This protocol has regard for the HRA guidance and order of content

FULL/LONG TITLE OF THE STUDY

Get Real with Meeting Centres: A Realist Evaluation of Locally-Driven Social Care For Those Affected By Dementia

SHORT STUDY TITLE / ACRONYM

Get Real with Meeting Centres

PROTOCOL VERSION NUMBER AND DATE

0.4 (15/03/2021)

RESEARCH REFERENCE NUMBERS

IRAS Number:	294636
SPONSORS Number:	19/20 0071
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SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publically available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:

Signature: .... Date: ....../....../......

Name (please print):

....

Position:

....

Chief Investigator:

Signature: .... Date: ....../....../......

Name: (please print):

....

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STUDY SUMMARY

Study Title	Get Real with Meeting Centres: A Realist Evaluation of Locally-Driven Social Care For Those Affected By Dementia
Internal ref. no. (or short title)	Get Real with Meeting Centres
Study Design	Realist Evaluation
Study Participants	MC attendees (inc. people living with dementia and people who support them); MC staff and volunteers; MC governors; supporting healthcare professionals; community stakeholder representatives
Planned Size of Sample(if applicable)	Case studies: 30 participants minimum Discrete Choice Experiment: 300-400 survey respondents
Follow up duration (if applicable)	N/A
Planned Study Period	04/01/2021 – 03/01/2023
Brief Synopsis	Social care for people living with dementia, who require support to live at home with a decent quality of life, is in crisis in many parts of the country, particularly in rural areas. Individuals and families need reliable long term support but many community initiatives struggle to maintain beyond 1-2 years. This research focuses on the sustainability of Meeting Centres for people and families living with dementia in rural communities in England and Wales. Many UK community groups find MCs attractive and achievable. However, it is not understood how these diverse communities can ensure they are putting in place strategies that will help them sustain in the longer term, over the initial 1-2 years start-up. This research aims to understand how three well-established MCs in rural counties have achieved this within the current UK context. Stakeholders from each MC, including members

	directly affected by dementia, provide qualitative and quantitative data to build a theoretical model of how, why, for whom, in what contexts and to what extent MCs are successfully adopted and implemented by diverse communities. Willingness to pay for MC provision is explored utilising a health economic analysis through a Discrete Choice Experiment. This knowledge will be shared with emerging MCs so that scale-up can be accelerated for the benefit of those living with dementia and those supporting and caring for them.
Research Question/Aim(s)	**Research question:** What are the factors affecting the sustainability of Meeting Centres for people affected by dementia in rural areas, how best these may be tackled, and what lessons does this offer for emerging Meeting Centres? **Aim 1:** To empirically test the theory developed by the SCI-Dem review regarding the factors involved in sustainability of a community intervention for people affected by dementia, by using data from real life case studies (MCs) currently tackling such challenges. **Aim 2:** To produce an in-depth transferable understanding of the key factors that may threaten the long-term delivery of an MC - in the form of a refined programme theory of how different contexts and mechanisms in the working of this complex intervention can produce differing outcomes. **Aim 3:** To explore peoples' willingness to fund the MC provision by conducting a Discrete Choice Experiment with people with dementia and those that support them. **Aim 4:** From the programme theory and Discrete Choice Experiment above, to build a model of how best to design, implement and deliver an MC so it has the best chance of sustaining long-term. **Aim 5:** To develop evidence-informed guidance materials disseminated to those involved with other MCs (or similar community-based interventions) on how to tackle issues of long-term sustainability, whether just starting up or struggling to continue. **Aim 6:** To develop and share evidence-informed recommendations regarding what would be helpful at a commissioning, policy and infrastructure level, locally and nationally.

FUNDING AND SUPPORT IN KIND

FUNDER(S)	FINANCIAL AND NON FINANCIALSUPPORT GIVEN
National Institute for Health Research (NIHR) Research for Patient Benefit (RfPB), Research for	£349,912

Social Care Programme (Grant Reference Number NIHR201861)	

ROLE OF STUDY SPONSOR AND FUNDER

The University of Worcester (UW) is the Sponsor for this study. UW takes responsibility for ensuring that the design of the study meets appropriate standards and that arrangements are in place to ensure appropriate conduct and reporting. UW will ensure that all necessary approvals from a HRA research ethics committee are obtained before engaging participants in the study. Signed ethically approved consent and acknowledgement forms from any participants who will be involved in the project will be obtained.

The study is funded by the National Institute for Health Research – Research for Patient Benefit (Social Care) funding stream. The funder has not had any influence over the study design or analysis.

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITEES/GROUPS & INDIVIDUALS

MC case study site stakeholder consultee groups (including patient and public involvement)

PPI/Stakeholder sub-groups will be created at each collaborating MC to input into the research over and above formal data gathering from participants at each site. Stakeholder meetings (inclusive of members living with dementia or supporting people living with dementia) will be held regularly at each site throughout the project, to a schedule to be agreed with each MC sub-group. There will also be whole-group (i.e. including all three MC stakeholder sub-groups) meetings at the start and end of the project. Stakeholders will act as content experts providing input and guidance regarding various aspects of the research, including: the design of study documentation; the design of interview and focus group questions; the interpretation of data gathered and the focus of analysis; the format, channels, and development of materials for dissemination.

3 Nations Working Group for Dementia (3NDWG)

The 3NDWG is a working group of people living with dementia across England, Northern Ireland and Wales. Members are based across the three nations, creating a network of voices on dementia who can lead on regional projects. It is led by a steering group of 12 people with dementia drawn from the membership. Mr Hullah is representing 3NDWG as a collaborator on this research and will be responsible for PPI input and steering group input alongside Prof Williamson.

UK-MCSP National Reference Group

This group exists to guide and inform the UK Meeting Support Programme and strategy for UK MCs, as well as disseminating learning. Established in 2018, this group meets twice a year and includes a range of representatives from organisations from across the UK with an interest in the needs of people living with dementia, and includes people directly affected by dementia. The group is engaged with this research to offer oversight and steering and support dissemination. The Get Real project team will update this group on project progress and take feedback on any actions to take forward from resulting discussion.

UK-MCSP Community of Learning and Practice

Overlapping with, but distinct from, the National Reference Group, this is a wide network of practitioners and stakeholders involved with MCs. This network's purpose is to share learning between different MCs, to support each other and to help those who are interested in setting up MCs and will be a key player in dissemination of learning from this research for effective impact on practice, for the benefit of those seeking support through MC attendence.

For more information on the UK-MCSP see: https://www.worcester.ac.uk/about/academic-schools/school-of-allied-health-and-community/allied-health-research/association-for-dementia-studies/ads-research/uk-meeting-centres.aspx

KEY WORDS: Dementia; Post-diagnostic support; Psychosocial; Implementation; Community; Realist evaluation; Soft Systems Methodology; Discrete Choice Experiment; Meeting Centres; Dementia Friendly Communities; Rural; Semi-rural; Adult social care

STUDY FLOW CHART

See **Appendix 1**: Get Real with Meeting Centres: Overview Diagram

And **Appendix 2**: Get Real with Meeting Centres Gantt Chart

STUDY PROTOCOL

Get Real with Meeting Centres: A Realist Evaluation of Locally-Driven Social Care For Those Affected By Dementia

1 BACKGROUND

Meeting Centres (MCs) for people affected by dementia are a community initiative based upon a successful Dutch model[1-3] that have emerged in the UK in the past five years. MCs are places where people with dementia and those that support them can regularly and routinely socialise, take part in activities and get support to meet their needs. Following substantial European research [MeetingDem: 2014–17][4-7], MCs were recommended as a social care intervention for those affected by dementia[4]. MCs help people, their families and communities build resilience for the longer term[2-4,24,29-35]. MCs are based on research evidence on what helps people to cope well in adjusting to the challenges that dementia brings[2-3,36].

At the heart of MCs is a small social club (15 people per day plus supporting family, friends and carers), based in an ordinary community building, close-by to where people live. MCs operate up to three times per week, providing people the chance to build friendships, peer support, understand their problems, get help and prepare for the future. Evidence-based post-diagnostic interventions are provided in a friendly manner, geared to the needs of members and facilitated by a small team of staff and volunteers trained in person-centred dementia care and the Adaptation-Coping Model[36]. All of the features of a MC are geared up to help people make the best emotional, social and practical adjustments to living with dementia. MCs are distinct from day care, supporting both people with dementia and those that support them (e.g. children, partners and friends) together, and connecting people to each other and their community. They build on Dementia Friendly Communities and are a step up in support from Dementia Cafes.

The proposed research dovetails directly with four other grants that fund research projects in which our team is working on. These include:

1. MEETINGDEM, 2014-2017, JPND (HC-559-018) & ESRC (ES/L00920X/1) grant that demonstrated that the Dutch MC intervention was transferable to other European countries and showed similar positive effects to the original Dutch effects studies.

2. SCI-Dem, 2018-20, Alzheimer’s Society Grant 402 (AS-PG-17b-023); This Realist Review has developed the Programme Theory of adoption and implementation of sustainable community interventions for people and families living with dementia.

3. UKMCSP 2018-2022, National Lottery Community Fund UK Portfolio (31061526); This grant is active until January 2022 to provide a community of learning and practice, national reference group, resources and training to support the development of 15-20 new Meeting Centres across the UK.

4. Worcestershire Meeting Centres Community Support Programme , 2020-2023, (reference 00211). This grant is to pump prime the costs of the adoption and implementation of MCs, which will provide access to all the citizens of Worcestershire.

There is a clear and well-developed community process for new MCs that engages local stakeholders in both the local development and longer-term implementation[6]. The MEETINGDEM research involved translating the Dutch MC implementation programme concepts and practicalities into new country contexts (Italy, Poland and UK), assessing the benefits and cost effectiveness[4,24]. MEETINGDEM found people with dementia attending MCs experienced greater self-esteem, feelings of happiness and sense of belonging than those who did not attend. Those who attended most regularly showed fewer of the more distressing symptoms of dementia and a greater feeling of support[4,35]. Family carers also experienced less burden and felt better able to cope. People with dementia and family carers both reported high levels of satisfaction with the MC approach, seeing it as an important way of keeping active and feeling supported[24,35].

The UK Meeting Centre Support Programme (UK-MCSP)[37], is making excellent progress in establishing new MCs across the UK. Thirteen MCs are now operational, with more than 20 due to open in 2021, making this particular intervention well placed, at this particular time, both to study and to make impactful use of the results for social care service-user benefit. Worcestershire County Council has agreed to back the creation of nine new MCs in communities over the next three years. This first countywide approach is likely to lead the way for other Local Authorities to follow suit, so research on how make a continued success of this type of intervention is timely. The focus is turning from how to establish these interventions, to how to keep them going long-term, in the face of a challenging social care-funding climate.

Our SCI-Dem Realist Review[28], also strongly suggests that establishing new community interventions is only part of the story. How these are maintained over the longer term is the biggest challenge. A number of MCs have now been established long enough to have become stable and learnt lessons about sustainability. To date, early adopter MC sites have devised different strategies to mitigate against threats and circumstances affecting their successful continuation. A better understanding is needed of the issues MC stakeholders have faced and are likely to face, and what can be learnt from this to prevent 'reinvention of the wheel' and help ensure sustainability. This is particularly true in rural communities where people and families living with dementia face increased barriers to being able to access support, guidance and connection[38]. If these MCs cannot survive long term, the gap in provision will remain and the situation can be expected to worsen significantly with the rise in numbers of people living with dementia needing support. This research will draw upon the knowledge, experience, perspectives and opinions of a range of participants involved at every level in three case-study MCs that have successfully managed to sustain beyond 2 years, to reveal the strategies used, the challenges faced and overcome, the conditions at each site and what challenges remain. Participants will include MC attendees (members), including people living with dementia and people that support or care for them such as family and friends, MC staff and volunteers, those involved with the governance of MCs, plus supporting health and social care professionals and stakeholder representatives in each MCs local community.

This research will also empirically test the theory developed in the SCI-Dem review[28]. Through a combination of literature review and stakeholder engagement, SCI-Dem has focussed on building a theoretical model of issues affecting the sustainability of community-based interventions in general that are targeted toward those affected by dementia, investigating what can promote, or get in the way of, their continuing over time. SCI-Dem used a 'realist' approach suited to studying complex interventions, designed to indicate what works for whom, in what respects and circumstances, and how[39]. Findings to date suggest key issues in sustainability include whether a group or activity can attract and keep members, appropriate staff, volunteers, resources or funding, with a range of contextual factors affecting these outcomes. SCI-Dem has also revealed that, in the majority of related research, the sole focus has been on effectiveness with minimal information about an intervention outside a time-limited trial period, with interventions often ceasing after a trial. In line with a realist approach, the outcome of SCI-Dem provides a theoretical model, mapping how contexts can trigger mechanisms (processes and responses in people/organisations) to produce different outcomes that affect sustainability. The research proposed here will test this theory to see if it stands up in a real-world setting.

2 RATIONALE

Supporting people living with dementia (and those that, in turn, care for or otherwise support them) to live as well as possible in their communities, with timely psychosocial support, is a global public health goal[13]. However, support following a diagnosis of dementia is patchy across the UK[14], with people and families in some areas lacking any formal proactive support beyond occasional contact with primary care and third sector. With an aging population[15] and increasing pressure on already stretched health services[16] policy has for some time pointed to the need to move towards a model of social care where more people are cared for and supported at home, in the community. Improving provision of early, post-diagnosis support, improving support for family/informal carers and improving support for integrated care (involving the voluntary and independent sectors) – all in a more dementia-friendly community environment – are contemporary UK Government priorities for dementia care[14]. However multiple recent reports describe a climate where the state of social care provision – mainly delivered piecemeal by private and third-sector organisations – is "precarious and dysfunctional" in many parts of the country[16] and in some areas has "broken down" creating "care deserts"[17]. There is an associated reliance on informal carers (e.g. family members) to step in to meet the needs of loved ones, but there is a growing recognition that informal carers' own health and wellbeing is often negatively impacted by their caring activities[18]. The detrimental health impact of social isolation and loneliness is also increasingly being recognised[19-20], with survey data revealing 60% of people living with dementia report loneliness, isolation and losing touch with people in their lives since diagnosis, around a quarter feeling they are not part of their community and that people avoid them[21]. Family carers can also be subject to such loneliness and isolation[22].

There have been various attempts to mitigate these challenges in communities across the UK, in the form of groups and activities for people with dementia and family/informal carers. These aim to serve a number of functions. However, there are significant gaps in social care for people affected by dementia across the UK[17-18,21]. Care systems are unprepared for the forecasted doubling of the number of people living with dementia (1.6 million) and tripling of social care costs by 2040[23]. Scaling up provision of evidence-based community initiatives for people with dementia and those that support them is imperative[2-4,24-27]. The benefits of community-based initiatives are now being recognised[4,24-27]. However, they face a variety of challenges in sustaining long-term. These challenges and how to meet them are much talked about in the dementia care policy, rhetoric and practice arenas but have received very little research attention, as identified in our own SCI-Dem review [2018-20][28]. This research also showed many community initiatives are not sustained beyond 1-2 years.

To date none of the above-mentioned MC-focused studies and projects have investigated the factors that are key for the sustaining MCs after the start-up stage, and there is very little focussing on this aspect with regards to other community-based interventions broadly serving similar function and demographic. This new knowledge is critical if as a country we want to implement a community-based and community-led approach to post-diagnostic support, of the kind represented by MCs, at scale. The National Lottery funded UK-MCSP identified that the issue of sustainability requires urgent attention to safeguard the future of existing MCs and ensure that those implementing new ones learn from their example.

We believe by studying the sustainability of Meeting Centres, an evidence-based intervention already shown to have benefit to people with dementia and those that support and care for them, we can impact significantly on communities across the UK who are desperate to find a practical local solution to supporting people and their families to live at home with a good quality of life.

3 THEORETICAL FRAMEWORK

The diagram in **Appendix 1** shows an overview of the study framework.

This study will comprise primary data collection from three research sites, using a Realist Evaluation approach[40] to what works, under what circumstances, for whom, how and why, regarding adopting and implementing MCs for long-term sustainability. Realist approaches aim to uncover causal processes in complex real-world systems (such as health and social care interventions) by tracing how differing contexts (background circumstances) can trigger different mechanisms (processes in people and organisations) to produce different outcomes. Data will be gathered at three established MCs, that have each taken different approaches to serving different rural community settings. These will be analysed to understand and articulate what works to sustain MCs over time. We will produce a case study of each MC with the aid of a Soft Systems Methodology (SSM)[41] approach, feeding into the overall Realist Evaluation. The SSM approach will be used as a tool to guide the gathering of data for the creation of a conceptual model of how each MC has sustained in the face of the conditions in which it has operated and what challenges remain. A conceptual model will be drawn up from the data gathered in line with SSM, to reveal the systems involved in sustaining each MC and its various parts and challenges. Synthesizing models from the three sites, Realist causal chains of context-mechanism-outcome will be drawn out, to further test the SCI-Dem model and inform recommendations and knowledge-sharing materials for dissemination. Feeding into these realist causal chains also will be documentary data from each MC site, as well as the results of our Discrete Choice Experiment regarding what activities and elements of MCs members are willing to pay for, and how much.

The use of systems approaches to complement Realist thinking is an area of growing interest with multiple successful examples integrating the two in recent years[45-46]. Both Realist and Systems approaches are appropriate for this research as they aim primarily to deal with, and understand, the complexity of systems with human actors in real-world settings. Social care interventions such as MCs tend to be especially complex as they can involve multiple agencies and are embedded in a wider community setting, often with informal and impermanent elements making up part of how they work. Realist approaches focus on explaining the causal mechanisms of action that underlie complex programmes or interventions, to explain why they may be successful in some instances but not in others[47]. Soft Systems Methodology[41] describes a process of enquiry to uncover real-world complexity by consulting those involved with a programme, to build up a conceptual model and determine what action can be taken to change things. The approach is designed to tackle organisational problems where the exact nature of the problem may not be agreed upon and need investigating. Hence, the issue of the sustainability of an MC programme, with all of the factors that could involve in a complex community-based setting, is a good fit for a combination of realist and systems approaches.

3.1 Note on participant terminology

MCs use the terms “member” (for all who attend no matter what their diagnosis or role) and “family carer” (to designate those who are supporting an attendee who is living with dementia), in line with the Essential Features of a Meeting Centre[42].

People attend MCs for a number of reasons and have an array of personal circumstances. The ethos of MCs is that they aim to be inclusive, informal, person-centred and de-stigmatizing in the way they approach those they are designed to support. MCs are community driven and run independently of NHS, local authority or central government. As such they do not use the terms “patient” or “service user” to designate people who attend. “Patient” can be problematic because it reduces an individual’s personhood by narrowing their identity to their medical condition and their relationship with health services only. “Service user” risks doing similar with regard to social care services, and is deliberately not used as MCs seek to foster the feel of an inclusive “social club” rather than a “care service”, a term which can have either commercial or medical connotations that are not appropriate.

Even the agreed MC terms “member” and “family carer” are not uncontroversial: The term “member” is used in spite of the fact that MCs are not in most cases run as clubs requiring a formal sign-up process for “membership” or club management committee; the term “family carer” is used to designate all those who informally support someone who is living with dementia, despite the fact they may or may not be family, may or may not see themselves in the role of a carer (in fact may find that term restricting of their identity), and may or may not attend the MC themselves.

DEEP (Dementia Engagement and Empowerment Project) guidance[65] suggests avoiding terms such as “patient”, “service user” or “client”, and suggests “person/people with dementia” may be more acceptable. Mr Hullah, this project team’s dementia advocacy expert, recommended avoiding terms where there may be connotations of a power imbalance, and suggested “people” is used to recognise people’s personhood.

For the purposes of this study we will use the terms “people living with dementia” and “people supporting those with dementia” (as we will have to distinguish for the purposes of data collection), as well as “people and families affected by dementia” to denote those attending Meeting Centres for support, as these are broader terms that catch most eventualities. We will use the term “stakeholders” as a broader and more general term to denote all of the above, but also anyone else who has an interest or involvement in MCs at any level (for example MC governors, staff and volunteers, health care professionals, community members and groups, local authority representatives or local charity representatives).

As the case studies have a heavily qualitative element, we will be able to be more specific about individuals’ roles and relationships where necessary to contextualise their data. As we are conducting case studies in MCs we anticipate will also have recourse to use the terms “members” and “family carers” at times to avoid confusion, with the caveat that we recognise these terms may not be an ideal fit for all who participate under those participant categories, and we will aim not to use those terms where they are not appropriate to an individual. It is also likely participants themselves will express a range of different terms in their qualitative data, as participants will be drawn from a range of different backgrounds, roles, and sectors; we will endeavour to make it clear how the varied terminology relates, where it coheres or diverges.

4 RESEARCH QUESTION/OBJECTIVES

Research question: What are the factors affecting the sustainability of Meeting Centres for people affected by dementia in rural areas, how best may these be tackled, and what lessons do they have for emerging Meeting Centres?

4.1 Objectives

Objective 1: To empirically test the theory developed by the SCI-Dem review regarding the factors involved in sustainability of a community intervention for people affected by dementia, by using data from real life case studies (MCs) currently tackling such challenges.

Objective 2: To produce and in-depth transferable understanding of the key factors that may threaten the long-term delivery of an MC - in the form of a refined programme theory of how different contexts and mechanisms in the working of this complex intervention can produce differing outcomes.

Objective 3: To explore peoples' willingness to pay for MC provision by conducting a Discrete Choice Experiment with people living with dementia and those who support them.

Objective 4: From the programme theory and Discrete Choice Experiment above, to build a model of how best to design, implement and deliver an MC so it has the best chance of sustaining long-term.

4.2 Outcome

Outcome 1: Learning at each site regarding actions and strategies that can be taken to improve each MCs chances of sustaining long-term.

Outcome 2: A transferable model of how best to design, implement and deliver an MC under different conditions so it has the best chance of sustaining long-term.

Outcome 3: Evidence-informed guidance materials based upon Outcome 1, disseminated to those involved with other MCs (or similar community-based interventions) on how to tackle issues of long-term sustainability, whether just starting up or struggling to continue.

Outcome 4: Evidence-informed recommendations regarding what would be helpful at a commissioning, policy and infrastructure level, locally and nationally, for dissemination.

5 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYIS

Work will be organised into four interlinked Work Packages (WPs):

- **WP1: Stakeholder Group Engagement and Enquiry**
- **WP2: Data Gathering and Meeting Centre Case Studies**
- **WP3: Funding Meeting Centres: A Discrete Choice Experiment to measure User Willingness to Pay for Successful MCs**
- **WP4: Realist Theory Refinement and Development of Materials for Practice**

5.1 WP1: Stakeholder Group Engagement and Enquiry (Months 1-24)

We have an integrated approach to stakeholder engagement and Patient and Public Involvement (PPI), which is organised through its own Work Package, as it is such an essential element of our proposal. Iterative stakeholder consultation throughout a project is a standard part of Realist Evaluation, in line with RAMESES guidelines[58]. In addition, close working and joint decision-making of MC members and paid staff/volunteers is a central principle to the way MCs operates and reflects the value-base of the research team. Our PPI activity is detailed in Section 8. Prof Williamson, an experienced PPI researcher will co-lead WP1 with lay Co-applicant Mr Hullah and will together ensure engagement activities are substantial and authentic.

Beyond PPI, this WP will develop approaches to build on relationships we already have and to forge new ones across UK MC staff, volunteers and an array of external agencies including statutory and voluntary health and social care service providers, businesses and technology developers, charities and policy developers. Our inclusive engagement approach will operate throughout the study to inform its conduct and analyses as well as informing findings implementation mechanisms. We will tailor approaches to identify stakeholder group perspectives and needs from MCs and their preferences for being communicated with so that our study findings will be conveyed in formats that optimise their utilisation for future practice and policy development. Furthermore, we will consider with stakeholders ways to capture longer-term impact of our research beyond the lifetime of the study (including monitoring and self-evaluation approaches) and future research priorities. WP1 activity will be channelled through the National MC Reference Group and UK-MCSP Community of Learning and Practice. We will utilise a senior local authority collaborators to bring a strategic lens to this activity.

5.2 WP2: Data Gathering and Meeting Centre Case Studies (Months 5-17)

At each of the 3 MC research sites (see Section 6), we will use interviews, focus groups and documentary analysis to gain an in-depth understanding of issues at each MC, and to construct a conceptual model of the systems relevant to long-term sustainability at each MC. This is likely to include data regarding the target group of people who attend MCs for support; the programme of interventions; type of venue used; type and training of personnel and volunteers; costs and funding; business case documents; collaboration between stakeholders and partners; public relations approaches and how people are helped to know about and use the service alongside the network of support for each centre and its members and the referral system. The SSM approach is designed to reveal such information and conceptualise its impact and how it fits together in a system.

Interviews and focus groups will take place with those involved at every level, in the following manner per MC, as shown in **Table 1**:

Role of participant in MC	**Method of data collection**	**Number of participants (minimum)**
MC attendees (people living with dementia)	Focus group of 3 to 6 people PLUS Face to face interviews (individual or supported by a partner) with 3 people	6
MC attendees (people supporting someone with dementia)	Focus group of 3 to 6 people PLUS Face to face interviews with 3 people	6
MC staff and volunteers	Focus group of 3 to 6 people PLUS Face to face interviews with 3 people	6
Those involved with governance at each MC	Face to face interviews with 4 people	4
Health/social care/third sector professionals involved in the local dementia care pathway	*Whichever is more convenient for participant*:* Face to face interview *OR* Telephone interview	4
Other stakeholders	*Whichever is more convenient for participant*:*	4

involved in local dementia strategy e.g. Dementia Friendly Communities Programme	Face to face interview *OR* Telephone interview	
	**These participants are outside of the MCs that has agreed to participate, hence a more flexible approach to data gathering will be taken to encourage and facilitate participation*	**Total:30**

Table 1. Participants and methods of data collection

We anticipate 30 participants per MC, with attendees who are living with dementia or supporting someone who is, who agree to participate, given the option of taking part in individual interviews, interviews in pairs or small focus groups of three-to-six people, depending with which they feel more comfortable. The team will follow established procedures developed specifically for people living with dementia to ensure all are fully supported in their participation. We anticipate interviews or group discussions to take about an hour. Interviews will be conducted, and focus groups led, by research associates Mr Morton and Mrs Frost, on site at each MC where possible, though by telephone or Zoom virtual meetings if not. Due to the ongoing impact of COVID-19, however, we anticipate less interview and focus group sessions will be able to be conducted face to face than originally anticipated, though we recognise face to face meetings are likely to be more appropriate and comfortable for some participants so will strive to accommodate this where it is safe to do so.

An interview schedule will be developed and piloted by the team guided by:

1) A modified SSM "BATWOE" structure (see **Table 2**)
2) The theory of factors involved in the sustainability of community-based interventions developed in the SCI-Dem Realist Review[28] (see **Appendix 3**). Among other factors, this covers: Funding: sources, length and ease of obtaining; Venue: type, location, facilities and transport links; Staff and volunteers: finding, recruiting and retaining the right people with the right skills in the right balance; Membership: Finding and recruiting attendees, engaging referrers, and overcoming stigma and anxiety barriers; The network of support with other local organisations and services, including partnership working and referrers; and relationships between attendees and those that support them (e.g. family, friends and other informal carers), and how these are responded to and managed.

B	Beneficiaries (who is the system aimed at helping, e.g. people living with dementia and those that support them)
A	Actors (people's roles and functions in the system, e.g. staff, volunteers, governors, referrers, social care professionals, community stakeholders)
T	Transformations (i.e. going from start-up MC to established MC to stable and thriving MC)
W	Worldview (e.g. how do things work regarding sustainability, what are the challenges and what should be done?)
O	Ownerships (i.e. who or what can influence or thwart success of an MC)
E	Environment (i.e. what are the background contextual factors that could boosts or constrain

	success?)

Table 2. The elements of the SSM “BATWOE” structure, which will inform questions asked of participants and conceptual models built for each MC[41, 45].

A preliminary draft interview schedule outlining the likely content of questions will be drawn up for the purposes of ethical approval, however this will be altered and refined further with stakeholder/PPI input, before interviews and focus groups commence, in the spirit of authentic co-production.

Data will be initially be analysed using Soft Systems Methodology[41] procedures. This will involve applying a sequence of steps to the data gathered, including identifying the nature of the problem for sustainability in detail and defining any relevant systems of activity involved in this (again see the BATWOE criteria). From this we will build a conceptual model of how things work then return to participants to review the model we have made, to compare it with their “real world” experience and identify what changes are feasible or desirable for action to help solve the problem situation. This will be done for each MC separately as a case study.

Data from each case study will then be synthesised and analysed further, together with documentary data on funding and governance processes from each MC using a realist logic of analysis[40] to re-state what is contained within the SSM models in terms of “If-then-because” causation. This second stage of analysis is needed to understand how differing contexts in different MCs can trigger different mechanisms (the often-hidden processes within people and organisations) to produce desired or undesired outcomes (see WP4 for more detail). Documentary data used in this process will include planning and training documents, meeting minutes, financial and attendance records, grant documentation, and partnership/collaboration protocols. This will be discussed with participants in interviews and focus groups for context and steering on what content is most pertinent to our research aims and reviewed in itself using a realist logic of analysis and NVivo qualitative analysis software. It is at this stage that we will also incorporate the results of our Discrete Choice Experiment (see WP3) to further inform what contexts and activities are likely to trigger (or fail to trigger) a response in the people who attend and other stakeholders in each MC, adding a further source of evidence to our final Realist analysis and an economic steer to the recommendations we make from what results from it.

5.3 WP3: Funding Meeting Centres: A Discrete Choice Experiment to measure User Willingness to Pay for Successful MCs (Months 1-24)

Successful implementation of evidence-based services in health and social care depends largely on the fit of the services with the values and priorities of stakeholders who are shaping and participating in their delivery and use[48]. A flexible health economics tool for measuring choices in health and social care-related settings is the discrete choice experiment (DCE)[49], which measures preferences from individual decision-makers over alternative scenarios (or service provisions). Each alternative is described by several attributes (or characteristics) and the choices subsequently determine how preferences are influenced by each attribute (as well as their relative importance). It can also provide a measure of the overall value attached to different alternatives (and identify optimal service provision that meets particular stakeholder requirements and have the best chance of sustainability in the long term). When a cost attribute is included, the DCE technique can also allow weighing of the benefits and costs of service provisions and calculating: how much stakeholders may be willing to pay for a particular service provision and measure how their willingness to pay may vary from current provision to their preferred option.

A DCE questionnaire will be developed by Dr Tinelli to examine preferences for community development service provision at MCs in the UK. MCs can be characterised by several attributes, such as: education/advice (e.g. information on coping with dementia); social engagement (e.g. sharing food, current affairs discussions, reminiscence, music, arts, crafts, games); emotional support (e.g. support with personal feelings, worries and relationships); peer support from members who are living through similar issues; cognitive and psychosocial interventions (e.g. cognitive stimulation, mindfulness); physical activity (e.g. sport, dance, exercise, Tai Chi) flexibility of provisions (e.g. meeting frequency); venue (e.g. location, transport) and the cost to the attendees (out-of-pocket money). In doing so the DCEs can enable to measure:

- The relative value of different components of MC provision (e.g. respondents may value education/advice more than social engagement) and the trade-offs between different attributes (e.g. how much they would be willing to pay to receive emotional support as part of the benefit of attending an MC);
- Attendees' overall willingness to pay to change their current provision (including for example: social engagement, but no information on coping with dementia, no peer support, no cognitive stimulation for early diagnosis, two meetings a week for a fee for the user is £20) to a new service provision (e.g. including information on coping with dementia, social engagement – gardening and art; emotional support; peer support from members who are living through similar issues; cognitive stimulation for early diagnosis; frequency of one meeting a week; fees for the attendee of £25).

The DCE will follow steps as laid out in the standard guidelines[50]. A key stage in the design of the DCE is ensuring that relevant attributes and levels are included and that these are described in a meaningful way[51]. Evidence from previous research (SCI-Dem realist review), DCE applications relevant to dementia care (for examples see[52-54]) as well as consultations with people living with dementia and those who support them from the stakeholder/PPI representatives will be used to achieve this. First, components identified from the sources above will inform an initial list of attributes and levels and a draft choice set for the DCE questionnaire. Secondly, an online meeting with PPI representatives (WP1) will be used to refine the list of attributes/levels and the relevant choice set format. We will discuss with them the possible addition of pictorial representations of attributes to facilitate comprehension of questions, engagement with respondents and minimise cognitive burden[55]. The survey will be tested with 5-10 attendees from one MC as part of already scheduled interviews for WP2.This testing will help to identify whether respondents understand the questions and instructions, whether the meaning of questions is the same for all respondents, the time needed to complete it, whether the online format would work and whether local site assistance is needed for the completion and if so how we can best support the recruitment and data collection process. The DCE choice set will be created using the Ngene software package. If the DCE questionnaires remain unchanged after testing, the responses will be added to the main dataset for analysis.

The method of questionnaire delivery will be informed by feedback stakeholder consultation (WP1), but we expect to be collecting data both by using online survey tool Survey Monkey and by distributing and collecting paper copies to participating MCs. Data will be modelled using logit techniques (NLOGIT 6 software). Results will be disseminated via study channels (e.g. website and social media, academic paper and evidence-based guidelines for commissioners and providers of community-based interventions for people with dementia).

5.4 WP4: Realist Theory Refinement and Development of Materials for Practice (Months 16-24)

As the project progresses, we will use the data from WP1, 2 and 3 to test the theoretical model (or programme theory) produced during SCI-Dem[28]. The SCI-Dem project was a desk-based Realist Review that brought together a wide range of literature to interrogate for data informing what is involved in fostering engagement and long-term sustainability in community-based interventions (such as, but not limited to, MCs). It identified the effect of contexts (specific circumstances) in triggering mechanisms (processes within people and organisations) that led to four identified key outcomes: getting and keeping members or attendees; getting and keeping staff and volunteers; getting and keeping the support of other organisations and services; and getting and keeping sufficient funding. A diagrammatic representation of the preliminary theory is appended (see **Appendix 3**. The proposed research aims to see if the SCI-Dem programme theory stands up when applied to empirical, primary data gathered real-world case studies (Objective 1). Hence, the proposed research will test the SCI-Dem programme theory by validating or refuting elements of it, leading to a more developed and nuanced theory with a more robust grounding, more specifically tailored towards MCs.

Data will be analysed using a realist logic of analysis (as for WP2). In other words, we will use relevant data to help identify and understand the relationships and position of a variety of context-mechanism-outcome configurations (CMOCs) within the SCI-Dem programme theory. The result of our analyses will be a more refined programme theory that explains how to best implement community-based interventions to sustain past the start-up phase, in a variety of settings. As it is developed, this programme theory will be presented back to stakeholders in each MC (see WP1) for feedback and advice that will be used to further validate and refine it. We will use this understanding to develop (amongst other things) tips on best practice, what pitfalls to avoid and what challenges may need to be planned for, grounded in the experiences and models of working of those involved with the three MCs at every level.

6 STUDY SETTING

We have identified three MCs in different rural communities that have been operational for over three years and that meet the 'Essential Features of Meeting Centres'[42]. Trustees at each MC are keen to collaborate and have provided letters of support. Three MCs will be sufficient to address the research questions and be manageable to study within the timescale, enabling us to engage respectfully and meaningfully with a range of participants at each MC. Because the SCI-Dem theory is based upon such a wide review of evidence, we are confident that its theory can be tested utilising three different community MC sites using a Realist Evaluation approach.

The three study sites are:

1. Leominster, a small market town surrounded by sparsely-populated countryside of north Herefordshire and south Shropshire (opened February 2016; rural; deprivation rank[43] around MC: 3,288 of 32,844 neighbourhoods in England)

2. Droitwich Spa, a larger market town close to the city of Worcester (opened September 2015; semi-rural; deprivation rank[43]: 17,429 of 32,844 neighbourhoods in England)

3. Powys, a rural county in Mid Wales with four federated small town MCs run by Dementia Matters (opened March 2017; rural; deprivation rank[44]: areas ranging from 284 to 1,687 of 1,909 neighbourhoods in Wales).

In addition to different geographic and demographic factors, MCs at each site have taken their own individual approach to the implementation and delivery of the service. We have strong links with each MC as each is an active member of the UK-MCSP Community of Learning and Practice and the National Reference Group.

7 SAMPLE AND RECRUITMENT

7.1 Eligibility Criteria

7.1.1 Inclusion criteria

Meeting Centre SSM case studies: Study sites have been selected purposefully for appropriateness (see Section 6). To be useful for this research they must have been able to continue operating for at least two years prior to the commencement of this study, notwithstanding some necessary pausing, reduction or alteration of activities during COVID-19 restrictions. Participants will likewise be selected purposefully for appropriateness, first and foremost regarding their involvement with and first-hand knowledge and experience of, one of the three MCs being studied. Participants will be one of the following: MC attendees (people living with dementia); MC attendees (people informally supporting those living with dementia, e.g. family members or friends); MC staff and volunteers; involved with governance at the MC; health and social care professionals (including third sector) involved in the MC's local dementia pathway; community stakeholders supporting the MC or involved with the local dementia strategy. Sampling will aim for as wide a representation of gender, age, ethnicity and socio-economic grouping as possible, but this will be largely determined by the circumstances and actualities of each MC location and the people involved with it.

Discrete Choice Experiment:

Participants will be 1) either living with dementia or supporting an attendee who is living with dementia and 2) have attended or have some experience of an MC.

7.1.2 Exclusion criteria

Meeting Centre SSM case studies: None.

Discrete Choice Experiment: Potential participants will be excluded if they have never attended or experienced an MC in the UK.

7.2 Sampling

7.2.1 Size of sample

Meeting Centre SSM case studies: We anticipate around 30 participants per MC. Minimum target numbers of each type of participant are between 4 and 6 interviewees or focus group participants, as shown in **Table 1** (see Section 5.2, WP2). This number should give us a range of perspectives per type of participant, at different levels, to draw on to create SSM conceptual models, while also being realistic in terms of numbers available to take part at each MC and practically manageable within the scope and timeframe of the study.

Discrete Choice Experiment: There is no agreement on the correct sample size required for a DCE[56]. However, research has shown that in all DCE studies with efficient designs, model estimate precision increases rapidly at sample sizes greater than 150 and then flattens out at around 300[57]. The DCE will aim to recruit about 400+ respondents (including both individuals living with dementia and people supporting them, such as family members or friends) from across the whole MC network. From previous research, participation in such surveys is managed well through the local MC coordinators and compliance is usually high. This is expected to be particularly the case as the focus is on finance, something about which most attendees have strong opinions. If about 20% of those approached do not engage, we will still have a manageable sample of 320- 350 for analyses.

7.2.2 Sampling technique

Meeting Centre SSM case studies: Sampling will be a combination of convenience with purposive sampling: i.e. participants will be those already attending, running or involved with the selected MC; but also individuals within each MC organisation, and the organisations that support it, will be targeted for their role and the likely perspective and experience they might bring regarding issues outlined in the research question and objectives. This is appropriate as in SSM it is the expertise and different perspectives of those individuals that constitute the system being studied that are most useful in modelling it to reveal both problems and possible changes that can be made. We are also aiming to create an authentic case study snapshot of each MCs functioning, hence the participants need to be those occupying/representing specific roles within each MC.

Discrete Choice Experiment: The DCE Survey will also use purposive sampling, directed to people with dementia and people supporting them that have experience of what MCs offer (and to those that recently joined an MC). They will be recruited across a network of 10 Dementia MCs in the UK.

7.3 Recruitment

7.3.1 Sample identification

Meeting Centre SSM case studies: Study sites have been selected purposefully for appropriateness (see Section 6). Within each MC case study there are a limited number of roles, and a limited number of individuals occupying them. Hence potential participants will be identifiable by their role within the MC organisation, or their link with the MC if their role is with an external supporting organisation. The project team already have strong links with each MC site: MC leads at each site are collaborators on this research and each MC has agreed to take part. Dr Evans, Mr Morton and Mrs Frost will work with MC leads to identify appropriate potential participants in each role and approach those in roles outside the MC itself. MC staff will approach MC attendees to invite them to participate in the study, help them to better understand the participant information and consent process, and assist them in deciding whether they would like to take part in an interview or focus group discussion if they do decide to take part. Where and how interviews and focus groups will take place will be determined by discussion with governors, staff and participants.

Discrete Choice Experiment: Local staff will approach MC attendees to invite them to participate in the study, help them to better understand the questionnaire and assist them in completing the questionnaire if needed. In preparation for data collection, local staff will receive ad-hoc training (as online seminars involving one staff representative per site) to collect DCE data and input responses using the online platform in case respondents prefer to complete the questionnaire on paper. MC staff have confirmed willingness and capacity to undertake this activity. All respondents will receive a link to the online survey, although users with no access to internet will be able to complete the survey either online or on paper at their MC.

7.3.2 Consent

Meeting Centre SSM case studies: All participants will be presented with a participant information sheet explaining the nature and objectives of the study, what will be required of them to take part and the possible risks associated with their participation. They will be given the opportunity to ask questions before being also presented with a consent form. Participant information will be tailored to each participant group (see **Table 1** in section **5.2 WP2** and **Table 3** below).The following will be designed, to be supplied to the participant with **consent forms** and talked through/explained:

1.	For **attendees of MCs** (including people living with dementia and those supporting them) and **those directly involved in running MCs** (including governors/ trustees, staff and volunteers)

1a.	A simplified “easy-read” version of the above
2.	For **those external to MCs but working with/supporting them** (including health, social care and third sector professionals, community-based partners and those involved with the local dementia pathway/DFC)
3.	For **people acting as a personal consultee** of someone unable to give informed consent (with a **consultee declaration form** rather than consent form)

Table 3: Versions of Participant Information Sheets and consent forms to be developed

Participant information and consent documents will be designed in line with HRA guidance (http://www.hra-decisiontools.org.uk/consent/) and approved by the appropriate HRA Research Ethics Committee (REC) (see section **8.2**).

It is important to include attendees of the MCs being studied in the research for two reasons: 1) for ethical reasons, to ensure the perspectives of the people MCs are designed for (people with dementia and those that support them) are fully and authentically represented in line with a “Nothing about us, without us” ethos; 2) for access to key knowledge and experience, because attendees are in a position to offer key first-hand perspectives not directly available to others such as staff and governors, particularly regarding the factors that can encourage or discourage, help facilitate or act as a barrier to, engaging with and attending a local MC, and continuing to do so long term.

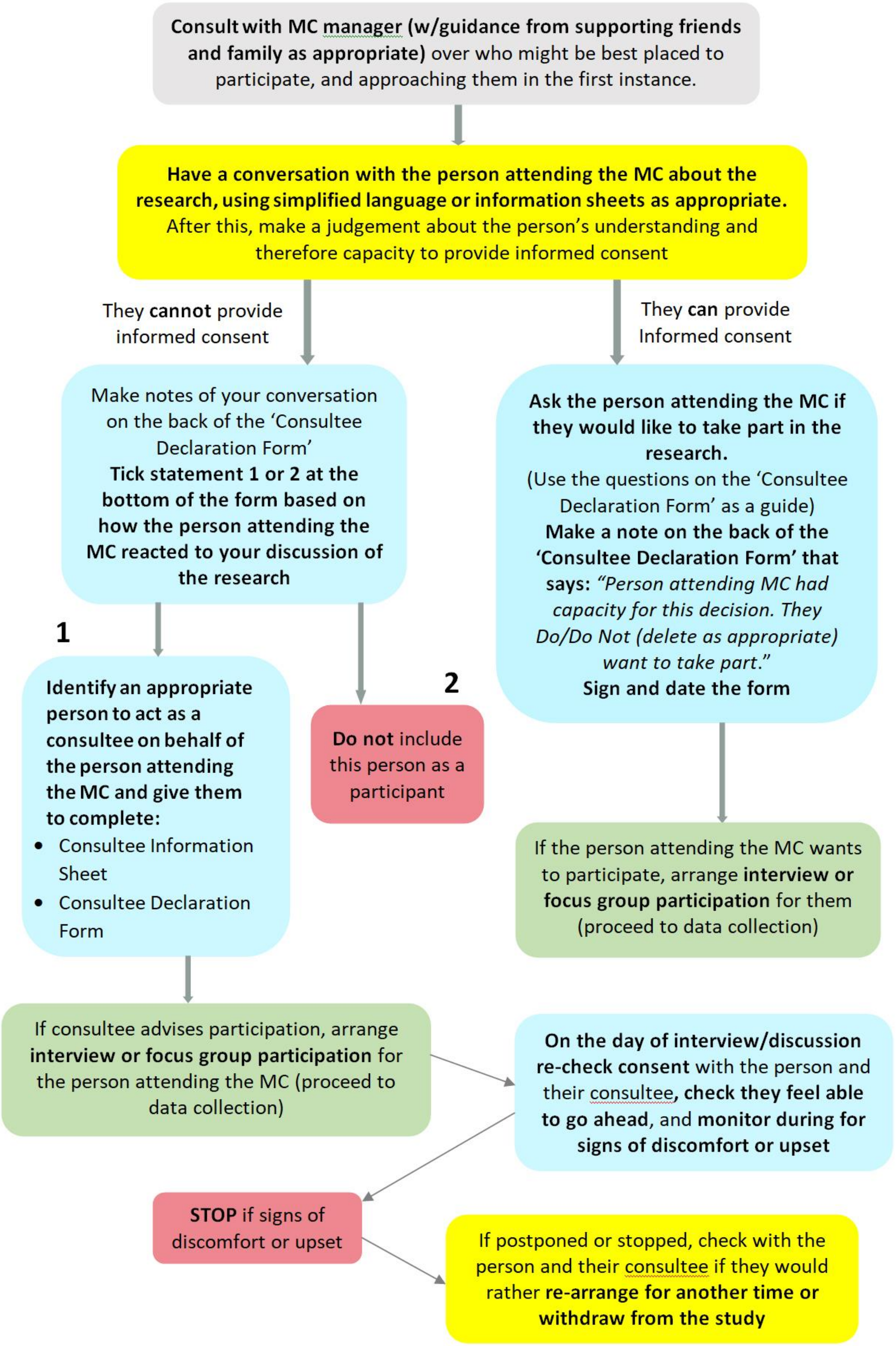
This will mean undertaking research with some participants who are unable to provide informed consent or whose ability to consent may change over time. The research team will develop ethical relationships with members of each of the groups of research participants. The research team will be mindful of the potential vulnerabilities and implications of participation in the research for each of these groups and will need to develop sensitive and relevant practices of informing and negotiating consent to participate. The researchers propose to make assessments of individuals' capacity to consent to taking part in the research. For those potential participants who are assessed to lack capacity to consent to participate in the research (at any point in the study) the research team will seek the advice of a nominated consultee who is not involved in the research in a way that would prejudice their advice. In such cases, the research team will:

a. Ask someone who knows the person well (e.g. a family member, friend or carer) whether they know if the person would object to taking part in (or continuing to take part in) the research

b. Consider what the person themselves appears to be telling us about being involved in (or continuing to be involved in) the research, (even if they can’t understand the whole idea of research project a person might still be able to show us signs of happiness or anxiety)

c. Monitor the person before and during the interview/discussion and if they show signs of discomfort or upset check that they are ok to continue or would rather stop.

The flow diagram below outlines the process of determining ability or provide informed consent:



Consult with MC manager (w/guidance from supporting friends and family as appropriate) over who might be best placed to participate, and approaching them in the first instance.

Have a conversation with the person attending the MC about the research, using simplified language or information sheets as appropriate. After this, make a judgement about the person's understanding and therefore capacity to provide informed consent

They **cannot** provide informed consent

Make notes of your conversation on the back of the 'Consultee Declaration Form' **Tick statement 1 or 2 at the bottom of the form based on how the person attending the MC reacted to your discussion of the research**

Identify an appropriate person to act as a consultee on behalf of the person attending the MC and give them to complete:

- Consultee Information Sheet
- Consultee Declaration Form

Do not include this person as a participant

If consultee advises participation, arrange **interview or focus group participation** for the person attending the MC (proceed to data collection)

They **can** provide Informed consent

Ask the person attending the MC if they would like to take part in the research. (Use the questions on the 'Consultee Declaration Form' as a guide) **Make a note on the back of the 'Consultee Declaration Form' that says:** *"Person attending MC had capacity for this decision. They Do/Do Not (delete as appropriate) want to take part."* **Sign and date the form**

If the person attending the MC wants to participate, arrange **interview or focus group participation** for them (proceed to data collection)

On the day of interview/discussion re-check consent with the person and their consultee**, check they feel able to go ahead**, and **monitor during for signs of discomfort or upset**

STOP if signs of discomfort or upset

If postponed or stopped, check with the person and their consultee if they would rather **re-arrange for another time or withdraw from the study**

Note: If it was necessary to make such an assessment for an individual prior to the start of data collection, it will be **necessary to revisit that assessment if a participant is to be returned to at a significantly later time in the study** (e.g. six months) to take part in further/follow-up interview or focus group participation.

Figure 1: Consent process flow diagram

The research team will be mindful of the particular research context of MCs and the types of research activities proposed, and of the ethical issues raised. There will be ethical issues to address in involving research participants within MCs. For attendees, an MC is first and foremost a form of support, a trusted place where they go to get help and seek connection with others, where they feel their needs are understood. In such a setting they are entitled to freedom from pressure to take part in any activity they do not want to take part in. However, older people, and particularly those with communication or cognitive difficulties frequently have little opportunity to voice their views and opinions. The extended periods of case study research and thus contact and familiarity with research team members will give time for researchers to make informed judgements about the capacity of individuals to consent to taking part in the research. The research team are sensitive to the need to ensure ethical participation both to engage MC attendees in an open and transparent way and to allow participants to disengage where necessary. While it is an ethical imperative that such groups of people should be given the opportunity to be consulted about issues of concern to them, there is also a need to ensure that in approaching and engaging people in the research process they are not exposed to harm.

Participants have the right to withdraw from the research at any time. They also have the right to withdraw their data after participation, which will be destroyed upon their request. It is considered unlikely that participants will experience any physical adverse effects as a result of their participation in the study. However, close attention will be paid to individual responses to the intervention by the staff in each care home and any adverse effects will be recorded, and the research team informed.

Discrete Choice Experiment: Local staff will approach MC attendees to invite them to participate in the study, help them to better understand the questionnaire and assist them in completing the questionnaire if needed. As this will simply be an anonymous questionnaire asking for opinions and preferences there are not anticipated to be any risks in taking part. Participant information explaining the nature and objectives of the questionnaire, and consent questions, will be presented as part of the questionnaire itself. Participants will be given the opportunity to ask questions before agreeing to complete the questionnaire. Again, participant information and consent questions will designed in line with HRA guidance (http://www.hra-decisiontools.org.uk/consent/) and will be approved by the appropriate HRA REC.

8 ETHICAL AND REGULATORY CONSIDERATIONS

8.1 Assessment and management of risk

8.1.1 Sensitive Topics, Distress and Upset

The focus of interviews, group discussions and questionnaire questions will be the MC, the issues in keeping it going and people's preferences regarding what it provides. This focus is not expected to include topics that might be overly personal, sensitive, embarrassing or upsetting. Questions will be framed in terms of how to overcome challenges for success, and what can be learned to help success in the future, and piloted to ensure there is no suggestion that our research means a MC's future is under threat or that blame for any perceived failings in running it is being sought. This is not the case and we will aim to avoid giving this erroneous and potentially upsetting impression.

Nevertheless there are a number of risks associated with this project. Despite the focus being on the MC rather than participants' personal circumstances, it is always possible that semi-structured interviews and discussion may stray into personal or sensitive areas that participants may not be comfortable with. A list of question topics will be shown and talked through with participants (and their consultee if they have one) before interview/group discussion. Participants will be told that they do not have to answer any question they are not comfortable with and may ask to move on, or stop the interview or leave the discussion, at any time. Researchers leading the interviews and discussions will also be on alert for any signs of distress. If a participant they shows signs of discomfort or upset, or of reluctance to take part, at any time before or during interview or group discussion, that interview or discussion will be stopped, and the participant (and their consultee if they have one) asked if they are happy to continue, would prefer to re-arrange for another time, or withdraw altogether. If there is any sign of discomfort with a sensitive or personal topic that is not necessary to discuss, researchers will automatically move the conversation on to a topic that is not personal or sensitive. Participants who are attendees of the MC will undertake interviews and discussions at the Meeting Centre itself, with trained staff on hand to help if they do become distressed or upset.

A transcript of the interview or discussion will be shown to participant (or their consultee if they have one) at a later date for checking to ensure it doesn't contain inaccuracies or anything the person might object to being used going forward. Pseudonyms will be used in the transcript and any specific identifying details will be removed or altered to anonymise. Personal data will be kept secure and only accessible by the research team, and will be destroyed after the study ends.

This research is being co-led by Professor Brooker is Qualified Chartered Clinical Psychologist who has over 30 years clinical experience of working with people and families affected by dementia and is on the HCPC (***Health & Care Professions Council***) Register of Clinical Psychologists (number PYL02758); and Dr Evans who has extensive MC engagement experience to liaise with each MC to cement our engagement approaches with them.

See section 8.4 for more on how we will support patient and public involvement.

8.1.2 Exposure to COVID-19

We will only undertake face to face data collection if local and national guidance allows visitors to MCs and the MC and interviewees/focus group members feel safe to do so, with appropriate PPE, physical distancing and room ventilation also in line with local and national guidance. This situation will be continually monitored as it is likely to change, perhaps multiple times, throughout the duration of the project. We will also ask participants if they feel safe to conduct interviews and discussion face-to-face, or if they'd prefer to do so online or by phone. Where face to face data collection is not possible or agreed, we will move to online data collection supplemented by telephone calls where participants prefer this. We will provide participants with the use of a tablet if they do not otherwise have access to the internet.

8.2 Research Ethics Committee (REC) and other Regulatory review & reports

HRA REC approval is necessary as it is possible some participants may lack the ability to provide informed consent, or their ability to consent may change over time. The University of Worcester's own ethic panels are not empowered to provide ethical approval for this. In addition, the *Research for Social Care, (RfSC) Research for Patient Benefit Programme Welcome pack and overview of the grant holders' project monitoring responsibilities* states that:

"NIHR requires, where appropriate, evidence that an approval has been granted by the HRA... Favourable ethical approval does not need to be provided before the project starts, but will need to be in place before any patient recruitment commences."

As those older people with cognitive impairment may lack capacity to consent to research, the research team will have to justify the need to involve these people in the research. Under the terms of the Mental Capacity Act 2005, people who lack the capacity to consent cannot be included in research unless the research concerns their condition. This research is concerned with improving the implementation and sustainability of social care interventions related to the condition of dementia, in order to improve the provision of support for the benefit of people living with dementia and those who support them. Hence the data collection stage of the research project will require ethical review. Before data collection commences HRA approval will also be applied for via the Social Care Research Ethics Committee (SCREC) using the Integrated Research Application System (IRAS). This will be in regard to both the MC case studies and the DCE elements of the research.

- Substantial amendments that require review by SCREC will not be implemented until that review is in place and other mechanisms are in place to implement at site.
- All correspondence with the SCREC will be retained.
- It is the Chief Investigator's responsibility to produce the annual reports as required.
- The Chief Investigator will notify the SCREC of the end of the study.
- An annual progress report (APR) will be submitted to the SCREC within 30 days of the anniversary date on which the favourable opinion was given, and annually until the study is declared ended.
- If the study is ended prematurely, the Chief Investigator will notify the SCREC, including the reasons for the premature termination.

- Within one year after the end of the study, the Chief Investigator will submit a final report with the results, including any publications/abstracts, to the SCREC.

8.2.1 Regulatory Review & Compliance

The Association for Dementia Studies is designated as a Research Centre within the University of Worcester. Its overall governance and quality assurance systems are rigorous and set in place by the University of Worcester. We work within the legislative framework of English Law. Of particular pertinence to our work are the Mental Capacity Act (2005); equalities legislation the Race Relations Amendment Act (2000); the Data Protection Act (1998) and the Freedom of Information Act (2000). We work as professionals within the codes of conduct from the General Social Care Council, British Psychology Society and the Nursing and Midwifery Council.

Permissions have been granted for access to each case study site (see Letters of Support) and researchers accessing those sites will familiarise themselves with local policies and procedures and abide by them e.g. identity badges, DBS clearance, health and safety, safeguarding, etc. Before any site can enrol service users into the study, the Chief Investigator or designee will ensure that appropriate approvals from participating organisations are in place. Specific arrangements on how to gain approval from participating organisations are in place and comply with the relevant guidance.

8.2.2 Amendments

Amendments will be decided amongst the project management team.For any amendment to the study, the Chief Investigator or designee, in agreement with the sponsor will submit information to the appropriate body in order for them to issue approval for the amendment. The Chief Investigator or designee will work with sites so they can put the necessary arrangements in place to implement the amendment to confirm their support for the study as amended.

8.3 Peer review

This study has undergone high quality peer review as part of the bidding process for funding. It was submitted to the NIHR RfSC (RfPB) programme, which is in two stages (outline proposal and full proposal). At both stages the study proposal was internally peer reviewed by two reviewers within the University of Worcester, as well as independent reviewers on the RfSC committee panel, with amendments made in line with reviewer feedback.

8.4 Patient &Public Involvement

The team will follow established procedures developed specifically for people living with dementia to ensure all are fully supported in their participation. The team has extensive experience of following such procedures in previous research projects such as the UKMCSP (2018-2020) and MEETINGDEM (2014-2017), both of which involved collecting data from Meeting Centre members living with dementia and the people who support them (e.g. family members, friends and other informal carers) as well as staff and volunteers. As people with cognitive impairment may lack capacity to consent to research, the research team will have to justify the need to involve these people in the research. Under the terms of the Mental Capacity Act (2005) people who lack the capacity to consent cannot be included in research unless the research concerns their condition. The research is concerned with specific elements of care related to the condition of dementia.

Interviews and focus groups with lay participants will be carried out on site at the MCs themselves collaboratively with MC staff. Attendees living with dementia and attendees who support people with dementia, who agree to participate, will be given the option of taking part in individual interviews, paired interviews or small focus groups of 3-6 people, depending on which they feel more comfortable with. If any participant prefers an interview at home or by telephone we will accommodate this but will aim for face-to-face interviews wherever possible. The research team will follow the University of Worcester Lone Worker policy where appropriate. Whilst this research is not overly sensitive in nature, simply talking about experiences of dementia can be upsetting for participants. The research team will be sensitive to participant's emotions and pause, stop and restart fieldwork according to individual's wishes. We have included Dr Evans who has extensive MC engagement experience to liaise with each MC to cement our engagement approaches with them.

Prior to applying for study funding from the NIHR RfSC (RfPB) programme, PPI was carried out with members of Leominster MC and lay members of the UK-MCSP National Reference Group. Views were sought about the importance of the study, its design, focus, recruitment approaches, factors likely to affect participation, payment/other reward for PPI, dissemination, approaches to PPI in the study, support needs (e.g. PPI training/development) and interest in further involvement if the study was funded. There was overwhelming support for the study. Those consulted advised study participants never be asked how they would feel if their centre closed, as this could cause distress and suspicion of a hidden agenda to the research; and that research should explore MCs recruitment and retention of volunteers as a priority.

This PPI activity confirmed need for a lay Co-Applicant (NH) who will be offered payment at INVOLVE rates. There was a unanimous view that engagement should be channelled through each MC rather than a separate Advisory Group, with mechanisms for peer support and shared learning between the three Centres, with planned stakeholder events. An end-of-study celebration party at each MC was agreed as a reward. Non-payment to individuals was preferred, as a strategy to widen inclusion and involvement opportunities to all who attend the centres or work there.

PPI reps will be fully supported to be involved in this research at every step – from the study design and focus (including interview questions), to synthesis and interpretation of data, to creation of recommendations and resources for dissemination, according to their wishes.

In addition we will work with members of the already-established UK-MCSP National Reference Group, which includes members of DEEP (Dementia Engagement and Empowerment Project network)[37] and TIDE (Together In Dementia Everyday carers' network)[38] , to provide steering input and also content expertise for theory refinement. For more information on stakeholder involvement in this study, see section 5.1 (WP1).

8.5 Protocol compliance

Protocol deviations will be adequately documented on the relevant forms and reported to the Chief Investigator and Sponsor immediately.

8.6 Data management, protection and patient confidentiality

All investigators and study site staff must comply with the requirements of the Data Protection Act 1998 with regards to the collection, storage, processing and disclosure of personal information and will uphold the Act's core principles.

Participants will be provided with a data privacy notice which outlines how we intend to use and store their data and that their data will be used for the stated purposes of the study. Only members of the research team will have access to the data. Data minimisation will be achieved by collecting minimal personal data. Personal data collected which include name and a contact number.

Any face-to-face meetings (interviews or focus groups) will be recorded digitally on an encrypted recording device, with recordings transferred to secure cloud-based storage on the University One Drive at the first opportunity, ready for transcription using a trusted external transcription service. Interviews and focus groups sessions conducted online meetings using Microsoft Teams will be recorded using the facilities provided on Teams, which includes an automatic transcription option. These recordings are saved to Microsoft Stream (a secure cloud-based service).

Transcripts will be checked for accuracy and anonymised through the removal of people's names and other personal information. Where necessary non-identifiable terms or pseudonyms will be used instead, with unique participant identification codes used in data storage. All study participants will have a code identifier known only to the research team. A key to codes will be securely stored separately. However, it should be noted that information on a participants' place/role within the system of each MC will be important to retain for the sake of context; it is possible participants with a particular role may be identifiable by that role, if the MC is identifiable, which is possible given the low numbers of long-running MCs in the UK at present (although such indirect identification is less likely for MC attendees). Hence participants' preferences on anonymity and identification will be gathered as part of the data collection process and materials reporting on this research will be checked by participants for satisfaction regarding the level of anonymity (see section 7.5.3). Following checking, the audio recordings will be deleted.

The transcripts will be stored electronically on computers and access will be controlled via passwords and permissions to dedicated study folders. Where it is necessary to create hard copies of transcripts or other data, then these will be securely stored in locked filing cabinets that are accessible only to research staff. Participants' personal details (including their names and addresses) will only be used to maintain contact with participants. This will be stored separately from transcriptions and will be kept in a separate file on a password protected computer at the relevant study site. Access to data will be limited to quality control, audit, and analyses. Data shared between sponsor and co-investigators will be de-identified to minimise breach of confidentiality.

8.6.1 Home working.

We anticipate that members of the research team will work from their University offices and store electronic data on either secure OneDrives, or on a hard drive on their office computer. Should guidance around the pandemic prohibit this and make it necessary to work from home, then we will store electronic data using a University OneDrive, following the relevant university guidelines for home working during the pandemic. Electronic data will not be stored using home computers. Hard (paper) copies of personal data will not be kept at home.

8.6.2 Sharing of data.

Data sharing agreements have been prepared and will be finalised between the three MCs taking part on the research and the University of Worcester. Data will be collected by the local researchers and collated by the University of Worcester having been transferred using processes that comply with safe management of data/GDPR e.g. encryption. IP will belong to the University of Worcester but we will agree the use of study data by our university partners as part of the study Collaboration Agreement.

As part of the checking of transcripts, it may be necessary to share recordings between researchers or between the research team and translators. Recordings will be cloud based and can only be accessed using a secure, password-based process. Recordings will not be downloaded and will be deleted once the checking and transcribing process has been completed.

8.6.3 Reporting of data.

In reports of the work, where excerpts are quoted from interviews, any information that might lead to the identity of participants, other people or organisations being inferred will be disguised where possible. Participants will be consulted regarding their preferences on identification and level of anonymity in the reporting of data. MCs will not be identified specifically by name or town, but only by region and pertinent demographic factors.

8.6.5 Data disposal.

Recordings of meetings including focus groups and online interviews will be deleted once a transcription of the meeting has been checked and agreed. Records of personal details will be securely deleted at the end of the study. All written records data will be kept for 10 years in line with University of Worcester (2013) Guidelines and Procedures for Good Research Practice. Stored information will be subject to the usual controls under the Data Protection Act 1998 and University of Worcester (2016) Policy for the effective management of research data.

8.7 Indemnity

Indemnity/insurance arrangements will be covered by the University of Worcester's Employer's Liability, Public Liability and Professional Indemnity insurance. More information and letters with policy details can be found on the University’s finance pages at: https://www2.worc.ac.uk/finance/758.htm

8.8 Access to the final study dataset

The co-applicants of this project detailed at the outset of the protocol will have access to the full dataset. Any secondary analysis of the data will be permitted with consent from participants.

The co-applicants will work together to identify at what points study progress can be promoted e.g. through social media and the ADS website. It is a contractual requirement for a Chief Investigator to send a draft copy of a proposed publication (including articles, presentations and press releases) to RfSC@nihr.ac.uk at the same time as submission for publication or at least 28 days before the date intended for publication, whichever is earlier.

9 DISSEMINATION POLICY

9.1 Dissemination policy

Within UK-MCSP we have created a UK-wide Community of Learning and Practice. It comprises 300 organisations who are interested in providing MCs in their communities to meet the pressing need to find more and better ways to support people with dementia and those who care for them, to adjust to change, connect with others and continue to live as well as possible in their own communities. UK-MCSP has also established a National Reference Group comprising 30 national organisations drawn from policy and practice to support the development of MCs into the future. By gathering evidence, knowledge and best practice on how to tackle the issue of sustainability in a challenging funding climate, this project will help community-based support for people affected by dementia to become more consistent and enduring across the UK. It aims to evaluate ways of working, and develop the delivery of a social care service, to improve outcomes for people with dementia and their families.

From this research programme, we will work with our stakeholder groups and the UK-MCSP Community of Learning and Practice to co-create accessible resources and involve them in dissemination according to their preferences to ensure knowledge from this research is accessible to those involved in the day-to-day governance, management and running of MCs. PPI representatives/stakeholders within the MCs and MC staff and volunteers may prefer to do this as a workshop activity in each MC which we will facilitate. We will provide an accessible publication and website downloads that detail the three case studies and the overall analysis, which in itself will be useful for others in similar community settings looking for a flexible template that they might implement. We also will create a video and associated clips detailing what we have learnt, in plain English, for online dissemination as well as presentation at organised events; and we will create and publish evidence-based guidelines for commissioners and providers of MCs and providers of community-based interventions for people affected by dementia.

Knowledge will be disseminated through the UK-MCSP Community of Learning and Practice, the National Reference Groups and their extensive further networks. This includes practitioner workshops, webinars, a video outlining findings, blogs/vlogs, newsletters, a website and social media e.g. twitter/twitter chats. A national UKMCSP conference is planned in 2021 where sustainability will be discussed operationally and strategically. Specifically, Worcestershire County Council, under the leadership of Ms Perrott, will use the knowledge from this research to help to support new MCs in the county. Other Local Authorities are watching Worcester County Council with keen interest to see if their approach could be replicated in other rural and urban council areas, to address the social care needs of citizens affected by dementia. Interest in the UK-MCSP is gathering pace and the snowball effect of this will generate further interest still. Findings will also be fed into our wider MC research programme and shared with our international MC partners[7].

All of our dissemination activities will be channelled through a comprehensive Dissemination and Impact Plan developed soon after project start so that impact can be planned for and embedded into the research process. This will draw on Implementation Science methodology which utilise evidence-based strategies for changing real world practice[62,63]. This provides frameworks, principles and methods for designing effective strategies and outcomes. Our stakeholder engagement will seek views about which media to use for which stakeholders to convey findings. Emphasis will be on identifying mechanisms to provide prompt, informative and timely knowledge exchange to stakeholders e.g. monthly webinars throughout the study, briefings, blogs, vlogs, social media including Twitter chats, posters in care settings, policy briefings, attendance at APPGs, Parliamentary inquiries and personal communication with policy leads. As the research progresses we will have six-monthly review points of the plan and adjust or add to it accordingly. At the final review meeting of the Dissemination and Impact Plan, we will plan additional activity to take place after the research ends. We will seek an Alzheimer's Society Implementation Grant to further promote uptake of findings. We will make a suite of digital, downloadable study dissemination resources freely available to education providers for use in relevant curricula. Through the UKMCSP grant we have responsibility for training emerging and existing MC personnel. In addition we provide advice and detailed guidance for those commissioning or in a governance role regarding MC development. These two vehicles provide us with a direct route to impact for project findings. Before the research ends we will gain consent to follow up some stakeholders post-project to capture shorter and longer-term evidence of impact of the research.

All contributing authors will be acknowledged in publications according to good practice authorship guidelines (see section 9.2); the funders will be acknowledged in all study outputs in line with NIHR guidance. A publicly accessible report summary will be available on University of Worcester Association for Dementia Studies website post study and findings will be promoted widely at MCs to reach study participants via posters, presentations and leaflets. A full study report will be made available on request.

9.2 Authorship eligibility guidelines and any intended use of professional writers

The final report will be written by the project team, in particular those at the Association for Dementia Studies, led by Prof Brooker and Dr Evans SE. Other members of the project team will contribute, revise and approve as appropriate. All authors who make a substantial contribution to the final study report will be named individually. By substantial contribution we mean (in line with guidance from the International Committee of Medical Journal Editors[64]) that they will have: Contributed to the conception or design of the work or the acquisition, analysis, or interpretation of data; helped draft or critically revise the report; had final approval of the version to be published; and agreed to be accountable for all aspects of the work.

10 REFERENCES

1. Dröes, R.M., Meiland, F.J.M., de Lange, J., Vernooij-Dassen, M.J., & van Tilburg, W. (2003). The meeting centres support programme; an effective way of supporting people with dementia who live at home and their carers. Dementia: The International Journal of Social Research and Practice, 2(3):421-438.

2. Dröes, R.M., Breebaart, E., Meiland, F.J., van Tilburg, W., &Mellenbergh, G.J. (2004a).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. doi.org/10.1080/13607860410001669732

3. Dröes, R.M., Meiland, F.J.M., Schmitz, M., & van Tilburg, W. (2004b). Effect of combined support for people with dementia and carers versus regular day care on behaviour and mood of persons with dementia: results from a multicentre implementation study. International Journal of Geriatric Psychiatry, 19:1-12.

4. Brooker, D., Evans, S.C., Evans, S.B., Bray, J., Saibene, F.L., Scorolli, C., Szczesniak, D., d'Arma, A., Urbanska, K., Atkinson, T., Farina, E., Rymaszewska, J., Chattat, R., Henderson, C., Rehill, A., Hendriks, I., Meiland, F., &Dröes, R.M. (2018). Evaluation of the implementation of the Meeting Centres Support Program in Italy, Poland, and the UK; exploration of the effects on people with dementia. International Journal of Geriatric Psychiatry, 33(7):883-892. doi: 10.1002/gps.4865.

5. Dröes, R. M., Meiland, F. J. M., Evans, S., Brooker, D., Farina, E., Szcześniak, D., Van Mierlo, L.D., Orrell, M., Rymaszewska, J., &Chattat, R. (2017). Comparison of the adaptive implementation and evaluation of the Meeting Centers Support Program for people with dementia and their family carers in Europe; study protocol of the MEETINGDEM project. BMC geriatrics, 17(1),79.

6. Mangiaracina, F., Chattat, R., Farina, E., Saibene, F., Gamberini, G., Brooker, D., Evans, S.C., Evans, S.B., Szcześniak, D., Urbanska, K., Rymaszewska, J., Hendriks, I., Dröes, R.M., & Meiland, F. (2016). 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. doi:10.1080/13607863.2016.1258540

7. The MeetingDem Network (2018). The MeetingDem Network website. Retrieved from:https://www.meetingdem.eu/

8. Logsdon, R.G., Gibbons, L.E., McCurry, S.M., & Teri. L. (2002). Assessing quality of life in older adults with cognitive impairment. Psychosomatic Medicine 64, 510–519.

9. Brod, M., Stewart, A.L., Sands, L., & Walton, P. (1999). Conceptualization and measurement of quality of life in dementia: The Dementia Quality of Life instrument (DQoL). Gerontologist, 39(1): 25-35.

10. Feng, Y., Devlin, N., Shah, K., Mulhern, B., & van Hout, B. (2016). New Methods for Modelling EQ-5D-5L Value Sets: An Application to English Data. London: OHE Publications https://www.ohe.org/publications/new-methods-modelling-eq-5d-5l-value-sets-application-english-data

11. Hounsome, N., Orrell, M., & Edwards, R. T. (2011). EQ-5D as a quality of life measure in people with dementia and their carers: evidence and key issues. Value Health, 14(2), 390-399. doi: 10.1016/j.jval.2010.08.002

12. Curtis, L., & Burns, A. (2015). Unit Costs of Health and Social Care 2015. Canterbury: PSSRU.

13. World Health Organisation (2017). Global action plan on the public health response to dementia 2017-2025. Retrieved from: https://www.who.int/publications-detail/global-action-plan-on-the-public-health-response-to-dementia-2017---2025

14. Department of Health (2015). Prime Minister's challenge on dementia 2020. Retrieved from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf

15. Office for National Statistics (ONS) (2019). Living longer: Caring in later life. Retrieved from: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/livinglongerhowourpopulationischangingandwhyitm atters/2019-03-15

16. Care Quality Commission (2019). The state of health care and adult social care in England 2018/19. Retrieved from: https://www.cqc.org.uk/sites/default/files/20191015b_stateofcare1819_fullreport.pdf

17. Incisive Health (2019). Care deserts: the impact of a dysfunctional market in adult social care provision. Retrieved from: https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/care-- support/care-deserts---age-ukreport.pdf

18. Age UK (2019). Briefing: Health and Care of Older People in England 2019. Retrieved from:https://www.ageuk.org.uk/globalassets/ageuk/documents/reports-and-publications/reports-and-briefings/health-- wellbeing/age_uk_briefing_state_of_health_and_care_of_older_people_july2019.pdf

19. Cornwell, E. Y., & Waite, L. J. (2009). Social disconnectedness, perceived isolation and health among older adults. Journal of Health and Social Behavior, 50(1), 31–48.doi.org/10.1177/002214650905000103

20. Holt-Lunstad, J., Smith, T. B., Baker, M., Harris, T., & Stephenson, D. (2015). Loneliness and social isolation as risk factors for mortality: A meta-analytic review. Perspectives on Psychological Science, 10(2), 227–237.doi.org/10.1177/1745691614568352

21. Alzheimer's Society, (2019). A lonely future: 120,000 people with dementia living alone, set to double in the next 20 years. Retrieved from: https://www.alzheimers.org.uk/news/2019-05-15/lonely-future-120000-people-dementia-living-alone-set-double-next-20-years

22. Brodaty, H., & Donkin, M. (2009). Family carers of people with dementia. Dialoguesin Clinical Neuroscience, 11(2):217–228.

23. Wittenberg, R., Hu, B., Barraza-Araiza, L., &Rehill, A. (2019). Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019-2040 (CPEC Working Paper 50). Retrieved from: https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

24. Evans, S.B., Evans, S.C., Brooker, D., Henderson, C., Szcześniak, D., Atkinson, T., Bray, J., Rehill, A., 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. doi: 10.1080/13607863.2018.1544207

25. Lord, K., Beresford-Dent, J., Rapaport, P., Burton, A., Leverton, M., Walters, K., Lang, I., Downs, M., Manthorpe, J., Boex, S., Jackson, J., Ogden, M., &Cooper, C. (2019). Developing the New Interventions for independence in Dementia Study (NIDUS) theoretical model for supporting people to live well with dementia at home for longer: a systematic review of theoretical models and Randomised Controlled Trial evidence. Social Psychiatry and Psychiatric Epidemiology. doi: 10.1007/s00127-019-01784-w

26. McDermott, O., Charlesworth, G., Hogervorst, E., Stoner, C., Moniz-Cook, E., Spector, A., Csipke, E., &Orrell, M. (2019). Psychosocial interventions for people with dementia: a synthesis of systematic reviews. Aging & Mental Health, 23(4), 393–403. doi: 10.1080/13607863.2017.1423031

27. Van't Leven, N., Prick, A.E., Groenewoud, J.G., Roelofs, P.D., de Lange, J., Pot, A.M. (2013). Dyadic interventions for community-dwelling people with dementia and their family caregivers: a systematic review. International Psychogeriatrics, 25(10):1581-1603.

28. Morton, T., Atkinson, T., Brooker, D., Wong, G., Evans, S., & Kennard, C. (2019). Sustainability of community-based interventions for people affected by dementia: a protocol for the SCI-Dem realist review. BMJ Open, 9:e032109. doi: 10.1136/bmjopen-2019-032109

29. 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):112-24. doi: 10.1080/13607860500310682

30. Dröes, R.M., Meiland, F.J.M., Schmitz, M.J. & Van Tilburg, W. (2011). How do people with dementia and their carers evaluate the Meeting Centres Support Programme? Non-pharmacological Therapies in Dementia, 2,1.

31. Lion, K.M., Szcześniak, D., Bulińska, K., Mazurek, J., Evans, S.B., Evans, S.C., Saibene, F.L., d'Arma, A., Scorolli, C., Farina, E., Brooker, D., Chattat, R., Meiland, F.J.M., Dröes R.M., &Rymaszewska, J. (2019). Does the Meeting Centre Support Programme decrease the experience of stigmatisation among people with cognitive deficits? Aging & Mental Health. doi:10.1080/13607863.2019.1683815

32. Mazurek, J., Szcześniak, D., Lion, K.M., Dröes, R.M., Karczewski, M., &Rymaszewska, J., (2019). Does the Meeting Centres Support Programme reduce unmet care needs of community-dwelling older people with dementia? A controlled, 6-month follow-up Polish study. Clinical Interventions in Aging, 14:113-122. https://doi.org/10.2147/CIA.S185683

33. Meiland, F.J.M., Dröes, R.M., de Lange, J., Vernooij-Dassen, M.J.F.J., & Van Tilburg, W. (2010). Predictors of effective support in meeting centers for people with dementia and their carers. Nonpharmacological Therapies in Dementia, 1(3) 251-270.

34. Szcześniak, D., Dröes, R., Meiland, F., Brooker, D., Farina, E., Chattat, R., Evans S.B., Evans, S.C., Saibene, F.L., Urbańska, K., &Rymaszewska, J. (2018). Does the community-based combined Meeting Center Support Programme (MCSP) make the pathway to day-care activities easier for people living with dementia? A comparison before and after implementation of MCSP in three European countries. International Psychogeriatrics, 30(11), 1717-1734. doi:10.1017/S1041610217002885

35. Szcześniak, D., Rymaszewska, J., Saibene, F.L., Lion, K.M., d'Arma, A., Brooker, D., Evans, S.B., Evans, S.C., Chattat, R., Scorolli, C., Meiland, F., Hendriks, I., Dröes, R.M., & Farina, E. (2019). Meeting centres support programme highly appreciated by people with dementia and carers: a European cross-country evaluation. Aging & Mental Health. doi:10.1080/13607863.2019.1683814

36. Brooker, D., Evans, S., & Droes, R. M. (2017). Framing outcomes of post-diagnostic psychosocial interventions in dementia: The Adaptation-Coping Model and Adjusting to Change. Working with Older People, 21(1). doi: 10.1108/WWOP-12-2016-0039

37. The Association for Dementia Studies (2018). UK Meeting Centres Support Programme (UK MCSP) webpage. Retrieved from: https://www.worcester.ac.uk/about/academic-schools/school-of-allied-health-and-community/allied-health-research/association-for-dementiastudies/ads-research/uk-meeting-centres.aspx

38. Bould, E., Ball, A., Donoghue, T., Jenkins, C. & Sherriff, I. (2018). Dementia-Friendly Rural Communities Guide. London: The Alzheimer's Society.

39. Pawson, R., Greenhalgh, T., Harvey, G., & Walshe, K. (2005). Realist review - a new method of systematic review designed for complex policy interventions. Journal of Health Services Research & Policy, 10(1_suppl), 21–34. doi.org/10.1258/1355819054308530

40. Pawson, R., & Tilley, N. (1997). Realistic Evaluation. London:SAGE.

41. Checkland P. (1999). Systems Thinking, Systems Practice. New York: J. Wiley.

42. Brooker, D. (2019). The Essential Features of a Meeting Centre: UK Meeting Centres Support Programme (UKMCSP). Retrieved from: https://www.worcester.ac.uk/documents/Essential-Features-of-a-Meeting-Centre-booklet-November-2019-edition.pdf

43. Ministry of Housing, Communities & Local Government (2019). English Indices of Deprivation 2019. Retrieved from:http://imd-bypostcode.opendatacommunities.org/imd/2019

44. Welsh Government (2019). Welsh Index of Multiple Deprivation 2019. Retrieved from: https://gov.wales/welsh-index-multiple-deprivation-full-indexupdate-ranks-2019

45. 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. doi.org/10.1177/1356389017749036

46. Williams, L., Rycroft-Malone, J., Burton, C.R., Edwards, S., Fisher, D., Hall, B., McCormack, B., Nutley, S.M., Seddon, D., & Williams, R. (2016). Improving skills and care standards in the support workforce for older people: a realist synthesis of workforce development interventions. BMJ Open.6:e011964. doi:10.1136/bmjopen-2016-011964

47. Hewitt, G., Sims, S.& Harris, R. (2012). The realist approach to evaluation research: An introduction. International Journal of Therapy and Rehabilitation 19: 250–9.

48. Salloum, R.G., Shenkman, E.A., Louviere, J.J., & Chambers, D.A. (2017). Application of discrete choice experiments to enhance stakeholder engagement as a strategy for advancing implementation: a systematic review. Implementation Science, 12, 140. https://doi.org/10.1186/s13012-017-0675-8

49. de Bekker-Grob, E. W., Ryan, M., & Gerard, K. (2012). Discrete choice experiments in health economics: a review of the literature. Health Economics, 21(2), 145-172. doi: 10.1002/hec.1697

50. Reed Johnson, F., Lancsar, E., Marshall, D., Kilambi, V., Muhlbacher, A., Regier, D.A., Bresnahan, B.W., Kanninen, B., Bridges, J.F. (2013). Constructing experimental designs for discrete-choice experiments: report of the ISPOR Conjoint Analysis Experimental Design Good Research Practices Task Force. Value Health, 16(1), 3–13. doi:10.1016/j.jval.2012.08.2223

51. Coast, J., &Horrocks. S. (2007). Developing attributes and levels for discrete choice experiments using qualitative methods. Journal of Health Services Research & Policy, 12(1):25–30. doi:10.1258/135581907779497602

52. Walsh, S., Oshea, E., Pierse, T., Kennelly, B., Keogh, F., & Doherty, E. (2020). Public preferences for home care services for people with dementia: A discrete choice experiment on personhood. Social Science & Medicine, 245, 112675. doi: 10.1016/j.socscimed.2019.112675

53. Chester, H., Clarkson, P., Davies, L., Sutcliffe, C., Davies, S., Feast, A., Hughes, J., Challis, D., & Members of the HOST-D (Home Support in Dementia) Programme Management Group (2018). People with dementia and carer preferences for home support services in early-stage dementia, Aging & Mental Health, 22:2, 270-279

54. O'Philbin, L., Woods, B., & Holmes, E. (2020) People with dementia and caregiver preferences for digital life story work service interventions. A discrete choice experiment and digital survey. Aging & Mental Health, 24:2,353-361

55. Negrín, M.A., Pinilla, J., León, C.J. (2008). Willingness to pay for alternative policies for patients with Alzheimer's Disease. Health Economics, Policy & Law, 3(3), 257–275.

56. de Bekker-Grob, E.W., Donkers, B., Jonker, M.F., &Stolk E.A. (2015). Sample Size Requirements for Discrete-Choice Experiments in Healthcare: a Practical Guide. Patient, 8(5), 373–384.https://doi.org/10.1007/s40271-015-0118-z

57. Johnson, F. R., Lancsar, E., Marshall, D., Kilambi, V., Mühlbacher, A., Regier, D. A., Bresnahan, B.W., Kanninen, B., & Bridges, J. F. (2013). Constructing Experimental Designs for Discrete-Choice Experiments: Report of the ISPOR Conjoint Analysis Experimental Design Good Research Practices Task Force. Value in Health, 16(1), 3–13. doi:10.1016/j.jval.2012.08.2223

58. Wong, G., Westhorp, G., Greenhalgh, J., Manzano, A., Jagosh, J. & Greenhalgh, T. (2017). Quality and reporting standards, resources, training materials and information for realist evaluation: the RAMESES II project. Health Services and Delivery Research, 5(28). https://doi.org/10.3310/hsdr05280

59. Morton, T.(2019). The SCI-Dem Project blog. Retrieved from: https://scidemreview.wordpress.com/

60. DEEP (2019). DEEP: The UK Network of Dementia Voices website. Retrieved from: http://dementiavoices.org.uk

61. TIDE (2019). TIDE: Together in Dementia Everyday website. Retrieved from: https://www.tide.uk.net/

62. Powell, B. J., Waltz, T. J., Chinman, M. J., Damschroder, L. J., Smith, J. L., Matthieu, M. M., ... & Kirchner, J. E. (2015). A refined compilation of implementation strategies: results from the Expert Recommendations for Implementing Change (ERIC) project. Implementation Science, 10(1), 21.

63. Curran, G. M. (2020). Implementation science made too simple: a teaching tool. Implementation Science Communications, 1(1), 1-3.

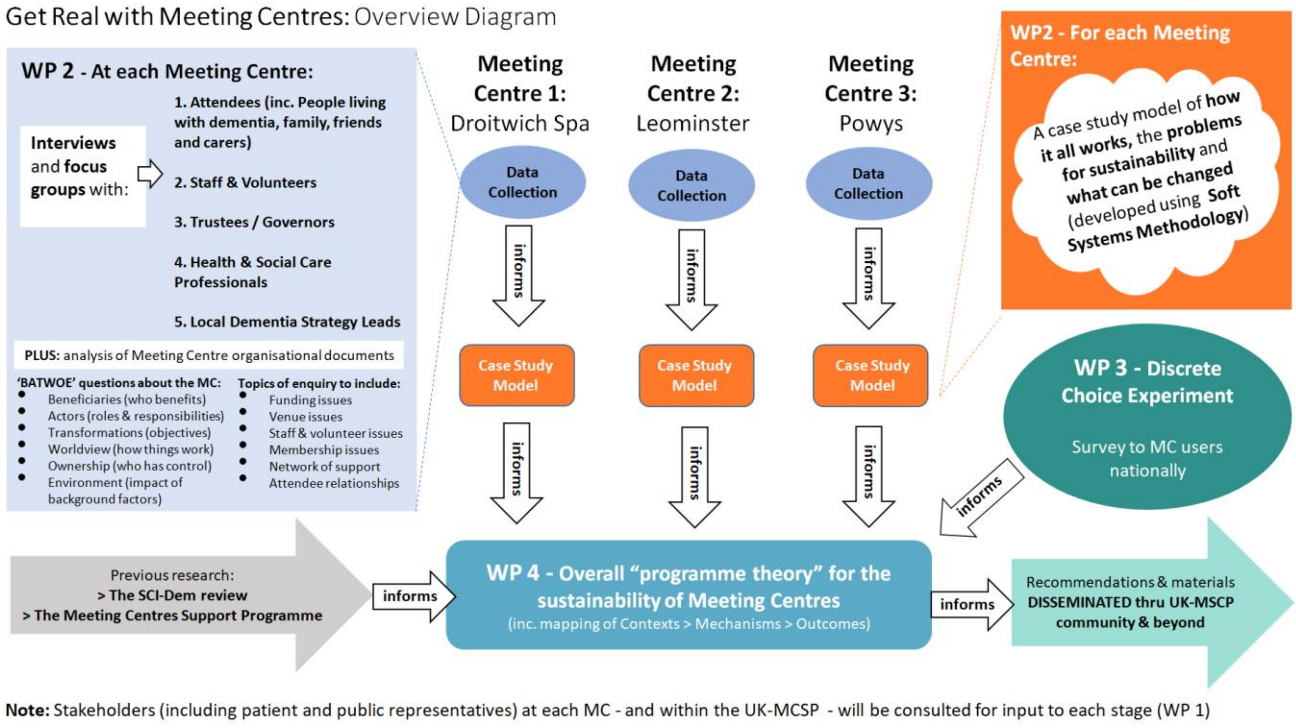
64. International Committee of Medical Journal Editors (2021). Defining the role of authors and contributers. ICMJE. http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html

65. DEEP (2015). Dementia words matter: Guidelines on language about dementia. Retrieved from:

https://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf

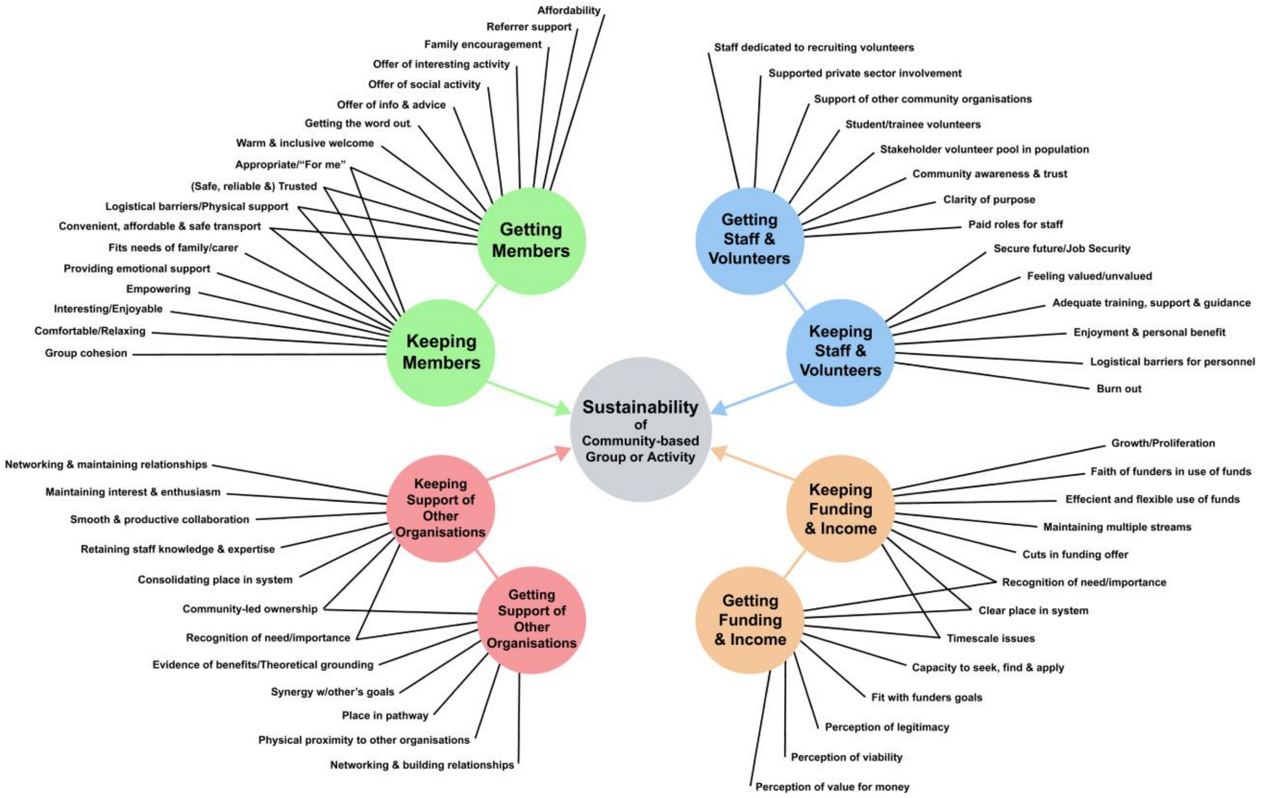
11. APPENDICES

Appendix 1: Get Real with Meeting Centres overview diagram



Appendix 2: Get Real with Meeting Centres Gantt chart

Appendix 3: SCI-Dem overview of factors affecting sustainability



SCI-Dem overview: Factors affecting the sustainability of community-based groups and activities

Amendment History

Amendment No.	**Protocol version no.**	**Date issued**	**Author(s) of changes**	**Details of changes made**

List details of all protocol amendments here whenever a new version of the protocol is produced.

Protocol amendments must be submitted to the Sponsor for approval prior to submission to the REC.