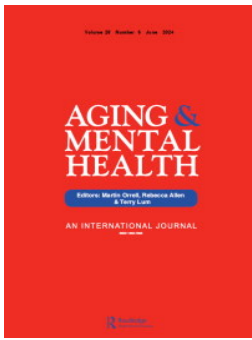


**Reaching people and managing membership in community-based dementia support groups: the Get Real with Meeting Centres realist evaluation part 1**

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# Reaching people and managing membership in community-based dementia support groups: the Get Real with Meeting Centres realist evaluation part 1

Thomas Morton<sup>a</sup> , Shirley B. Evans<sup>a</sup> , Ruby Swift<sup>a</sup> , Jennifer Bray<sup>a</sup> , Faith Frost<sup>a</sup> , Chris Russell<sup>a</sup> , Dawn Brooker<sup>a</sup> , Geoff Wong<sup>b</sup>  and Nigel Hullah<sup>c</sup>

<sup>a</sup>Association for Dementia Studies, University of Worcester, Worcester, UK; <sup>b</sup>Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK; <sup>c</sup>3 Nations Dementia Working Group, Swansea, UK

## ABSTRACT

**Objectives:** There is a need to improve the provision and reach of community services for people living with dementia, a goal in which community-based support groups can play a key role. The Get Real with Meeting Centres project aimed to explore factors involved in the success and sustainability of Meeting Centres (MCs) a form of community-based support proliferating in the UK. This is the first of two linked articles outlining learning from this realist evaluation of MCs, which focusses on findings around reach and membership.

**Method:** Semi-structured interviews and focus group discussions were conducted with 77 participants across three case study MC sites in England and Wales, including people living with dementia, informal carers, staff, volunteers, trustees, and supporting professionals/practitioners. Data were themed, then analysed using both soft systems methodology and realist logic of analysis.

**Results:** Fifty-two 'context-mechanism-outcome' statements were generated, explaining how background circumstances might trigger responses/processes to produce wanted or unwanted outcomes regarding four key areas for MC sustainability: *Referrals and the dementia care pathway; Reaching people and membership; Carer engagement and benefit; and Venue and location.*

**Conclusion:** Strong links with formal services and a well-functioning dementia care pathway are essential to sustaining community-based group support such as MCs; group support is also well-placed to assist work to improve pathway issues. Clarity of offer (including benefit to carers), and a wide range of activities, are key to appeal and reach; transport to, and use of, venue are challenges, as are pressures to support people with more advanced dementia.

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## KEYWORDS

Dementia; post-diagnosis; psycho-social; community support; social isolation

## Introduction

Improving the provision of, and engagement with, community services for people affected by dementia remains both a national health goal in the UK and a global one (ADI, 2022; DHSC, 2022; WHO, 2017). With the number of people with dementia predicted to grow significantly between now and 2050 (Luengo-Fernandez & Landeiro, 2023), this is a pressing concern for health and care services worldwide. Of the people aged over 65 estimated to have dementia in the UK, only about 63% have a diagnosis (NHS, 2023), and rates are not currently improving. Those living with dementia in the community experience 'Fragmented dementia services, which are inadequately resourced and staffed, and mainly community-based' (Belder et al., 2023). Improvement in early diagnosis, also a global health goal (Belder et al., 2023), would require a corresponding improvement in community support for those diagnosed.

### The role of community support groups

Community groups can play a major role in improving the support available. Often third sector or informally run, they have the potential not only to provide valued support to people with dementia and those that care for them, but also raise awareness, combat stigma, and signpost people to other services. Such

groups are a form of dementia-friendly initiative (DFI). DFIs are activities to promote engagement, empowerment, and autonomy for the well-being of people living with dementia in society (Hebert & Scales, 2019; WHO, 2021) and can act as 'building blocks' of dementia-friendly communities (DFCs) (Thijssen et al., 2021, 2023), the development of which is recognised as an urgent imperative by international health organisations (WHO, 2017). DFIs include group activities that seek to include people living with dementia, or groups specifically for them; dementia-specific groups can be based around a specific activity, such as a choir, community garden, physical activity, cognitive stimulation or peer support, or as a platform or hub for various activities.

Meeting Centres (MCs) are one such form of community-based DFI. Originating in the Netherlands (Dröes et al., 2004) and adapted to other European settings (Mangiaracina et al., 2017), MCs are now proliferating internationally, and in the UK have grown from 13 before the COVID-19 pandemic to more than 70 in 2024. They mostly comprise a small social club based in a community building, operating up to three times a week. They are typically run by community/third sector organisations, with a small team of staff and volunteers, supported by local health and care professionals. They share much in common with other DFIs, hence learning regarding the challenges that face them is likely to be transferrable. However there are features that

**CONTACT** Shirley B. Evans  [shirley.evans@worc.ac.uk](mailto:shirley.evans@worc.ac.uk)

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make MCs distinct: They are targeted towards people with mild to moderate dementia, and also those that support them (e.g. friends and family). The length and regularity of sessions, and range of activities, are likely to be greater than at a lunch club or Dementia Café (another common DFI that acts as a place for people with dementia to socialise and get support). The features of MCs (Brooker, 2020; Evans et al., 2023) are designed to help people make emotional, social, and practical adjustments to living with dementia, with staff trained in person-centred care and the Adaptation-Coping (Adjusting to Change) model (Brooker et al., 2017). MCs in the UK usually provide a programme of activities based on the wishes of people who attend, including movement and co-ordination (e.g. seated exercise, tea dances, gardening, and walks), talks, quizzes, discussions, visits to local attractions, arts and crafts. They may include more formal therapeutic activities, but this varies from MC to MC.

### **The Get Real with Meeting Centres project**

The Get Real project investigated factors affecting the sustainability of MCs, particularly in rural areas, with the aim of learning lessons for current and emerging MCs. This multi-work package research project ran from January 2021 to March 2023. It followed the SCI-Dem realist review (Morton et al., 2021), which investigated factors affecting the sustainability of community-based DFIs in general. SCI-Dem found being able to continually 'get' and 'keep' members was a key factor in the long-term sustainability of DFIs, and their reach could impact on related services in the wider dementia pathway. Get Real aimed to further specify and test (confirm, refute, or refine) the conclusions of SCI-Dem with primary research, by evaluating MCs as a specific type of DFI.

This is the first of two linked articles outlining results from this realist evaluation of case study MC sites. Membership-related issues (pertaining to sustainability) were found to be the largest topic area by volume of data, with multiple, multi-faceted themes relating to it. As such it was decided to split the findings from this study across two articles. Themes pertaining to strategic and operational issues at MCs (finances, collaboration, staffing, and working practices) will be dealt with in part 2. This first article explores how MCs reach people and manage their membership, and how MCs' interaction and fit with local dementia care pathways impact upon their membership.

### **Methods**

A realist evaluation (Pawson & Tilley, 1997) was conducted incorporating mixed methods of data collection and analysis. Interviews and focus group discussions were conducted at MC sites that have been sustained for more than three years in England and Wales. Participants included people living with dementia, informal carers, staff, volunteers, and trustees as well as external professionals/practitioners supporting them. Public stakeholders were consulted for ongoing feedback and advice on all aspects of the project. This study is registered with ISRCTN, ref: 39861. A full protocol for the project has been published (Morton et al., 2022).

### **Meeting Centre case study sites**

Data was collected at three case study research sites: An MC run as an independent charity in a small market town in Herefordshire, England; An MC run by a national charity in a

larger market town in Worcestershire, England; A cluster of four federated small-town MCs run by a single organisation within the rural county of Powys, Wales. These were accessed through the UK Meeting Centres Support Programme network (now Meeting Centres UK network). Study sites were selected purposefully for longevity, and for their contrasting approaches to the implementation and delivery of MCs, while operating within the Essential Features of Meeting Centres (Brooker, 2020; Evans et al., 2023), together comprising a range of contexts conducive to a rich variety of data for realist evaluation. At project start, they were among only a few MCs in the UK operating for at least 3 years prior (each was among the first MCs in the UK).

### **Participants**

Participants at the study sites were selected purposefully for their role and involvement in MCs, to cover a range of perspectives and experience. Interviews and focus group discussions were conducted with attendees living with dementia (members); attendees supporting someone with dementia (e.g. family carers); staff and volunteers; those involved with MC governance (e.g. trustees); and health/care professionals and stakeholders (e.g. activity-delivering practitioners, individuals from partner community groups) external to, but involved with, an MC.

It was important to include attendees living with dementia for two reasons: (1) to ensure the perspectives of the people MCs are for were fully, authentically represented in line with a 'Nothing about us, without us' ethos; (2) to access the knowledge and experience of attendees who can offer first-hand perspectives not directly available to staff and governors, particularly regarding factors that can encourage or act as a barrier to engaging with and attending an MC.

### **Data collection processes**

Two researchers arranged with those involved in the governance and management of each MC to visit each site to identify potential participants for semi-structured interviews or focus group discussions. Where this was not possible due to COVID-19 pandemic restrictions, this was done *via* online group sessions. MC managers and trustees also helped identify external collaborators to contact as potential interviewees. Individual interviews were preferred, but potential participants were offered the option of dual interviews or participation in focus group discussions if they wished, or if individual interviews were not possible at that time (e.g. due to logistical restraints at the MC or pandemic restrictions). Depending on pandemic restrictions and participant preferences, interviews and discussions were conducted either on-site at an MC, or *via* video conferencing/telephone, between July 2021 and July 2022, with secondary 'update' interviews with MC leads (managers or trustees) from each site in September and October 2022.

Favourable ethical opinion was granted by Health Research Authority research ethics committee Wales REC4 (ref: 21/WA/0185). To undertake research ethically with participants living with dementia, the research team developed sensitive and relevant practices of informing and negotiating consent to participate (see Morton et al., 2022). Members of the project team were introduced to the group at each MC site, where they worked with MC staff to ask for volunteers and identify appropriate attendees to invite to participate, as well as helping them

to understand the participant information and consent process to make an informed decision on taking part. A log was not kept of everyone approached, as these were often made informally in the first instance on an 'opt in' rather than 'opt out' basis. Participants were assured their responses would be kept confidential with their personal details anonymised in reporting. Interviews and focus groups took place in a private area away from the main activity of the MC, or by telephone or online with participants in their own homes.

### Interview schedule and focus group topics

Interview schedules (see Morton et al., 2022) were developed with the involvement of public stakeholders, guided by factors involved in the sustainability of community-based DFIs found in the SCI-Dem review (Morton et al., 2021), but also informed by soft systems methodology, using a modified 'BATWOE' structure (Checkland, 1999; Dalkin et al., 2018), considering the following elements in the system of an MC: Beneficiaries (who the system is aimed at helping); Actors (people's roles and functions in the system); Transformations (going from start-up to established to stable and thriving MC); Worldview (opinions on how things work regarding sustainability, the challenges and what should be done); Ownerships (who or what can influence or thwart success of an MC?); and Environment (background contextual factors that could boost or constrain success). The same question topics were covered in interviews and focus group discussions. These schedules were available to both interviewer and interviewee to steer conversation, comprising a topic guide with suggested prompts only: interviewees were encouraged to speak freely and digress if they wished, with interviewers adapting and responding to the interviewee what they said, with alternative suggestions explored to avoid leading, in line with realist interviewing (Manzano, 2016).

### Analysis

Interview and focus group discussions were transcribed, with transcript content initially organised using NVivo qualitative data analysis software. Relevant content was coded by themes, generated both deductively (initially following categories in the programme theory from the SCI-Dem review, Morton et al., 2021) and inductively (as themes arose in the data). Coding was flexible and evolving, in line with a reflexive Thematic Analysis approach (Braun & Clarke, 2013), though aiming only to organise data for soft systems and realist analysis. Coding was carried out initially by one researcher, with a second independently coding 10% of the data before comparing and discussing the codes, and any discrepancies, for standardisation purposes, with codes added, altered, split, or merged, accordingly. Coding was also refined in this way by discussion among project team members familiar with the data.

These organised data were then analysed in two ways: using soft systems methodology (Checkland, 1999) and a realist logic of analysis (Pawson & Tilley, 1997). These analyses were conducted in tandem, with each informing the other iteratively. Soft systems methodology was used to identify systems, within MCs and MC-running organisations, impacting upon sustainability. Over a series of sessions, the project team drew upon the organised interview data to create initial 'rich picture' diagrams for each case study site (see [Supplementary File 1](#)) to identify systems of activity pertaining to sustainability. 'Root definition' statements of these identified systems were then created and a single, synthesised 'conceptual model' of each system (with its component activities) was created to cover all three MC case study sites. These conceptual model diagrams were then presented to stakeholders at each case study site for feedback, from which they were refined.

In tandem and informed by this, a realist analysis aimed to understand causation with regard to the factors impacting on long-term sustainability. A realist logic of analysis (Pawson & Tilley, 1997) was applied to the themed and organised data to draw out, understand, and evidence how differing contexts might be triggering mechanisms (i.e. the hidden causal processes within people and organisations) to cause wanted or unwanted outcomes. These context-mechanism-outcome configurations (CMOCs), written as a series 'if-then-because' statements, were initially drafted by two of project team, then refined by rewording or re-organising if necessary following discussion with the wider team and re-checking against the data.

### Results

Seventy-seven people across three MC case study sites took part in qualitative interviews and focus group discussions: 27 at the Herefordshire site, 21 at the Worcestershire site, and 29 at the Powys MCs. As shown in [Table 1](#), the range of participants (attendees, family carers, staff, volunteers, trustees, and external collaborators) was as planned. Unfortunately, due to a lack of engagement of carers at the Worcestershire MC no interviews with family carers were carried out at this site, which was a notable finding in itself (see below).

Attendees living with dementia ranged between 61 and 96 years old, with an even split of male and female. The majority of attending carers interviewed (77%) were female, and in most cases (77%) carers were spousal, though some adult child carers were also interviewed. Supporting health and care professionals interviewed included three Dementia Advisors, two local Clinical Commissioning Group leads, two third-sector Community Connectors, a local authority adult social care lead, a formal carer, a third-sector personal dementia support worker, and an Ambulance Service representative; other external partners interviewed included two dance practitioners, one music practitioner, one walking and heritage practitioner, one GP patient's group and local Rotary Club member, and one

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

Role in relation to MC	No. interviewed individually	No. interviewed as a pair	No. taking part in focus groups
Attendees	10 (5 male/5 female)	4 (2 male/2 female)	4 (2 male/2 female)
Attendees supporting someone with dementia (carers)	4 (1 male/3 female; 2 spousal/2 adult child)	2 (2 female; 2 spousal)	7 (2 male/5 female; 6 spousal/1 adult child)
MC staff and volunteers	16 (10 staff/6 volunteers)		1 (1 volunteer)
MC trustees and governance	11		1
Professionals and other stakeholders external to MC	14 (8 health and care professionals/6 other)	2 (2 health and care professionals)	1 (1 health and care professional)

researcher (not involved with this study or the project team). Only one attendee couple and two staff members overall formally declined to be interviewed after considering participant information. Interviews with two people with dementia were halted as it became clear during the process they did not have capacity to understand the research, so they were thanked but withdrawn from the study.

Interviews lasted between ~10 and ~75 min, with the majority taking between 30 min and an hour; focus group discussions lasted between ~20 and 30 min. Of the interviews, 30 were conducted in person (mostly with attendees, carers, staff, and volunteers), 33 online or by telephone (predominantly with trustees and external professionals/stakeholders). More interviews took place online at the Powys site as its MCs remained physically closed for longer during pandemic restrictions (Morton et al., 2023). Three focus group discussions were conducted, all with people at Powys MCs: two online with groups of mainly family carers, one in person with mainly attendees living with dementia.

Interview and focus group transcript content was then organised under 20 identified themes (see [Supplementary File 2](#)). This informed a soft systems methodology analysis (Checkland, 1999) where systems of activity relevant to the sustainability of MCs were identified, along with and their component activities. [Figure 1](#) shows the system of activity regarding membership, which includes reference to the referral/care pathway, venue/location issues, and the needs of family carers. This in turn further informed the development of the CMOCs outlined below.

### Realist analysis

A total of 94 CMOCs were developed, grouped under seven broad and overlapping themes: (1) *Referrals and the dementia care 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*. Themes one to four (CMOCs 1–52), which pertain to MC membership are dealt with in this paper (part 1) and presented below. A second paper (part 2) covers themes five to seven (CMOCs 53–94), which pertain to the strategic and operational running of MCs. While these CMOCs refer to MCs specifically, many contain transferrable learning for community group DFIs occupying a similar place in the care pathway, more broadly.

### Referrals and the dementia care pathway

The CMOCs detailed in [Table 2](#) relate to the dementia care pathway and barriers and facilitators to referral to the MC provision. While MCs are typically provided by the third sector and not statutory health and care services, statutory services can work together with MCs beyond simply referring. A functioning ecosystem of services for MCs to work within is a major benefit to them.

### Reaching people and membership

The CMOCs detailed in [Table 3](#) relate to how MCs reach people who may benefit from their support. Central to the sustainability of an MC is its membership and ability to reach and appeal to the people it is targeted towards. Social connection, with a variety of activities, is at the heart of MCs, with the welcome people feel and friendships created highly valued by members.

### Carer benefit and engagement

The CMOCs detailed in [Table 4](#) relate to how carers engage (or not) with MC and the benefits of doing so. If those in a caring role do not engage, see the benefit of it, or feel it meets their needs, this can impact on how the MC functions and its sustainability.

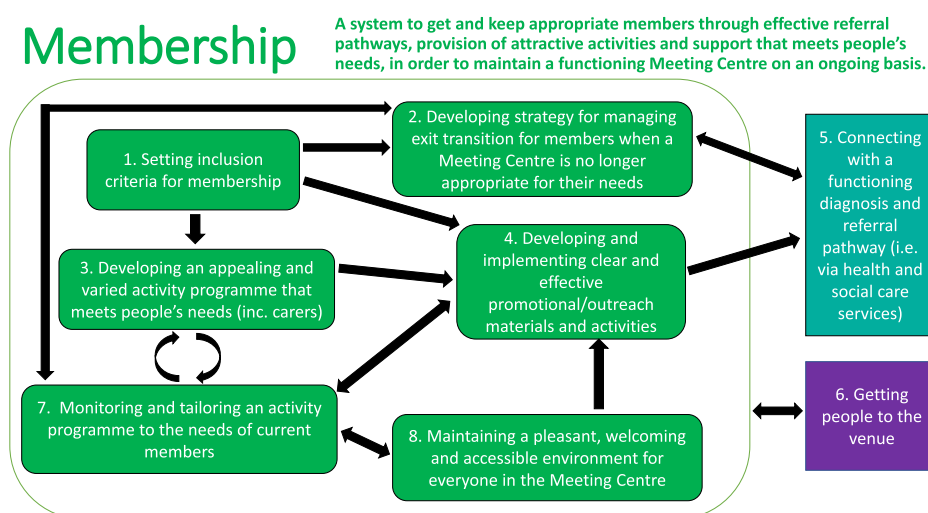
### Venue and location

The CMOCs detailed in [Table 5](#) relate to the impact of the MC venue and location, which can be key to an MCs success and sustainability, though issues relating to this are complex.

[Supplementary File 3](#) details a series of recommendations based on these CMOCs: 36 for those running or overseeing MCs, nine for people attending (or considering attending) an MC, and 12 for health and care professionals.

### Discussion

Issues raised with MCs in this new primary research closely mirrored those found more broadly with community groups and activities in the SCI-Dem review (Morton et al., 2021), adding to the validity and robustness of the SCI-Dem findings, as well as



**Figure 1.** Conceptual model of the MC 'membership' system.

**Table 2.** 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, 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/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 care services then professionals are more likely to signpost or refer, as they will understand the purpose and potential benefits to the right people.
- CMOC 4:** If health and care professionals and services can be helped to understand the benefits MCs can offer to their service and 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 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 knowing about and fully understanding services like MCs that 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.
- CMOC 8:** If a person with dementia relies on driving to get about then they may not attend an MC because they are worried engaging with health, care or support services may lead to losing their license.
- 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 seen as non-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 or, if aware MCs, may think they are 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.

**Table 3.** 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 do not 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 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 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 not want 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 with dementia remain undiagnosed, whether through delays or lack of engagement with healthcare services.
- CMOC 24:** If MCs are not run and/or clearly promoted as intended, or the offer is not understood, then people may not attend/be referred because there is confusion or uncertainty about who the MC is for or what it offers, or the 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 either not sufficient/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 costs involved.
- CMOC 27:** If MCs support people to source and access funds (where eligible) to meet the costs involved in attendance 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 consistently 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 the provision of meals and snacks then this may attract members as food activity is seen as valuable and enjoyable in multiple ways (e.g. it's nutritious, a meaningful activity and a social occasion).
- CMOC 35:** If there are restrictions and limitations on facilities, resources and personnel then food may not be part of an MCs offer as it will be seen as too difficult, labour intensive and interfering with delivering other activities.

**Table 4.** 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 fit it around other responsibilities.

**Table 5.** CMOCs pertaining to venue and location.**Transport and rurality issues**

**CMOC 41:** If the MC catchment is a sparsely populated rural area then support with transport will be important as potential members are more likely to have travel challenges.

**CMOC 42:** If the catchment covers multiple geographic areas with different identities then people may not come to the MC as they may not see it as 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 unable to drive or less able to 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 there is no 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 then 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 MC's 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).

**CMOC 50:** If an MC is only open 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 because a supportive community meeting multiple needs 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.

adding more nuanced detail for the MC context. Notably, SCI-Dem examined DFIs before 2018, while this research was conducted post-pandemic, demonstrating that in many areas the same issues persist despite a changed health and care landscape. In both SCI-Dem and the Get Real study, reaching new people while meeting existing members' needs was the most discussed theme for community group sustainability, with CMOCs covering: problems with referrals; problems with transport; the need to be clear about what is on offer; the need to support people's transition into membership; community networking as a way to promote the group; the benefits of sharing a location with other locally valued services; the offer of food as an incentive for membership; and opportunities for socialising in a safe and welcoming environment as key to appeal.

The need for a wide range of activities on offer to cover a range of abilities and preferences, while present in SCI-Dem, came across more clearly in the current research, hence its centrality to the sustainability of a community group DFI is a novel finding. This validates the MC ethos (Brooker, 2020; Evans et al., 2023) that members should be involved in choosing what they do at an MC and is key to a person-centred approach (NICE, 2018). This also links with recent theory regarding DFI sustainability, that people with dementia and carers need to actively participate in decision-making regarding DFIs to feel they have a choice and are being respected (Thijssen et al., 2023). The Get Real findings suggest choice is not just important regarding which kind of DFI people participate in, but also what they do within a DFI—and mechanisms and resources need to be in place to ensure choice is embedded. Food as an incentive for membership reflects wider research regarding using food to

tackle social isolation in the older population (Dunbar, 2017; The National Lottery Community Fund, 2017), though how best to offer this in community group DFIs (including, again, choice) needs more exploration.

**Meeting Centres and the dementia care pathway**

Collaboration between various organisations and stakeholders involved in a DFI (e.g. in sharing information and decision-making), is thought to be central to its sustaining (Thijssen et al., 2023). This was found to be so with MCs, though collaboration issues impacting upon MC membership were wider than regarding MC itself, but regarding the functioning of the local dementia care pathway as a whole: from diagnosis to referral to availability of supporting services beyond MCs. The challenge of reaching people with dementia at earlier stages to make a timely diagnosis is well recognised in practice and literature (ADI, 2021; Alzheimer's Society, 2021), but particularly pertinent for the membership of DFI groups such as MCs where people with mild to moderate dementia are their target demographic. If combined with a paucity of appropriate follow-on services to support people beyond MCs, this can lead MCs to attempt to stretch what they offer to whom, but result in them failing to appeal to, or meet the needs of, their intended demographic.

Notably, DFIs such as MCs have the potential to reach people pre-diagnosis and help them access the dementia pathway, so close working with memory assessment services could be mutually beneficial. However, communication and collaboration between MCs and statutory services were not felt to be robust in this research, with the distinction between a managed



referral and simple signposting not always understood. Communication between services within the pathway was also an issue. Improving such integrated working is recognised as both a need and a challenge in UK health and social care, with Integrated Care Systems (local partnerships bringing together NHS organisations, local councils, voluntary sector groups, care providers, and others) recently formalised as bodies with their own statutory powers and responsibilities in the UK Health and Care Act (2022), with the aim of developing shared plans and more joined-up services. For all of the issues outlined above, health and care services and community/third sector groups—such as those running MCs—working together more closely would help to tackle these challenges. Issues with the functioning of the local dementia care pathway may be beyond the control of those running and overseeing DFI groups such as MCs, but maintaining communication with services in the pathway, as well as raising awareness of issues and lobbying for change, are to some extent within their remit.

### **Location-related barriers to attendance and sustainability**

Access to transport is a major issue for community groups, and multifaceted: members and carers may both be unable to drive; public transport can be scarce or people might not be confident using it; some may need someone to help them get ready to go out, or accompany them on their journey. The lack of appropriate, accessible transport is a well-recognised challenge in access to health and care support for older people in rural areas (Public Health England, 2019; UK Parliament, 2023). Without significant resources, such issues are likely beyond the capacity of MCs to solve. However, holding information about transport options, and how to access financial support to travel, could be critical for members wishing to attend, and a safe drop off point is a minimum requirement.

Venue guidance for DFIs (e.g. WHO, 2021) tends to focus on accessibility of the physical environment, but this research found venue issues are complex in relation to sustainability, especially in enabling or restricting what MCs can offer. Having multiple spaces can allow members more choice of activity, while fixed and exclusive venue use means members can make the space their own and lend the MC a visible presence in the community. Without this, staff and volunteers will face additional demands, setting up and packing away each session, and members may feel less secure and comfortable. However, sharing a venue with other valued services can be convenient for members and an opportunity to build multi-agency relationships and support.

### **Appeal to family carers**

MCs aim to involve and benefit carers alongside the people that they care for but this research found carers' attendance varied from being the norm to carers rarely attending at all. Where engagement was low, this was attributed either to a change of habits following pandemic restrictions (see Morton et al., 2023) or the membership profile becoming more advanced, therefore respite becoming a more pressing need for carers. There were concerns, however, that there was not enough on offer specifically for carers, or the benefits for carers (Dröes et al., 2004, 2006; Evans et al., 2018) were not being promoted well enough. Since the Adaptation-Coping (Adjusting to Change) model (Brooker et al., 2017) involves the

person with dementia and family carers adapting to a diagnosis together, an MC will struggle to deliver its full range of benefits without the engagement of family carers. For this reason, it is recommended MCs communicate benefits to carers clearly, make time for their needs within sessions, design activities to include and appeal to them, and be flexible to fit with carers' circumstances (see [Supplementary File 3](#)).

### **Strengths and limitations**

The exploratory breadth of the Get Real study was a strength in uncovering a wide range of issues, but a limitation in that it could only highlight issues in overview, with no definitive answers to some identified problems. While valuably informing each other, the soft systems and realist analyses largely took place in a non-linear parallel, with parallel outputs. This was a strength in the sense of bringing two diverse lenses to the data, but these processes could have been more tightly integrated. Due to the mixing of individual, pair, and (focus) group interviews, the level of response from each participant was not consistent: groups tended to cover broader ground at a faster pace but in less depth than interviews, and one or two participants could dominate (though efforts were made to give all chance to answer questions). The analysis did not differentiate by demographics such as age or gender, beyond highlighting issues regarding these raised in the content of the interviews. More attention to what different demographics were saying may have been revealing. The demographic diversity of MC attendees was limited to that of the MC case studies. Though representative of the socio-economic, ethnic, and cultural population make-up of their largely rural areas, these MCs had predominantly white British membership, meaning limited conclusions can be drawn regarding the experience of culturally diverse groups or individuals.

### **Conclusions**

Strong links with health and care services are essential for community-based support such as MCs, as is a functioning dementia care pathway with good communication within and throughout. Issues with diagnosis and referral—both to and on from MCs—are challenging, though MCs are well placed to help in working to improve pathway issues.

Clarity of offer, including benefits to carers, and a wide range of activities are key to boosting an MC's appeal and reach; transport to, and use of, venue are significant challenges to MCs being able to offer what they would like to those they would like to reach. Pressures to serve a more advanced membership profile than originally intended are also an issue for the integrity of MCs as a distinct, targeted intervention.

Many issues identified here are transferrable to other DFIs and would benefit from more detailed examination in future research: Where healthcare pathways are most vulnerable to poor functioning, regarding people's progress through them and their linking with third sector support; what the most effective solutions are to types of venue use and provision of transport; how activities on offer might best be differentiated in group settings for different needs and preferences; how food might be used most effectively and achievably; and how to best engage different types of family carer so that their needs are met. These questions should be explored with groups serving culturally diverse populations, as the context and factors involved will also be diverse.

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## ORCID

Thomas Morton  <http://orcid.org/0000-0001-8264-0834>  
 Shirley B. Evans  <http://orcid.org/0000-0001-6158-1433>  
 Ruby Swift  <http://orcid.org/0000-0001-7861-4238>  
 Jennifer Bray  <http://orcid.org/0000-0002-1315-7643>  
 Faith Frost  <http://orcid.org/0000-0002-8872-581X>  
 Chris Russell  <http://orcid.org/0000-0001-5165-9700>  
 Dawn Brooker  <http://orcid.org/0000-0001-8636-5147>  
 Geoff Wong  <http://orcid.org/0000-0002-5384-4157>

## Data availability statement

Data and study materials will be made available upon request from the corresponding author. This study was pre-registered with the ISRCTN, ref: 39861.

## References

- Alzheimer's Disease International (2021). *World Alzheimer Report 2021: Journey through the diagnosis of dementia*. Alzheimer's Disease International. <https://www.alzint.org/u/World-Alzheimer-Report-2021.pdf>
- Alzheimer's Disease International (2022). *World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support*. Alzheimer's Disease International. <https://www.alzint.org/u/World-Alzheimer-Report-2022.pdf>
- Alzheimer's Society (2021). *Regional variation: Increasing access to a dementia diagnosis*. Alzheimer's Society. [https://www.alzheimers.org.uk/sites/default/files/2021-09/regional\\_variations\\_increasing\\_access\\_to\\_diagnosis.pdf](https://www.alzheimers.org.uk/sites/default/files/2021-09/regional_variations_increasing_access_to_diagnosis.pdf)
- Belder, C. R. S., Schott, J. M., & Fox, M. C. (2023). Insight: Preparing for disease-modifying therapies in Alzheimer's disease. *The Lancet. Neurology*, 22(9), 782–783. [https://doi.org/10.1016/S1474-4422\(23\)00274-0](https://doi.org/10.1016/S1474-4422(23)00274-0)
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage Publications.
- Brooker, D. (2020). *The essential features of a Meeting Centre: UK Meeting Centres Support Programme (UKMCSP)*. University of Worcester. <https://www.worcester.ac.uk/documents/Essential-Features-of-a-Meeting-Centre-booklet-February-2020-edition.pdf>
- Brooker, D., Dröes, R. M., & Evans, S. (2017). Framing outcomes of post-diagnostic psychosocial interventions in dementia: The adaptation-coping model and adjusting to change. *Working with Older People*, 21(1), 13–21. <https://doi.org/10.1108/WWOP-12-2016-0039>
- Checkland, P. (1999). *Systems thinking, systems practice*. J. Wiley.
- Dalkin, S., Lhussier, M., Williams, L., Burton, C. R., & Rycroft-Malone, J. (2018). Exploring the use of soft systems methodology with realist approaches: A novel way to map programme complexity and develop and refine programme theory. *Evaluation*, 24(1), 84–97. <https://doi.org/10.1177/1356389017749036>
- Department of Health and Social Care (2022). *Health Secretary announces 10-year plan for dementia*. UK Government. <https://www.gov.uk/government/news/health-secretary-announces-10-year-plan-for-dementia>
- Dröes, R. M., Breebaart, E., Meiland, F. J., van Tilburg, W., & Mellenbergh, G. J. (2004). Effect of meeting centres support program on feelings of competence of family carers and delay of institutionalization of people with dementia. *Aging & Mental Health*, 8(3), 201–211. <https://doi.org/10.1080/13607860410001669732>
- Dröes, R. M., Meiland, F. J. M., Schmitz, M. J., & Van Tilburg, W. (2006). Effect of the Meeting Centres Support Program on informal carers of people with dementia: Results from a multi-centre study. *Aging & Mental Health*, 10(2), 112–124. <https://doi.org/10.1080/13607860500310682>
- Dunbar, R. I. M. (2017). Breaking bread: The functions of social eating. *Adaptive Human Behavior and Physiology*, 3(3), 198–211. <https://doi.org/10.1007/s40750-017-0061-4>
- Evans, S. B., Bray, J., Brooker, D., & Stephens, N. (2023). The essential features of Meeting Centres: Development of the UK criteria for community support for people affected by dementia. *Working with Older People*, 27(3), 191–201. <https://doi.org/10.1108/WWOP-03-2022-0009>
- Evans, S., Evans, S., Brooker, D., Henderson, C., Szcześniak, D., Atkinson, T., Bray, J., Amritpal, R., Saibene, F. L., d'Arma, A., Scorolli, C., Chattat, R., Farina, E., Urbańska, K., Rymaszewska, J., Meiland, F., & Dröes, R.-M. (2018). The impact of the implementation of the Dutch combined Meeting Centres Support Programme for family caregivers of people with dementia in Italy, Poland and UK. *Aging & Mental Health*, 24(2), 280–290. <https://doi.org/10.1080/13607863.2018.1544207>
- Health and Care Act (2022). c. 31. UK Parliament. <https://www.legislation.gov.uk/ukpga/2022/31/contents/enacted>
- Hebert, C. A., & Scales, K. (2019). Dementia friendly initiatives: A state of the science review. *Dementia*, 18(5), 1858–1895. <https://doi.org/10.1177/1471301217731>
- Luengo-Fernandez, R., & Landeiro, F. (2023). *The economic burden of dementia in the UK*. Alzheimer's Research UK Dementia Statistics Hub. <https://dementiastatistics.org/about-dementia/prevalence-and-incidence/>
- Mangiaracina, F., Chattat, R., Farina, E., Saibene, F. L., Gamberini, G., Brooker, D., Evans, S. C., Evans, S. B., Szcześniak, D., Urbanska, K., Rymaszewska, J., Hendriks, I., Dröes, R. M., & Meiland, F. J. (2017). Not re-inventing the wheel: The adaptive implementation of the meeting centres support programme in four European countries. *Aging & Mental Health*, 21(1), 40–48. <https://doi.org/10.1080/13607863.2016.1258540>
- Manzano, A. (2016). The craft of interviewing in realist evaluation. *Evaluation*, 22(3), 342–360. <https://doi.org/10.1177/1356389016638615>
- Morton, T., Evans, S. B., Brooker, D., Williamson, T., Wong, G., Tinelli, M., Frost, F., Bray, J., & 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*, 12(5), e062697. <https://doi.org/10.1136/bmjopen-2022-062697>
- Morton, T., Evans, S. B., Swift, R., Bray, J., & Frost, F. (2023). The legacy of COVID-19 in dementia community support: Ongoing impacts on the running of Meeting Centres. *Working with Older People*, 28(1), 74–83. <https://doi.org/10.1108/WWOP-03-2023-0006>
- Morton, T., Wong, G., Atkinson, T., & Brooker, D. (2021). Sustaining community-based interventions for people affected by dementia long term: The SCI-Dem realist review. *BMJ Open*, 11(7), e047789. <https://doi.org/10.1136/bmjopen-2020-047789>
- National Institute for Health and Care Excellence (2018). *Dementia: Assessment, management and support for people living with dementia and their carers* [NICE Guideline No. 97]. <https://www.nice.org.uk/guidance/ng97>
- NHS (2023). *Primary care dementia data*. NHS. <https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data/may-2023#related-links>
- Pawson, R., & Tilley, N. (1997). *Realistic evaluation*. Sage Publications.
- Public Health England (2019). *An evidence summary of health inequalities in older populations in coastal and rural areas*. Public Health England. <https://assets.publishing.service.gov.uk/government/uploads/system/>

- [uploads/attachment\\_data/file/824723/Health\\_Inequalities\\_in\\_Ageing\\_in\\_Rural\\_and\\_Coastal\\_Areas-Full\\_report.pdf](#)
- The National Lottery Community Fund (2017). *Ageing better: The role of food in building connections and relationships*. The National Lottery Community Fund. <https://www.tnlcommunityfund.org.uk/funding/strategic-investments/ageing-better#section-4>
- Thijssen, M., Daniels, R., Lexis, M., Jansens, R., Peeters, J., Chadborn, N., Nijhuis-van der Sanden, M. W. G., Kuijer-Siebelink, W., & Graff, M. (2021). How do community based dementia friendly initiatives work for people with dementia and their caregivers, and why? A rapid realist review. *International Journal of Geriatric Psychiatry*, 37(2), 1–14. <https://doi.org/10.1002/gps.5662>
- Thijssen, M., Kuijer-Siebelink, W., Lexis, M., Nijhuis-van der Sanden, M. W. G., Daniels, R., & Graff, M. (2023). What matters in development and sustainment of community dementia friendly initiatives and why? A realist multiple case study. *BMC Public Health*, 23(1), 296. <https://doi.org/10.1186/s12889-023-15125-9>
- UK Parliament (2023). *In focus: Health care in rural areas*. House of Lords Library. <https://lordslibrary.parliament.uk/health-care-in-rural-areas/>
- World Health Organisation (2017). *Global action plan on the public health response to dementia 2017–2025*. World Health Organisation. <https://www.who.int/publications-detail/global-action-plan-on-the-public-healthresponse-to-dementia-2017-2025>
- World Health Organisation (2021). *Towards a dementia-inclusive society: WHO toolkit for dementia friendly initiatives (DFIs)*. World Health Organisation. <https://www.who.int/publications/i/item/9789240031531>