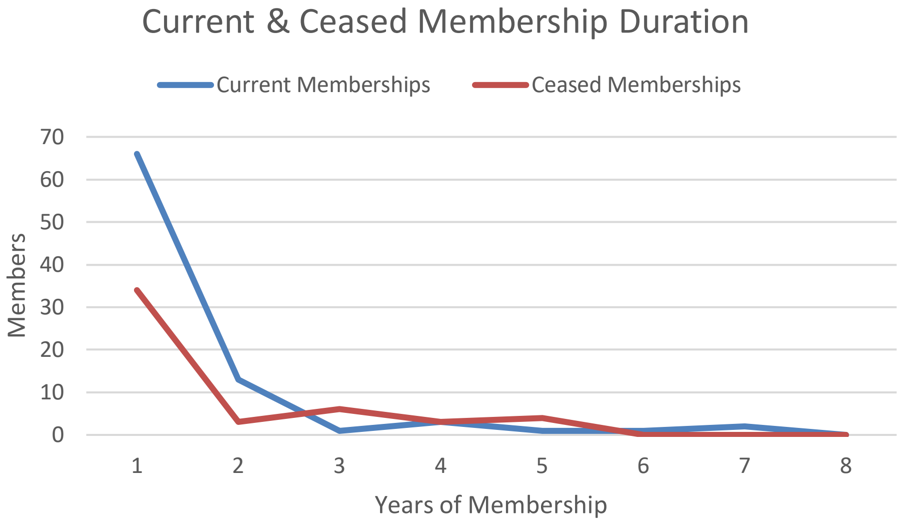
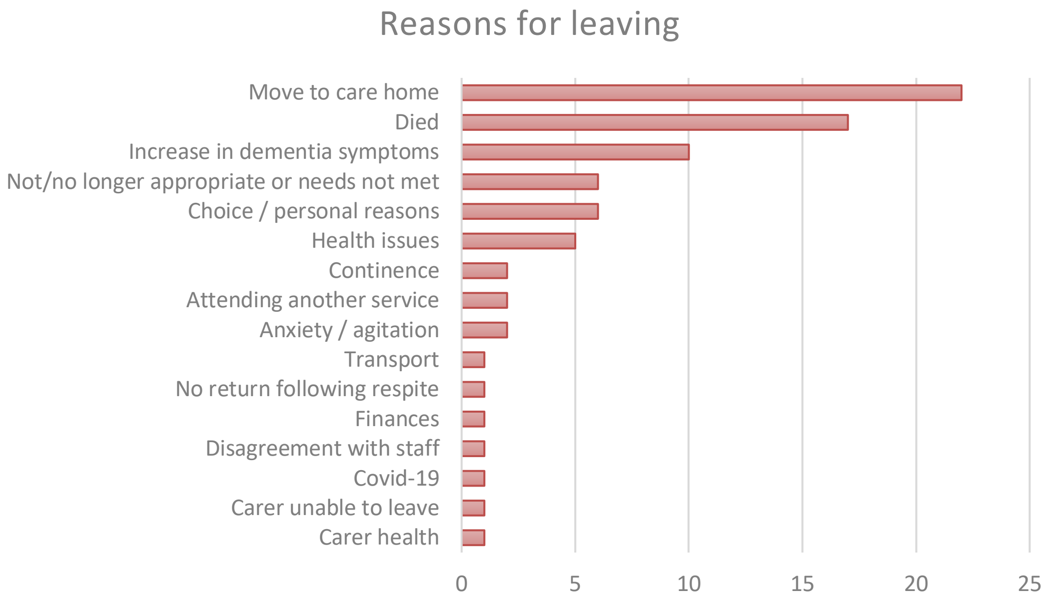
[4] Estimate based on statistic percentages (Alzheimer's Society, 2014) applied to H&W ICB population with a dementia diagnosis (NHS Digital, 2022b)



For the 87 MC members currently attending who have a recorded joining date, it is clear from the following chart that more than three-quarters (66) have attended for a year or less, which may not be surprising given the recent expansion of MC provision in Worcestershire. However, the significant decrease in attendance after the first year is a trend that is also evident for the 50 ceased memberships that have both a recorded joining and leaving date, with more than two-thirds of memberships (34) lasting up to one year and only 16 lasting longer:



Reasons for leaving are recorded for 79 leaving members. As shown in the following chart, the two most common reasons provided for a membership ending are members moving into a care home or passing away:



Of the reasons listed, the following might be expected for people as they age and their dementia progresses:

| Reasons | Ceased memberships |
|---|---|
| Moving into care | 22 |
| Passing away | 17 |
| Increase in dementia symptoms | 10 |
| Health issues | 5 |
| Anxiety and agitation | 2 |
| Carer health | 1 |

Anxiety and agitation being recorded as barriers to attendance may give indication for MCs to consider these issues in planning their provision of support.

There are four reasons for leaving which do not offer enough information to identify whether there is a barrier to attendance:

| Reasons | Ceased memberships |
|---|---|
| Choice / personal reasons | 6 |
| Attending another service | 2 |
| Disagreement with staff | 1 |

| | |
|---|---|
| No return following respite | 1 |

Personal reasons include wanting only to be with their partner, feeling tired and wishing to remain at home and not liking their family member enjoying themself at the MC. As for anxiety and agitation, disagreements and cessation of membership following a respite break may give indication for MCs to consider these issues in planning their provision of support.

Three reasons highlight a difference between the needs or wishes of members and/or carers and the features of an MC:

| **Reasons** | **Ceased memberships** |
|---|---|
| Not/no longer appropriate or needs not met | 6 |
| Continence | 2 |
| Carer unable to leave | 1 |

The reason that MC membership was not/no longer appropriate, or members felt their needs were not met were identified for four members as either needing more physical activity, wanting one-to-one support or being verbally abusive due to their dementia. Support with personal care is not usually provided by MC staff and requires a carer to remain and provide (University of Worcester, 2022). MCs are intended for both the person with dementia and their carer to attend rather than solely as a respite service for family carers to leaved their loved ones (Ibid.).

The remaining three reasons may potentially prevent others from joining or continuing membership:

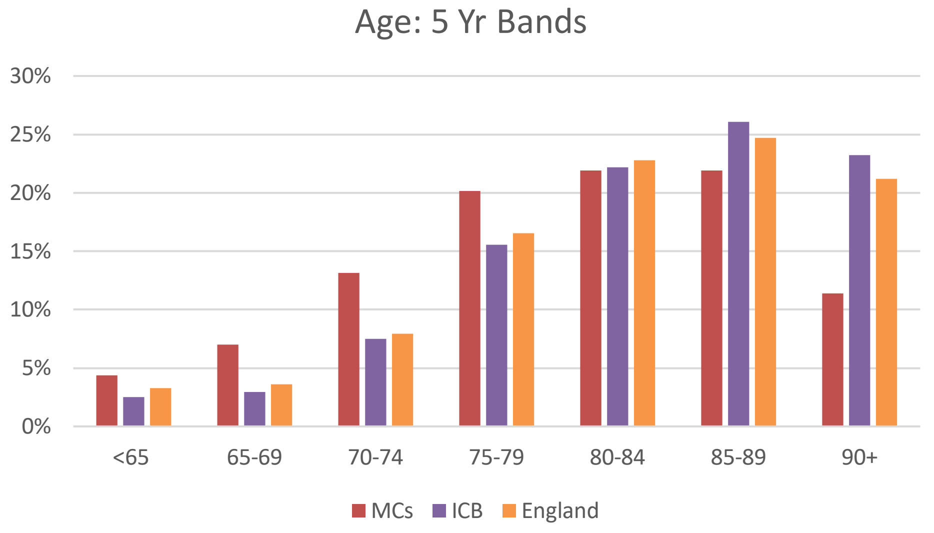
| **Reasons** | **Ceased memberships** |
|---|---|
| Transport | 1 |
| Finances | 1 |
| Covid-19 | 1 |

Transport is a potential barrier to MC attendance that is discussed more fully later in this report (see Transport). Finances is assumed to be a variable barrier as it not only depends upon individual circumstances, but charges for membership can differ between MCs. Covid-19 infections, risk and impact on health may continue to be a barrier to some members and potential members following the pandemic.

## Age

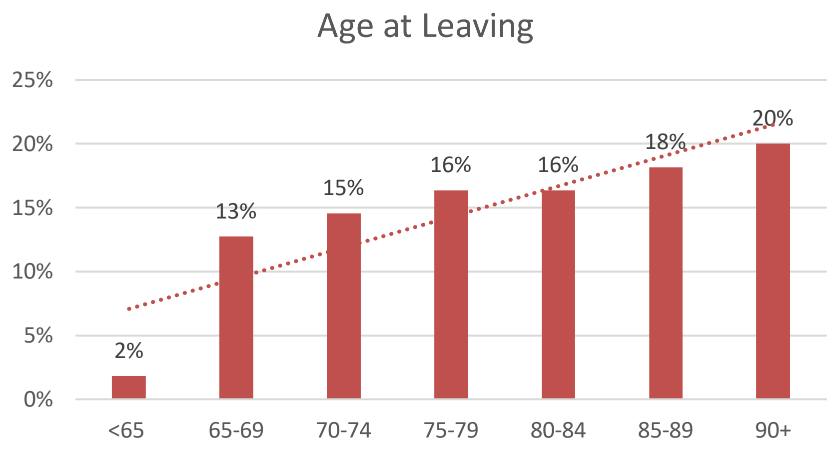
The ages of the 114 members with a joining date and DOB recorded range between 56 - 96 years. Five members (4%) were <65 years of age at the time of joining; slightly higher than the proportion of people in this age group with a dementia diagnosis across H&W ICB (3%) and England (3%) (NHS Digital, 2022a; NHS Digital, 2022b).

Of the same 114 members, those aged 80 – 84 and 85 – 89 years at the time of joining were the largest two groups (50 members). When compared to dementia diagnosis records for H&W ICB (NHS Digital, 2022c), there are 18 more members under the age of 80 and 18 fewer aged 85+ than would be expected when compared to ICB and national diagnosis figures:

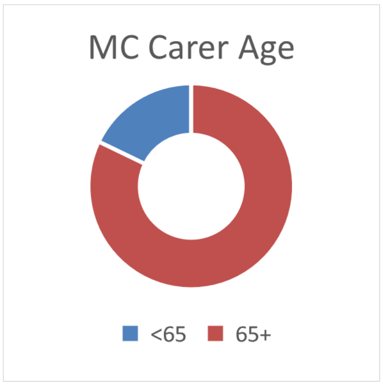


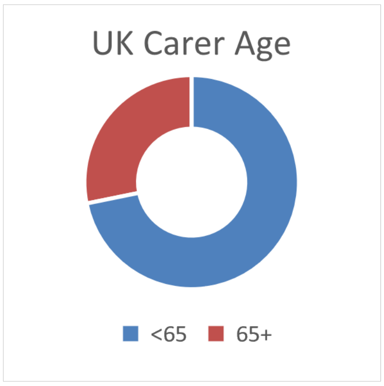
Most members "…experience what is classified as mild to moderate dementia" (University of Worcester, 2022, 9) and will cease to attend as their dementia progresses over time, and so the higher numbers at a younger age and lower at an older age may be anticipated. However, given that the likelihood of developing dementia past the age of 65 roughly doubles every five years (NHS, 2020a), it is possible that members under the age of 80 may be disproportionately represented. It is difficult to draw conclusions, not only due to the lack of data, but also because people in the younger age groups may have been more inclined to attend a community support group and/or provide data.

Of the 55 members with a DOB and leaving date, the age range for leaving an MC is 62 - 96 years, with the most members (11) leaving aged 90+. The breakdown of age in five-year bands at the time of leaving shows cessation of membership increasing by age band as an overall trend; this trend would appear to be in line with MC provision being intended for members in the mild to moderate stages of their dementia:



Aging is also a pertinent issue for the family carers of MC members. At the time of joining, 23 of the 28 carers with a recorded DOB and joining date were aged 65+. These figures are very different to the national figures from the most recent UK Family Resources Survey (Department for Work and Pensions, 2022b) that indicate 72% of informal carers are under the age of 65:

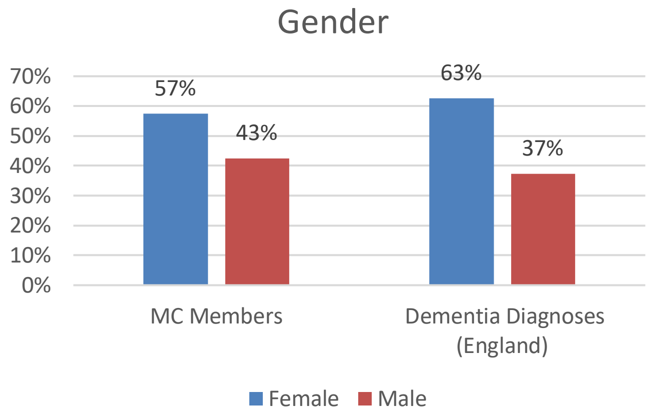




The UK figures correlate with statistics from 2014 US poll that indicates approximately 30% of family members caring specifically for people living with dementia are aged 65+ (Alzheimer's Association, 2022). Although more data is needed to ascertain whether or not the small sample is representative of H&W MCs as a whole, it is possible that potential members with younger family carers face barriers to attendance, such as working hours. There is a lack of publicly available data on the rate of older carers for people with dementia. The apparently high number of older carers in MCs can at least in part be explained by the fact that the majority of MC carers are a spouse or partner (see Living Situation) and the vast majority of people with dementia are aged 65+ (NHS Digital, 2022a).

## Gender

The available MC data for members with gender recorded shows 100 (57%) female members to 74 (43%) male members; nine fewer female/more male members than would be expected compared to gender ratios for dementia diagnosis in England (NHS Digital, 2022a).



The NHS Digital data on the gender of people with a dementia diagnosis is only available at ICB level for those aged 65+ (NHS Digital, 2022c), which is the same as for England as a whole. The gender ratio disparity is small but cannot be accounted for by general population statistics, as the gender ratio for the population aged 65+ in H&W is the same as for England, 54% female, 46% male (ONS, 2022a). However, older females are more likely to experience 'not good' health than older males, and to live longer (ONS, 2013). Given that the majority of MC carers are spouses (see Living Situation and Relationships), these factors could go some way towards explaining the apparent lack of female members and indicate that there are barriers for some females to attending H&W MCs.

A breakdown of the data for MC members with both gender and age recorded shows no significant differences from the figures that would be expected according to dementia diagnosis data from England[5] (NHS Digital, 2022a):

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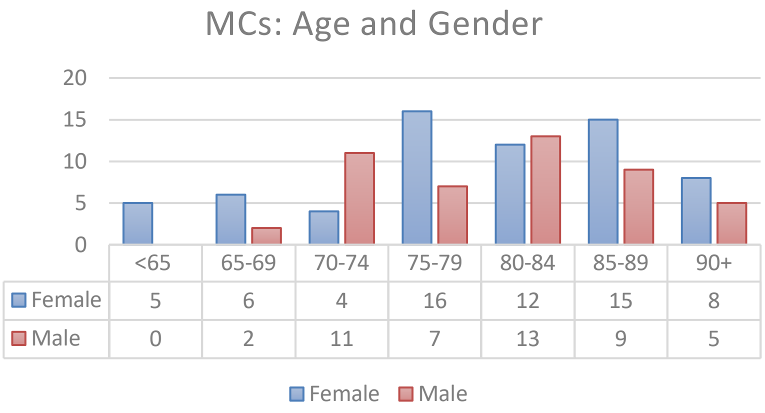
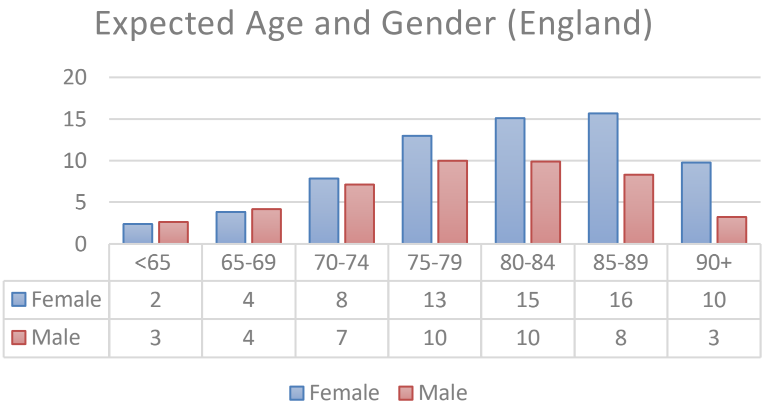
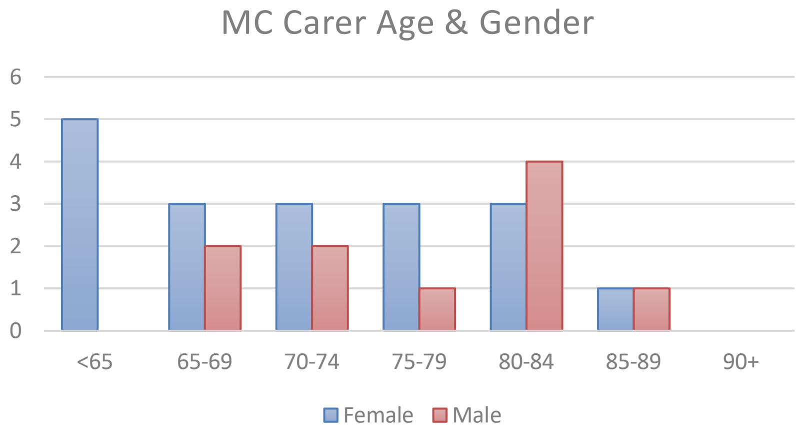
[5] The H&W ICB data for age and gender of people with a diagnosis available for age 65+ does not differ significantly from that of England as a whole (NHS Digital, 2022c).





However, the five fewer male members than expected under the age of 70 years could suggest younger males are less likely to attend than younger females, but further data would be needed to support this. Due to the limited information recorded for carers, it is not possible to look for trends in this data, for example whether male spousal carers are less likely to accompany female members than *visa versa*.

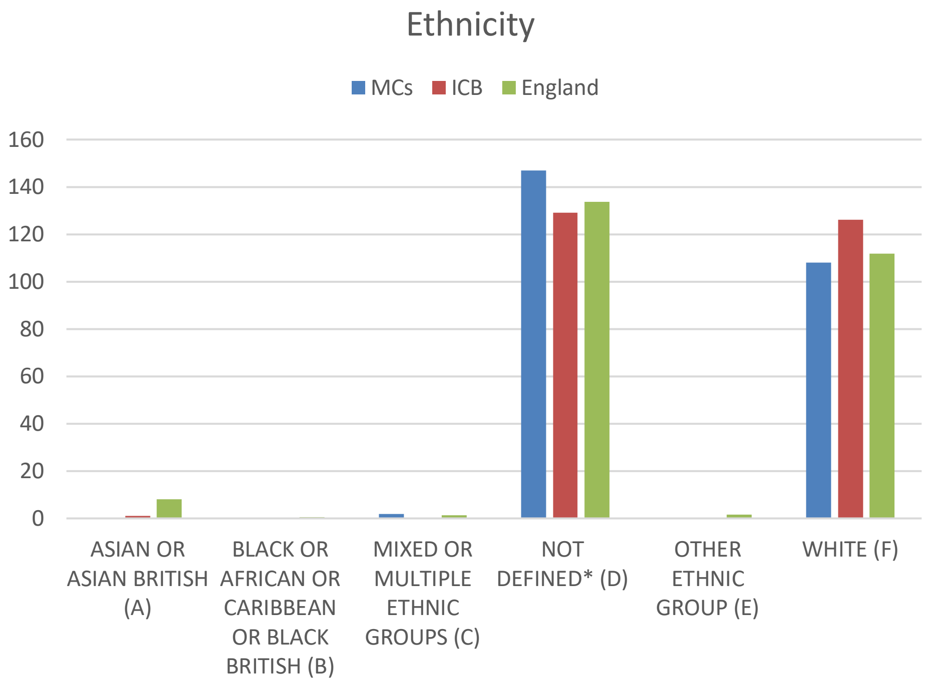
Only 28 MC carers have both age at time of joining and gender recorded, as shown in the following chart:



Although it is not possible to infer any statistical significance for such a small number of carers, the number of female carers (18 of 28) is roughly in keeping with a report by the Alzheimer's Association (2014) in the US, which states that women account for 63% of informal carers for people living with dementia. There would also appear to be a lack of male carers under the age of 65, which may not be surprising given that they are statistically less likely to have a caring role than females (ONS, 2013).

## Equality, Diversity and Inclusion

Of the 257 recorded MC members, 110 (43%) have ethnicity defined[6]. Of these 110, 108 (98%) identify as 'White'. The following chart includes records with undefined ethnicity, the number of which is higher for H&W MCs than would be expected in comparison to levels in H&W ICB and England for people with a dementia diagnosis (NHS Digital, 2022b). MC members who identify as 'White' account for 42% compared with 49% of people with a dementia diagnosis in H&W ICB and 43% in England. It is also clear that H&W ICB 'Asian', 'Mixed' and 'Other' populations are slightly lower and 'White' higher than for England as a whole (Ibid.) and that the MCs predominantly white population across these two counties is not unexpected:



The preponderance of people who identify as 'White' is also evident for H&W MC carers, accounting for all 36 carers with their ethnicity defined.

A more detailed breakdown of ethnicity is provided by data collected from H&W MCs, showing that 99 (97%) of the 102 members with more specific ethnic data

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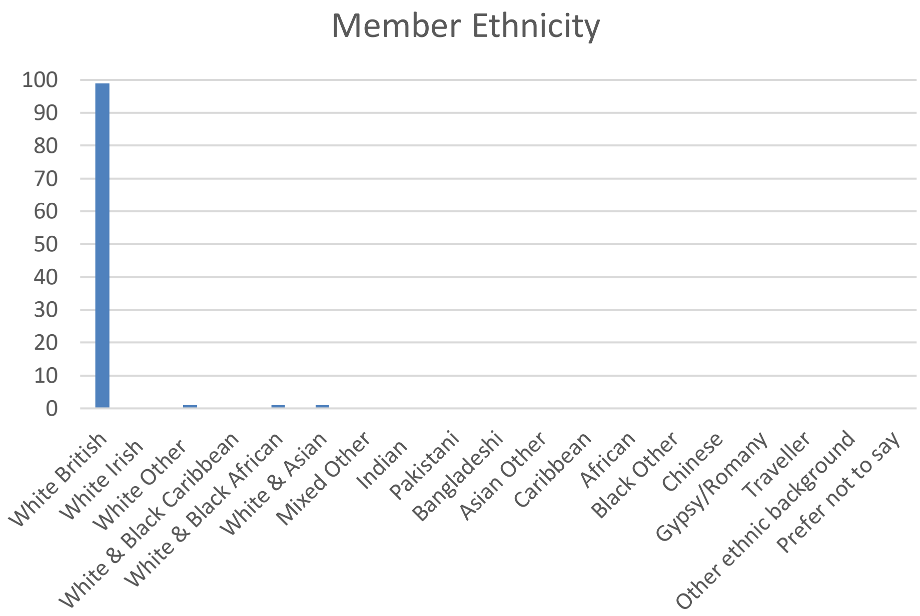
[6] NHS Digital classify undefined as "no data was given for race or the race is unknown" (NHS Digital, 2022d); for the purposes of MC data, undefined is used to denote members whose ethnicity is not recorded.

identify as ‘White British’, one member as ‘White Other’, one member as ‘White & Black African and one member as ‘White & Asian’:



Thirty-three of 34 carers with their ethnicity defined identified as ‘White British’ and one ‘White Other’. These findings appear slightly higher than might be expected considering the ethnic makeup of the H&W population which is comprised of 89% ‘White British’ and 11% Black and Minority Ethnic (BME) people (Nomis, 2021a). This may be an indication that a lower proportion of people from ethnic minorities are being diagnosed. However, the proportion of the older ‘White British’ people is likely to be higher than for the general population based on Census 2011 statistics (Nomis, 2011f), although the release of the most recent Census figures is needed to confirm this. The BME population of H&W is significantly lower than for England, which stands at 27% (Nomis, 2021a), with the highest proportions residing in the districts of Redditch and Worcester (NHS, 2020c)[7]. Additional MC data is needed, but currently suggests that the proportion of ‘White’ members may be slightly higher than expected.

## Minority groups in Herefordshire and Worcestershire

More than half of H&W residents identify as Christian, with the second largest religion being Muslim (Nomis, 2021b). Roughly 1% of the UK population aged 65+ identifies as lesbian, gay, bisexual or other (ONS, 2022f). Of the population of H&W aged 65+, this translates as 1,865 people (ONS, 2022c), 14 of whom are living with dementia based on dementia prevalence rates for England (NHS Digital, 2022a). It is also estimated that less than 1% of people in the UK are transgender, although there

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[7] At the time of writing this report, NHS population demographics were not available for H&W ICB.

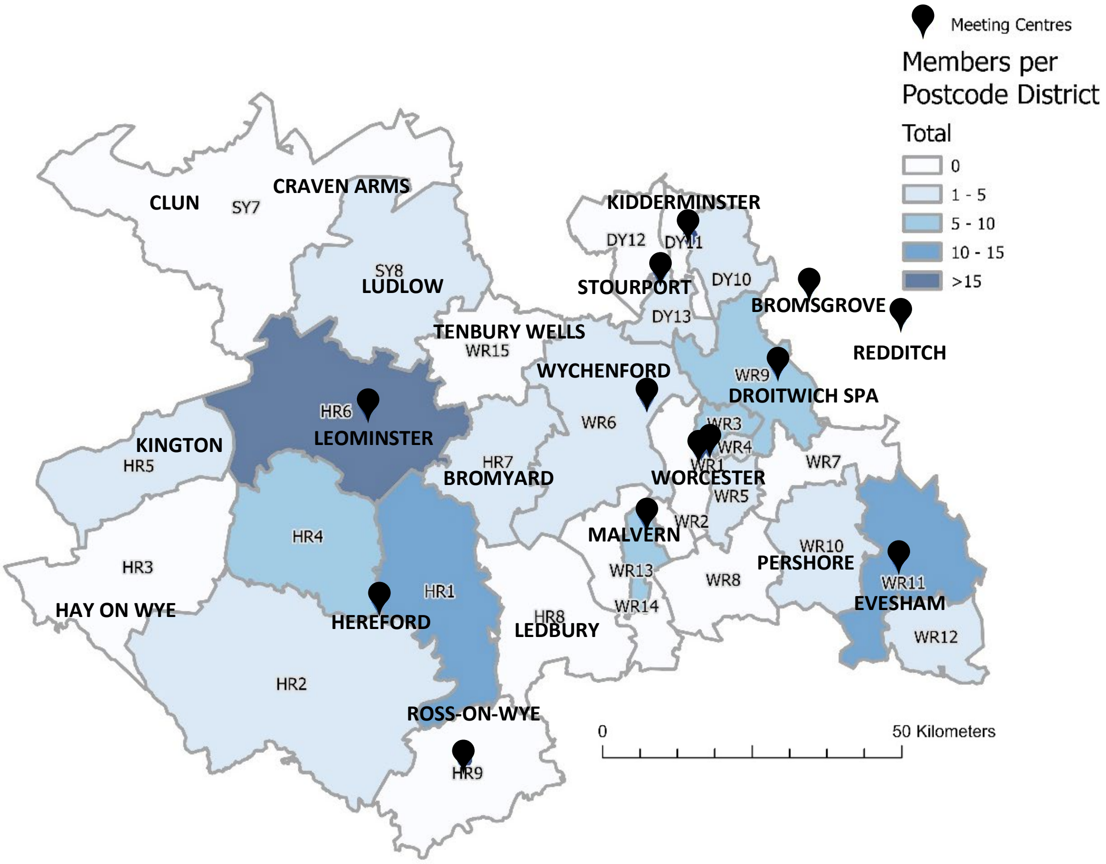
appear to be no official statistics published to very this data and no reference to age (Kelley and de Santos, 2022).

The most common non-British nationality within H&W is Polish, accounting for 2% of the population, with a higher proportion in Herefordshire than Worcestershire (ONS, 2022c; ONS, 2022e). A total of 1,848 (0.2%) people across H&W identify as 'White: Gypsy or Irish Traveller', which is double the 0.1% for England (Nomis, 2021a). In Herefordshire, this population live predominantly around Evesham and Hereford (NHS, 2020c).

It is not clear the extent to which the listed minority groups are represented within MC memberships as data categories do not include nationality, sexuality and religion. Given the small proportions of minority groups across H&W, it would not necessarily be expected for them to be statistically represented in the small number of MC members. However, these minorities are living in the community and there is a lack of data on the number of people within these groups who are living with dementia. It is possible that there are people within these minorities who are not being reached and who could benefit from the support of MC membership.

## Location and Status

The number of records that contain the first half of the member's postcode (outward code) is 132. Of these, 67 attend Herefordshire MCs and 65 attend Worcestershire MCs. The meeting centres for each county are indicated in the map below (Esri, 2015; tdixon911, 2020), accompanied by a breakdown of members by outward code, which show that MCs are reaching people from 25 postcode across H&W and parts of Shropshire and 19 of 24 (79%) HR and WR outward codes and that most recorded members are resident in HR6, HR1 and WR11:



| | | | | |
|---|---|---|---|---|
| **HR1** | **HR2** | **HR3** | **HR4** | **HR5** |
| 12 | 3 | 1 | 10 | 4 |
| **HR6** | **HR7** | **HR8** | **HR9** | **SY7** |
| 29 | 3 | 0 | 0 | 1 |
| **SY8** | **WR1** | **WR2** | **WR3** | **WR4** |
| 3 | 0 | 0 | 6 | 3 |
| **WR5** | **WR6** | **WR7** | **WR8** | **WR9** |
| 3 | 5 | 1 | 1 | 9 |
| **WR10** | **WR11** | **WR12** | **WR13** | **WR14** |
| 2 | 15 | 4 | 1 | 7 |
| **WR15** | **DY10** | **DY11** | **DY12** | **DY13** |
| 0 | 4 | 1 | 1 | 3 |

The population density of Herefordshire is the fourth lowest of counties/unitary authorities in England (ONS, 2022a), and although Worcestershire is geographically smaller by 439 sq. km (ONS, 2021), it is estimated to be far more densely populated, with 347 people per sq. km, compared to 86 in Herefordshire (ONS, 2022a).

The Unitary Authority of Herefordshire covers 2,180 sq. km (ONS, 2021). MC data indicates that members travel from seven of nine Herefordshire areas and from the neighbouring county of Shropshire to the Leominster MC. None of the recorded members have attended from HR8 and HR9. It is probable that Ross MC, located in

HR9 and for which no MC data is currently held, provides memberships for people living in these two areas.

The county of Worcestershire covers 1,741 sq. km (ONS, 2021). Worcestershire MC members attend predominantly from areas surrounding each MC. WR1 has no recorded members, with those attending the Worcester Bank House MC located in WR1 travelling from neighbouring areas. This may be due to the venue being located in Worcester town centre rather than in a residential area. Beyond this, people living in WR2, WR7, WR8, WR13 and WR15 appear to be the least reached.

The four most recently established MCs in Kidderminster, Stourport, Bromsgrove and Redditch have DY (Dudley) postcodes, although these fall under the county of Worcestershire. Kidderminster and Stourport appear to be drawing members from the areas immediately surrounding them; no location data is yet available for Bromsgrove and Redditch.

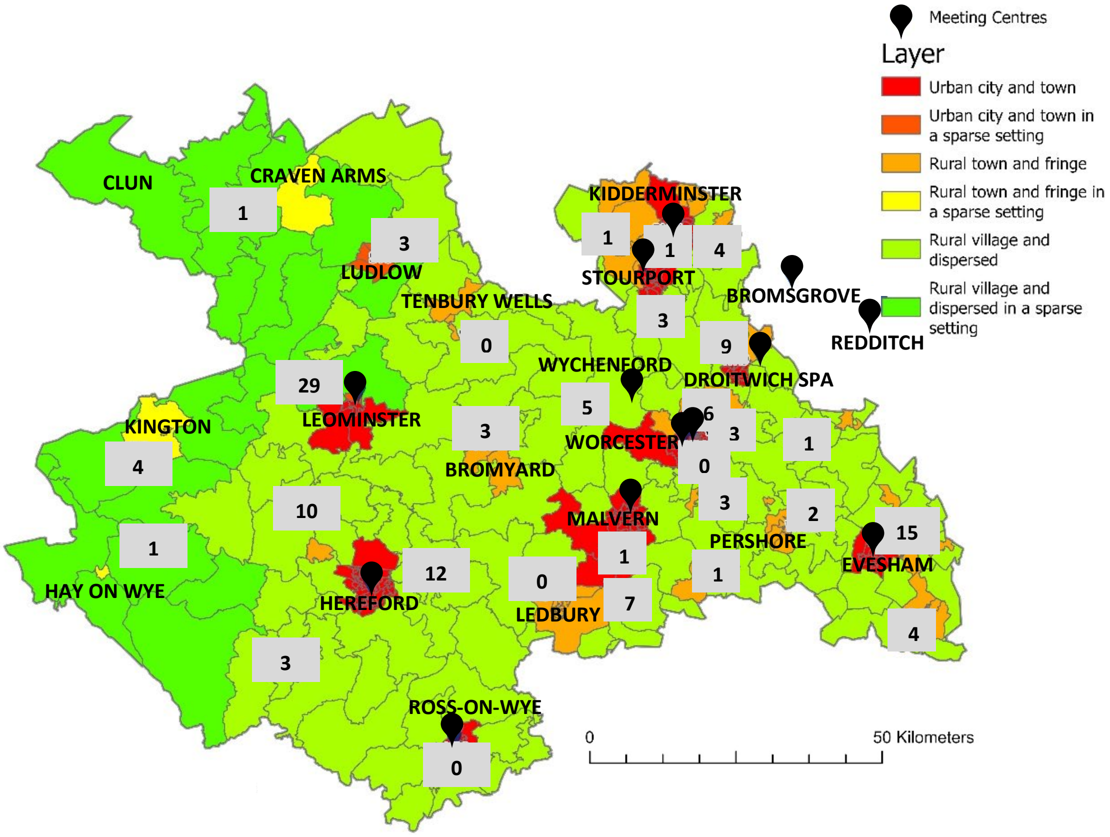
## Rurality

Herefordshire is a mainly rural county, with the latest estimated figures indicating that 47% of people live in urban areas compared to 53% living in areas classed as rural (Herefordshire Council, 2020). An even greater majority of residents living in rural areas are aged 65+, accounting for 61% people in this older age group (Ibid.). In contrast, 2011 Census (Nomis, 2011d) figures for Worcestershire show a much smaller proportion of 26% living in rural areas and of those aged 65+, 33% live rurally. Applying these statistics to current estimated population and dementia diagnosis figures (ONS 2022c; NHS Digital 2022a) offers indicative figures in the absence of current rural urban data:

| People aged 65+ | People aged 65+ diagnosed with dementia |
|---|---|
| • 29,571 live rurally in Herefordshire | • 1,016 live rurally in Herefordshire |
| • 45,552 live rurally in Worcestershire | • 1,570 live rurally in Worcestershire |
| • 75,123 live rurally in H&W | • 2,586 live rurally in H&W |

In addition, the number of people aged 65+ with a dementia diagnosis in H&W is estimated to be only 52% (NHS Digital, 2022a), which would equate to the number of people living with dementia rurally to be around 4,979.

The following map locates H&W MCs withing the Rural Urban Classification for H&W (Esri, 2015; tdixon911, 2020; ONSGeography_data, 2022) and shows the extent of rurality across the two counties. It is clear that the majority of MCs are in the most urban areas and that there is little provision in the most rural areas.



It appears that diagnosis can often occur later for people living with dementia in rural communities compared to urban areas (Alzheimer's Society, 2021). Reasons for this include reticence among people living with dementia in accessing services over concerns about the stigma of having a diagnosis and losing driving licenses (NHS, 2017). It may be that such stigma is also a factor influencing attendance of MCs.

According to the Alzheimer's Society (2018), people with dementia who live rurally can experience isolation:

> …the double jeopardy of living in a rural community and having dementia means many people feel excluded and disempowered, unable to access support, guidance and basic elements of community life like transport, shops, healthcare, pharmacies and banks.

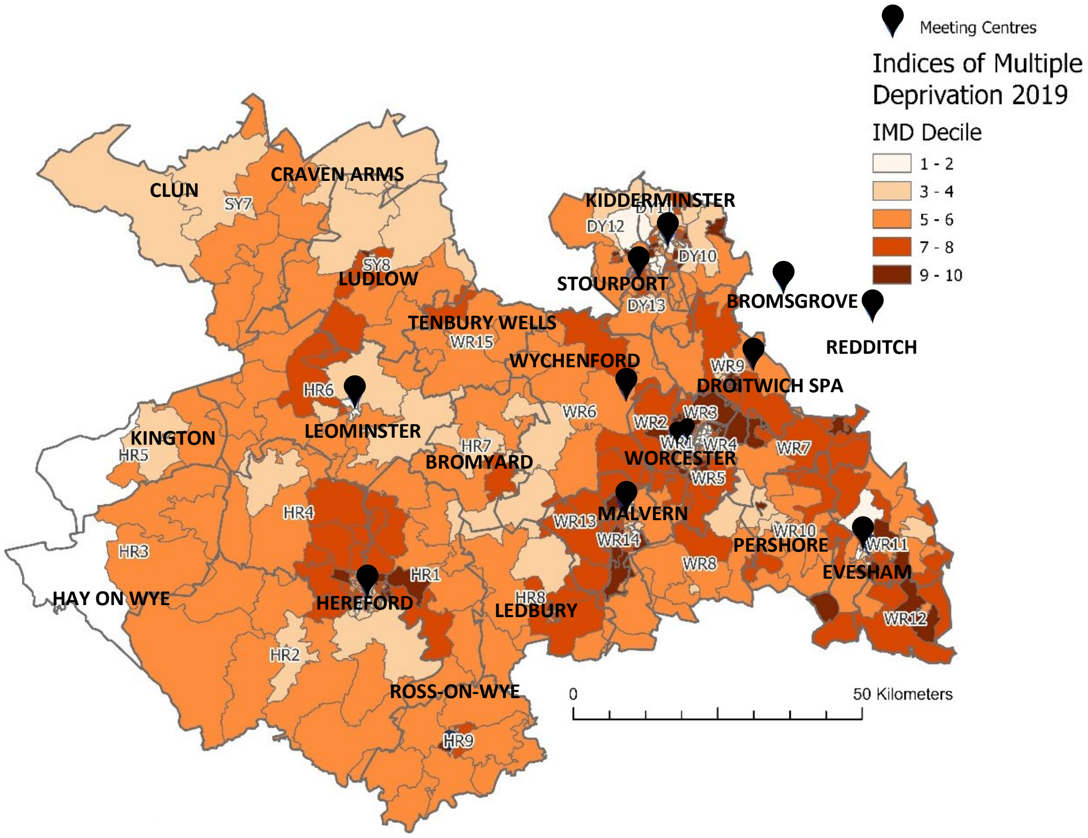
Among farming communities more specifically, living with dementia presents four particular arears of concern: working carer strain and hazards of the farm environment; a reluctance to ask for help and concerns over the impact on the running of farm businesses; lack of awareness of, engagement with and cost of accessing support services; changing rural communities resulting in less support (Gould, 2017). Research conducted by the University of Plymouth that identified these areas of concern (Ibid.) offers recommendations for farming communities to try and tackle these issues that could be helpful for MCs, and dementia support services more broadly, that serve rural communities. These issues potentially pose barriers for people living with dementia rurally to accessing diagnosis and support from services and communities, including MCs.

## Deprivation

The deprivation status of households in H&W is slightly below that of England (ONS, 2022g; ONS, 2022h). There are 170,971 households across H&W recorded as being deprived in one or more of the following dimensions: employment, education, health and disability and housing (ONS, 2022g). This figure accounts for 50% of the households in H&W, which is 2% below the number for England (ONS, 2022g; ONS, 2022h). Although it is not possible to determine the number of people with dementia living in deprived households from the available data, research suggests that there is an increased risk of dementia mortality and difficulties accessing diagnostic services as a result of socioeconomic deprivation (Jitlal et al., 2021).

Deprivation could pose barriers to MC attendance such as financial constraints, poor health, disability or homelessness. For people living with dementia, 91.8% also have at least one other health condition (Browne et al.,2017) and, across England, 18.7% of carers report their health as ‘bad’ or ‘very bad’ (NHS Digital, 2022e). Between April 2021 to March 2022, 2,480 households were assessed as either homeless or at risk of homelessness across H&W (GOV.UK, 2022b). Of these, 120 primary applicants were aged 65+ (Ibid.). Applying the national statistic of dementia prevalence for people aged 65+ of 7% (NHS, 2020b) to these primary applicants would indicate that eight people with dementia are either homeless or at risk of homelessness in H&W.

MCs in H&W tend to be situated in or near areas of lower levels (7-10) of deprivation as shown in the map below (Esri, 2015; tdixon911, 2020; AGOLportaladmin, 2020). There are few areas with the highest levels of deprivation (1-4). However, the areas with mid-high levels (1-6) tend to be further from MCs, meaning it may be harder for people from more deprived areas to access their support.

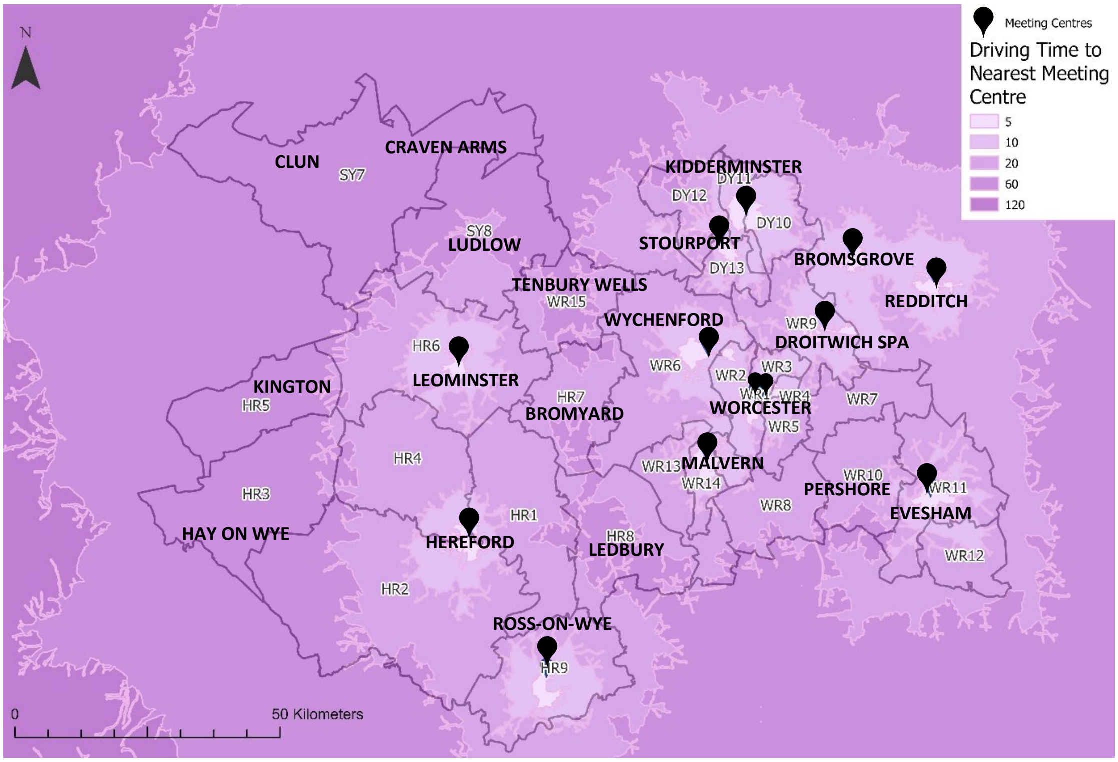


## Transport

According to the 2011 census (Nomis 2011b, Nomis 2011c), 17% of households across H&W counties do not have a car or van. This figure is 9% lower than for England as a whole (Nomis 2011d), yet still significant, equating to 77,121 households at the time where all persons were aged 65+. Given that 7% of people aged 65+ are living with dementia (NHS, 2020b), it can be estimated that around 5,398 of these households without a car or van included a person with dementia. Such households without their own transport are likely to be dependent upon other friends, family and public transport to access community services such as MCs.

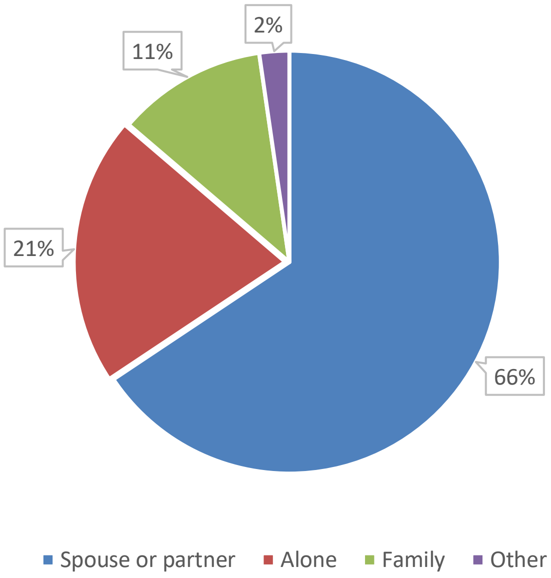
For those in rural areas across H&W, public transport is also an issue, as many rural villages do not have access to a daily bus service (NHS, 2020c) and bus users in Worcestershire currently face challenges that require a dedicated task force to address (Worcestershire County Council, 2022b). Of people aged 65+ living in Herefordshire, 53% of those living alone live rurally (Nomis, 2011e). This figure is more than double that for England (Ibid.) and may have increased given the 8.3% rise in the number of people living alone in the past 10 year (ONS, 2022i). People with dementia who live alone in rural areas may face additional transport barriers (Alzheimer's Society, 2022) that could impact on their ability to access community-based support such as MCs. Although only one H&W MC member cited transport issues as their reason for leaving (see Meeting Centre Membership), it is possible that lack of transport may be preventing other potential members from joining at all.

The driving distance and time to an MC may also be a factor for some, as the nearest MC is an hour or more from several areas, particularly in Herefordshire, as shown in the following map (Esri, 2015; tdixon911, 2020).



## Living Situation and Relationships

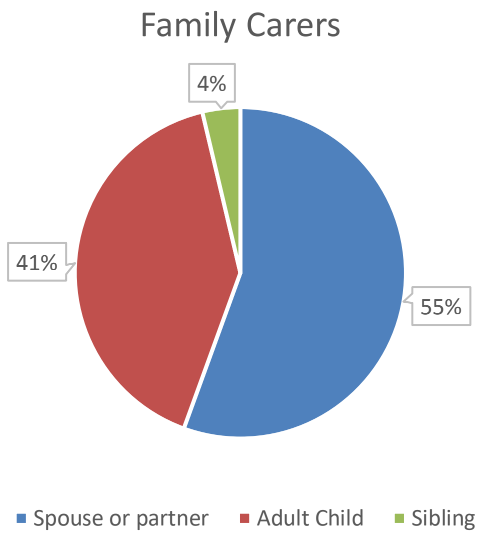
Of the 131 MC members whose living situation is recorded, two-thirds are listed as living with a spouse or partner:



It is likely that >29% of people aged 65+ in H&W live alone given the 8.3% increase in UK figures since the Census 2021 (ONS, 2022i; Nomis, 2011e). Of people with dementia, estimates suggest that a third (33%) live alone (Mirando-Costillo et al, 2010). Of MC members, 27 of 131 (21%) are recorded as living alone. This number equates to 16 fewer members than would be expected for those with their living situation recorded, so it would appear that there are barriers for people living alone to attending an MC. These barriers hold potential for further investigation and could include the organisation and transport to and from MCs and the challenge of trying a new activity alone.

According to 2011 figures, 11% of people provide one or more hours of unpaid care across H&W counties (Nomis 2011b, Nomis 2011c), just slightly above the 10% for England (Nomis, 2011c). Nationally, the largest group (20%) of all informal carers living in the same household are caring for spouse/civil partner/cohabitee (Department for Work and Pensions, 2022a). If the spouses/partners who live with members are also care providers, they would account for more than three times the number than would be expected. However, this caring role cannot be assumed from the data, as care may not be needed or may be provided by external family or care professionals.

Of the 54 family carers of members recorded[8], 30 (55%) are spouses or partners, 22 (41%) are adult children (including sons/daughters-in-law) and two (4%) are siblings:



These figures differ from the findings of three American surveys that indicate more than half of family carers for people with dementia are adult children and less than a quarter are spouses or partners (Riffin et al., 2017; University of Michigan, 2017; Fisher et al., 2011). This apparent disparity suggests that there may be barriers to attendance for people with dementia and their adult child carers that reinforce the

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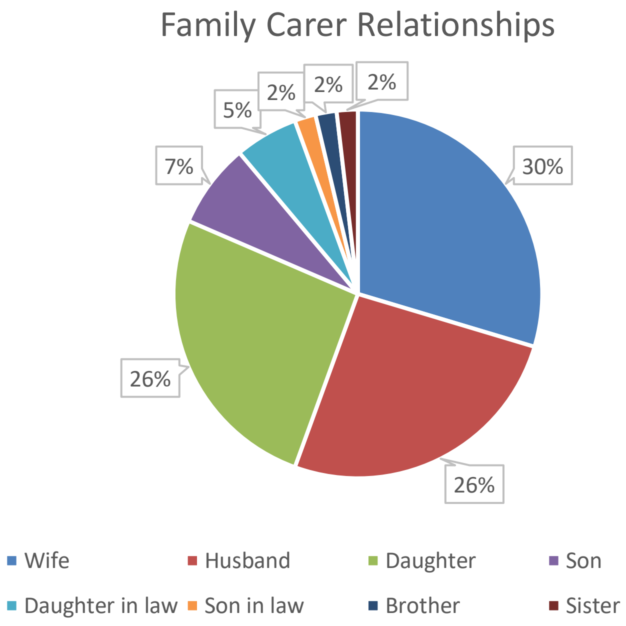
[8] Members may have more than one carer recorded.

earlier indication that there are fewer younger (aged <65) people caring for MC members than would be expected (see Age).

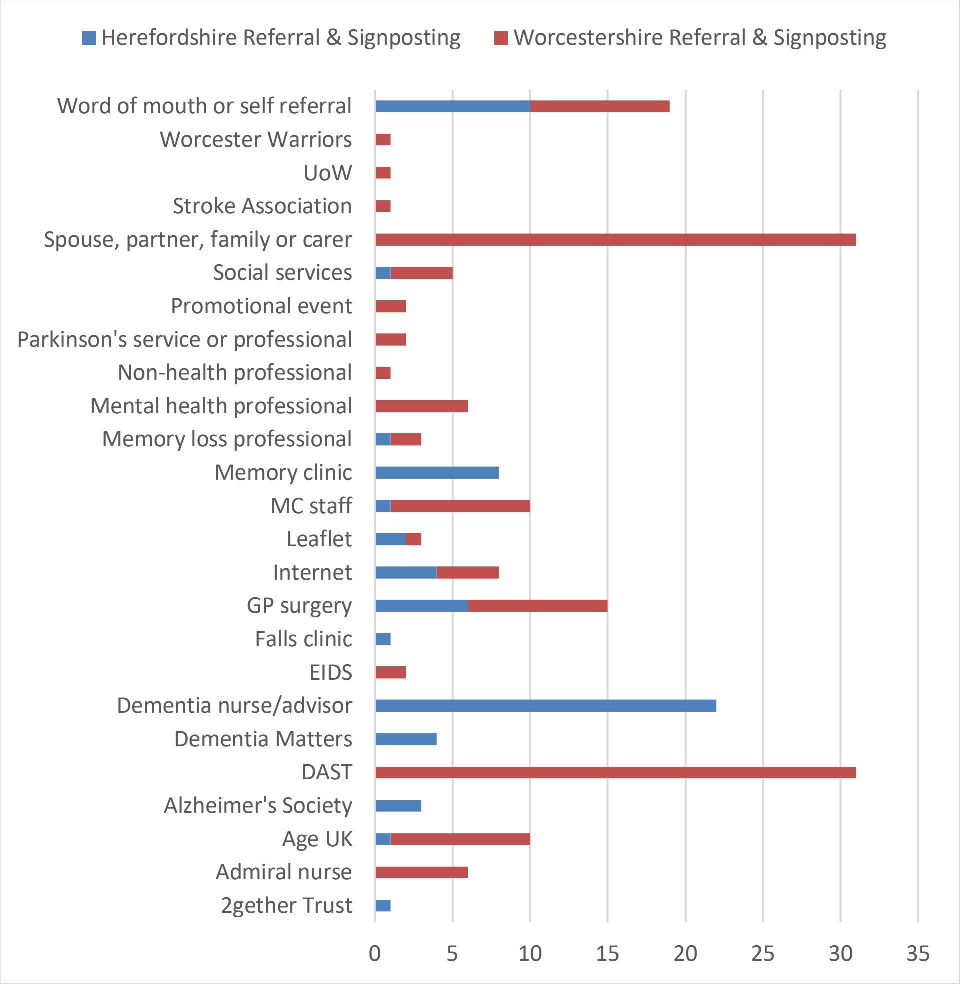
In a breakdown of relationship types, wives, husbands and daughters account for the three largest groups:



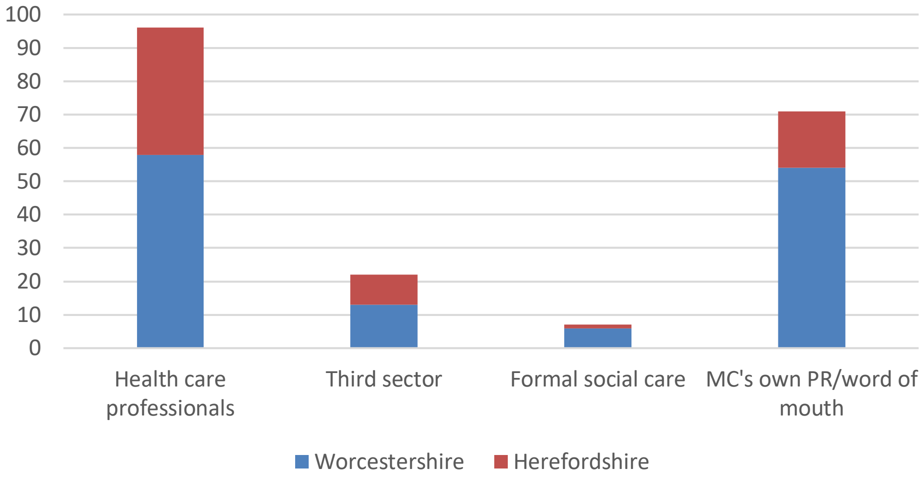
Here again, MC figures differ, if only slightly, from US statistics. According to Kasper et al (2015) and Friedman et al. (2015), more than a third of family and unpaid dementia carers are daughters. Friedman et al (2015) place spousal carers as the fourth largest group after daughters, sons and other family carers respectively. In addition to MC family carers, one paid carer is recorded.

## Referral & Signposting

The most common source of referral or signposting to an MC recorded for Herefordshire is via a dementia nurse/advisor, accounting for 22 of 65 (34%) recorded sources, followed by 10 (15%) word of mouth and 8 (12%) from a memory clinic. For Worcestershire, the most common routes of referral or signposting have been through the Dementia Assessment and Support Team (DAST) that operated in previous years, or through spouse, partner, family or carer; each accounting for 31 of 131 (24%). It is unclear from the data whether the source spouse, family or carer is self-referral following information being sought or from signposting.



When grouped by referral or signposting type[9], these figures show that, for H&W, most come through healthcare professionals (49%) followed by MCs' awareness raising and informal channels (36%):



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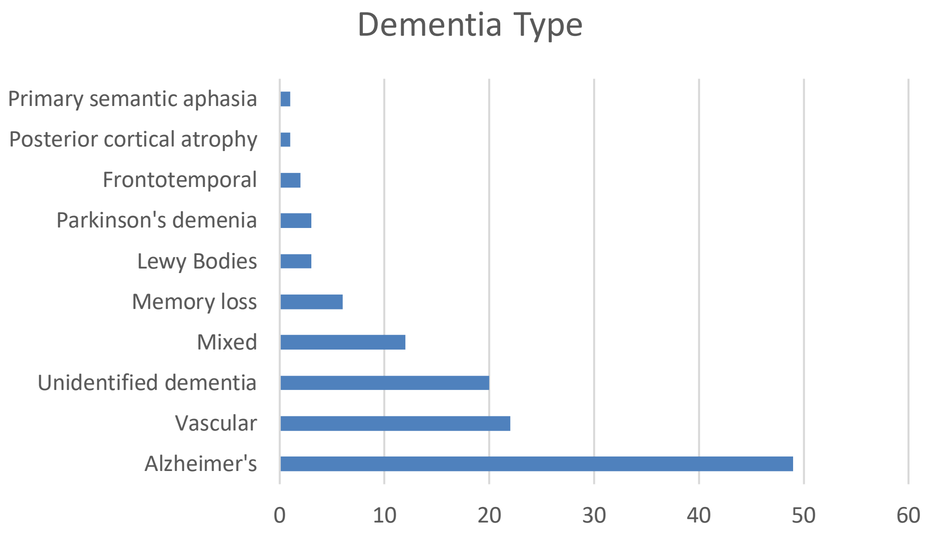
[9] For the purposes of the chart, Admiral Nurses are classed as healthcare professionals although they are employed by a third sector organisation.

Although it is not possible to determine whether lack of referral or signposting is a barrier to attendance without further research, these figures offer a strong indication for targeted awareness raising among professionals, particularly in the third and social care sectors, and development of PR materials to promote MC memberships, particularly in Herefordshire. They also indicate that spouses, family and other carers can be an important part of the referral and signposting process. It may be helpful to understand more about their role to better support MC referrals and signposting.

## Dementia diagnosis

Of the 119 H&W MC member records with a dementia diagnosis listed, 93 identified a specific dementia type and 26 reported an unidentified dementia or memory loss. The Alzheimer's type is recorded for the largest group of 49 members (41%). Vascular is recorded for 22 members (18%) and mixed dementia for 12 members (10%):



The three most common dementia types correlate with those recorded for the UK as Alzheimer's, vascular and mixed dementias (GOV.UK, 2022a). The greatest difference between MC and UK figures is seen for Alzheimer's type with a 9% difference that equates to 9 fewer members than expected[10] (GOV.UK, 2022a; Alzheimer's Society, 2014):

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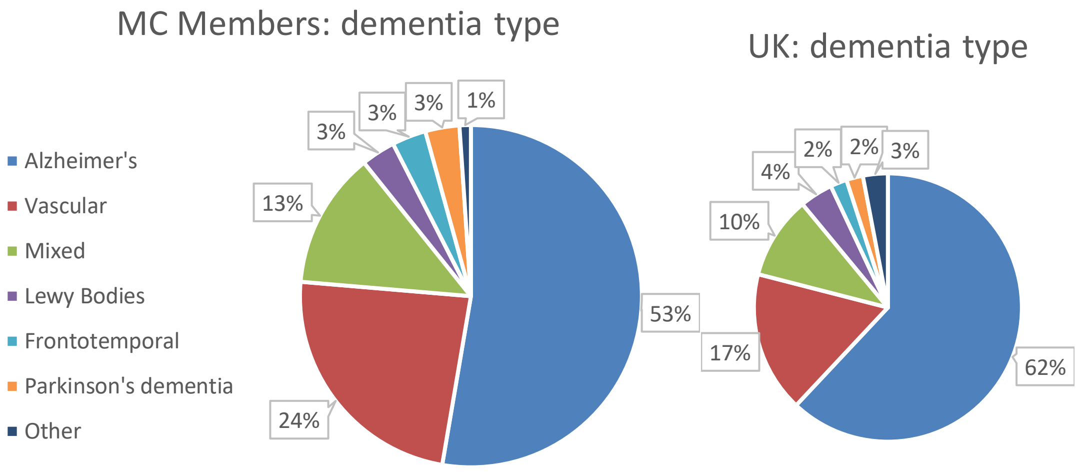
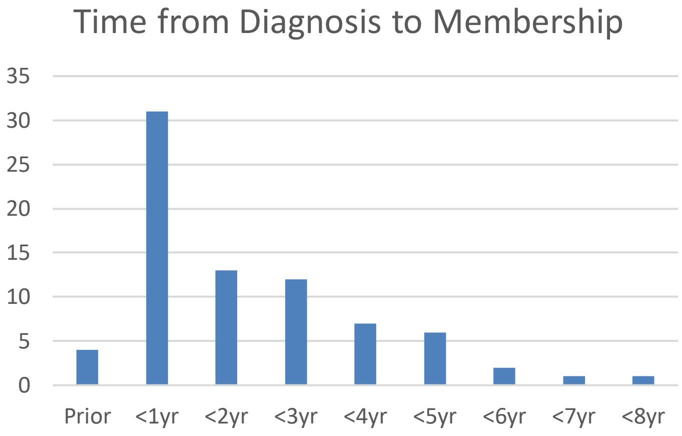
[10] For the purposes of this chart, primary semantic aphasia has been included in frontotemporal dementia as a subtype (University of California San Francisco, 2022)



The most common time interval between diagnosis and joining an H&W MC for the 77 members with the relevant dates recorded is up to one year, with 48 members (62%) joining prior to or within two years following diagnosis:



The average time from recorded diagnosis until the need for institutional care for people living with dementia is 3.9 years (Joling, 2020). The Adjusting to Change model offered by MCs is intended to support people to "…make good emotional, social and practical adjustment following diagnosis" towards the goal "…that they will experience fewer distressing symptoms later and will be able to live at home for longer with a better quality of life for them and their families" (University of Worcester, 2022, 7). It is to be assumed that the sooner individuals and their families are supported to adjusting to change in this way, the more helpful it will be to them. The fact that 29 members (38%) joined MCs two to seven years following diagnosis indicates the need to identify and address any barriers that are preventing earlier MC membership to maximise benefit. These barriers include timely diagnosis, especially in H&W ICB, given that is has the lowest diagnosis rate in England (NHS Digital, 2022a).

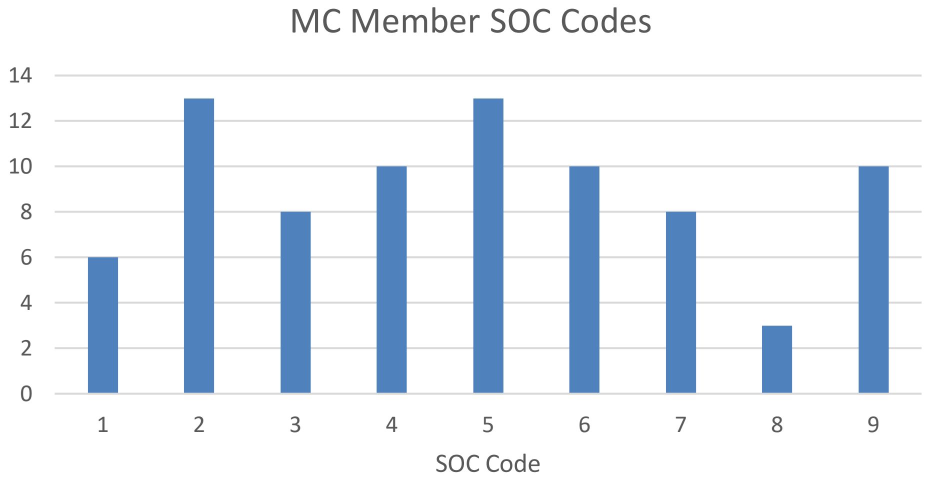
The length of time diagnosis takes is also an issue, with only 26% of patients in the UK being diagnosed within the six-week target timeframe, and some waiting as long as 34 weeks (Cook, Souris and Isaacs, 2020; Department of Health, 2016). It is important to note that the recent COVID-19 pandemic has had a detrimental impact on the dementia diagnosis pathway and data, with waiting times for diagnosis reaching up to 104 weeks (Corrado et al., 2022; NHS Digital 2022a; Alzheimer's Society, 2020). Parker et al. (2021) identify stigma impeding discussion between families and with healthcare professionals as a factor that can also delay diagnosis.

## Previous Occupation

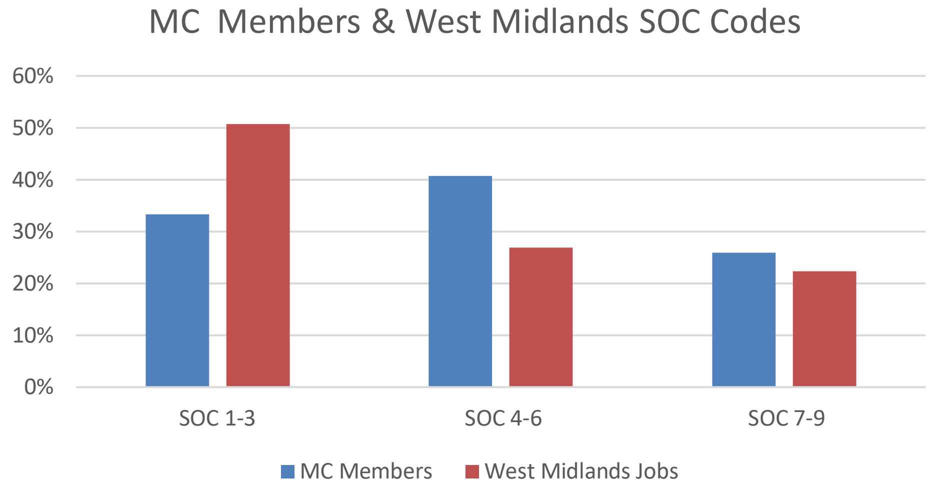
Previous occupations recorded for H&W MC members and carers have been assigned Standard Occupational Classification (SOC) hierarchy codes by major group (ONS, 2020) on a 'best guess' basis to offer a broad picture of socioeconomic class:

1. Managers, directors and senior officials
2. Professional occupations
3. Associate professional occupations
4. Administrative and secretarial occupations
5. Skilled trades occupations
6. Caring, leisure and other service occupations
7. Sales and customer service occupations
8. Process, plant and machine operatives
9. Elementary occupations

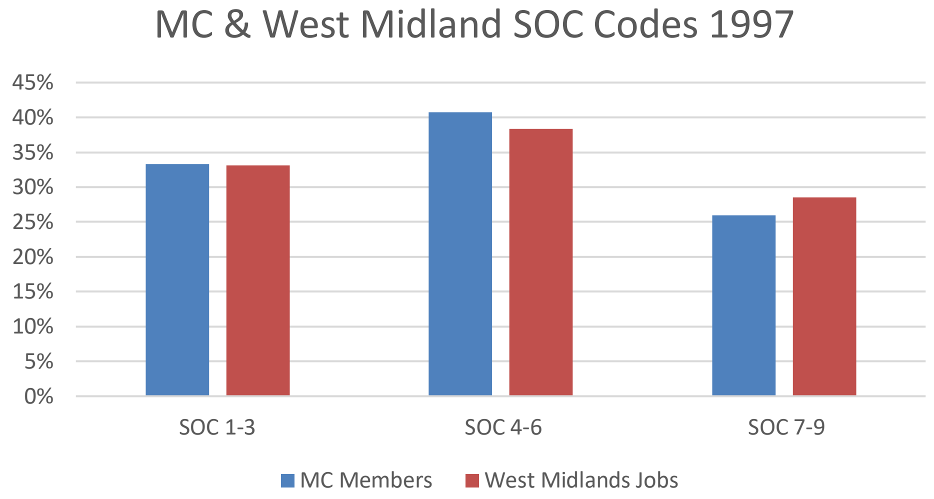
Of the 81 members whose recorded previous occupation correlates with a SOC code, occupations with mid-range incomes (groups 4-6) are most represented. Twenty-seven members (33%) fall within groups 1-3, 33 (41%) within groups 4-6 and 21 (26%) within groups 7-9:



When compared to the latest job figures for the West Midlands (ONS, 2022j), there are 14 (17%) fewer members than would be expected in groups 1-3, 11 (14%) more members in groups 4-6 and three (4%) more in groups 7-9:



These figures raise a question over whether H&W MCs are not reaching or appealing to people in the 'upper' socioeconomic groups as much as to 'mid' and 'lower' groups. However, the socioeconomic makeup of the West Midlands appears to have changed over time. When compared with the earliest West Midlands job figures available from 1997 (ONS, 2022k) when the majority of members would have been below the age of 65 years, there only remains a difference of two members more/less in the mid and lower range groups, indicating that the socioeconomic status of MC members was fairly representative at that time:



# Conclusion

## Barriers to Meeting Centre Attendance

It is clear that only a small proportion of the eligible H&W population who could potentially benefit from MC membership attend H&W MCs. It is also apparent that many of those who do attend, are not doing so until as many as eight years post diagnosis. These members and their families could potentially experience more benefit from earlier MC support. The findings from this study indicate the following possible barriers to attendance for potential members in H&W:

**Diagnosis**
Proportion and time targets are not being met

**Transport**
Personal and public forms of transport are not available to many, especially in rural areas

**Provision**
MCs are not available in all areas of Herefordshire.

**Rurality**
Isolation and challenges specific to people who live rurally, particularly from farming communities, can pose barriers to accessing support

**Finances**
The cost of attending an MC may pose a financial barrier for some potential members

**Stigma**
Diagnosis and access to services can be delayed due to stigma, and may influence the willingness of potential members to attend MCs

This report has also highlighted that there are potentially barriers to attending MCs for the following groups of people with dementia and/or their carers that are yet to be identified:

**Females living with dementia**

**Males living with dementia aged <70**

**People with dementia living alone**

**People living with dementia in the community within H&W more broadly, given the low number that attend MCs**

**Younger family carers aged <65**

**Adult child carers**

**Male carers aged <65**

## Limitations

Gaps in the data provided by MCs (see Appendix) and the publicly available demographic data relevant to MCs, locally and nationally, limit the conclusions that can be drawn in this report. The data in this report is also limited by factors associated with the COVID-19 pandemic. Further data is needed in the following areas:

| |
|---|
| **MC demographic data** |
| **BME people and other minority groups living with dementia**<br>This is particularly pertinent to commissioners aiming to tackle equality, diversity and inclusion |
| **Publicly available UK statistics on age, gender and familial relationship of family/informal dementia carers** |
| **NHS digital local dementia diagnosis datasets to include people of all ages, not only those aged 65+** |
| **More comprehensive NHS dementia diagnosis data collection and publication for Wales** |
| **Publicly available UK statistics on deprivation, aging and dementia** |
| **Publicly available UK statistics on the transgender population, aging and dementia** |

## Further Research

Moving forwards, the following topics stand out as holding potential for further exploration for H&W MCs, in addition to the barriers to attendance identified above (see Barriers to Meeting Centre Attendance):

| |
|---|
| **The role of family carers in referral and signposting** |
| **Support for resuming attendance following a break such as respite** |
| **How MCs support people with dementia experiencing anxiety and agitation, disputes and those who do not offer a clear reason for leaving** |
| **Comparison of MC attendance and barriers with other community dementia interventions and services** |

# Appendix: MC Data Overview

The following table shows the number of records for H&W MC members and carers within each demographic category:

| **Members** | **MC 1** | **MC 2** | **MC 3** | **MC 4** | **MC 5** | **MC 6** | **MC 7** | **MC 8** | **MC 9** | **MC 10** | **MC 11** | **All** |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **No. of members** | 71 | 22 | 13 | 6 | 32 | 9 | 88 | 6 | 5 | 3 | 2 | 257 |
| **DOB** | 66 | 22 | 8 | 0 | 13 | 5 | 31 | 5 | 4 | 0 | 0 | 154 |
| **Postcode** | 67 | 22 | 8 | 0 | 8 | 5 | 13 | 5 | 4 | 0 | 0 | 132 |
| **Gender** | 71 | 22 | 13 | 6 | 24 | 9 | 15 | 6 | 5 | 3 | 0 | 174 |
| **Previous occupation** | 60 | 21 | 0 | 0 | 0 | 0 | 3 | 0 | 0 | 0 | 0 | 84 |
| **Ethnicity** | 67 | 22 | 0 | 0 | 0 | 0 | 12 | 5 | 4 | 0 | 0 | 110 |
| **Living situation** | 67 | 22 | 8 | 0 | 8 | 5 | 12 | 5 | 4 | 0 | 0 | 131 |
| **Referral/ signposting** | 65 | 22 | 9 | 0 | 8 | 5 | 78 | 5 | 4 | 0 | 0 | 196 |
| **Dementia type** | 62 | 22 | 9 | 0 | 8 | 5 | 13 | 0 | 0 | 0 | 0 | 119 |
| **Diagnosis date** | 59 | 17 | 0 | 0 | 0 | 0 | 3 | 0 | 0 | 0 | 0 | 79 |
| **Joining date** | 68 | 22 | 8 | 1 | 9 | 0 | 13 | 6 | 5 | 3 | 2 | 137 |
| **Leaving date** | 39 | 8 | 1 | 0 | 3 | 0 | 12 | 0 | 2 | 0 | 0 | 65 |
| **Reason for leaving** | 33 | 8 | 1 | 0 | 5 | 1 | 29 | 0 | 2 | 0 | 0 | 79 |

| **Carers** | **MC 1** | **MC 2** | **MC 3** | **MC 4** | **MC 5** | **MC 6** | **MC 7** | **MC 8** | **MC 9** | **MC 10** | **MC 11** | **All** |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **No. of carers** | 63 | 21 | 3 | 1 | 12 | 5 | 18 | 0 | 0 | 0 | 0 | 123 |
| **DOB** | 32 | 19 | 2 | 0 | 4 | 0 | 18 | 0 | 0 | 0 | 0 | 75 |
| **Postcode** | 27 | 21 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 49 |
| **Gender** | 36 | 21 | 2 | 1 | 12 | 5 | 2 | 0 | 0 | 0 | 0 | 79 |
| **Previous occupation** | 2 | 20 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 23 |
| **Ethnicity** | 14 | 21 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 36 |
| **Living situation** | 15 | 20 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 36 |
| **Relationship to member** | 28 | 21 | 3 | 0 | 2 | 0 | 1 | 0 | 0 | 0 | 0 | 55 |
| **Joining date** | 28 | 21 | 1 | 0 | 2 | 0 | 1 | 0 | 0 | 0 | 0 | 53 |
| **Leaving date** | 22 | 9 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 31 |
| **Reason for leaving** | 19 | 9 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 28 |

# References

AGOLportaladmin (2020) “LSOA (IMD 2019)_public” [Feature layer]. Scale: 1:577,791. “Public feature layer view of "LSOA_All_Data" showing IMD 2019 data only”. Jun 12, 2020. https://worc.maps.arcgis.com/home/item.html?id=c36d15e0067947c0afe027039122a519. (Dec 15, 2022).

Alzheimer’s Association (2022) 2022 Alzheimer’s Disease Facts and Figures. Available at: https://www.alz.org/alzheimers-dementia/facts-figures (Accessed: 02 November 2022)

Alzheimer’s Association (2014) Women and Dementia: A Marginalised Majority. Available: https://www.alzheimersresearchuk.org/about-us/our-influence/policy-work/reports/women-dementia/ (Accessed: 24 November 2022)

Alzheimer’s Society (2022) Staying active as a person with dementia. Available: https://www.alzheimers.org.uk/get-support/staying-independent/dementia-staying-active-community (Accessed: 07 November 2022)

Alzheimer’s Society (2021) Regional variation: Increasing access to a dementia diagnosis. Available: https://www.alzheimers.org.uk/sites/default/files/2021-09/regional_variations_increasing_access_to_diagnosis.pdf (Accessed: 07 November 2022)

Alzheimer’s Society (2020) Alzheimer’s Society comment on how coronavirus is affecting dementia assessment and diagnosis. Available: https://www.alzheimers.org.uk/news/2020-08-10/coronavirus-affecting-dementia-assessment-diagnosis (Accessed: 09 June 2022)

Alzheimer’s Society (2018) People with dementia in rural communities increasingly isolated , Available: https://www.alzheimers.org.uk/news/2018-10-09/people-dementia-rural-communities-increasingly-isolated (Accessed: 07 November 2022)

Alzheimer’s Society (2014) Dementia UK: Second edition – Overview. Available: https://www.pssru.ac.uk/pub/Dementia_UK_Second_edition_-_Overview.pdf (Accessed: 09 November 2022)

Browne, J., Edwards, D.A., Rhodes, K.M., Brimicombe, D.J. and Payne, R.A. (2017) Association of comorbidity and health service usage among patients with dementia in the UK: a population-based study. BMJ Open 2017;7:e012546. doi: 10.1136/bmjopen-2016-012546. Available: https://bmjopen.bmj.com/content/7/3/e012546 (Accessed 10 November 2022)

Cook, L. Souris, H. and Isaacs, J. (2020) The 2019 national memory service audit, Dementia Clinical Network, NHS England and Improvement (London Region). Available: https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2020/04/The-2019-national-memory-service-audit.pdf (Accessed: 09 November 2022)

Corrado, O., Essel, R., Fitch-Bunce, C., Garling, E., Hood, C., Nicholls, D., Quirk, A. and Swanson, B. (2022) Royal College of Psychiatrists: National Audit of Dementia Memory Assessment Services Spotlight Audit 2021. Available: https://www.hqip.org.uk/resource/national-audit-of-dementia-memory-assessment-services-spotlight-audit-2021/#.Y2tsO-TP02x (Accessed: 09 November 2022)

Department of Health (2016) Prime Minister’s Challenge on Dementia 2020: Implementation plan. Available: https://www.gov.uk/government/publications/challenge-on-dementia-2020-implementation-plan (Accessed: 09 November 2022)

Department for Work and Pensions (2022a) Family Resources Survey: financial year 2020 to 2021. Available at: https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2020-to-2021 (Accessed: 08 November 2022)

Department for Work and Pensions (2022b) Care Data Tables. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1063013/Ch5_Care.xlsx (Accessed: 02 November 2022)

Esri. (2015) "Light Gray Canvas" [basemap]. Scale Not Given. " Light Gray Canvas Map". November 13, 2015. https://www.arcgis.com/home/item.html?id=979c6cc89af9449cbeb5342a439c6a76. (Dec 15, 2022).

Fisher, G., Franks, M., Plassman, B., Brown, S., Potter, G., and Llewellyn, D. (2011) Caring for individuals with dementia and cognitive impairment, not dementia: Findings from The Aging, Demographics, and Memory Study. J Am Geriatr Soc, 59(3), 488-94. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3646395/ (Accessed: 08 November 2022)

Friedman EM, Shih RA, Langa KM, Hurd MD. (2015) U.S. prevalence and predictors of informal caregiving for dementia. Health Aff, 34(10):1637-41. Available: https://www.healthaffairs.org/doi/10.1377/hlthaff.2015.0510?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%3dpubmed (Accessed: 08 November 2022)

Gould, A. (2017) Rural dementia – we need to talk. Available: https://www.plymouth.ac.uk/news/rural-dementia-nil-we-need-to-talk (Accessed: 07 November 2022)

GOV.UK (2022a) Official Statistics: Statistical commentary: Dementia profile, March 2021 update. Available: https://www.gov.uk/government/statistics/dementia-profile-updates/statistical-commentary-dementia-profile-march-2021-update (Accessed 09 November 2022)

GOV.UK (2022b) Statistical data set Live tables on homelessness: Detailed local authority level tables: Financial Year 2021-22. Available: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1105929/Detailed_LA_2021-22.ods (Accessed: 07 November 2022)

Herefordshire Council (2020) 2020-mid-year-population-of-lsoas-wards-parishes. Available: https://understanding.herefordshire.gov.uk/population/population-around-the-county/ (Accessed: 07 November 2022)

Herefordshire Council (2019) Future population estimates for sub-localities in Herefordshire, analysis tool. Available: https://understanding.herefordshire.gov.uk/population/ (Accessed: 31 October 2022)

Jitlal, M., Amirthalingam, G., Karania, T., Parry, E., Neligan, A., Dobson, R., Noyce, A. and Marshall, C. (2021) The Influence of Socioeconomic Deprivation on Dementia Mortality, Age at Death, and Quality of Diagnosis: A Nationwide Death Records Study in England and Wales

2001–2017. 1 Jan: 321 – 328. Available: https://content.iospress.com/articles/journal-of-alzheimers-disease/jad210089 (Accessed: 10 November 2022)

Joling, KJ, Janssen, O, Francke, AL, et al. (2020) Time from diagnosis to institutionalization and death in people with dementia. Alzheimer's Dement, 16: 662– 671. Available: https://alz-journals.onlinelibrary.wiley.com/action/showCitFormats?doi=10.1002%2Falz.12063 (Accessed: 09 November 2022)

Kasper JD, Freedman VA, Spillman BC, Wolff JL. (2015) The disproportionate impact of dementia on family and unpaid caregiving to older adults. Health Aff, 34(10):1642-49. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4635557/ (Accessed: 08 November 2022)

Kelley, N. and de Santos, R. (2022) Rainbow Britain Report. Available: https://www.stonewall.org.uk/system/files/rainbow_britain_report.pdf (Accessed: 05 November 2022)

Miranda-Castillo C, Woods B, Orrell M. (2010) People with dementia living alone: what are their needs and what kind of support are they receiving? Int Psychogeriatr. Jun;22(4):607-17. Available: https://www.cambridge.org/core/journals/international-psychogeriatrics/article/abs/people-with-dementia-living-alone-what-are-their-needs-and-what-kind-of-support-are-they-receiving/6AE02C5BA023C45A8A5A79F6A30B6963 (Accessed 08 November 2022)

NHS (2022) NHS Herefordshire and Worcestershire: About. Available: https://herefordshireandworcestershire.icb.nhs.uk/about-us (Accessed: 28 Ocober 2022)

NHS (2020a) Dementia. Available at: https://www.england.nhs.uk/mental-health/dementia/ (Accessed 07 November 2022)

NHS (2020b) About Dementia: Dementia Guide. Available at: https://www.nhs.uk/conditions/dementia/about/ (Accessed 07 November 2022)

NHS (2020c) Herefordshire and Worcestershire Clinical Commissioning Group: Our Population. Available: https://herefordshireandworcestershireccg.nhs.uk/about-us/our-population (Accessed: 05 November 2022)

NHS (2017) Mental Health Intensive Support Team NHS England & NHS Improvement: Dementia Diagnostic Review: South Worcestershire CCG and Worcestershire Health and Care Trust. Available: http://education.worcestershire.nhs.uk/EasySiteWeb/GatewayLink.aspx?alId=144204 (Accessed: 07 November 2022)

NHS Digital (2022a) Recorded Dementia Diagnoses, September 2022: Summary. Available at: https://files.digital.nhs.uk/87/0749A5/dem-diag-sum-Sep-2022.xlsx (Accessed: 31 October 2022)

NHS Digital (2022b) Recorded Dementia Diagnoses by Ethnicity, September 2022. Available at: https://files.digital.nhs.uk/99/F1F257/rec-dem-sicbl-Sep-2022.csv (Accessed: 28 October 2022)

NHS Digital (2022c) Recorded Dementia Diagnoses by 5 Year Age Bands for 65+, September 2022: Sub ICB Location level. Available at: https://files.digital.nhs.uk/5D/BA7AEE/dem-diag-sicbl-quin-Sep-2022.csv (Accessed: 28 October 2022)

NHS Digital (2022d) *NHS Digital data on Recorded Dementia Diagnoses Enquiry*. [email].

NHS Digital (2022e) Personal Social Services Adult Social Care Survey (ASCS). Available: https://files.digital.nhs.uk/B8/E75BA3/pss-ascs-eng-report-2021-22.pdf (Accessed 10 November 2022)

Nomis (2021a) TS022 - Ethnic group (detailed). Available: https://www.nomisweb.co.uk/query/construct/summary.asp?mode=construct&version=0&dataset=2095 (Accessed 01 December 2022)

Nomis (2021b) TS030 – Religion. Available: https://www.nomisweb.co.uk/query/construct/summary.asp?mode=construct&version=0&dataset=2049 (Accessed 01 December 2022)

Nomis (2011a) Herefordshire, County of Local Authority: Local area report. Available at: https://www.nomisweb.co.uk/reports/localarea?compare=E06000019 (Accessed: 04 November 2022)

Nomis (2011b) Worcestershire County: Local area report. Available at: https://www.nomisweb.co.uk/reports/localarea?compare=E10000034 (Accessed: 04 November 2022)

Nomis (2011c) England Country: Local area report. Available at: https://www.nomisweb.co.uk/reports/localarea?compare=E92000001 (Accessed: 04 November 2022)

Nomis (2011d) Table KS102EW: 2011 Census: Age structure. Available: https://www.nomisweb.co.uk/census/2011/ks102ew (Accessed: 09 November 2022)

Nomis (2011e) QS112EW - Household composition – People. Available: https://www.nomisweb.co.uk/query/construct/summary.asp?reset=yes&mode=construct&dataset=512&version=0&anal=1&initsel= (Accessed: 20 June 2022)

Nomis (2011f) DC2101EW - Ethnic group by sex by age. Available: https://www.nomisweb.co.uk/census/2011/dc2101ew (Accessed: 01 December 2022)

ONS (2022a) Population and household estimates, England and Wales: Census 2021. Available from: https://www.ons.gov.uk/file?uri=/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationandhouseholdestimatesenglandandwalescensus2021/census2021/census2021firstresultsenglandwales1.xlsx (Accessed 28 October 2022)

ONS (2022b) Age by single year (Countries): TS007. Available from: https://ons-dp-prod-census-publication.s3.eu-west-2.amazonaws.com/TS007_resident_age_101a/UR-ctry%2Bresident_age_101a.xlsx (Accessed 07 November 2022)

ONS (2022c) Age by single year (Upper Tier Local Authorities): TS007. Available from: https://ons-dp-prod-census-publication.s3.eu-west-2.amazonaws.com/TS007_resident_age_101a/UR-utla%2Bresident_age_101a.xlsx (Accessed 07 November 2022)

ONS (2022d) Preliminary counts of country of birth by local authority data from the 2021 Census - CT21_0001v4 - Selected countries of birth based on Census 2021 responses. Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/adhocs/14354ct210001 (Accessed 05 November 2022)

ONS (2022e) E CT21_0001v4 - Selected countries of birth based on Census 2021 responses. Available: https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/adhocs/14354ct210001 (Accessed: 05 November 2022)

ONS (2022f) Sexual orientation, UK. Available: https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/sexuality/datasets/sexualidentityuk (Accessed: 04 November 2022)

ONS (2022g) Households by Deprivation Dimensions (Upper Tier Local Authorities): TS011. Available: https://ons-dp-prod-census-publication.s3.eu-west-2.amazonaws.com/TS011_hh_deprivation/HH-utla%2Bhh_deprivation.xlsx (Accessed 07 November 2022)

ONS (2022h) Households by Deprivation Dimensions (Countries): TS011. Available: https://ons-dp-prod-census-publication.s3.eu-west-2.amazonaws.com/TS011_hh_deprivation/HH-ctry%2Bhh_deprivation.xlsx (Accessed 07 November 2022)

ONS (2022i) Families and households in the UK: 2021. Available: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/families/bulletins/familiesandhouseholds/2021 (Accessed: 07 November 2022)

ONS (2022j) Earnings and hours worked, region by occupation by two-digit SOC: ASHE Table 3, 2022 Provisional edition. Available: https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/earningsandworkinghours/datasets/regionbyoccupation2digitsocashetable3 (Accessed: 09 November 2022)

ONS (2021) Estimates of the population for the UK, England and Wales, Scotland and Northern Ireland. Available : https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland (Accessed: 07 November 2022)

ONS (2020) SOC 2020 Volume 2: the coding index and coding rules and conventions (Version 6, 14 Feb 2022). Available at: https://www.ons.gov.uk/methodology/classificationsandstandards/standardoccupationalclassificationsoc/soc2020/soc2020volume2codingrulesandconventions (Accessed 04 May 2022)

ONS (2013) Full story: The gender gap in unpaid care provision: is there an impact on health and economic position? Available: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/articles/fullstorythegendergapinunpaidcareprovisionisthereanimpactonhealthandeconomicposition/2013-05-16#unpaid-care-provision-by-age-and-sex (Accessed: 24 November 2022)

ONSGeography_data (2022) “Rural Urban Classification (2011) of Lower Layer Super Output Areas in England and Wales” [Table]. Aug 11, 2022. https://worc.maps.arcgis.com/home/item.html?id=803b5eba7f6f4c998b7d2c5be6729693. (Dec 15, 2022).

Parker, M., Barlow, S., Hoe, J. and Aitken, L. (2021) The Bubble of Normalisation: A Qualitative Study of Carers of People With Dementia Who Do Not Seek Help for a Diagnosis. J Geriatr Psychiatry Neurol.

Riffin, C., Van Ness, P., Wolff, J. and Fried, T. (2017) Family and other unpaid caregivers and older adults with and without dementia and disability. J Am Geriatr Soc, 65(8), 1821-8. Available: https://agsjournals.onlinelibrary.wiley.com/doi/10.1111/jgs.14910 (Accessed: 08 November 2022)

tdixon911 (2020) "United Kingdom Postcode District Boundaries 2019" [feature layer]. Scale: 1:1,155,581. Jul 14, 2020. https://worc.maps.arcgis.com/home/item.html?id=a52fe238cef84e30b0a65dcf8018c272. (Dec 15, 2022).

University of Worcester (Association for Dementia Studies) (2022) The Essential Features of a Meeting Centre. Available: https://www.worcester.ac.uk/documents/Essential-Features-of-a-Meeting-Centre-booklet-May22.pdf (Accessed 31 October 2022)

University of California San Francisco (2022) Weill Institute for Neurosciences: Semantic Variant Primary Progressive Aphasia. Available: https://memory.ucsf.edu/dementia/primary-progressive-aphasia/semantic-variant-primary-progressive-aphasia (Accessed: 09 November 2022)

University of Michigan (2017) National Poll on Healthy Aging. Dementia Caregivers: Juggling, Delaying and Looking Forward. Available: http://www.healthyagingpoll.org/sites/default/files/2017-10/NPHA_Caregivers-Report-PROOF_101817_v2.pdf (Accessed: 08 November 2022)

Worcestershire County Council (2022a) Population Statistics and Projections. Available: https://www.worcestershire.gov.uk/info/20044/research_and_feedback/795/population_statistics (Accessed: 31 October 2022)

Worcestershire County Council (2022b) Bus travel task force will be set up in Worcestershire. Available: https://www.worcestershire.gov.uk/news/article/2873/bus_travel_task_force_will_be_set_up_in_worcestershire (Accessed: 07 November 2022)

# About Us

The Association for Dementia Studies is a multi-professional university research centre with many years of experience in the field of person-centred dementia care and support. People living with dementia, their families and their carers inform our work at all stages.

Through its research, education programmes and knowledge transfer activities the Association for Dementia Studies (ADS) has touched the lives of many people since it was established in 2009. Further information can be found on our website www.worcester.ac.uk/dementia. We work proactively at the interface between the experience of those living with dementia, those developing practice and those undertaking research to ensure real knowledge transfer and translation between these different world-views. ADS have a strong track record in working collaboratively with many care providers and charities.

We are committed to a person-centred approach in all our work. This is our ethical code that encompasses all our relationships both within our team and in our education and research collaborations. This includes people living with dementia their families and carers and those of us who are privileged to work in this area. It is a code that values all people as unique individuals, tries to see things from the viewpoint of the other and recognises the interdependence of all of us.  We are committed to raising awareness, challenging stigma and improving quality of life and wellbeing.

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# Get Real with Meeting Centres

## Herefordshire and Worcestershire Meeting Centres: barriers to attendance and recommendations for how to address them

**Report**

MEETING CENTRES UK

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# Overview

Sustaining Meeting Centre provision for people affected by dementia over time can be challenging. To investigate the sustainability of Meeting Centres, the Association for Dementia studies has launched the Get Real with Meeting Centres project (Morton et al., 2022), funded by the National Institute for Health and Care Research (NIHR, 2021). The aim of this research is to support Meeting Centres to keep running and flourish in the longer term through better understanding the challenges they face.

A challenge to sustainability is getting and keeping members, as only a small proportion of those who might benefit from Meeting Centre support attend. This report identifies barriers to people joining and attending Meeting Centres on a regular basis in Herefordshire and Worcestershire, based on interviews with relevant stakeholders. These barriers cover seven broad themes:

*Unmet support needs*
*Costs*
*Health*
*Meeting Centres*
*Perceptions*
*Dementia Pathway*
*Travel*

To address these barriers, recommendations are offered to people running Meeting Centres, professionals involved in the dementia pathway and potential members and those who care for them. These recommendations cover four broad themes:

*Meeting needs*
*Transforming perceptions*
*Improving inclusion & raising awareness*
*Transforming practice*

The barriers and recommendations contained in this report are relevant to Meeting Centres and their communities across Herefordshire and Worcestershire and may be transferrable to others across the UK.

# Background

From their introduction to the UK in 2015, the Association for Dementia Studies (ADS) has supported and evaluated the development Meeting Centres (MCs) to help address gaps in the support available to people affected by dementia (University of Worcester, 2022a). Community groups initiate and run MCs as local social clubs, providing on-going social care that is accessible and supports people in adapting to the changes that dementia brings. Funded by the subscriptions of paying members, grants and fundraising, MCs offer a low-cost form of community support for people living with dementia and their families.

The first two UK MCs were established in Herefordshire and Worcestershire. The number of MCs has since expanded across these two counties and the UK. Sustaining MC provision in the longer term is a challenge and so ADS research has responded by seeking to understand and support their sustainability, particularly in rural areas where this can be most difficult. The Get Real project (Morton et al., 2022) is funded by the National Institute for Health and Care Research (NIHR, 2021) and builds on a prior theoretical study (Morton et al., 2021) to gain the views of stakeholders involved in MCs that have continued to run for more than three years. Guided by service users and members of the public, this study involves MC staff and members at all stages. The findings will form a basis to developing user friendly guidance and materials to promote the sustainability and growth of more MCs and inform policy makers and governments about the support that is needed from them.

Early indications from the Get Real project show that those who attend the three case study sites located in Herefordshire, Powys and Worcestershire are only a fraction of those diagnosed with dementia in each locality, highlighting a need to expand the project's original aims and objectives to include the following:

**Aims**

1. To understand who the MCs are reaching, appealing to and helping, and who they are not.
2. To provide a clear indication on the equality of access to support and where new strategies and further work needs to be focused to ensure that the needs of the whole community are met in the post-diagnostic phase in dementia.

**Objectives**

1. To determine whether those who attend MCs are representative of the local diagnosed population.

2. To identify if there are any particular barriers for people who do not attend or are not being reached (e.g. from certain demographics or with certain personal circumstances).

   In conjunction with a demographic report looking at the profile of people who access MCs, this report forms a basis for tackling disparities and overcoming barriers to accessing MC support. Insufficient demographic data necessitated a focus on the counties of Herefordshire and Worcestershire (H&W) for this part of the Get Real project, excluding Powys. Of the 13 MCs operating in H&W, 10 have been established for only one to two years. Within Worcestershire, nine of the 10 MCs were initiated since the Covid-19 pandemic restrictions eased. This report identifies barriers to MC attendance experienced by people living with dementia who are non-attenders, their family carers/supporters, dementia pathway professionals and MC staff from across H&W.

## Design

In order to understand who the MCs are reaching, appealing to and helping, and who they are not, interviews were conducted with people living with dementia in H&W, and family members/supporters who care for them. Interviews were also conducted with MC staff and professionals who provide referrals and signposting to services and support for people with dementia living in the community. All participants were aware of MCs. Interviewees living with dementia did not attend an MC at the time of interview and only one had attended a taster session.

We recruited six managerial MC staff members involved in the running of 12 of the 13 MCs[1] across H&W, and nine health care and third sector professionals who could offer referrals and signposting to these MCs. We also recruited three people living with dementia, two family carers and one person in a supporting role. These recruitment figures met our planned requirement for a convenience sample.

Staff involved in the running of H&W MCs were approached directly and relevant professionals were identified through existing ADS research and practice networks, and via MC staff interviews. Participants with dementia and family carers were identified through a ‘snowballing’ process via interviews with professionals and MC staff and liaison with representatives from organisations supporting related conditions and dementia friendly communities. These gatekeepers gained consent from individuals/dyads meeting the inclusion criteria to pass on their contact details to the researcher. Favourable ethical opinion was given by Wales REC4 for this additional work package within the Get Real project in May 2022 (21/WA/0185). The

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[1] Current in 2022

ethical considerations are covered in a separate publication for the overarching project (Morton et al., 2022).

# Methods

## Interviews

Each individual/dyad was asked to participate in one interview or focus group of up to one hour. The location for interviews was determined by participant preference as either face-to-face or by telephone/video call. Interviews were informal and followed a simple topic guide to aid discussion.

The following table shows the breakdown of the 15 interviews/focus groups conducted by stakeholder role and interview type:

| | Individual | Joint | Focus group |
|---|---|---|---|
| **Staff** | 6 | - | - |
| **Professionals** | 3 | - | 1 |
| **Nonattender individuals/dyads** | 3 | 2 | - |

## Data analysis

In accordance with the methodology for the overarching Get Real project, a realist approach to evaluating the data was taken. The aim of this approach is to explain how and why outcomes are influenced by different contexts as a means to understand and account for social complexity (Pawson and Tilley, 1997).

The interviews and focus groups were recorded and transcribed. These were anonymised and uploaded into NVivo, qualitative data analysis management software, and the data relevant to barriers to MC attendance were coded inductively to form broad themes. A random transcript sample of 10% was checked independently by a member of the Get Real research team at ADS. Checked transcripts were discussed for consistency and the relevance of data to developing understanding of the barriers to MC attendance. Data were organised into themes, which were gradually refined throughout the analysis process based on our interpretations of the emerging data.

Context sensitive cause-and-effect within realist evaluations are explained using the concept of context-mechanism-outcome configurations (CMOCs). One way that CMOCs may be expressed is in the form of ‘if-then-because’ statements. The realist logic of analysis was applied to the data within each theme to derive ‘if-then-because' statements that explicated how, why, for whom and under what circumstances barriers to MC attendance arose in the data. These statements constituted our CMOCs, uncovering the cause-and-effect factors evident within the data. These CMOCs were then grouped to form recommendations for overcoming barriers to MC attendance (see Appendix 1 and Recommendations). These CMOCs and recommendations will also be combined with the results of other work packages within the Get Real project to create an overall theoretical model, with recommendations, regarding what might help or hinder the sustainability of Meeting Centres.

# Barriers to MC attendance: CMOCs

From analysis of the data, seven broad themes were identified encompassing 24 CMOCs (A-X), which are listed in Appendix 2. In this section of the report, each CMOC is presented by theme, alongside supporting quotes from interviews. Only quoted examples that were deemed most pertinent are included for brevity. All CMOCs[2] evident within interview data are provided for inclusivity, even if discussed by only one participant. For quotes, pseudonyms are used for anonymity.

## Theme 1: Unmet support needs

For potential and returning members to access MCs, the need for support from a variety of sources including family, professionals, Meeting Centres and animals were identified by interview participants.

### CMOC A. Lack of support

Lack of support can pose a barrier to MC attendance for people with dementia who face a range of challenges, including personal care, family carer availability and health, transport and organisation. This appears a particularly pertinent barrier for people who live alone or as a couple with dementia.

**CMOC A:** If a person/couple do not have someone to help them when going out, they may be unable to attend because they cannot manage getting ready/getting to/being at the MC without additional support

> *My mum for times and dates and appointments it is a no go, she will forget. That is going to be a massive factor for someone on their own. (Family carer)*

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[2] One additional CMOC was identified specific to the Covid-19 pandemic that is intended for inclusion in a separate publication

*...I have had people ring and say, I've got this person but I work so I can't bring them and they won't come with anybody else. (MC staff)*

*...it is that person living on their own that needs help or shown where the toilet is and waiting for outside the toilet. (Professional)*

*...transport...that can be quite a challenge. Again, particularly for people who are living on their own and haven't got...a partner...or family member who could take them and pick them up. (Professional)*

*...a lot of my people have same aged carers, and a lot don't have children... they've got their own health issues and things as well...The carer themselves may have deteriorated. (MC staff)*

*I just think that's such a hard barrier...not to be able to go...because you're incontinent...I know there's a lot of people that would have gone and enjoyed it, but they can't go... (Professional)*

### CMOC B. Membership disruption

MC membership can be disrupted for various reasons, including respite care and hospitalisation. People returning to membership following such a disruption may need additional support to make the transition.

**CMOC B:** If there is a disruption to a person's attendance due to poor health, then members may stop attending altogether because they do not have the energy or support to overcome their health issues to re-engage and re-establish their previous routine

*...there's a period of other illness...and then the mobility drops and that's where people stop...so spouses or carer being unwell, patient being unwell...there's a sudden stopping...and then you don't get back into it. (Professional)*

### CMOC C. Language

Language can be a barrier to communication for people affected by dementia whose primary language is not that spoken at an MC. This may be exacerbated for people living with dementia as their condition progresses, as use of primary language can increase (Goth, U.S. and Strøm, 2018; McMurtray et al, 2009).

**CMOC C:** If a person affected by dementia has challenges communicating in the language the MC uses, then they may not attend because they find the language barrier too difficult to overcome.

*...we couldn't really communicate with him 'cause he was Polish, plus he'd got the dementia, he was in a strange place with strange people. He didn't know where he was, his family had gone and...it was distressing for him... (Professional)*

### CMOC D. Pets

For some people living with dementia, the companionship of animals plays an important role in daily life (Alzheimer's Society, 2022a). Leaving a pet behind to attend an MC can pose a barrier.

**CMOC D:** If a person has strong attachments to a pet then they may not be able to attend an MC because their pet cannot accompany them or they are unwilling to leave them

*...I've had a couple of people...who are incredibly attached to their dogs and live on their own. And there is no way they're gonna leave their dog to go out, so that's one definite barrier...They just would not feel comfortable leaving their dog at home because they're kind of like a safety net. (Professional)*

## Theme 2: Costs

The costs involved in attending an MC can be unaffordable or seen as not offering value for money. However, it may be possible for people living with dementia to receive financial support to help with costs, such as Attendance Allowance or Personal Independence Payments (Alzheimer's Society,2022b).

### CMOC E. Affordability

The cost of membership can vary between MCs, and there can be additional costs involved for people to attend such as paying for transport and care. For some, these costs can be a barrier to attendance.

**CMOC E:** If the costs involved in attending and accessing an MC (including transport) are perceived as too great or not affordable then potential members may not attend because they are unable or unwilling to pay the involved costs

*(Interviewer) ...the meeting centre, do you think it's something that you might like to try and attend?*

*(Person living with dementia) I think no...I have support at home...Purchase...And so priority.*

*If you're being supported by…paid carers coming in…a couple of times a day…it would be incredibly expensive to pay for four hours and then come in to the Meeting Centre… (Professional)*

*…transport…is an issue. And…costs as well now because fuel costs and…cost of taxis are going up…certainly, for some people, that can be quite a challenge. (Professional)*

### CMOC F. Attendance duration

Attending an MC for a whole day may not always be possible or desirable for potential members, who may then not wish to pay fees for a whole day.

**CMOC F:** If an MC charges a daily rate but a potential member is unable or unwilling to attend for the duration of that day then they may not attend because they may feel they are not receiving value for money

*I've got one chap…he likes to come for the short periods but not the whole day, and then he's like "Well I don't want to have to pay £25 to come for a couple of hours"…he tends to come to us in a morning then goes off somewhere to a café for lunch…I've got a couple that only come for two or three hours…it is a lot of money if you're not getting your money's worth (Professional)*

## Theme 3: Health

Dementia symptoms or other health conditions can prevent MC attendance for both existing and potential members.

### CMOC G. Challenges presented by symptoms

For people living with dementia, anxiety and agitation can communicate feelings and needs (Sandilyan and Dening, 2015) and in some instances can be supported within MCs but may also be a barrier to attendance. Toilet problems and sensory issues including increased sensitivity and impairment, are also common (Rhodus et al., 2022; Alzheimer's Society, 2021a; Social Care Institute for Excellence, 2020). Symptoms may result is some people being unwilling to attend due to the challenges of the environment or feeling self-conscious around others.

**CMOC G:** If a person's condition leads to symptoms such as distress in unfamiliar places, sensory sensitivity or incontinence then they may not attend an MC because they find the environment/group setting too challenging

*I react to sensory overload…it's a real thing called hyperacusis…it's one of the reasons I don't go very often to centres like that. (Person living with dementia)*

*…it's only just recently…that he's been a little bit a stick-in-the-mud…I just wish that we could persuade him… (Carer)*

*It would upset him and I won't say frighten but nearly, it's on those borders… (Carer)*

*…you'll have people that get very anxious, they'll get in there and they'll panic… (Professional)*

*…we've had members that need to go to the toilet all the time…so that sometimes puts people off, they get embarrassed about that. (MC staff)*

## Theme 4: Meeting Centres

MCs themselves can present barriers to attendance in the ways that they are run, their accessibility and their environments.

### CMOC H. Activities

Group activities plays a central role in the life of an MC and the contribution, interests and strengths of members are intended as the basis for activity planning and development (University of Worcester, 2022b). It seems that activities need to be carefully selected and planned as they can be a barrier to attendance, for example if they are unfamiliar or have associations with childhood. Sufficient staff and resources are also needed to plan and provide suitable activities.

**CMOC H:** If MC activities lack sufficient staff and resources and are not planned with awareness of people's needs and interests then people may not attend/refer/signpost because they may perceive the activities as unfamiliar, unsuitable, uncomfortable or poorly implemented

*…I can't imagine my husband sitting there, he wouldn't enjoy that at all…I don't know quite what it is, but it's not something that he would comfortably do …they've got the flag, why, why are they doing that…? (Carer)*

*…when you walk into a meeting centre, you don't necessarily need to look at crayons and colouring books on a table…somebody I know…wouldn't go and he said it's cause he'd feel like he was in play school. (Professional)*

*I don't think that can be underestimated if you're trying to run…a day from ten to three for a group of people with very different needs…that's a huge amount of time to organise… constructive activities... (Professional)*

*...I do think people can end up spending a lot of time just sitting...you've got [the manager] and volunteers and I'm not sure that is adequate really to do what is needed. (Professional)*

## CMOC I. Supporting members

People who are unfamiliar with MCs may need additional time and support in adapting to membership, requiring greater staff capacity. Finding funding can be an ongoing challenge and MCs are less able to provide quality support if they are under resourced meaning that people may be less likely to attend as a consequence.

**CMOC I:** If MCs are insufficiently staffed and resourced then people may be less likely to attend because staff will not have the time and energy to support potential new members into the MC

*I've had a lot of...emails...voicemail...I must have sent out at least 30 lots of information...And because I've just been on my own, I haven't been able to follow it up as I'd have liked to. (MC staff)*

*...trying to get hold of somebody to discuss a visit, it's practically impossible...if we are telling people about the Meetings Centres and saying...ring...and arrange a visit and they're having the same issues that we're having...I think that could put people off. (Professional)*

*...turnover of volunteers and availability of volunteers as well is an issue... (MC staff)*

*...here we are within health going...Meeting Centres are great, but you've got to fund them all yourself...system-wise we should be supporting them and we're not...(Professional)*

## CMOC J. Flexible membership

It is not always possible for people living with dementia and those who care for them to attend an MC consistently or for whole days (usually five hours). Some people may experience other challenges with aspects of membership, such as eating away from home. MCs that do not offer membership flexibility may find this a barrier for some members/potential members.

**CMOC J:** If MC membership does not accommodate varying and irregular attendance patterns (over time or on a single day) then people may not attend because they may feel it does not fit with their circumstances and the challenges of living with dementia

*I'd probably feel poorly.*

*(Person living with dementia, referring to attending for a full MC day)*

*...[my husband]'s not good at eating...So that might become an issue, to be sat there and being expected to eat this meal. (Carer)*

*If it was too long...he wouldn't stick it out then. (Carer)*

*Carers don't generally come because it's respite for them, so they can leave their loved ones here...a bit of rest and recuperation. Other people are working... (MC staff)*

*...weekends would be really hard to run it, but you'll have more people who are accessible on say Saturday... (Professional)*

*He goes to the pub every day and that's his routine. (Professional)*

## CMOC K. Car parking

Mobility difficulties can affect people as they age and those living with dementia (National Institute on Aging, 2020; Gras et al., 2015). Having adequate parking and drop of space that is within easy access of an MC is necessary, as this can be a very practical barrier to attendance.

**CMOC K:** If MC car parking is insufficient or not accessible then people may not attend because the challenges of parking are off-putting or unmanageable

*...there was maybe one gentleman that came...his main issue was the parking and he kept saying, "Oh, the parking's bad...". And then he came a couple of weeks ago, I wasn't there...and then left because the parking was pants... (MC staff)*

*...[the MC] is quite a bit of a walk from the car park...And the one lady I took there, she said "Will I have to walk that way every time...because I didn't feel safe walking that way". (Professional)*

*...where we are currently you have to park and then walk or drop somebody if they've mobility needs, so that's quite difficult. (MC staff)*

*...it's nice and central, but there's nowhere to park. There's nowhere to drop off... (Professional)*

## CMOC L. Venue

The Essential Features of a Meeting Centre (University of Worcester, 2022b) highlights the need for an acceptable and accessible venue and the importance of involving people living with dementia and family carers in the decision making over venue selection. From the interview data, it is clear that the environment of an MC can be off-putting to potential members and professionals if it is not a pleasant and accessible space in which to spend time. It is also apparent that the venue needs to be suitable for the purposes of an MC in meeting the differing needs of members and that buildings with an associated purpose, such as religious buildings, may also deter some potential members.

**CMOC L:** If the venue is not welcoming, well-lit, accessible and suitable for the needs of different member groups then people may not attend because they will find going to the MC difficult or unpleasant

*... it just felt like a gloomy day centre... Grim. (Person living with dementia)*

*They're all cramped round a table...no space to put anything... (Professional)*

*I wouldn't want to spend all day...there's no daylight, it's dark, it's dingy... (Professional)*

*...we're actually in a church building and people are not religious, they think we're a church organisation...So I think that may have been a barrier to some people... (MC staff)*

*... you need that better disabled access... (Professional)*

*...we haven't got another area that we could split off to have one or two younger people in and do something really, really specific with them...we need to be meeting the different needs of these people, but it's very, very difficult when you've kind of got those sorts of premises... (Professional)*

## CMOC M. Promotion

Awareness raising and communicating value are important for sustaining community-based interventions (Morton et al., 2021), and information is not reaching everyone across H&W who might benefit from MC support. However, people who are being reached with information can be put off if the promotional materials produced by MCs are not appealing and inclusive.

**CMOC M:** If MCs are not promoted widely with broadly inclusive and appealing materials then people may not attend because they find the promotional material off-putting or don't know about the MC

*...there is a little photograph there of the...venue...it just seems to me as if it's people who...don't know what to do with themselves and can't think for themselves and let's have a jolly together one morning a week (Carer)*

*…it didn't get sense of connection with things…I didn't realise it was an open day…So none the wiser. (Person living with dementia)*

*…they sent me a photograph…we know there are people outside that would look at that and come up with a different picture…they're just seeing the wheelchairs. And thinking…that's not for me. (Professional)*

*…I think if more people knew about us, however we do that, we would get more people… I'm sure there are lots of people not being reached… (MC staff)*

*…anyone should know about it, should be able to access it, and should be widely signposted towards it rather than, oh, you could have gone to see your GP to get a referral… (Professional)*

*…people are not aware that this Meeting Centre is here…we're not in town, we can't put out a sign… (MC staff)*

*…carers…they need to be spoon fed. They don't need extra pressure on them. (MC staff)*

### CMOC N. Membership profile

People who are younger and/or living with milder symptoms of dementia can be deterred from attending an MC that has an older and/or more advanced membership profile. Carers and professionals may also see the MC as not suitable or relevant to the person living with dementia and so do not encourage attendance. Factors that may contribute to an MC developing such a membership profile include lack of local day care provision (see CMOC T) and people postponing membership (see CMOC O).

**CMOC N:** If an MC has an older/more advanced dementia membership profile, then younger persons/those experiencing milder symptoms may not attend because they may feel the MC is not for them

*…perhaps I'm wrong but I…feel that maybe the Meeting Centres are for people older than me…I'm 66, but I don't feel it…and because I was young onset as well. (Person living with dementia)*

*…I would not like to sit there with…people…in various stages of dementia which are worse than I am facing and having to look at someone and think, I'm going to have to face that…I couldn't handle that…I know that he would not like to sit there and look round and see these people…in various stages, it would drive him mad, really, it would. (Carer)*

> *...she was only 64, she...said...it was so depressing, everybody there is in their 80s...I don't want to sit there like that, I don't want to look down the line of what I'm going to be like. (MC staff)*

> *...that's often the thing people say...I'm much younger. I don't want to meet with older people, so it isn't something I would generally tell people about, personally. (Professional)*

## Theme 5: Perceptions

It is evident from interview data, that the way in which MCs are perceived can be a barrier not only to attendance for potential members, but also for encouragement from carers and signposting and support from professionals. Staff perceptions can lead to MCs being run and promoted differently than intended, which can lead to confusion about what an MC is and who it is for.

### CMOC O. Early dementia

MCs are intended to support people in adapting to the changes that dementia brings towards a better quality of life and helping people to come to terms with a dementia diagnosis. However, people early in the dementia journey who are active and independent, and those around them, may not feel that they need community support yet. It may be that a different or tailored form of community support in adapting to change could be beneficial in meeting the needs of this group.

**CMOC O:** If a person is early in their dementia journey, active and independent, then they may not want to attend because they don't see the MC offer as relevant to them and their needs yet

> *It just didn't tap into anything that I feel I need, at the moment...if I didn't have such a supportive partner, and if I wasn't still so active, maybe I would consider going...in the future I might well do...while I can, I want to carry on doing things as normally as I possibly can...If I went to a Meeting Centre now, I could see myself helping rather than being 'involved with activities' (Person living with dementia)*

> *...I think the issue [is] that they don't really offer something that's going to meet what [she] needs each week. Actually, at the moment what she needs is the in-home support to manage emails, to manage work...Life. (Supporter)*

> *...one of the ladies...she's only just on her journey with dementia, so she's on a lot of forums and groups...she's busy out and about so she's not really quite ready for it yet. (MC staff)*

*...if they are at the mild stages they feel like coming to a Meeting Centre is like one step towards residential care...I don't think it's until it progresses that loved ones then think, "Oh, I need help now"...and that's almost too late to catch the people at Meeting Centres. (MC staff)*

*...groups/activities that are specifically for people living with dementia can appeal because they have potential to offer a sense of belonging, and promise that they can be a safe place where I can be me. However, they don't always fulfil their potential in reality. Some feel more carer-focussed and this can make me feel excluded. (Person with dementia)*

## CMOC P. Unfamiliar with groups or community support

People living with dementia and those who care for them who have little or no experience of participating in groups or community support may not relate to the idea of MC attendance.

**CMOC P:** If people are not familiar with attending groups/community support then they may not attend an MC because they do not see it as being for them

*I'm not a good mixer but I'm just a private bloke……I don't like being organised but I just like being me, you understand? (Person living with dementia)*

*I don't consider myself a group person. (Person living with dementia)*

*...one of my fears...is I didn't want to go along to a group that was defined by a diagnosis...because that might well be the only thing I've got in common with those people...where all we'd be talking about is our symptoms. (Person living with dementia)*

*Mum has never been great with mixing...she didn't do any of those groups...with me when I was younger. (Carer)*

*I can't see the goodness that would be there...I can't imagine what they're going to do in that time that would stimulate my partner...it would be absolutely devastating...for both of us...I couldn't see me ever going...every morning I get up, every night I go to bed, I am a carer...and going to meet a group of other people who are in the same situation is not going to help me...for me it is just aberrant. (Carer)*

*...sometimes they don't give it a good enough go...if they're going to pull out it's probably after their first or second initial visit...I think people should go for about a month...whenever someone goes into that Meeting Centre, their preconceptions are huge.*
*(Professional)*

*… I think they're just a little bit wary of it's something new, something they've never had to use before. It's a little daunting. (Professional)*

*… people will say, "Oh no, groups aren't for me". (Professional)*

### CMOC Q. Disagreement

Disagreements or misunderstandings can occur within an MC. If they cannot be resolved, a disagreement or misunderstanding may result in a person discontinuing their membership.

**CMOC Q:** If there is an unresolved disagreement or misunderstanding between people at an MC then the parties concerned may not attend because they do not feel comfortable

*There was one…that left…just didn't get on…with people…I don't know exactly what it was, but…[they] took offence…misinterpreted what had been said… (MC staff)*

### CMOC R. Stigma, denial & dementia awareness

It is evident that some people experience stigma around living with dementia or difficulty accepting their own or their loved one's diagnosis. Not identifying or not wishing to be associated with dementia can prevent potential members from attending an MC. Cultural stigma may lead to lack of awareness of the need for dementia support or its benefits (Hossain et al., 2020), and subsequently its availability.

**CMOC R:** If people experience stigma or lack of awareness about dementia then they may not attend an MC because they may not wish to identify, acknowledge or be associated with dementia, and will be unaware of the need for/existence of MCs

*It is probably facing it…When she said she doesn't want to go I couldn't push her because I just felt like, oh, no, I don't think I would want to go there either. (Carer)*

*From the initial thing of we don't go to clubs and that usually, this is alien to us, we never hear him say that anymore…he went through one hell of a barrier…he was ashamed of how she was. (MC staff)*

*…we were going to put some signs up outside to advertise that we're there, but then…people know, "Oh they're going in there, so they've got…dementia". (MC staff)*

> *...this particular person didn't like the idea of other members of the family or public picking up that there was dementia, they were attending anything with dementia. (MC staff)*

> *...his wife said...please don't mention dementia...he just won't accept that he's got dementia...it brings bad images up for him...So, sometimes it's the family don't want them to know, or they don't want to put them through the tests...And some people are just in denial, they don't want to acknowledge that they've got dementia. (MC staff)*

> *I met with a gentleman at [the Mosque] to try and link in with the Muslim community. I'd asked if anyone in the community had dementia...And his answer was, no, no-one in the community has got dementia. Which I don't think is necessarily the case...I'm sure that there are people in his community that have been touched...by dementia but he's just not aware of it, so it's making sure that we're tapping into those that do know about it. (MC staff)*

### CMOC S. Practice & understanding of MC model

MC staff who are not fully aware of who and how MCs are intended to support, as laid out in the Essential Features of a Meeting Centre (University of Worcester, 2022b), can lead to MCs being run and promoted differently. Consequently, this can result in confusion and misconceptions about what an MC is and who it is for by people in the community and professionals. Lack of understanding by people living in the community and professionals about how MCs differ from other dementia support, such as day care, can mean they do not see the value or relevance of attendance. It is likely that MCs will needs to overcome preconceptions about dementia support, making it even more important to run and promote MCs as intended.

**CMOC S:** If MCs are not run and/or clearly promoted as intended then people may not attend or be referred/signposted because of confusion or uncertainty about who the MC is for or what it offers, or failure to appeal to/meet the needs of the people it is intended for

> *It's correct what you say about thinking it's a day centre, because that's exactly what I thought. (Carer)*

> *...it's called a Dementia Meeting Centre. But in the leaflets it's saying you don't have to have a confirmed diagnosis. And so I took somebody who didn't have a confirmed diagnosis, but then the centre manager spoke about dementia...I think that can be a bit confusing. (Professional)*

> *…because it's such a different concept, Meeting Centres, they don't understand what we're trying to do. And so, they just see the day care label… it's a constant…educating people as to what kind of a service we're delivering here, and that we're not somewhere where you can just dump your loved one and go…we're not day care. (MC staff)*

> *It's not promoted for something for the carers, it's promoted for somewhere they can take the person along. I've yet to go to a Meeting Centre and see a carer remain…Maybe it's people's understanding, but then I struggle myself…what is a Meeting Centre? Is this a day centre?…Is it for 'earlies'? Is it for 'mids'? Is it for 'lates'? It's like, even I'm confused, and I think people use it as a day centre…What is it you're offering that's different? (Professional)*

## Theme 6: Dementia pathway

### CMOC T. Lack of local day care provision

When a person's dementia progresses to the point that their needs can no longer be met by an MC, a higher level of support is indicated, such as day care. It appears that in some areas such support is not available. In this situation, MC can be reluctant to discontinue membership and leave the member and those who care for them without follow-on support. If these members continue to attend, the MC can develop an older/more advanced dementia profile, which can be off-putting to new members (see CMOC N).

**CMOC T:** If there is a lack of local provision for those with more advanced dementia to move on to then an older/more advanced dementia membership profile is more likely in the MC because staff will not want to stop supporting members who are no longer supposed to be appropriate for MC membership

> *And there's only one other thing that I feel we lack…we don't have a through input. So, when we get some people to a certain stage there's a reluctance from the staff…and the carer, to make that change where we say…we can't meet those needs now. They do it, they have to, but we hang onto people a lot longer because there's nowhere to send them to… (Professional)*

### CMOC U. Referral pathway

Professionals supporting people living with the mild to moderate stages of dementia in the community can signpost or refer people to MCs. In addition to information, some potential members need support in taking the first step to attend. It appears that can be a lack of resources in order for professionals to provide support for the transition into membership and that the pathway between professionals can sometimes lack continuity, resulting in potential members not receiving the signposting or support they need to attend.

**CMOC U:** If the referral pathway lacks continuity and adequate resources then people may not attend an MC because they do not receive enough signposting and/or support

*You wouldn't necessarily know what the Meeting Centre was unless I'd talked to you about it…it's actually a symptom of the way in which services have changed…it used to be that Brenda was very well connected through there being a specialist…support worker,…with [Dementia Service], with the [Dementia Network Group], and now in fact all three of those things have gone…it's not that Brenda isn't online or digitally connected… (Supporter)*

*…we send out things to GPs that we're here for people…but I don't think the GPs are actually listening and connecting, this person's got dementia, they're struggling at home, maybe they need this here and not pass their information on, because I know a lot of people that have been in contact with a professional person and they're not getting any help… (MC staff)*

*…it's how you move from letting people know to actually…encouraging people to take that step to go. And…capacity, I think sometimes as well for staff to actually be involved in that taking somebody along, because that's just not always there. And certainly when you're working with people who live with dementia who live on their own, you really need to be able to do that, I think. (Professional)*

*…sometimes…it needs somebody outside to really encourage that individual to attend. Because…it's harder I think for families to encourage somebody to go… (Professional)*

## CMOC V. Diagnosis

The diagnosis rate in H&W is the lowest in England (NHS Digital, 2022). Not only are a low number of people being diagnosed, but it appears people are receiving delayed diagnoses, whether due to waiting times (Cook, Souris and Isaacs, 2020), lack of follow up for people experiencing mild cognitive impairment, or not seeking a diagnosis until support becomes a necessity. Another factor is that Herefordshire is predominantly rural, and later diagnosis is more common in rural areas (Alzheimer's Society, 2021b) and fear of losing their driving licence can also deter people (See CMOC W). The prospect of a dementia assessment can be daunting, however timely diagnosis means that people are more likely to receive the help they need and community support, such as MCs. Because MCs are principally for people living with dementia and their carers, people without a diagnosis may not know about the support available or think it is available to them or may not be eligible to attend. In addition, some MCs only accept members with a diagnosis.

**CMOC V:** If a person with dementia does not have a formal diagnosis then they may not attend an MC because they do not think they need to or believe that they are not eligible

*...one of the things I try to encourage people to do, is to get a diagnosis because...you may not have dementia, it could be all sorts of other things, it could actually just be getting old...I also think that you can make plans. If you know what you're dealing with and... I get why people don't do it, it's scary but, knowledge is power, isn't it, they say, and I think [my partner] and I have found that. (Person living with dementia)*

*...people in Herefordshire, especially...they're not getting a diagnosis early in the stages of their dementia...it is further on down the line, and whether that's because they might be in denial and not want to go to the doctors, or whether it's when they get to the doctors and get referred to the clinics, then how long is the waiting list, I don't know. (MC staff)*

*...mild cognitive impairment they don't review at all...that's a forgotten group of people...where potentially there could be a good chunk of diagnosis...you've given that diagnosis of mild cognitive impairment to whoever, and you're saying bye-bye now, and you're saying, go to your GP if there's any changes. Well, that person is going to be too frightened to go to that GP...There's people out there they've had mild cognitive impairment for years, never been reviewed. (Professional)*

*We are saying that to attend our Meeting Centre, people have to have a diagnosis. (MC staff)*

## Theme 7: Travel

### CMOC W. Driving

Fear of losing their driving licence can deter people living with dementia from seeking a diagnosis, particularly in rural areas where dependence on driving is greater (Alzheimer's Society, 2021b). As discussed above (see CMOC V), lack of a dementia diagnosis can be a barrier to MC attendance. Even if a person without an official diagnosis were aware of the MC support available to them, they may avoid drawing attention to their condition and their driving by not attending.

**CMOC W:** If a person with dementia relies on driving to get about then they may not attend an MC because they are concerned that engaging with health, social care or support services regarding their condition may lead to losing their licence

*Now, I still drive. I have a medical licence which is renewed every year, and every year I have a month of waiting and angsting about whether or not they'll stop me…And in fact, after five years of diagnosis, they did send me a letter saying, oh well you've had dementia for five years now, so you've got to stop driving…DVLA didn't understand the complexity of dementia, in that, we are all different. And I do think that the day that I have to stop driving, will be quite a significant one, 'cause we live out in the sticks, which is part of my wellbeing…what I also say to people is, if you're not safe to drive then you shouldn't…a lot of people assume that as soon as you get a dementia diagnosis, you have to give up your licence. That's not true. You have to inform the DVLA, and you then have to fill in a medical form and go through a couple of hoops… (Person living with dementia)*

*…it's the driving that's the biggest push against getting a dementia diagnosis…you're so reliant on transport round here, and our village has got one bus a week… So that's a real disincentive to getting a diagnosis, it's far better just to ignore those symptoms, so that really puts people off. And then how do you get into something like [an MC]… (Professional)*

## CMOC X. Rurality & distance

For people living with dementia who do not live close to an MC, transport to attend can pose logistical challenges, as well as the need for additional support due to dementia (see CMOC A).

**CMOC X:** If people live rurally or do not live locally to an MC then they may not be able to attend because they are not able to get there

*…living rurally…I have no idea how I would get to [the MC town] from here. I'd probably have to get a bus into [the city] and then a train to [town], or a bus to [town]… But the bus, here in the village, doesn't go to [town], so I would probably have to go into [the city] again. So…huge barriers. Especially for people who are older…I think transport is a huge, a huge issue. (Person living with dementia)*

*I've had a couple where it's been the distance: "Yes, she enjoyed it, but I take her there, we don't live in [town], so I'm in [town] then all day". (Professional)*

*…you've got to make sure that person with the diagnosis is comfortable being in a different vehicle. (Professional)*

*We haven't got any [public transport]. We haven't got it…there is no bus…if you want to go to the Meeting Centre you've got to have private transport. (Professional)*

# Recommendations

CMOCs were grouped to form 18 recommendations (A-R) for overcoming barriers to MC attendance (see Appendix 1 for grouping example). These groupings consolidate the seven barrier themes into four themes for overcoming these barriers that are relevant to people involved in running MCs (Recommendations A-J). Of these themes, three are relevant to professionals involved in the dementia pathway (e.g. GPs, community mental health teams, social workers, social prescribing link workers) (Recommendations K-O) and two relevant to people living with dementia and those who care for them (Recommendations P-R).

## Recommendations for MCs

### Meeting needs

**Recommendation A**

Provide information and practical support for potential and returning MC members to access financial support, homecare and personal support and community transport in order to attend.

**CMOCs**: A, B, E

**Recommendation B**

Where possible, make adaptations to service provision and secure additional resources and training to accommodate individual needs whilst, considering the implications for other members. This may include:

- Provision of an outreach programme for people unable to attend or who live remotely
- Distinct provision for specific groups/needs e.g. early/more advanced dementia, people who speak other languages
- Accommodating pet attendance
- Needs arising from symptoms, e.g. agitation or sensory difficulties
- Flexible/reduced attendance and payment

- Signposting to other services when needs cannot be met by the MC

**CMOCs**: C, D, F, G, J, N, O, R, T, X

## Transforming perceptions

**Recommendation C**

Provide an introductory information package and attendance programme that offers an extended opportunity to experience the MC, promoting the importance and benefits of adapting to change and MC attendance

**CMOCs**: P, R

**Recommendation D**

Plan ahead on how conflicts can be avoided and supported and consider conflict resolution training for staff

**CMOCs**: Q

**Recommendation E**

Ensure that MCs are run as intended according to the Essential Features of an MC booklet (University of Worcester, 2022b)

**CMOCs**: S

## Improving inclusion and raising awareness

**Recommendation F**

Liaise with local ethnic minority groups and community dementia services, including mild cognitive impairment, to raise awareness of the MC offer and understand the needs of these groups, and responsively adapt practice where possible

**CMOCs**: C, R, V, W

**Recommendation G**

Create clear, appealing and inclusive promotional material on what an MC is, who it is for and how it differs from other forms of dementia support in consultation with a variety of stakeholders and promote widely to dementia pathway professionals and in the community

**CMOCs**: M, S

**Recommendation H**

Share information with the organisations, services and professionals you work with on their potential role in helping tackle the following barriers to attendance, where applicable:

- lack of referral pathway continuity and resources
- lack of diagnosis, particularly for people with community dementia services, including mild cognitive impairment, or who fear losing their driving licence
- lack of local day care provision
- lack of awareness for undiagnosed people with dementia that they can attend an MC
- lack of dementia awareness and availability of MC support among ethnic minority groups

**CMOCs**: R, T, U, V, W

## Transforming practice

**Recommendation I**

Ensure sufficient staff, staff time, volunteers and budget for:

- member/carer activity consultation and involvement
- activity training, planning, sourcing and development of resources and external partners and regular activity provision
- supporting potential/new members and liaising with referring/signposting professionals

**CMOCs**: H, I

**Recommendation J**

Ensure that the MC venue:

- has a sufficient, accessible carpark
- is a welcoming, accessible environment with good lighting
- has more than one room for working with different member groups/individual needs when necessary
- can accommodate the needs of people living with dementia/older people, e.g. hearing impairment/sensitivity

**CMOCs**: G, K, L

# Recommendations for Professionals

## Meeting needs

**Recommendation K**

Provide information and practical support for potential MC members to access financial support, homecare and personal support and community transport in order to attend

**CMOCs**: A, E

## Transforming perceptions

**Recommendation L**

Ensure that the MC offer and how it differs from other forms of dementia support is clearly understood by professionals and articulated to potential members/carers and discuss any perceived inconsistencies between model and practice with MC staff

**CMOCs**: S

## Improving inclusion and raising awareness

**Recommendation M**

Liaise with local ethnic minority groups and mild cognitive impairment services to raise awareness of the importance and benefits of diagnosis, adapting to change and MC attendance and liaise with MCs on how they can meet the needs of these groups

**CMOCs**: C, R, V, W

**Recommendation N**

Share information provided by MCs widely with people living with dementia/carers and in the community

**CMOCs**: M

**Recommendation O**

Focus on tackling the following barriers to MC attendance, where applicable:

- lack of referral pathway continuity and resources
- lack of diagnosis, particularly for people with mild cognitive impairment or who fear losing their driving licence
- lack of local day care provision

- lack of awareness for undiagnosed people with dementia that they can attend an MC
- lack of dementia awareness and availability of MC support among ethnic minority groups

**CMOCs**: R, T, U, V, W

## Recommendations for People Living with Dementia and Carers

### Meeting needs

**Recommendation P**

If you need additional support to access an MC, or are unsure if an MC is right for you, discuss your situation with professionals and MC staff so they can help you get the right support

**CMOCs**: A, B, C, D, E, F, G, J, N, O, T, V, W, X

### Transforming perceptions

**Recommendation Q**

If you are unfamiliar with attending groups or community support, discuss your concerns with professionals and MC staff so they can help you get the right support to give membership a try

**CMOCs**: P, Q, R

**Recommendation R**

If you are unfamiliar with what MCs are and offer, read the Essential Features of an MC booklet (University of Worcester, 2022b) to find out more

**CMOCs**: S

# Summary of findings

People living with dementia and those who care for them can face a range of barriers to MC attendance. The support a person needs to navigate their dementia journey changes over time and differs between individuals and their circumstances. In addition, financial constraints, health problems and transport difficulties are all needs to be met in order to attend an MC.

Not all people living in the community who could benefit from attendance at an MC are aware of them and some may be uncertain as to what they are and offer. Perceptions held about attending groups or community support can also stand in the way. Understanding what MCs are intended to be and offer appears to be pivotal for transforming perceptions for MC staff and professionals and the running of MCs in practice to offer and promote inclusive, appealing support.

People affected by dementia may not know about or be able to access an MC due to a lack of consistent support or assessment from dementia pathway professionals. These barriers appear compounded by perceptions held by people living in the community about the stigma and consequences of diagnosis. MCs and dementia pathway professionals have a central role to play in meeting needs, transforming perceptions, improving inclusion and raising awareness to promote attendance and, ultimately, support for people in their communities affected by dementia.

## Strengths & Limitations

The recent introduction of MCs to the UK has been accompanied and informed in its development by research conducted by the Association for Dementia Studies. This report addresses a previously unexplored topic in seeking to understand barriers to MC attendance and offer practical recommendations for overcoming them. While this research has specific relevance to H&W MCs the findings and recommendations will potentially be transferrable to other MCs across the UK and may provide insights for other dementia community support groups and services.

By taking a realist approach, this research has sought to account for, understand and be informed by the rich complexity of everyday life. In keeping with this approach, and the scope of this section of research within the overarching project, the number of interview participants was intended to give a breadth of perspectives, but not constitute a representative sample. While the number of participants interviewed met our design criteria, the potential to interview more participants living with dementia and carers was hampered by the challenges of reaching those willing to participate in research. Further interviews may refine and add to the understanding of barriers to MC attendance, and so the findings and recommendations are more tentative and would benefit from broader subsequent research at a national level.

The recommendations produced in this report do not constitute a complete or conclusive means of overcoming barriers to MC attendance, rather they consolidate the CMOC findings from the perspectives of a finite group of stakeholders. This research offers a starting point for improving MC accessibility and membership from which to develop future research and practice.

# Appendix 1: Grouping Example

| **Recommendation A** | **CMOCs** |
|---|---|
| Provide information and practical support for potential and returning MC members to access financial support, homecare and personal support and community transport in order to attend | A. If a person/couple do not have someone to help them when going out, they may be unable to attend because they cannot manage getting ready/getting to/being at the MC without additional support<br>B. If there is a disruption to a person's attendance due to poor health, then members may stop attending altogether because they do not have the energy or support to overcome their health issues to re-engage and re-establish their previous routine<br>E. If the costs involved in attending and accessing an MC (including transport) are perceived as too great or not affordable then potential members may not attend because they are unable or unwilling to pay the involved costs |

# Appendix 2: CMOCs listed by theme

**Theme 1: Unmet support needs**

| |
|---|
| **CMOC A Lack of support**<br>If a person/couple do not have someone to help them when going out, they may be unable to attend because they cannot manage getting ready/getting to/being at the MC without additional support |
| **CMOC B Membership disruption**<br>If there is a disruption to a person's attendance due to poor health, then members may stop attending altogether because they do not have the energy or support to overcome their health issues to re-engage and re-establish their previous routine |
| **CMOC C Language**<br>If a person living with dementia or their carer has challenges communicating in the language the MC uses, then they may not attend because of the language barrier. |
| **CMOC D Pets**<br>If a person has strong attachments to a pet then they may not be able to attend an MC because their pet cannot accompany them, or they are unwilling to leave them |

**Theme 2: Costs**

**CMOC E Affordability**
If the costs involved in attending and accessing an MC (including transport) are perceived as too great or not affordable then potential members may not attend because they are unable or unwilling to pay the involved costs

**CMOC F Attendance duration**
If an MC charges a daily rate but a potential member is unable or unwilling to attend for the duration of that day then they may not attend because they may feel they are not receiving value for money

**Theme 3: Health**

**CMOC G Challenges presented by symptoms**
If a person's condition leads to symptoms such as distress in unfamiliar places, sensory sensitivity or incontinence then they may not attend an MC because they find the environment/group setting too challenging

**Theme 4: Meeting Centre**

**CMOC H Activities**
If MC activities are unfamiliar, have infantile associations or lack sufficient planning/awareness, staff and resources then people may not attend/refer/ signpost because they find the activities unsuitable, uncomfortable, off-putting or lacking

**CMOC I Staff & resources**
If MCs are insufficiently staffed and resourced then people may be less likely to attend because staff will not have the time and energy to support potential new members into the MC

**CMOC J Flexible membership**
If MC membership does not accommodate varying and irregular attendance patterns (over time or on a single day) then people may not attend because they may feel it does not fit with their circumstances and the challenges of living with dementia

**CMOC K Car parking**
If MC car parking is insufficient or not accessible then people may not attend because the challenges of parking are off-putting or unmanageable

**CMOC L Venue**
If the venue is not welcoming, well-lit, accessible and suitable for the needs of different member groups then people may not attend because they will find going to the MC difficult or unpleasant

**CMOC M Promotion**

If MCs are not promoted widely with broadly inclusive and appealing materials then people may not attend because they find the promotional material off-putting or don't see it

**CMOC N Membership profile**

If an MC has an older/more advanced dementia membership profile, then younger persons/those experiencing milder symptoms may not attend because they may feel the MC is not for them

**Theme 5: Perceptions**

**CMOC O Early dementia**

If a person is early in their dementia journey, active and independent, then they may not want to attend because they don't see the MC offer as relevant to them and their needs yet

**CMOC P Unfamiliar with groups or community support**

If people are not familiar with attending groups/community support then they may not attend an MC because they do not see it as being for them

**CMOC Q Disagreement**

If there is a disagreement or misunderstanding between people at an MC then the parties concerned may not attend because they do not feel comfortable

**CMOC R Stigma, denial & dementia awareness**

If people experience stigma, denial or lack of awareness about dementia then they may not attend an MC because they do not identify, or wish to be associated with dementia, or are unaware of the need for/existence of MCs

**CMOC S Practice & understanding of MC model**

If MCs are not run and/or clearly promoted as intended or the MC offer is not understood then people may not attend or be referred/signposted because there is confusion or uncertainty about who the MC is for or what it offers, or the MC offer does not appeal to/meet the needs of the people it is intended for

**Theme 6: Dementia pathway**

**CMOC T Lack of local day care provision**

If there is a lack of local provision for those with more advanced dementia to move on to then an older/more advanced dementia membership profile is more likely in the MC because staff will not want to stop supporting members who are no longer supposed to be appropriate for MC membership

**CMOC U Referral pathway**

If the referral pathway lacks continuity and adequate resources then people may not attend an MC because they do not receive enough signposting and/or support

**CMOC V Diagnosis**
If a person with dementia does not have a formal diagnosis then they may not attend an MC because they do not think they need to or believe that they are not eligible

**Theme 7: Travel**

**CMOC W Driving**
If a person with dementia relies on driving to get about then they may not attend an MC because they may be reluctant to seek a diagnosis

**CMOC X Rurality & distance**
If people live rurally or do not live locally to an MC then they may not be able to attend because they are not able to get there

# References

Alzheimer's Society (2022a) Can caring for a pet help a person with dementia? Available: https://www.alzheimers.org.uk/blog/can-caring-for-a-pet-help-a-person-with-dementia (Accessed: 14 November 2022)

Alzheimer's Society (2022b) Disability and mobility benefits for people living with dementia. Available from: https://www.alzheimers.org.uk/get-support/legal-financial/benefits-dementia/disability-mobility-benefits (Accessed: 14 November 2022)

Alzheimer's Society (2021a) Toilet problems, continence and dementia. Available from: https://www.alzheimers.org.uk/get-support/daily-living/toilet-problems-continence (Accessed: 14 November 2022)

Alzheimer's Society (2021b) Regional variation: Increasing access to a dementia diagnosis. Available: https://www.alzheimers.org.uk/sites/default/files/2021-09/regional_variations_increasing_access_to_diagnosis.pdf (Accessed: 07 November 2022)

Cook, L. Souris, H. and Isaacs, J. (2020) The 2019 national memory service audit, Dementia Clinical Network, NHS England and Improvement (London Region). Available: https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2020/04/The-2019-national-memory-service-audit.pdf (Accessed: 09 November 2022)

Goth, U.S. and Strøm, B.S. (2018) Language disintegration: communication ability in elderly immigrants with dementia. The Lancet, 3 (12), e563, December 01. Available: https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(18)30184-1/fulltext#articleInformation (Accessed: 02 December 2022)

Gras L.Z., Kanaan S.F., McDowd J.M., Colgrove Y.M., Burns, J., and Pohl P.S. (2015) Balance and gait of adults with very mild Alzheimer disease. J Geriatr Phys Ther. Jan-Mar;38(1):1-7. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4632639/ (Accessed: 14 November 2022)

Hossain, M., Crossland, J., Stores, R., Dewey, A. and Hakak, Y. (2020) Awareness and understanding of dementia in South Asians: A synthesis of qualitative evidence. Dementia (London). Jul;19(5):1441-1473. doi: 10.1177/1471301218800641. Epub 2018 Oct 8. PMID: 30296834. Available: https://journals.sagepub.com/doi/10.1177/1471301218800641?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed (Accessed 02 December 2022)

Pawson, R. and Tilley, N. (1997) Realistic Evaluation. United Kingdom: SAGE Publications.

Morton, T., Evans, S.B., Brooker, D., Williamson, T., Wong, G., Tinelli, M., Frost, F., Bray, J. and Hullah, N. (2022) Sustainability of locally driven centres for those affected by dementia: a protocol for the get real with meeting centres realist evaluation. BMJ Open 2022;12:e062697. doi: 10.1136/bmjopen-2022-062697

McMurtray, A., Saito, E. and Nakamoto, B. (2009) Language preference and development of dementia among bilingual individuals. Hawaii Med J. Oct;68(9):223-6. PMID: 19842364; PMCID: PMC4335728.

Morton , T., Wong, G., Atkinson, T. and Brooker, D. (2021) Sustaining community-based interventions for people affected by dementia long term: the SCI-Dem realist review. BMJ Open 2021;11:e047789. doi:10.1136/ bmjopen-2020-047789

National Institute on Aging (2020) The National Institute on Aging: Strategic Directions for Research, 2020-2025. Available: https://www.nia.nih.gov/about/aging-strategic-directions-research (Accessed: 14 November 2022)

NHS Digital (2022) Recorded Dementia Diagnoses, September 2022: Summary. Available at: https://files.digital.nhs.uk/87/0749A5/dem-diag-sum-Sep-2022.xlsx (Accessed: 31 October 2022)

NIHR (2021) Sustaining locally-driven social care for those affected by dementia: A realist evaluation of successful Meeting Centres. Available: https://fundingawards.nihr.ac.uk/award/NIHR201861 (Accessed 28 November 2022)

Rhodus, E.K., Barber, J.M., Gibson, A., Thompson, M., Shady, K.E. and Jicha, G.A. (2022) Cognitive impairment associated with global sensory processing abnormalities. Alzheimer's and Dementia: Dementia care and psychosocial factors, poster presentation. Available from: https://alz-journals-onlinelibrary-wiley-com.apollo.worc.ac.uk/doi/10.1002/alz.053263 (Accessed 14 November 2022)

Social Care Institute for Excellence (2020) Dementia and sensory loss: an introduction. Available from: https://www.scie.org.uk/dementia/living-with-dementia/sensory-loss/introduction.asp (Accessed: 14 November 2022)

University of Worcester (2022a) Meeting Centres. Available: https://www.worcester.ac.uk/about/academic-schools/school-of-allied-health-and-community/allied-health-research/association-for-dementia-studies/ads-research/uk-meeting-centres.aspx (Accessed 28 November 2022)

University of Worcester (2022b) The Essential Features of a Meeting Centre, May 2022 Edition. Available: https://www.worcester.ac.uk/about/academic-schools/school-of-allied-health-and-community/allied-health-research/association-for-dementia-studies/ads-research/essential-features-of-a-meeting-centre.aspx (Accessed 14 November 2022)

# About Us

The Association for Dementia Studies is a multi-professional university research centre with many years of experience in the field of person-centred dementia care and support. People living with dementia, their families and their carers inform our work at all stages.

Through its research, education programmes and knowledge transfer activities the Association for Dementia Studies (ADS) has touched the lives of many people since it was established in 2009. Further information can be found on our website www.worcester.ac.uk/dementia. We work proactively at the interface between the experience of those living with dementia, those developing practice and those undertaking research to ensure real knowledge transfer and translation between these different world-views. ADS have a strong track record in working collaboratively with many care providers and charities.

We are committed to a person-centred approach in all our work. This is our ethical code that encompasses all our relationships both within our team and in our education and research collaborations. This includes people living with dementia their families and carers and those of us who are privileged to work in this area. It is a code that values all people as unique individuals, tries to see things from the viewpoint of the other and recognises the interdependence of all of us.  We are committed to raising awareness, challenging stigma and improving quality of life and wellbeing.