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Get Real With Meeting Centres: how meeting centres for people affected by dementia can sustain long term

Submission date 07/05/2021	**Recruitment status** No longer recruiting	[X] Prospectively registered [X] Protocol
Registration date 13/05/2021	**Overall study status** Completed	[_] Statistical analysis plan [X] Results
Last Edited 26/09/2023	**Condition category** Mental and Behavioural Disorders	[_] Individual participant data

Plain English summary of protocol

Background and study aims

Helping people to live well with dementia following diagnosis, supported in their own homes and communities where possible, is a global public health goal. However, social care for people living with dementia, especially in the earlier stages after diagnosis, is in crisis in many parts of the country, particularly in rural areas. Individuals and families often experience social isolation and loneliness as a result of the life changes that a diagnosis brings, and how and where to access help can often be confusing. They need reliable, long-term support but there is no formal, standard, guaranteed provision applied consistently across the UK, and it often falls to community, third sector and voluntary organisations to attempt to fill the gap. Many community initiatives start up with the aim of doing so, but struggle to keep going long term.

This research focuses on the sustainability of one such intervention: Meeting Centres for people and families living with dementia in rural and semi-rural communities in England and Wales. Many UK community groups find Meeting Centres an attractive and achievable model of dementia support in the community. 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 Meeting Centres in rural counties have achieved this within the current UK context. Stakeholders from each Meeting Centre will provide data to build a model of how, why, for whom, in what contexts and to what extent Meeting Centres are successfully adopted and implemented by diverse communities. Willingness to pay for the various elements of Meeting Centre provision will be explored using a questionnaire survey which will go out to all Meeting Centres across the UK. The resulting learning will be shared both with existing Meeting Centres to help inform their strategy and provision going forward, and with emerging Meeting Centres so that scale-up can be accelerated for the benefit of those living with dementia and those supporting and caring for them.

Who can participate?

For the case studies, participants can include anyone who has involvement with or direct knowledge of the workings of the three Meeting Centres under study, including staff, volunteers, governors, third sector workers, health and social care professionals, community partners and also attendees affected by dementia, with their families or others who support them. For the questionnaire, participants will be attendees only, though this will include both people with dementia and the carers or people who personally support them.

What does the study involve?
The study will involve data being gathered via interviews (individually or in pairs, in person), focus group discussions and analysis of planning documents and records to build up a model of each of the three case study sites, what they have done, how they have got to where they have, how they are running presently and what challenges remain in the future. It will also involve a "Discrete Choice Experiment" questionnaire survey, distributed to all UK Meeting Centres, to survey what elements of Meeting Centre provision people most value and what they are willing and able to pay for them. All data gathered will then be used to create a model of how different contexts (background circumstances) can trigger different mechanisms (responses and process in people and organisations) to produce outcomes that can help or hinder a Meeting Centre's sustainability. These findings will then be used to make recommendations for practice and policy.

What are the possible benefits and risks of participating?
There are no risks to taking part. Participants with a vested interest in Meeting Centres get to share opinions on the intervention and how they might be improved to help those who attend them. It is also hoped that taking part in the interviews will be interesting and enjoyable for participants. The learning may help participants' own Meeting Centre to improve and become more sustainable in the future. Results will be shared in detail with stakeholders at the study sites.

Where is the study run from?
This research is being led by the Association for Dementia Studies at the University of Worcester, collaborating with the London School of Economics and Political Science, Oxford University's Nuffield Department of Primary Care Health Sciences, the Three Nations Dementia Working Group and Worcestershire County Council (UK)

When is the study starting and how long is it expected to run for? (what are the overall start and end dates?)
January 2021 to January 2023

Who is funding the study?
National Institute for Health Research (UK)

Who is the main contact?
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Contact information

Type(s)
Scientific

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Type(s)

Public

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Additional identifiers

EudraCT/CTIS number

Nil known

IRAS number

294636

ClinicalTrials.gov number

Nil known

Secondary identifying numbers

19/20 0071, IRAS 294636, NIHR 201861

Study information

Scientific Title

Get Real With Meeting Centres: a realist evaluation of the sustainability of a locally-driven social care intervention for those affected by dementia

Study objectives

This study is not an interventional trial but a realist evaluation aiming to gather observational qualitative case study and survey data with which to build a theoretical model. As such it is not focussed upon testing strictly defined hypotheses, but is open ended. However, to an extent it does aim to test and refine existing multi-faceted theory from previous research (The SCI-Dem Realist Review).

The research question and objectives are as follows:

Research Question: What are the factors affecting the long-term 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?

Objective 1: To put to the test the theory developed by our previous "SCI-Dem" realist review regarding the factors involved in the long-term sustainability of community interventions (e.g. groups and activities) for people affected by dementia, by using data from real life case studies (Meeting Centres) currently tackling such challenges.

Objective 2: To produce in-depth understanding of the key factors that may help or threaten the long-term delivery of a Meeting Centre (MC) in the form of a refined theoretical model (or "programme theory") of how different contexts (background circumstances) and mechanisms (processes within people and organisations) in the working of this complex intervention can produce differing outcomes.

Objective 3: To explore peoples’ willingness to fund what is done and what is available at an MC by conducting a survey asking what people with dementia and those that support them are willing to pay for what elements, and which they most value (called a Discrete Choice Experiment)

Updated 15/06/2021:
Objective 3: To explore peoples’ willingness to fund what is done and what is available at an MC by conducting a survey (called a Discrete Choice Experiment) asking what those who support someone living with dementia are willing to pay for what elements, and which they most value, triangulated with focus groups with people living with dementia on the same subjects.

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.

Objective 5: To develop evidence-informed guidance materials, to disseminate 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.

Objective 6: To develop and share evidence-informed recommendations regarding what would be helpful at a commissioning, policy and infrastructure level, both locally and nationally.

Ethics approval required

Old ethics approval format

Ethics approval(s)
Approved 11/06/2021, Wales Research Ethics Committee 4 (Wrexham) (Health and Care Research Wales, Castlebridge 4, 15-19 Cowbridge Road East, Cardiff, CF11 9AB, UK; +44 (0)2920 785738; Wales.REC4@wales.nhs.uk), REC ref: 21/WA/0185

Study design
Multicentre observational case series and survey (as part of a realist evaluation)

Primary study design
Observational

Secondary study design
Case series

Study setting(s)
Community

Study type(s)
Other

Participant information sheet
See additional file ISRCTN10332079_PIS_v3_28Apr21 (added 01/06/2021)

Health condition(s) or problem(s) studied
Post-diagnostic support for people with dementia (typically early stages)

Interventions
This study is a Realist Evaluation, a theory-driven approach to evaluating what works, for whom, in what circumstances, how and why regarding the sustainability of Meeting Centres for people affected by dementia, a community-led social care intervention. Data will be gathered and analysed in the first instance using Soft Systems Methodology with semi-structured interviews, focus group discussions and documentary evidence at three Meeting Centre case studies, alongside a Discrete Choice Experiment survey distributed to examples of the Meeting Centres across the UK. Data will then be further synthesized and analysed using a Realist logic of analysis to create an overall theoretical model (or "programme theory") involving statements of how different contexts (background circumstances) trigger different mechanisms (responses and processes in people and organisations) to produce different outcomes that have a bearing on the research question.

Intervention Type
Other

Primary outcome measure
This study is not an interventional trial and does not focus upon specific outcome measures. The data gathered will be qualitative in the main and analysed using a combination of Soft Systems Methodology modelling and Realist logic of analysis.

Topics upon which qualitative evidence will be gathered will include:
1. Soft Systems "BATWOE" categories:
1.1. Beneficiaries (who is the system aimed at helping, e.g. people living with dementia and

those that support them)
1.2. Actors (people's roles and functions in the system, e.g. staff, volunteers, governors, referrers, social care professionals, community stakeholders)
1.3. Transformations (i.e. going from start-up MC to established MC to stable and thriving MC)
1.4. Worldview (e.g. how do things work regarding sustainability, what are the challenges and what should be done?)
1.5. Ownerships (i.e. who or what can influence or thwart the success of an MC)
1.6. Environment (i.e. what are the background contextual factors that could boost or constrain success?)
2. The theory of factors involved in the sustainability of community-based interventions developed in the SCI-Dem Realist Review, including:
2.1. Funding: sources, length and ease of obtaining
2.2. Venue: type, location, facilities and transport links
2.3. Staff and volunteers: finding, recruiting and retaining the right people with the right skills in the right balance
2.4. Membership: finding and recruiting attendees, engaging referrers, and overcoming stigma and anxiety barriers
2.5. The network of support with other local organisations and services, including partnership working and referrers
2.6. Relationships between attendees and those that support them (e.g. family, friends and other informal carers), and how these are responded to and managed

Data collected using qualitative interviews and focus group discussions for systems and realist analysis in a rolling programme of sessions planned to take place between July 2021 and April 2022

Secondary outcome measures
The priorities, preferences and willingness to pay for the various elements of the Meeting Centre offer will be measured and analysed using a Discrete Choice Experiment questionnaire, a flexible health economics survey tool, which is planned to run from October 2021 to March 2022

Overall study start date
04/01/2021

Completion date
03/03/2023

Eligibility

Key inclusion criteria
For interviews and focus groups at the three Meeting Centre (MC) case studies, participants will:
1. Have involvement with, and first-hand knowledge and experience of, one of the three MCs being studied
2. Occupy one of the following roles:
2.1. An attendee living with dementia
2.2. An attendee informally supporting a person living with dementia (e.g. family member or friend)
2.3. A member of paid staff
2.4. An unpaid volunteer helping to run the MC
2.5. A person overseeing governance/strategic planning at the MC
2.6. A health or social care professional (including third sector) involved in the MC's local

dementia pathway
2.7. A community stakeholder supporting the MC or involved with the local dementia strategy

For the Discrete Choice Experiment survey, participants will:
1. Be either living with dementia or supporting an attendee who is living with dementia
2. Have attended an MC in the UK

Participant type(s)
Mixed

Age group
Mixed

Sex
Both

Target number of participants
490 (90 case study participants; 400 DCE questionnaire respondents)

Total final enrolment
226

Key exclusion criteria
Participants will be excluded if:
1. They have never attended nor had involvement with an MC
2. They do not have the capacity to take part in interviews or discussions, or to follow the questionnaire
3. They refuse consent or request to be withdrawn from the study after they have done so
4. A personal consultee advises against their participation on their behalf
5. They shows signs of negative attitude, discomfort or upset, or of not wishing to take part, when explaining the study and study processes, or before or during interview or group discussion /questionnaire completion

Date of first enrolment
01/07/2021

Date of final enrolment
18/10/2022

Locations

Countries of recruitment
England

United Kingdom

Wales

Study participating centre

Droitwich Spa Meeting Centre
The Glyn Mitchell Memorial Ground
Hanbury Road
Droitwich Spa
United Kingdom
WR9 7DU

Study participating centre
Leominster Meeting Centre
The Old Priory
The Priory
Leominster
United Kingdom
HR6 8EQ

Study participating centre
Powys Meeting Centre
Dementia Matters in Powys
Unit 27, Ddole Road Enterprise Park
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LD1 6DF

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Sponsor type
University/education

Website
http://www.worcester.ac.uk/

ROR
https://ror.org/00v6s9648

Funder(s)

Funder type
Government

Funder Name
National Institute for Health Research

Alternative Name(s)
National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Results and Publications

Publication and dissemination plan
The researchers will publish results in a high impact peer-reviewed journal, as well as presenting at appropriate conferences.

The Association for Dementia Studies currently leads the UK Meeting Centre Support Programme (UK-MCSP) that includes a UK-wide Community of Learning and Practice, comprising 300 organisations who are interested in providing MCs in their communities, as well as a National Reference Group comprising 30 national organisations drawn from policy and practice to support the development of MCs into the future. Knowledge will be disseminated through these and their extensive further networks. 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. Findings will also be fed into our wider MC research programme and shared with our international MC partners.

The research team will also work with PPI representatives/study stakeholder groups, 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, through workshop activity in each MC, which the researchers will facilitate.

The researchers' 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 All-Party Parliamentary Groups (APPGs), Parliamentary inquiries and personal communication with policy leads. As the research progresses the researchers 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, the researchers will plan additional activities to take place after the research ends. They will seek an Alzheimer’s Society Implementation Grant to further promote uptake of findings. They will make a suite of digital, downloadable study dissemination resources freely available to education providers for use in relevant curricula. Through the UK-MCSP grant the researchers have responsibility for training emerging and existing MC personnel. In addition, they 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 the researchers will gain consent to follow up some stakeholders post-project to capture shorter and longer-term evidence of the impact of the research.

The researchers 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. They also will create a video and associated clips detailing what they have learnt, in plain English, for online dissemination as well as presentation at organised events; and they will create and publish evidence-based guidelines for commissioners and providers of MCs and providers of community-based interventions for people affected by dementia. A publicly accessible report summary will be available on the 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.

Intention to publish date
03/01/2024

Individual participant data (IPD) sharing plan
Data will be available to share upon request to the Association for Dementia Studies at the University of Worcester, after completion of the study (03/01/2023). It will include anonymised transcripts of interviews and group discussions (for qualitative analysis), as well as raw questionnaire data (for Discrete Choice Experiment analysis). This data will be retained for 10 years. Personal data from participants will not be shared and will be securely destroyed three months after the end of the study. Participants will give consent for the use of their anonymised data, for the purposes of research, at the point of collection. For access to datasets following the completion of this study, contact research associate Thomas Morton at t.morton@worc.ac.uk in the first instance, or the Association for Dementia Studies generally at dementia@worc.ac.uk.

IPD sharing plan summary
Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Participant information sheet	version v3	28/04/2021	01/06/2021	No	Yes
Protocol file	version v4	15/03/2021	01/06/2021	No	No
Protocol file	version V0.5	09/06/2021	15/06/2021	No	No
Protocol article		02/05/2022	26/05/2022	Yes	No
HRA research summary			28/06/2023	No	No
Funder report results			26/09/2023	No	No