



The Essential Features of Meeting Centres: development of the UK criteria for community support for people affected by dementia

Journal:	<i>Working with Older People</i>
Manuscript ID	WWOP-03-2022-0009
Manuscript Type:	Research Paper
Keywords:	Post-diagnostic intervention, community support, concept analysis, Meeting Centres, family carers, people living with dementia

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Abstract

Purpose

Meeting Centres are a complex community-based psychosocial intervention to support people affected by dementia. The aim of this article is to describe the process of identifying the Essential Features of Meeting Centres from a UK perspective.

Design/methodology/approach

The Essential Features were examined within a Concept Analysis framework which combines both static and evolutionary methods, enabling multiple stakeholder groups to be included in the process in an iterative manner.

Findings

Eleven Essential Features were developed, providing a conceptual model of UK Meeting Centres. The underpinning rationale is sufficiently flexible to enable community-based development, whilst at the same time providing a robust platform upon which to build the evidence base.

Originality

While some features may be common to other types of community-based support, the combination of characteristics and the underpinning ethos differentiates Meeting Centres and enables each one to meet the needs of its own community.

Introduction

Post-diagnostic psychosocial support in the UK

Dementia strategies internationally recommend that diagnosis should occur at an earlier stage when people can make lifestyle changes and decisions for the future (Alzheimer's Disease International, 2021). This provides an opportunity for individuals and families to adjust together and build resilience to bring about improvements in health and wellbeing. However, people often live with a dementia diagnosis for a long period of time, during which the needs of both the person with dementia and their family carer will change (Brooker *et al.*, 2014). Supporting people affected by dementia to live well in their communities, with timely psychosocial support, is a global public health goal (World Health Organisation, 2012). Post-diagnostic interventions are under-researched though, and psychosocial support is patchy across the UK (Department of Health and Social Care, 2019). Families in some areas lack formal support beyond occasional contact with primary care and the third sector, and many interventions are undertaken by national and local charities.

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5 There have been various attempts to mitigate these challenges in the form of groups and activities
6 providing post-diagnostic psychosocial interventions for people affected by dementia (Oyebode and
7 Parveen, 2019). Many such interventions occur weekly or less frequently for up to two hours and are
8 often delivered on a short-term basis. Only a limited number have been running for at least two
9 years, are regular and on-going, and are available at least one day a week (Morton *et al.*, 2021).
10 Meeting Centres (MCs) are one such intervention which has the potential to offer long-term
11 community provision for people affected by dementia.
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18 ***Meeting Centres for people affected by dementia***

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20 MCs are based upon a Dutch model (Dröes and Breebaart, 1994) following interviews and focus
21 groups on what would help people enjoy a good quality of life and live at home for as long as
22 possible. It was clear that people needed practical help and reliable local information, but also
23 emotional and social support. Loneliness among caregivers, their feelings of being overburdened,
24 and not really understanding the consequences of dementia, indicated that intensive guidance and
25 support was needed not just by the person with dementia, but also their caregivers.
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31 The first two MCs opened in Amsterdam in 1993 and showed promising results: caregivers felt more
32 competent to provide care and experienced less burden, while people with dementia felt happier,
33 became more active and developed new friendships in the MCs (Dröes, 1996; Dröes *et al.*, 2000,
34 2004a, 2004b). Attending MCs also resulted in fewer care home admissions, and delayed admission
35 by an average of seven months (Dröes *et al.*, 2004b). There are now over 170 MCs in the
36 Netherlands, with a pledge to provide 80% of families with access to an MC by 2030 (Ministry of
37 Health, Welfare and Sport, 2020). The Dutch National Working Group of MCs developed guidance
38 for setting up and running MCs and offers training, support and helplines across the Netherlands.
39 This includes embedding the MCs underpinning theoretical model, known as the 'Adaptation and
40 Coping Model' (Dröes, 1991; Meiland *et al.*, 2010), which focuses on helping people adapt and cope
41 with the social, emotional and practical challenges of dementia.
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51 MCs are places where people with mild to moderate dementia and their family carers can regularly
52 and routinely socialise, take part in activities, and get support to meet their needs. The MC is usually
53 open three days a week, with 12-20 members per day meeting in an easily accessible community
54 location. A typical MC supports a local community of around 12,000 older people and is open to
55 people of all ages and types of dementia diagnosis. Evidence-based post-diagnostic interventions are
56 provided within the MC, driven by the needs, wishes and interests of the members. MCs are
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3 facilitated by staff and volunteers trained in person-centred dementia care and the Adaptation and
4 Coping Model (Brooker *et al.*, 2017a).
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8 Between 2014 and 2017, the authors of this article were co-investigators on the EU Joint Programme
9 for Neurodegenerative Diseases funded 'MEETINGDEM' research which aimed to adapt, implement
10 and evaluate the MC model across the UK, Italy and Poland (Dröes *et al.*, 2017). This included
11 adapting the Dutch materials, setting up Demonstrator MCs in each country, training staff and
12 undertaking a controlled trial comparing MC to 'usual care' for people affected by dementia. A UK
13 version of the Adaptation and Coping Model was also developed, called the 'Adjusting to Change'
14 Model (Brooker *et al.*, 2017a). The resulting Meeting Centre Support Programme (MCSP) was
15 successfully upheld across each country, with adherence to the key components from the Dutch
16 model. To account for different national contexts, adjustments were made around inclusion criteria,
17 frequency of components within the programme, and adoption of culturally relevant activities.
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26 For people with dementia, attendance at MCs had a positive impact on quality of life when
27 compared to usual care. Higher attendance levels were associated with a greater reduction in
28 neuropsychiatric symptoms and increased feelings of support (Brooker *et al.*, 2018). For family
29 carers, attendance at MCs reduced carer burden and distress, and enhanced overall mental health
30 compared to usual care (Evans *et al.*, 2018). The research concluded that MCs are a transferable
31 model of post-diagnostic support for people affected by dementia across different countries,
32 including the UK. MCs are now being developed in Spain, Chile, USA, Aruba, Singapore, Japan and
33 Australia.
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42 As part of MEETINGDEM, two UK Demonstrator MCs were established in Worcestershire and
43 Herefordshire. In 2018 the authors of this article were awarded a National Lottery implementation
44 grant to establish further MCs across the UK and share learning about successful implementation.
45 There are now four Demonstrator MCs including sites in Wales and Scotland, and a UK-wide network
46 and Community of Learning and Practice (CoLP) to oversee established and emerging MCs. The
47 Demonstrator MCs work together to enhance the evidence base and know-how about MCs, and
48 host visitors to showcase MCs. At the time of writing, around 30 MCs have been funded in the UK,
49 with more planning to open in 2022.
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56 As well as coordinating the CoLP, the authors of this article help new communities establish MCs,
57 train staff teams and lead a UK-wide National Reference Group. Due to the pandemic, much of the
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3 work with the CoLP in 2020-2021 was around facilitating the switch from in-person group meetings
4 to remote home-based support, building confidence in re-opening as lockdown eased, and re-
5 building as the vaccination programme meant a return to some sense of normality.
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10 **Research design and methods**

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12 A systematic approach was required to identify the 'Essential Features' of an MC. Concept Analysis
13 was chosen as it is often used to 'provide a standard language for measuring the concept and/or
14 identify gaps in knowledge,' (Fitzpatrick and McCarthy, 2018, p.4). It is often used to draw together
15 understanding of broad terms such as anxiety and fear, as well as more tangible terms like
16 'community engagement' (Nuuyoma and Makhene, 2020). While several conceptual analysis
17 frameworks exist, a synthesis of the static (Walker and Avant, 2005) and evolutionary (Rodgers and
18 Knafl, 1993) methods was chosen, as illustrated in Figure 1. The numbered steps from the static
19 model provide clarity, while the iterative process around steps 4 to 9, as per the evolutionary model,
20 work well considering the variety of stakeholder groups included in the process. Part of the MC
21 ethos is the inclusion of many different stakeholders including people living with dementia, their
22 families and those providing and commissioning support. These groups are represented within the
23 National Reference Group and CoLP and were included in reviewing and refining the Essential
24 Features.
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-----Insert Figure 1 here-----

39 **Results**

40 ***Steps 1 & 2 – Select concept and establish purpose of the analysis***

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42 MCs should meet the needs of their local communities and members so will, by their very nature, be
43 diverse in their operation. Enabling diversity, innovation and responsiveness is important, whilst still
44 ensuring that MCs adhere to the underpinning model and core principles. Guidance was therefore
45 required that would encourage development and enable new MCs to feel confident in their
46 approach by following an accessible, light touch framework.
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53 MCs in the UK can use the MC logo and appear on the MC website, but there is neither the funding
54 nor the infrastructure to audit the growing number of MCs. Thus, a clearly defined set of essential
55 features will help individual MCs to self-assess while ensuring consistent quality of what is being
56 offered. The research purpose was to understand MCs in the UK context to establish the 'Essential
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3 Features' of an MC. In this article we describe our investigation of the characteristics of MCs in the
4 UK utilising Concept Analysis principles.
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8 **Step 3 – Review of literature to identify uses of the concept**

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10 A search of the CINAHL, Medline, APA and PsychINFO databases yielded 32 returns of which 25
11 referred directly to the MCSP. Eleven of these were directly related to the MEETINGDEM project.
12 Several articles defined the MCSP as the specific programme of activities taking place at MCs
13 supporting people with dementia and family carers individually and together, group meetings for the
14 MC, and education and training for the community (Dröes *et al.* 2004a, 2004b, 2006; Szczesniak *et*
15 *al.* 2019). The nature of the activities is not prescribed but supports practical, emotional, and social
16 adjustment in line with the Adjusting to Change model.
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23 One area of interest in the literature was the variation in activities delivered at MCs. Dröes *et al.*
24 (2004c) and Mangiaracina (2017) conclude that adaptive implementation of MCs is necessary to
25 meet the requirements of different communities. Van Rijn *et al.* (2020) describe three new
26 interventions introduced to Dutch MCs to provide additional support, while Evans *et al.* (2021)
27 explore remote support strategies developed during the initial lockdown period of the COVID
28 pandemic.
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35 **Steps 4 & 5 – Identify general attributes and model cases**

36 The general attributes distilled from the literature and the MEETINGDEM research are set out in
37 Table 1.
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45 Table 2 illustrates each attribute with examples from MCs in the UK during 'usual times' and during
46 the pandemic.
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51 **Step 6 – Identify borderline/related and contrary cases**

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53 Many community-based initiatives have aspects in common with MCs and may be considered
54 borderline cases from a Concept Analysis perspective. The SCI-Dem study (Morton *et al.*, 2021)
55 focused on the sustainability of MCs and similar regular and on-going community-based initiatives
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3 that are open for at least one day a week and have been in existence for more than two years.
4 Examples including The Debenham Project (n.d.) and Men in Sheds (n.d.) have a similar ethos of
5 bringing people together in a local community to provide post-diagnostic support.
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10 There are a number of examples of contrary cases which vary in terms of availability and purpose.
11 The following are frequently queried in terms of similarity to MCs, but represent two ends of the
12 scale around availability and purpose:
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16 • **Alzheimer Cafés:** Alzheimer Cafés are an informal form of post-diagnostic group intervention
17 held monthly for around two hours, with talks, activities, refreshments and/or light lunch.
18 They provide education, information, and support for people with dementia and their
19 caregivers (The Alzheimer Cafe UK, n.d.).
- 20 • **Day care:** Tester (2001) defines day care as offering ‘communal care, with paid or voluntary
21 care givers present, in a setting outside the user’s own home. Individuals come or are
22 brought to use the services, which are available for at least 4 hours during the day and
23 return home on the same day.’ (p.37) Day care for people with dementia is usually aimed at
24 people with moderate to severe dementia who may need personal care. They commonly
25 offer activities for the person attending while providing respite and occasional support for
26 family caregivers (Tretteteig *et al.*, 2016).
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37 ***Step 7 – Delineate antecedents***

38 Antecedents must be in place before an MC opens. Based on the Dutch experience, there must be a
39 need and demand within the local community, potentially due to a gap in the dementia care
40 pathway around post-diagnostic support. This is identified by community engagement through a
41 consultation event with interested stakeholders. From this, a planning group is established to meet
42 regularly and address seven key areas: programme, target group, location, staffing, finance,
43 marketing, and collaboration. This process is detailed in the UK MC Guidebook (Brooker *et al.*, 2017).
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50 ***Step 8 & 9 – Delineate consequences and empirical referents***

51 The key consequence of an MC is that people are supported to adjust to the changes that a diagnosis
52 of dementia brings. The aim is that people will benefit from attending the MC through improved
53 health and well-being, signposting to support services, or person-centred/peer support. While the
54 MEETINGDEM study used a range of validated measures to assess impact on people with dementia
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(Brooker *et al.*, 2017a) and family carers (Evans *et al.*, 2018), it is not expected that such measures could be utilised regularly by community groups.

Steps 10 & 11 – Collate and analyse data and identify defining features

A draft set of 'Essential Features' was developed based on the literature review and experiences from the UK MCs and honed through consultation with the National Reference Group. Drafts were presented at two meetings held two months apart and updated based on subsequent discussions which were recorded and transcribed each time. Table 3 sets out the resulting Essential Features of an MC. The evidence required for (self-)assessment is included for each feature to ensure a service is entitled to use the MC logo. The Essential Features are set out fully in a downloadable document (Brooker, 2020).

---Insert Table 3 here---

The underpinning rationale for the Essential Features was that MCs must be flexible to meet the needs of individual communities. For example, whilst the Dutch literature indicates that an MC should be open three days a week, this is not always possible in sparsely populated areas. In such cases, one day a week is deemed the minimum requirement for opening, giving sufficient time for staff to become familiar to people and support them to adjust to change. Some aspects that might be perceived as Essential Features are not included, such as finance and attendance fees. Such aspects are for individual MCs to decide, based on the means of their community. Another example is the need for a dementia diagnosis. While some MCs insist on this, others do not but will usually support someone to obtain a diagnosis. The Essential Features allow sufficient flexibility to accommodate what people want and local community requirements, opportunities and constraints, whilst also supporting people affected by dementia to live well in their community for longer.

Discussion and conclusion

The following definition of a UK MC captures the Essential Features from Table 3 and is used in all relevant literature, including reports to commissioners, funding applications, guidance and marketing.

In essence an MC is a local resource, operating out of ordinary community buildings, that offers on-going warm and friendly expert support to people with mild to moderate dementia and their families. At the heart of the MC is a social club where people meet to have fun, talk to others and get help that focusses on what they need. MCs are based on sound research evidence on what helps people

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3 *to cope well in adjusting to living with the symptoms and changes that dementia*
4 *brings.*
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6 While other initiatives are likely to replicate at least some MC activities, MCs are differentiated by
7 the combination of the various elements, the overall ethos, and the underpinning Adjusting to
8 Change model.
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13 Analysing the pre-conditions, consequences and measures in the MC context has been useful in
14 identifying them as being part of the Essential Features. For example, the role of community
15 engagement from the very outset of establishing an MC is part of the ethos. Identifying borderline
16 and contrary cases is also important for situating MCs in the dementia care pathway. For example, a
17 Memory Café may be more suitable for people with early stages of dementia, while day care may be
18 more appropriate for people with moderate to severe dementia. This helps reduce blurring of
19 boundaries between interventions and should help people to receive the right support at the right
20 time.
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28 In the same vein, the consequences and measures in terms of assessing benefits are illustrated by
29 the inclusion of data collection as an Essential Feature. The study by Evans *et al.* (2021) sought to
30 specifically address the question of whether MCs could continue to support people to adjust to
31 change during the pandemic. Having a clear understanding of what constitutes an MC made it
32 possible to conclude that MCs were able to adapt rapidly and provide support in line with the
33 underpinning MC approach.
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40 MCs are complex support interventions, but the Concept Analysis approach enabled their essence to
41 be distilled into a consistent and commonly understood format. If it works for MCs it is likely to be a
42 beneficial approach for similar initiatives.
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46 **Acknowledgements**

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48 The authors would like to thank members of the National Reference Group for their support in
49 identifying and refining the Essential Features of an MC. This work was supported by The National
50 Lottery Community Fund, Project Number 10333678.
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54 **Declaration of interest statement**

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57 No potential competing interests were reported by the authors.
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Tables

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Figures

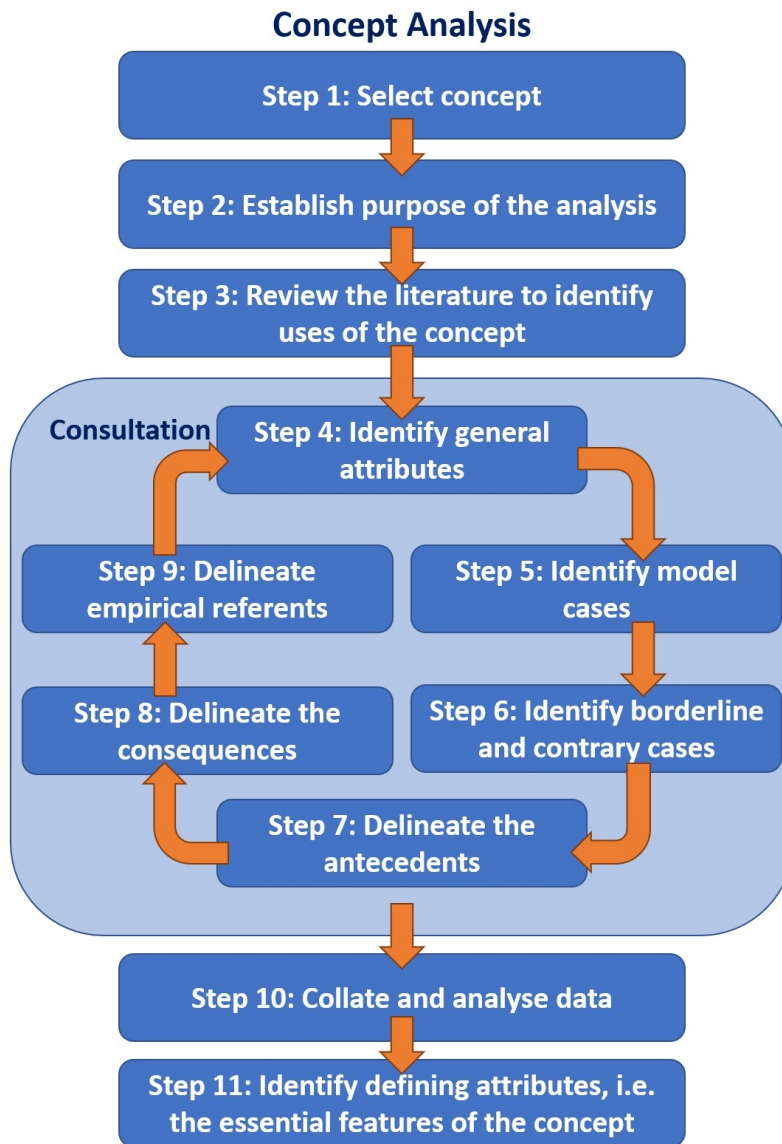
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Figure captions

Figure 1: Adapted Concept Analysis Framework (Adapted from Walker and Avant (2005) and Rodgers and Knafl (1993))

Working with Older People

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Concept Analysis

190x275mm (150 x 150 DPI)

Table 1: Key elements of an MC from the literature review

Element	Description
Frequency	The MC 'club' is usually offered three days per week. People attend three days a week or less, according to their need and preference.
Number of people attending	Supporting 10-15 people plus families on any one day.
Location	Easily accessible community locations.
Staff and volunteers	The small team of staff is led by a manager with relevant health and social care qualifications and experience and who has the skills to lead the team and engage with people with dementia, their families, and the local community.
Programme of activities	Evidence-based post-diagnostic psychosocial interventions relating to information and psychoeducation and emotional, social, and physical well-being are provided in a friendly manner, tailored to the needs of members. The interventions are informed by the Adjusting to Change model. Co-ordination and movement (psychomotor activity) and eating together are also important elements. Family caregivers are encouraged to engage in and contribute to the club activities by, for example, sharing skills and expertise.
Carer meetings	As well as this general attendance at the MC there are a number of MC activities that focus more specifically on family caregivers. Families will need different support at different times to help them adjust to their changing situation. This might be information and signposting in the initial stages after diagnosis and at a later stage practical and emotional support.
Programme of education and training open to the wider public	MCs provide informative/educational meetings by expert guest speakers from care and welfare organisations, which are usually held in a series of ten monthly meetings covering a wide range of topics such as different types of dementia, responding to changes in behaviour and mood, legal aspects of dementia and the support needs of family caregivers. These meetings are open to the wider public as well as MC participants.
Collaboration between stakeholders	The local focus enables collaboration between services counteracting the fragmentation of care.

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Working with Older People

Table 2: Attributes of a Meeting Centre from the literature review and UK example cases in usual times and during the pandemic

Element	Model Cases – illustrations from UK MCs usual times	Model Cases – illustrations from UK MCs during the pandemic
Frequency	This varies from one to five days a week depending on location e.g. Powys county, Wales, is very rural and sparsely populated with four MCs running for one day a week in different locations. Leominster MC opens five days a week with people attending up to three days.	Where remote support was offered, this was available multiple days per week. people could be supported for shorter amounts of time but more frequently. Note that the majority of people who attend MCs do not have the technology and/or the skills or interest to engage in Zoom type support.
Number of people attending	This varies depending largely on the density of the population and the size of the MC. It can vary between eight and 15 people with dementia plus family caregivers.	Once MCs re-opened for in-person sessions, numbers of people attending were greatly reduced due to restrictions with fewer family caregivers choosing to attend, possibly taking the opportunity of respite.
Location	MCs are located in village halls, community centres, sports clubs, GP surgeries, church halls and residential care settings. It depends on what is available in the local community.	During the initial lockdown some MCs provided remote support online (Zoom), newsletters, telephone calls and, later on, garden visits and walks were possible. The only way to hold group meetings during lockdown was online.
Staff and volunteers	Some of the MCs are staffed by a manager and two support staff plus volunteers, depending on the number of people attending. Two MCs are run entirely by volunteers but where this is the case it is for one day a week.	Of the MCs which were able to re-open in-person, none reduced the number of staff and volunteers and in one case an MC took on extra staff.
Programme of activities	All MCs run a day-long programme of activities geared to the needs of those attending, who are consulted about what they want to do and supporting them to adjust to change within the MCSP framework and strategies. Activities include preparing and eating together where possible but some take packed lunches, seated exercise, excursions, dancing, quizzes and bowling as well as signposting and information sessions.	This has been limited to what can be delivered remotely but MCs have been very creative with their provision, for example choir, seated exercise, quizzes and memory activities. As lockdown eased it was possible to provide most of the activities.
Carer meetings	Most MCs hold separate carer meetings. Usually these are at the MC but sometimes they are at a separate site in order for the carer to feel more relaxed and comfortable when seeking support.	Many caregivers benefited from online meetings which were at a time to suit them and gave them more opportunities for peer support.
Programme of education and training open to the wider public	Most MCs operate both sides of the door with considerable community-based activity. However, this is quite difficult to do when an MC is operating one day a week. Often, such education and training overlaps with the work of Dementia Friendly Communities/Dementia Action Week.	This was not a priority for MCs but there was evidence of online activity during Dementia Action Week. Where this occurred, it appeared to have greater reach and interest than in usual times.

Element	Model Cases – illustrations from UK MCs usual times	Model Cases – illustrations from UK MCs during the pandemic
Collaboration between stakeholders	There is strong evidence of all MCs collaborating with local organisations and services prior to implementation as well as on an on-going basis, for example, by holding community engagement events and establishing an Advisory Group. However, not all MCs continue with an Advisory Group.	MCs were, in some cases, more able to engage with other organisations, locally, regionally and nationally as these were all online and there was no travel time involved. Moving forwards a mix of online and face-to-face engagement could support stronger links.

Working with Older People

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Working with Older People

Table 3: The Essential Features of a Meeting Centre

Essential Features of an MC	
1. On-going regular MC Club	The MC club meets regularly at a fixed time and is attended by around 15 members (people with dementia attending an MC) most days, plus family caregivers who wish to attend.
2. We are in this together	Everyone experiences a warm and inclusive atmosphere at the MC and there are processes in place (such as regular discussions and feedback) to ensure this is the case for members, families and friends.
3. Adjusting to Change	The MC is a place that promotes practical, emotional, and social adjustments for members and family caregivers. There are processes in place for this to be promoted and monitored over time.
4. Skilled and stable team plus volunteers	There is an identifiable skilled and stable team which is fully conversant with the MC ethos and is known and valued by the MC members.
5. MC Leadership	There is a named person who has an in-depth understanding of the MC approach and is able to lead the team to deliver the MCSP in an enjoyable manner with due regard for safety and well-being of all concerned.
6. Focusses on both members living with dementia and family caregivers	The MC meets the needs of the members and family caregivers in a safe and enjoyable manner. Both people with dementia and family caregivers feel actively supported by the MC and to be able to attend.
7. Programme of Activities	The programme reflects the interests and utilises the talents of those attending. Mechanisms are in place to ensure this is the case (regular MC meetings, discussions and feedback opportunities). The programme includes a range of evidence-based physical, cognitive, (re)creative and social activities that occur within the MC and in the wider community and support people to adjust to change.
8. Location	Members feel comfortable about attending an MC at the location where it meets. The location provides adequate facilities in which to run the programme.
9. Community Engagement	The MC includes a variety of community stakeholders in positively contributing to the planning and the delivery of the MC Support Programme.
10. MCs Community of Learning and Practice	The MC is open to receiving visits and information sharing, shares examples of good practice and attends updates and networking events.
11. UK MCs Data Collection	The MC provides the minimum data set which covers attendance, baseline characteristics, health and well-being, case studies and contextual information all in a format that is easy to administer for community groups.