

## **The legacy of COVID-19 in dementia community support: Ongoing impacts on the running of Meeting Centres**

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### **Abstract**

**Purpose** – *The COVID-19 pandemic caused major disruption in community support for vulnerable older people and is thought to have exacerbated existing issues within UK adult social care. This study examines the legacy of that disruption on how Meeting Centres for people affected by dementia have been impacted in continually evolving circumstances.*

**Design/methodology/approach** – *Semi-structured interviews and focus group discussions were conducted at three Meeting Centre case study sites. Ninety-eight participants including people living with dementia, family carers, staff, volunteers, trustees and external partners were asked about the impact and legacy of the pandemic upon Meeting Centres. A thematic analysis was carried out on the data.*

**Findings** – *Ten themes were identified: Ability to re-open venues; Increased health decline and loss of members due to isolation; Closure or halting of linking services and dementia community support; Disruption to diagnosis and referrals; Increase in outreach, building communities and overall reach; Digital access and use of technology (boom and decline); Changes to carer involvement and engagement; Continued uncertainty and changes to funding, resources and governance; Staff and volunteer recruitment issues; Relief at/wish for return to pre-pandemic norms.*

**Originality and value** – *This paper offers new insight into a still-developing situation, namely the legacy effects of the pandemic upon third-sector community support for people affected by dementia, and the health and social care services that support it. The reduction in maintenance of pandemic-era technological innovations is a key finding.*

**Key words** *Dementia, COVID-19, community-based support, social inclusion, digital exclusion, aging well*

**Paper type** *Research paper*

## **Introduction**

People living with dementia, and those that support them, were significantly impacted by the COVID-19 pandemic (Alzheimer's Society, 2020). For those living at home in the community, social opportunities and formal support were severely curtailed during successive lockdowns, with the suspension or reduction of community services and difficulty in accessing health services (Alzheimer's Society *et al.*, 2021; Pentecost, 2022). This is internationally reported to have increased carer burden and led to faster cognitive, physical and behavioural decline for those with dementia, and impacted mental health for both (Geibel *et al.*, 2022a, 2022b).

Since the lifting of pandemic restrictions in the UK, older people have experienced continued impacts, including increased anxiety and low mood, reduced mobility, loss of social skills and loss of confidence in engaging in previously routine activities (Age UK, 2021). The pandemic is also thought to have exacerbated existing dementia support issues with UK adult social care (Britton and Zimmermann, 2022). Access to health and social care support continues to be difficult and delayed for many due to what the UK Care Quality Commission (CQC) calls a "gridlock" caused by reduced service capacity (CQC, 2022).

This is the climate in which third-sector community support, often seeking to address gaps in formal care provision, has been operating since the pandemic's onset. Shortly after the height of the pandemic, we reported how UK Meeting Centres (MCs), a form of community-led post-diagnostic support for people with mild to moderate dementia and family caregivers, were responding to the situation (Evans *et al.*, 2021). While the circumstances were extremely challenging, with MCs physically shut during

lockdowns, many continued to offer some form of support with outreach activities and remote contact. This presented an opportunity to investigate ways in which technology could be used to help people connect during this time (Evans *et al.*, 2022). Continued research with MCs has allowed us to monitor if and how MCs have managed to “bounce back” following the lifting of pandemic restrictions, as well as if and how practices have changed because of the pandemic, including the use of technology and outreach activities.

### *The initial response of Meeting Centres*

Originating in the Netherlands (Dröes *et al.*, 2004), MCs are places where people can socialise, take part in activities and get support. At the heart is a small social club (15 people with dementia per day, plus family caregivers), based in an ordinary community building, operating up to three times a week and facilitated by a small team of staff and volunteers. The features of MCs are designed to help people make emotional, social and practical adjustments to living with dementia, with staff and volunteers trained in person-centred dementia care and the adjusting to change model (Brooker *et al.*, 2017). MCs 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. The use of technology prior to the pandemic was typically limited.

With the onset of the pandemic, data collection at four MC ‘demonstrator’ sites, carried out as part of the UK Meeting Centres Support Programme (UKMCSP, 2018-2021) was widened to include insights into the impact of lockdown. This demonstrated that, to some extent, MCs could continue to support people to adjust to change during a period of no or limited face-to-face contact by introducing remote support. In some cases, support was found to be more flexible and accessible for people due to not having to physically attend, and in some cases relationships between staff, carers, and people with dementia were

enhanced. However, such benefits were only felt by a minority, and online activities were only accessible by a minority, hence non-technological approaches such as newsletters and garden visits were vital. Cost and staff workload were at least equivalent to regular MC activity. The possibility of introducing a blended approach of remote and face-to-face MC provision after the lifting of lockdown restrictions was considered to offer greater flexibility and reach for people, particularly in rural areas to address social isolation (Evans *et al.*, 2020).

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

The Get Real with Meeting Centres project (2021-2023) was a Realist Evaluation investigating factors involved in the long-term sustainability of MCs. Planned prior to the pandemic, it was awarded funding by the NIHR in 2020 and commenced January 2021 as the UK emerged from the most restrictive lockdowns. Hence it presented an opportunity to gather data on how MCs coped in response to the challenges of the pandemic in continually evolving circumstances. This paper focusses on that data; results from the full Realist Evaluation will be reported elsewhere.

## **Methods**

A protocol for the full Get Real project has been published elsewhere (Morton *et al.*, 2022). Only the elements relevant to the legacy of the COVID-19 pandemic are presented here. Favourable ethical opinion was granted by Health Research Authority research ethics committee Wales REC4 on 11 June 2021, reference: 21/WA/0185.

### *Meeting Centre case studies*

Qualitative data was collected via semi-structured interviews and focus group discussions with participants in a range of roles at three case study research sites: An MC in a small market town in Herefordshire; An MC in a larger market town in Worcestershire; A cluster of four federated small town

MCs run by a single organisation within a rural county in Wales. In addition to different geographic and demographic factors, each site had taken their own individual approach to the implementation and delivery of MCs while operating within the Essential Features of Meeting Centres (Brooker, 2020). Each also responded differently to the successive lockdowns of the pandemic.

Participants at these sites were selected purposefully for their role and involvement in MCs, to cover a range of perspectives and experience regarding MC running and functioning. 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 the governance of MCs (e.g. trustees); and health/social care professionals and other stakeholders external to, but involved with, an MC. The same question topics were covered in interviews and focus group discussions. Depending on pandemic restrictions and participant preferences, these 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 from each site in September and October 2022.

#### *Investigation of who Meeting Centres do not reach or benefit*

In addition to the above, further interviews and focus group discussions took place focusing specifically on barriers to attendance. The impact of the pandemic arose during this work also. This ‘barriers work package’ focused on 13 MCs run by various different organisations in Herefordshire and Worcestershire (treated as single region by NHS bodies such as the Integrated Care Board). Participants again included MC staff and volunteers, those involved with the governance of MCs and health/social care professionals external to, but involved with, an MC (e.g. referrers). People living with dementia, and family carers supporting them, who had decided against attending an MC or stopped attending, were also interviewed. This work was carried out between March and August 2022.

#### *Analysis*

A thematic analysis (Braun and Clarke, 2006) of the interview and focus group discussion transcripts was carried out using NVivo qualitative data analysis software. Relevant content within the transcripts was categorised (coded) by themes, generated both deductively and inductively, for data from the MC case studies and barriers work package. In both work streams the 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. The coding categories and process was also refined by discussion among the whole team.

## Results

Ninety-eight participants took part in interviews and focus group discussions that touched on the impact and legacy of the COVID-19 pandemic (see Table 1). Seventy-seven participants were people involved with three MC case study sites in England and Wales; a further 21 participants were involved with the barriers work package.

**Table 1** Number and role of participants in interviews and focus groups (Total n=98)

<i>Role in relation to MC</i>	<i>No. interviewed (MC case studies/barriers work package)</i>	<i>No. taking part in focus groups (MC case studies/barriers work package)</i>
<b>Attendees/Non-attendees living with dementia</b>	<b>14/3</b>	<b>4</b>
<b>Attendees/Non attendees supporting someone with dementia</b>	<b>6/3</b>	<b>7</b>
<b>MC staff &amp; volunteers</b>	<b>16/6</b>	<b>1</b>
<b>MC trustees &amp; governance</b>	<b>11/1</b>	<b>1</b>
<b>Professionals &amp; other stakeholders external to MC</b>	<b>16/2</b>	<b>1/6</b>

The following 10 themes regarding the impact and legacy of the pandemic were identified:

*1. Ability to re-open venues*

The nature of an MC organisation's arrangements with its physical venue made a significant difference to how quickly an MC could return to physical meeting. The first to return – and to keep physically meeting during subsequent restrictions – was an MC where the organisation running it had sole use of their venue:

“They can control the numbers, they can control who is using the premises... [It] really minimises risk factors... I think that is one of the reasons they were able to get going as quickly as they were after lockdowns.” (MC trustee)

In contrast, MCs where venues were multi-use and rented for just a few hours each week, were much later to return.

*2. Increased health decline and loss of members due to isolation*

MC personnel and families attending MCs commonly reported that isolation due to pandemic restrictions appeared to hasten a decline in health for people living at home with dementia:

“Hubby has lost so much muscle wastage he can hardly walk, he is losing his speech as well. Because there's no socialising or interaction.” (Family carer)

Some MCs found membership reduced as longstanding members passed away or their health deteriorated to a point where the MC could no longer support their needs:

“We had lost quite a few members, through natural progression, but we hadn't brought anybody in because of... COVID.” (MC manager)

Many MCs felt their overall membership profile had shifted to have a greater proportion of members at more advanced stages of dementia:

“The MC since COVID has changed in a way. Because we set out to be an MC for people early diagnosed and now because there are people here that really should have moved on but there isn’t anywhere to go on to.” (MC staff member)

However, staff reported signs a new cohort was now coming through with numbers increasing again.

### *3. Closure or halting of linking services and dementia community support*

At the height of the pandemic many services supporting people in the community were suspended or halted. The case study MCs all managed to keep some form of support going, often remotely, but felt many other services did not do likewise:

“A lot of the people that we were supporting during that time, particularly during the first 12 months of COVID pandemic restrictions, were telling us that we were the only organisation that was supporting them, for example, day centres closed... during that time, it did feel like... this could be the only contact that this person’s had this week.” (Lead of MC-running organisation)

Many felt support for people with dementia in the community – whether in the form of available services MCs could link with, or dementia-friendly community activity in general – had not returned to pre-pandemic levels:

“I don’t think they’re opening any of the... council run [day] centres... It does feel like COVID has been a little bit of a smokescreen to kind of cut services in the background.” (External practitioner who works with MCs)

### *4. Disruption to diagnosis and referrals*



The pandemic disrupted both diagnosis and referrals into MCs. Participants felt that, while things were now returning to normal, for the couple of years following the onset of the pandemic it had been more difficult to for people to access GP appointments, especially face-to-face, with a knock-on-effect on the number of people coming through the health and social care pathway:

“GP appointments have changed completely... How much more difficult that must be [for families] with the new system is unimaginable really... The knock-on effect of that is how much longer are people having to wait now to seek that professional support to even talk about diagnosis or looking at medication... The memory assessment teams are very active here in [county], but of course they need that first link from a GP to activate what they’re doing.” (Lead of MC-running organisation)

In addition, some MCs found it impossible to maintain their links with local health services during the pandemic, with more work needed to re-establish them. Obtaining up-to-date (i.e. post-pandemic) information such as diagnosis data was still “ridiculously painful” (Lead of MC-running organisation). However, there was a feeling that referrals were increasing again:

“They’re starting to come back through again... from having 32 members prior to COVID, going back with 11 members... we’ve now got 26 members.” (MC manager)

##### *5. Increase in outreach, community building and overall reach*

During lockdowns each of the organisations running the case study MCs began extra outreach activities to maintain remote support for MC members while the physical venue was closed. Such activity included home visits, regular telephone calls, postal contact and newsletters, and in some cases online peer support meetings and online activity groups (Evans *et al.*, 2020). This was often a diversification of what MC staff and volunteers usually provided:

“We maintained contact with the people, because we knew that they would be even more isolated than anybody else... we made phone calls, and when we were allowed to, we went walking with a person with dementia. We made use of Zoom... we would play card bingo... or we would do quizzes, so we did carry on as normal, albeit virtually.” (MC staff member)

Some participants reported these activities had a positive ongoing effect on the building of an active community around the MCs, and in reaching new people, despite formal healthcare referrals being disrupted:

“Referrals that I’ve had during COVID have more than doubled the numbers that I am supporting now... If COVID hadn’t happened, I don’t think we’d have seen this need being out there because people wouldn’t have just come to the MC.” (MC manager)

“Since we’ve reopened after COVID... they formed such bonds... two of the main carers were attending that carer support meeting that we started at COVID... and those two are part of that hardcore group that have connected with others and are socialising outside of the MC.” (Lead of MC-running organisation)

Some elements have continued beyond the pandemic restrictions and now constitute extra ongoing outreach and community-building contact:

“I think COVID has taught us that we need to still keep in contact via email and phone and Zoom, have that ability to be able to do some wider sort of things as well as the MC. Because I think it all brings the support in.” (MC manager)

## 6. *Digital access and use of technology (boom and decline)*

At one MC site, no virtual sessions were provided during lockdowns as it was felt members would not be interested. At another, Zoom sessions were put on when the MC was shut and considered a valued

lifeline to carers. However, these stopped after re-opening because it was felt they were of limited benefit once able to meet again in person, and staff were busy running the physical MC:

“We don’t do things like the virtual meetings... anymore, and to be honest, they were not ideal for people with dementia... real people, real faces, real voices counts for a lot more than a flat face on a flat screen... It was mainly for the carers.” (MC trustee)

However, at four other MCs, run by the same organisation in one region, a wide range of social, peer support and activity-specific online meetings were started at the beginning of lockdown in March 2020. An ongoing calendar of provision was accessible by people living dementia and family carers across that region, until the physical MCs re-opened at the end of 2021, with some online sessions continuing after. During this time equipment was distributed to people who lived remotely to help them get connected and access the virtual sessions, if requested. Participants expressed a desire to continue online provision for a number of reasons: so that people from all four MCs could continue to meet; to enable access for people who were more isolated or lacked support to get to a physical MC; and to continue online peer support for carers:

“We’re running four carers’ support sessions a week for those four distinct areas, and we’ve been doing that since March [2020]. And the carers soon started saying to us, when we go back to the physical Meeting Centre, please don’t take this away... The virtual Meeting Centres have enabled some to attend who couldn’t or wouldn’t attend before.” (MC trustee)

However, participants also recognised that only a small proportion of members had taken to online interaction, and virtual meetings could be particularly challenging for them:

“A lot of our guys aren't able to get or aren't interested in getting the internet. A lot of people have found that Zoom and people on a screen, it causes confusion, agitation afterwards, paranoia, hallucinations, all of those things we know go along with dementia.” (MC staff member)

Upon re-opening, the four MCs piloted a 'hybrid' model, where people living remotely could 'dial in' to the physical meetings, but by the end of 2022 this was only in use at one of the MCs:

“It hasn't taken off in the other MCs... we haven't lost it altogether, but we're not rigidly offering that out on a weekly basis... we weren't getting the people interested in linking in, in the main, so as I say, that's fizzled out, but still hanging on to it for one-off occasions such as Christmas... when the time is right, we definitely bring out the hybrid equipment again.” (Lead of MC-running organisation)

Overall, despite efforts to continue online support to supplement physical MCs, it was felt that the call for it had dwindled by the end of 2022, with even the once-popular online carer sessions ceasing to be staffed by a facilitator due to low numbers:

“[The use of online technology]'s been abandoned, hasn't it, in many ways? We currently have a cupboard full of IoT [Internet of things technology] that we can loan out to people, easy to use tablets, Alexa-type devices... so people aren't... certainly in the north of the county... they couldn't wait to get back out in the physical community.” (Lead of MC-running organisation)

## *7. Changes to carer involvement and engagement*

The amount and nature of involvement from people who support and care for MC attendees, such as spouses, adult children, other family members and friends, varies across different MCs. During and following the pandemic period, MCs saw changes in the both the level and nature of this involvement and engagement, but in different ways, for different reasons. Restrictions on numbers attending, and

caution over social mixing when physical meetings were first re-started, led to fewer family carers attending MCs in some places:

“Pre-COVID we'd have relatively quite a few [carers] attending the Meeting Centre... that obviously dropped off during COVID because we couldn't have any carers there cos we had to limit the numbers and we prioritised people with dementia... since we've got more people there, less carers are coming, because they're valuing respite.” (MC trustee)

However, in some MCs the increased remote networking of family carers during lockdowns led to stronger carer involvement once physical meetings resumed. In another MC where the number of family carers attending was very low pre-pandemic, levels had increased by the end of 2022 due to an influx of new members:

“We're getting more [family] members coming... Before COVID, I mean, a lot of the members families just used to come, drop them off.” (MC manager)

#### *8. Continued uncertainty and changes to funding, resources and governance*

While uncertainty regarding long-term funding and stability is common in third-sector enterprises, participants felt the pandemic had in some ways added to this. For some, the reduction in membership numbers and ability to fundraise in the community had a significant negative effect on finances.

However, paying of venue rents and spending of grant money could be postponed during the worst restriction periods. Some MCs saw changes to their governance structure and use of resources (e.g. the need for an office building), related to the financial challenges experienced during the pandemic period.

#### *9. Staff and volunteer recruitment issues*

Those running MCs all agreed that recruitment of appropriate staff and volunteers had become more challenging following the pandemic period. Some experienced a surge in volunteer availability at the height of the pandemic that subsequently fell again as people went back to work; others lost volunteers while the doors of their physical venues were closed:

“I’ve lost over half of my volunteers during COVID now, so I’ve got to regroup and start again really on that in order to make it work.” (MC manager)

There was general agreement that there was now an ongoing shortage of qualified staff in the social care sector, possibly due to people changing profession:

“The other impact of COVID is a lot of people have changed their work, their lifestyles... things like the day centres that might have supported people otherwise find it very difficult, both on grounds of costs, but staffing too.” (MC trustee)

#### *10. Relief at/wish for return to pre-pandemic norms*

In earlier interviews MC personnel commonly expressed a desire to return to pre-pandemic normality:

“It would be nice to get back to normal, that they could just come in and out when they want to.” (MC staff member)

In the final interviews towards the end of 2022, all said the running of MCs had largely returned to ‘normal’:

“We’re back to running the centre as we used to run it. Everybody is sitting close together. Everybody is enjoying sharing things again which is what we used to do, as opposed to sitting six feet away from each other and do these tests and all that. Nobody is testing anymore, unless they’re feeling unwell... it’s great. Literally great.” (MC manager)

## Discussion

Much of what participants reported concerning the impact of the pandemic was congruent with reports from the wider health and social care landscape. For example, the impact pandemic-instigated isolation had upon people affected by dementia, and the accelerated decline they experienced as a result (Alzheimer's Society, 2020; Age UK, 2021; Geibel *et al.*, 2022a, 2022b); and continuing difficulties with delays and access to health and social care support, as services struggle to recover (Bhome *et al.*, 2022; Britton and Zimmermann, 2022; CQC, 2022). The difficulties reported by participants in recruiting staff is reflected in UK-wide data, with a recent House of Commons report stating: "The National Health Service and the social care sector are facing the greatest workforce crisis in their history." (UK Parliament, 2022).

In MCs themselves, the independence of the organisations running them was a strength in being able to make decisions regarding how to continue support through the pandemic, such as how to deploy staff and whether they could re-open venues. All three case study sites reported a shift in the nature of attendance at MCs. The membership profile typically moved towards older people with more advanced symptoms than before the pandemic, ascribed variously to: accelerated decline in health in existing members; fewer new members referred during the pandemic period; and delays to diagnosis for those who were referred. Less universal, but commonly reported, was a reduced amount of attendance from family carers, ascribed to either a change in habit after getting used to not being allowed to attend during pandemic restrictions, or because they now had a greater need for respite as the person they cared for had more advanced symptoms. However, later interviews suggested carer attendance was increasing once more. Conversely, some MCs reported a wider and closer-knit community around the MCs, including family carers, as a result of outreach activities under pandemic restrictions.

The data from the Get Real study supports the earlier UKMCSF data (Evans *et al.*, 2021) in showing a significant diversification in the activity of MCs to reach out to their members and others in the communities they serve, to support them through the worst of the pandemic. This included (to various degrees) a drive to use digital technology to connect with people. For some this stopped as soon as face-to-face meeting resumed; for others this maintained beyond the return to face-to-face meeting in a concerted effort to continue support outside the physical MCs themselves, and boost inclusion and access for those not able to physically attend. Internationally, the potential of digital technology to aid social inclusion for people living with dementia was noted following various online activities being instigated during the pandemic (Alves *et al.* 2021; Heol *et al.*, 2022; Lee *et al.*, 2022;).

However, all MCs also recognised the significant challenges of encouraging and enabling a population that may have little experience of digital technology, as well as sensory and cognitive challenges, to use it. Despite a concerted effort at some MCs, within one year of physically re-opening, the regular, routine use of such digital technology in MCs had stopped. This was ascribed to: a lack of staff and staff time to support this, as they were now fully engaged in face-to-face work; and a lack of interest from members and potential members, possibly due to symptoms, possibly due to a preference for face-to-face activity. In terms of the factors identified in the recent Community Makers toolkit regarding how to support digitally excluded people (Evans *et al.*, 2022) we can see that while the MC *community* may have been in place with potential technology users, the other factors were not necessarily present. For example, tailoring the *technology* to people's specific needs and preferences, helping them understand the benefits as *purpose* to overcome their barriers, and being on hand to continually support and encourage their use of digital technology (*relationships*) require significant staff time and resource.

## **Conclusion**



Data regarding the impact and legacy of the COVID-19 pandemic on MCs supports the notion that older people living with dementia were particularly affected, and the health and social care services that serve them continue to be impacted by the disruption caused, though in some cases experiences are returning to pre-pandemic norms.

In MCs, a 'boom' in interest in, and the use of, technology to keep people connected during the pandemic did not sustain once the urgent need for it during lockdown was no longer there and demands on staff time and attention were necessarily diverted elsewhere. There remains the potential for learning from the pandemic period to help address both social inclusion and digital exclusion, but it will take significant resources and focused effort on overcoming the considerable challenges involved to implement and maintain.

Regarding the sustainability of MCs in general, they have maintained through the pandemic remarkably well, with both activities and membership numbers largely returning to pre-pandemic norms, and interest in the model continuing to grow.

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