BMJ Open

Sustaining community-based interventions for people affected by dementia long term: The SCI-Dem realist review

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2020-047789
Article Type:	Original research
Date Submitted by the Author:	08-Dec-2020
Complete List of Authors:	Morton, Thomas; University of Worcester, Association for Dementia Studies Wong, Geoffrey; Oxford University, Nuffield Department of Primary Care Health Sciences Atkinson, Teresa; University of Worcester, Association for Dementia Studies Brooker, Dawn; University of Worcester, Association for Dementia Studies
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Organisation of health services < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Dementia < NEUROLOGY, Old age psychiatry < PSYCHIATRY, SOCIAL MEDICINE

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Sustaining community-based interventions for people affected by dementia long term: The SCI-Dem realist review

Authors:

Thomas Morton, Association for Dementia Studies, University of Worcester, Worcester, UK.

Geoff Wong, Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK.

Teresa Atkinson, Association for Dementia Studies, University of Worcester, Worcester, UK.

Dawn Brooker, Association for Dementia Studies, University of Worcester, Worcester, UK.

Corresponding Author:

Professor Dawn Brooker, Director of the Association for Dementia Studies, School of Allied Health and Community, University of Worcester, Henwick Grove, Worcester WR2 6AJ.

Email: *d.brooker@worc.ac.uk*. Tel: 01905 855250

Sustaining community-based interventions for people affected by dementia long term: The SCI-Dem realist review

Thomas Morton[1] Geoff Wong[2] Teresa Atkinson[1] Dawn Brooker[1]

ABSTRACT

Objectives: Community-based support for people with dementia and their care partners, such as regularly-meeting groups and activities, can play an important part in post-diagnostic care. Typically delivered piecemeal in the UK by a variety of agencies with inconsistent funding, provision is fragmented and many such interventions struggle to continue after only a short start-up period. This realist review investigates what can promote or hinder them in being able to sustain long-term.

Methods: Key sources of evidence were gathered using formal searches of electronic databases and grey literature, together with informal search methods such as citation tracking and snowballing. No restrictions were made on type of article or study design, but only data pertaining to regularly-meeting, ongoing, community-based interventions for those affected by dementia were included. Data were extracted, assessed, organised and synthesised and a realist logic of analysis applied to trace context-mechanism-outcome configurations as part an overall programme theory. Consultation with stakeholders, involved with a variety of such interventions in various roles, informed this process throughout.

Results: Ability to continually get and keep members; staff and volunteers; the support of other services and organisations; and funding/income were found to be critical in long-term sustainability, with multiple mechanisms feeding into these sub-outcomes, sensitive to context. These included an emphasis on socialising and person-centredness; lowering stigma and logistical barriers; providing satisfaction, support and recognition for personnel; networking, raising awareness and sharing with other organisations, while avoiding conflict; and skilled financial planning and management. Challenges were especially acute for small-scale and rural groups.

Conclusions: This review presents a theoretical model of the factors and mechanisms involved in the long term sustainability of community-based interventions. While the data used predated the COVID-19 pandemic, it can provide a framework for new research to look at what sustainability-impacting elements might have been affected, and how.

Article Summary

- This review brings together transferrable learning from a wide range of intervention types on a topic that has received little formal, integrated research attention, to deepen our understanding on how such interventions could be implemented and supported to sustain more universally and consistently across the sector.
- This review's realist approach is well suited to accommodate and account for the complexity of such 'real life' intervention programmes, as implemented under different conditions in different settings, to extract transferable conclusions.
- This review was designed to gather evidence regarding how interventions can be sustained, not on the efficacy/effectiveness of interventions of this type, hence conclusions regarding the latter are beyond its scope.
- Literature was limited as this research question is not commonly the main focus of study in dementia care research.
- Not all of the data were of equal depth and detail or the highest empirical rigour, rather contributing together in a way that is useful to an overall programme theory that will benefit from further refinement and revision with empirical testing in subsequent research.

Keywords

Dementia; Post-diagnosis; Peer support; Psychosocial; Implementation

INTRODUCTION

Supporting people with dementia and their carers to live as well as possible in their communities, with timely psychosocial support, is a global public health goal,[1] though remains a challenging aspiration in many countries. In the UK, with an aging population[2] and increasing pressure on already-stretched health services[3] 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, support for family carers and 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.[4]

Support following a diagnosis of dementia is patchy,[4] however, with families in some areas lacking any formal proactive support beyond occasional contact with primary care and third sector. There are significant gaps in social care for people affected by dementia across the UK.[5 6 7] 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[6] and in some areas has "broken down" creating "care deserts".[5] There is an associated reliance on informal carers (e.g. family members) to provide support but there is a growing recognition that informal carers' own health and wellbeing is often negatively impacted by their caring activities.[6] The detrimental health impact of social isolation and loneliness is also increasingly being recognised,[8 9] with survey data revealing nearly 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.[7] Family carers can also be subject to such loneliness and isolation.[10] This situation has only been exacerbated by the recent impact of COVID-19[11], bringing the need for groups and activities that provide social connection and support for people and families affected by dementia into stark relief.

There have been various attempts to mitigate these challenges in communities across the country, in the form of groups and activities for people with dementia and family carers. These aim to serve a number of functions: peer support, companionship and help for people to reintegrate with their communities; delivery of professional support, psychosocial interventions and physical exercise; a point of contact, signposting and referral for other services; or raising awareness and acting as a dementia-friendly community hub. The benefits of such community-based initiatives are now being recognised.[12 13 14 15 16] There is evidence that regular social activity, where people are able to leave their homes and gather together in a communal setting on a frequent and ongoing basis, can be helpful both for people living with dementia and the people who care for them.[12 13 17 18 19] With care systems unprepared for the forecasted UK doubling of the number of people living with dementia (1.6 million) and tripling of social care costs by 2040,[20] improving provision of evidence-based community initiatives for people with dementia, and their families, is imperative.[12 13 14 15 16 21 22] However, even prior to the 2020 pandemic restrictions, such initiatives, groups and activities already faced a variety of challenges with long-term sustainability. 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.

This realist review aims to deepen our understanding of what can help or hinder the long-term sustainability of regularly meeting, place-based community interventions, such as groups and activities, for people affected by dementia. It aims to use data gathered as the basis of evidence-informed recommendations for policy and practice.

METHODS

This review was conducted from December 2018 to December 2020. A project protocol was registered with PROSPERO in March 2019[23] and the protocol was published in this journal in June 2019.[24]

The realist review is an interpretive, theory-driven approach to synthesising evidence from a range of sources, including qualitative, quantitative and mixed-methods research.[25] This approach is designed to accommodate and account for the complexity of 'real life' intervention programmes, as implemented under different conditions in different settings, aiming to explain how and why context can influence outcomes.[26] Hence it is well suited to extracting transferable lessons from reviewing the functioning and success (or otherwise) of a range of community-based interventions for people affected by dementia, as these are likely to involve a high level of complexity and be responsive to contextual factors which are likely to vary considerably from intervention to intervention. Data was gathered and synthesized, with a realist logic of analysis applied to identify causal chains involving different contexts, mechanisms and outcomes that can in turn affect an initiative's long-term sustainability. We define context as the conditions that trigger or modify the behaviour of mechanisms;[27] mechanisms are the usually-hidden processes that generate outcomes, defined as "underlying entities, processes, or structures which operate in particular contexts to generate outcomes of interest."[28]

Our review followed Pawson's five iterative stages[29] as outlined below.

Step 1: Locating existing theories

This initial step was to identify and gather existing ideas around what can help or hinder the sustainability of a group or activity, from those who have first-hand experience of them. In line with realist review guidelines (RAMESES),[30] stakeholders were contacted by TA and TM and consulted for input at points throughout the project. These stakeholders were lay experts involved with community-based interventions in various capacities, whether commissioning, leading, running, supporting or attending. In the first instance a workshop was held in March 2019 with a group of 13 invited stakeholders to gather their content expertise on barriers and facilitators to engagement and sustainability. Eight others were subsequently consulted by TM individually, in person, by telephone or by email. Input was also taken by TA and TM from members and facilitators of various local DEEP

(Dementia Engagement and Empowerment Project)[31] groups at a national meeting in June 2019, and TM also visited three community groups in Herefordshire, Oxfordshire and Wolverhampton. In addition, an exploratory search of the literature was conducted by TM, using informal methods such as citation tracking and snow-balling[32] along with informal scoping searches[33] and the gathering of relevant publications and materials recommended by stakeholders. Together, this contributed towards the building of an initial theoretical model, or *programme theory*, with the guidance of GW, prior to our main search, both to inform our formal search strategy and to be tested and refined by the data subsequently found.

Step 2: Search for evidence

Formal search

Formal searching activity took place between May and September 2019. A search strategy was designed, piloted and conducted by the research team with the guidance from an information specialist (CK) (see Supplementary file 1). The following databases were searched: Academic Search Complete; AMED; CINAHL; EMBASE; MEDLINE; ProQuest; PsycINFO; PubMed; Scopus and Social Care Online. In keeping with RAMESES guidelines,[30] no restrictions were made on the type of article or study design eligible for inclusion, other than being more recent than 1990. Documents such as editorials, opinion pieces, information guides, publicity materials, newspaper and magazine articles, evaluation reports, PhD theses and research poster and slide presentations were included along with peer-reviewed journal articles, if found to be holding relevant information.

After removing duplicates, records were screened by title and abstract by TM using the eligibility criteria, ensuring interventions covered were those targeted at people with dementia and their families living in the community, that brought people together physically and met on a frequent, regular and an on-going basis (these criteria are outlined in full detail in Supplementary file 2). Full text of documents were then obtained of the remaining records, and again screened by close reading against the eligibility criteria by TM. A 10% random subsample of was reviewed

independently at each of these stages by a second reviewer (TA) with disagreements recorded and resolved by discussion. Informal searching continued iteratively alongside the formal search and in response to articles found in it, congruent with the realist review process which allows searching to be revised as necessary as the review progresses.[30] In certain cases, documents regarding on interventions that met only some, not all, of the inclusion criteria were included if found to contain information on hypothesised mechanisms, with reason to believe such mechanisms may function similarly or analogously in types of intervention that are closely related.[29]

Steps 3 and 4: Article selection, data extraction and organisation

Figure 1 shows a PRISMA diagram outlining the full screening and selection process.

[Figure 1 here]

Following screening and close-reading of full texts for eligibility, full texts of the remaining 122 articles were loaded into NVivo qualitative data analysis software to help locate and categorise (code) relevant sections of text containing data regarding contexts, mechanisms or outcomes pertinent to the long-term sustainability of the intervention they described. Coding was both inductive (codes created in response to data as found) and deductive (codes created in advance, informed by the initial programme theory) and carried out by TM. The characteristics of the articles were also extracted separately into an EXCEL spreadsheet.

During this extraction and organisation process, more fine-grained assessments of relevance (to answering the research question) and rigour (the trustworthiness and credibility of the data and its source)[25 34] were made by TM, with a random sample of 10% of articles again selected, assessed independently and discussed with TA. The data an article contained was assessed on its own merits, not on that of the paper or study as a whole. This is because it was recognised that poorly designed or conducted research may still contain good quality 'nuggets' of information for a realist review,[34 35] or a document meeting inclusion criteria may not contain any relevant data. Due to the variety

and breadth of the type of article included in the review, a standardised relevance and rigour assessment tool that would be appropriate in all cases was impossible to design.[25] Rather a set of general principles was agreed to guide a 'traffic light' assessment system of low, medium and high relevance, and low, medium and high rigour (see Supplementary file 2 for detail). Reasons for each assessment were outlined and logged for each article, and compared with each other to ensure consistency. Ambiguous cases of relevance or rigour were discussed with the wider project team as they arose. A decision was made by the project team to exclude articles assessed to have data of low relevance or low rigour to ensure a more robust data-set with which to build the final programme theory and context-mechanism-outcome configurations.

Step 5: Synthesising the evidence and drawing conclusions

Once data from the remaining articles were extracted and categorised, key outcome themes were identified by discussion with the whole team. These themes and categories were presented to the stakeholders for comment and feedback, to determine what was most important to focus upon, if they felt anything had been overlooked and if any changes or refinements should be made. Four key outcome areas (getting and keeping members, personnel, support of other organisations and funding/income) were settled upon. Data was then organised under these headings in the form of "If-then" statements that provided initial explanations of how, why, for whom and in which contexts these outcomes might arise, initially by TM but with input from DB and TA. These were then further refined, with guidance from GW, using a realist logic of analysis to identify cause-and-effect chains in the data and finally elaborated into context-mechanism-outcome configurations (CMOCs).[30] Related CMOCs were then grouped together to create recommendations for practice or policy that also acted as a summary of the CMOCs found. Diagrams of the factors found affecting sustainability, and how they are likely to relate to each other within an overall programme theory, were also designed through team discussion and drawn by TM.

RESULTS

In total, 61 articles were coded to develop the CMOCs used to refine and expand our initial programme theory (see Supplementary file 3 for a detailed list of included articles). They were published between 1990 and 2020, and ranged in type: most were either peer-reviewed journal articles (28) or formal reports/evaluations (18); information guides (8), news feature articles (3), doctoral theses (2) and conference presentation paraphernalia (2) were also analysed. About half of these articles (33) were authored (or co-authored) in the UK, consistent with a proportion being identified informally through UK-based stakeholders (see Figure 2). Four articles had international authorship. Other countries of origin (or co-origin) comprised the US (8), Netherlands (7), Germany (5), Canada (4), Italy (4), Norway (3), Poland (3), Australia (2), Ireland (2), Sweden (2), Chile (1), Japan (1), Portugal (1) and Thailand (1). The type of intervention discussed in these articles varied broadly, including: day centres/day care, social activities, sports and exercise initiatives, peer support groups, arts and crafts groups, singing and music groups, cognitive stimulation, gardening activities and other outdoor activities. Many interventions had multiple and overlapping elements: for example a sports activity may have a social function, a drop-in day centre may have exercise and cognitive stimulation activities or a craft club may have peer support built in. When an article's remit was general (for example community support services, outdoor activities, social and leisure activities or third sector groups) the data included from the article was only that which was relevant to our programme theory and the kind of interventions outlined in the inclusion criteria (see Supplementary file 2).

Our analysis, together with stakeholder input, identified four critical areas affecting the sustainability of an intervention: members, staff and volunteers, support of other organisations and funding/income. These were each sub-divided into "getting" and "keeping" outcomes in recognition of changes in focus over time regarding these areas, and likely different contexts and mechanisms involved as an intervention continues. Figure 2 shows an overview of factors leading to the getting

and keeping of members, staff and volunteers, support of other organisations and funding/income, found in the article data (individual diagrams tracing factors for each critical area can be found in Supplementary file 4).

[Figure 2 here]

Our analysis of the data produced 201 CMOCs (outlined in full in Supplementary file 5), all covered by the above eight sub-divisions. These CMOCs provide causal explanations relating to sustainability of community-based groups and activities either at the level of the individual, organisation or wider. Due to the high number of CMOCs, they were further organised by grouping them under practical recommendations that could follow. These recommendations are not simply an end conclusion, but were also part of the data synthesizing process, as they act as a way in which to categorise and summarise the large number of CMOCs. Examples of how a number of grouped CMOCs were related to a recommendation can be seen in Table 1.

[Table 1 here]

Recommendations for practice

In total, 41 recommendations for practice were drawn from the CMOCs as can be seen in Table 2.

[Table 2 here]

Data regarding getting and keeping members was the most abundant and showed most consensus. As may be expected, boosting the motivation and understanding of potential referrers, while lowering bureaucratic and logistical barriers, was important to getting members (CMOC 10-CMOC 14; CMOC 31-CMOC 46; CMOC64-CMOC 65). Transport from home to venue was particularly key: not just its availability, but people's experiences of the accessibility, appropriateness and convenience of it (CMOC 10-CMOC 14). Other salient mechanisms involved how respected, valued and comfortable members felt, or perceived they would feel should they attend: both for overcoming initial anxiety and stigma and fostering a happy, cohesive group (CMOC 3-CMOC 9;

CMOC 15-CMOC 24; CMOC 53-CMOC 63; CMOC 71-CMOC72). Staff attitudes and a comfortable, accessible venue play a role in this, but also planned practices, such as involving members in decision making (CMOC 58-CMOC 63), differentiating activities for need and ability (CMOC 21- CMOC24; CMOC 66-CMOC 70) and ensuring enough opportunity and time for socialising (reported to be of high importance to people no matter what the intervention or activity) (CMOC 1-CMOC 2; CMOC 47-CMOC 52). The stability and reliability of an intervention was also important, though often at odds with nature of groups run informally with few personnel and unstable income (CMOC 73-CMOC 77). Overall, ensuring individual wants and needs are met – that people they feel they are gaining something useful and appropriate to them in particular – was important to keeping members long-term (CMOC 47-CMOC 72).

Data regarding getting and keeping staff and volunteers was least abundant of the four critical outcome areas, though working with other organisations was frequently alluded to as helpful in finding personnel (CMOC 78-CMOC 83). Data regarding skills of personnel was largely around the role of communication and collaboration in creating an encouraging and effective environment for staff and volunteers (CMOC 84-CMOC 97). Context was key with regards to the availability of potential volunteers in the local population, as this could be very different depending on location (e.g. rural or urban), with different likely mechanisms requiring different approaches to finding and encouraging volunteers from different demographic groups (CMOC 84-CMOC 90). With regard to keeping volunteers, issues raised included the importance of maintaining work satisfaction and avoiding burnout, and having financial support available (CMOC 98-CMOC 108).

Getting and keeping support of other organisations, such as other community groups, health and social care services, third sector bodies, local authorities and local businesses was a widely recurring theme in the data. Actively involving other organisations, minimising overlap, sharing knowledge and resources and offering something of benefit were all ways to encourage them to feel invested in supporting an intervention rather than threatened or indifferent to it (CMOC 122-CMOC

131), in addition to pro-active awareness raising and networking (CMOC 110-CMOC 121). Good collaboration planning, with expert advice on collaborative working and continual attention to maintaining communication were strategies to avoid problems developing or loss of enthusiasm with partner organisations (CMOC 138-CMOC 152).

On getting and keeping funding and income, salient CMOCs again involved continual networking and communication, for the reason that this would support multiple mechanisms: by reducing costs through sharing and partnership; boosting visibility, legitimacy and value in the eyes of potential and existing funders; and helping to locate more funding and income opportunities (CMOC 153-CMOC 175; CMOC 185-CMOC 190). Data made some reference to the importance of strategic planning in finding and managing funds, with outside expertise and dedicated personnel helpful in carrying this out (CMOC 170-CMOC 175; CMOC 191-CMOC 197). While tailoring an intervention to national (and therefore funders') priorities may increase its chances of obtaining funding, this is not always possible or desirable for a group (CMOC 180-CMOC 184). Groups in rural areas particularly, or experienced groups unable to find anything but short-term solutions, may have to raise greater awareness with commissioners and policy-makers about the specific challenges that face them, and lobby for change to ensure better conditions for groups in their situation long term (CMOC 170-CMOC 179; CMOC 198-CMOC 201). For example rural groups with a small number of members and personnel can struggle to meet funders demands, especially if put in competition with larger, well-resourced organisations.

Recommendations for policy and commissioning

In addition, 13 recommendations for policy-making and commissioning were also drawn (see Table 3), for the most part mirroring those for practice and drawing on the same CMOCs.

[Table 3 here]

The final recommendation covers CMOCs unique to policy-making and commissioning, highlighting issues such as the detrimental effect of a disjoin between national policy and local need on an intervention finding support (as by adhering to one they will neglect the other) (CMOC 132). Practices that could benefit the sustainability of community interventions included ring-fencing funding specifically for dementia-targeted community initiatives; commissioning health and social care services to work with community initiatives; and developing health pathways around existing community networks (CMOC 133-CMOC 135). National and official organisations can also encourage a more strategic, joined up direction regarding community-based dementia support by showing leadership in working with smaller, local initiatives and support for potential private sector partners (CMOC 136-CMOC 137).

DISCUSSION

Summary of findings

Being able to continually get and hold on to members, staff and volunteers, the support of other services and organisations, and funding/income are the key factors in the long-term sustainability of a community-based intervention for people affected by dementia. There are multiple mechanisms that feed into these sub-outcomes, sensitive to context. Ability to attract members was found to be driven by perceptions that a group or activity was “for them”, and expectations they would be welcomed, respected and supported without stigma once attending, as well as having motivated referrers and low logistical barriers including transport. Members are more likely to keep attending if feeling comfortable, at home, respected and empowered, with individual needs understood. Opportunity to socialising was found to be of high importance no matter what intervention type, with stability and reliability also important. Networking and outreach were found to be important in getting staff and volunteers; feeling satisfied, valued and supported (including financially) was important in keeping them. Proactive measures to raise awareness and involve other organisations, avoiding conflict and sharing knowledge and resources, were found to help in securing essential

support, though requiring significant maintenance through skilled communication, planning and working practices. Such networking and collaboration was found to be helpful in finding and securing funding and income, with skilled planning and management of multiple income streams helpful in sustaining long term. However, the often short term nature of funding was found to be a barrier to retaining deep learning and experience, and disjoins between national policy and local need a barrier to securing both funding and wider support. Challenges in meeting funders requirements and overcoming logistical barriers were especially acute for small-scale and rural groups.

Strengths and limitations

This review was designed to gather evidence regarding how regularly-meeting community-based interventions for people affected by dementia can be sustained, not on the efficacy/effectiveness of interventions of this type, hence conclusions regarding the latter are beyond its scope. Literature was limited as this research question is not commonly the main focus of study in dementia care research. This meant some CMOCs arrived at were the result of abundant data sources, while others were not, hence the CMOCs here vary in robustness (see Supplementary file 5). While efforts were made to exclude data of low rigour (see Supplementary file 2), it is the nature of a realist review to include data from a variety of source types to build a theoretical model piecemeal; not all of the data were of equal depth and detail and many will not meet the highest level of empirical rigour, rather they contribute together in a way that is useful to the theoretical constructs that are the CMOCs and overall programme theory.[29] The results of this review therefore should be taken as theory and sit in relation to other research: SCI-Dem provides a theoretical framework which can be put to the test and further refines by subsequent empirical research.[29] The breadth of intervention types covered in this review is on the one hand a strength, as it has enabled the surfacing of commonalities in experience likely relevant to a wide range of real-world initiatives broadly in the same category; on the other hand, it means this review cannot be specific on certain details. An example is that little

could be concluded on the cost-effectiveness or economic functioning of the interventions covered, because details were both too scant and too specific to draw robust CMOCs that might usefully be applicable to others.

Recommendations and comparison with existing literature

Recommendations for practice and policy are presented in Tables 2 and 3 in the results section. However, they also highlight some common problems for which there may be no easy solution: for example what to do in rural areas where public transport coverage is poor and potential members and volunteers are few and widespread, given that transport to venue is a key factor in getting and keeping members. The issue of whether interventions can be entirely self-sustaining or must rely on service-level agreements and grant funding is also a key one. This review suggests that costs can be reduced and income opportunities found by pro-active networking and collaborative working; though rather than removing the need for grant funding, this is more likely useful in leveraging it, adding to it and helping it to go further. Recent research into whether social enterprises delivering adult social care services (not dementia specific) could be self-sustaining suggests that marketing is key, but needs to focus upon building relationships with stakeholders at multiple levels rather than adopting an approach akin to selling a product:[97] networking and marketing are closely bound up with each other. Delivering social quality as well as service quality, having a hybrid workforce and diverse income streams to strengthen financial viability and reduce reliance on grants were also found to help[98]. This review echoes all of these points with regards to dementia-targeted community-based interventions, in particular that interventions cannot sustain without a cultivated support network around them, as well as careful collaborative financial planning and management.

The emphasis found in this review on the value to members of social activity and a respectful, empowering person-centred approach, reinforces the benefits of community-based initiatives and regular social activity, both for people living with dementia and the people who care

for them.[12 13 14 15 16 17 18 19] However, the time-limited nature of most research in this area is unhelpful when seeking data on the long-term sustainability of such interventions, with a large number of articles excluded from this review due to this. Recent systematic reviews have found that psychosocial interventions tend to be short term, with short-term trials only measuring short-term impact, and a pressing need for more longer-term studies with larger sample sizes.[14 99] However, there is a "chicken and egg" problem: if policy and commissioning is hesitant to support interventions unless there is evidence of robust statistical effects, then such interventions will struggle to sustain long enough, in enough abundance, to have the numbers to carry out the research required to produce that evidence. Equally, if research focuses only on efficacy/effectiveness without attention to the implementation process, and reporting of how costs were met and resources, personnel, and service users were found, then little can be learnt about sustaining them.

Future research directions

When drafting inclusion criteria for this review in 2018 it was decided to focus upon interventions that brought people together to meet physically and socially, as distinct from community services that go into people's homes. It did not take into account virtual community activities or communities at-a-distance, which at the time seemed like a distinct niche. In 2020, however, this kind of activity has become much more important, and integrated with the activities of existing community groups that met physically prior to the COVID-19 pandemic. With COVID-19 the landscape for community-based interventions has changed significantly, presenting further unprecedented challenges, but the need for groups that connect people socially remains acute. A recent study by the Alzheimer's Society[11] revealed COVID-19 restrictions have had particularly negative impacts on the health and well-being of people affected by dementia and their carers, a finding echoed by the Alzheimer's Disease International's update report for 2020.[100] Restrictions have forced changes to routine, causing anxiety and strain in relationships; led to a reduction in skills and confidence; and increased

pressure on home carers, not least through the erosion of support systems.[101] Many support initiatives will have ceased operating either temporarily or permanently. As the effects of the pandemic continue to be felt, there is an urgent need for community-based interventions to find ways to keep going or re-establish quickly when emerging from COVID-19 restrictions. While the data used in this review predated the pandemic, it can provide a framework for new research to look at what sustainability-impacting elements have been affected and how. This review presents a theoretical model of the factors and mechanisms involved in the long term sustainability of community-based interventions. As such it is for further research to put this model to the test by comparing it empirically with real-world interventions going forward, which will further refine and add to this programme theory in a post-pandemic climate.

Word count: 4684

Figure legends

Figure 1 PRISMA flow diagram

Figure 2 Factors affecting the sustainability of community-based groups and activities

Author affiliations and email

1 Association for Dementia Studies, University of Worcester, Worcester, UK. *t.morton@worc.ac.uk*

2 Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK. *geoffrey.wong@phc.ox.ac.uk*

1 Association for Dementia Studies, University of Worcester, Worcester, UK. *t.atkinson@worc.ac.uk*

1 Association for Dementia Studies, University of Worcester, Worcester, UK. *d.brooker@worc.ac.uk*

Author Contributions DB and TA conceptualised the study along with Dr Shirley Evans (Association for Dementia Studies, University of Worcester) with input from GW, TM and Clive Kennard (Information specialist, University of Worcester). The study was conducted by DB as principal investigator, TA as project manager, TM research associate and GW providing methodological expertise. TM wrote the first draft of this manuscript. GW, DB and TA critically contributed to and refined this manuscript. All authors have read and approved the final manuscript.

Corresponding Author Professor Dawn Brooker, Director of the Association for Dementia Studies, School of Allied Health and Community, University of Worcester, Henwick Grove, Worcester WR2 6AJ. Email: *d.brooker@worc.ac.uk*. Tel: 01905 855250

Twitter Follow Thomas Morton @ThomasMortonADS

Original protocol: http://dx.doi.org/10.1136/bmjopen-2019-032109

Funding: This work was supported by The Alzheimer's Society, Grant No: 402, AS-PG-17b-023

Acknowledgements This project was funded by the Alzheimer's Society. Dr Shirley Evans (Association for Dementia Studies, University of Worcester) contributed to the writing of the protocol for this review. Clive Kennard (information specialist, University of Worcester), helped design, pilot and carry out the formal search. The authors would like to thank all those who shared their invaluable experience and contributed to advising and guiding this project as a stakeholder consultant: Philly Hare, Rachael Litherland, Damian Murphy and Rachel Niblock of DEEP/Innovations in Dementia, and all who attended the national meeting of DEEP groups at Wooodbrooke, Birmingham, July 2019; Dory, James McKillop and Dreane Williams of DEEP; Judith Baron and the Face It Together group; Jill Turley and The Buddys group; Kim Badcock of Kim's Cafe (Denmead, Havant and Waterlooville, Hampshire); Jo Barrow and the Forget Me Not Lunch and Friendship Club (Bicester, Oxfordshire); Elizabeth Bartlett of the Laverstock Memory Support Group (Wiltshire); Shirley Bradley of Friends of the Elderly (Worcester); David Budd of Our Connected Neighbourhoods

(Stirling); Di Burbidge of Liverpool DAA Diversity Sub-Group and Chinese Wellbeing (Liverpool); Kishwar Butt of the South Asian Ladies' Milaap Group (Wolverhampton); Michelle Candlish of Ceartas Advocacy (Kirkintilloch, East Dunbartonshire); Annette Darby of Brierly Hill Health and Social Care Centre (West Midlands); Sue Denman of Solva Care (Haverfordwest); Gerry Fouracres of Scrubditch Farm, Cirencester; Graham Galloway of Kirrie Connections (Kirriemuir, Angus); Reinhard Guss; Deborah Harrold of Agewell CIC (Oldbury, West Midlands); June Hennell; Jacoba Huizenga of Health and Social Care in Communities, Utrecht (Netherlands); Lynden Jackson of the Debenham Project (Suffolk); Cheryl Poole of Leominster Meeting Centre; Anita Tomaszewski and Jennifer Williams of Me, Myself and I (Briton Ferry, Neath Port Talbot); Dame Louise Robinson; Droitwich Meeting Centre; Leominster Meeting Centre; the members of the UKMCSP National Reference Group; and Jennifer Bray, Shirley Evans, Nicola Jacobson-Wright, Chris Russell and Mike Watts of the Association for Dementia Studies, University of Worcester.

Competing interests Geoff Wong is Deputy Chair of the National Institute for Health Research Health Technology Assessment Prioritisation Committee: Integrated Community Health and Social Care (A).

Disclaimer The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the Alzheimer's Society.

Ethics approval This project has been reviewed by the University of Worcester College of Health, Life and Environmental Sciences Research Ethics Panel.

PROSPERO registration number CRD42019125889.

REFERENCES

1. World Health Organisation. *Global action plan on the public health response to dementia 2017-2025.* Geneva: world Health Organisation, 2017. https://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/
2. Office for National Statistics (ONS). *Living longer: Caring in later life.* London: ONS, 2019. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/livinglongerhowourpopulationischangingandwhyitmatters/2019-03-15
3. Care Quality Commission. *The state of health care and adult social care in England 2018/19.* Newcastle-upon-Tyne: Care Quality Commission, 2019. https://www.cqc.org.uk/sites/default/files/20191015b_stateofcare1819_fullreport.pdf
4. Department of Health. *Prime Minister's challenge on dementia 2020.* London: Department of Health, 2015. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf
5. Incisive Health. *Care deserts: the impact of a dysfunctional market in adult social care provision.* London: Incisive Health, 2019: https://www.incisivehealth.com/wp-content/uploads/2019/05/care-deserts-age-uk-report.pdf
6. Age UK. *Briefing: Health and Care of Older People in England 2019.* London: Age UK, 2019. https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/health--wellbeing/age_uk_briefing_state_of_health_and_care_of_older_people_july2019.pdf
7. Alzheimer's Society. *A lonely future: 120,000 people with dementia living alone, set to double in the next 20 years.* London: Alzheimer's Society, 2019. https://www.alzheimers.org.uk/news/2019-05-15/lonely-future-120000-people-dementia-living-alone-set-double-next-20-years
8. Cornwell EY, Waite, LJ. Social disconnectedness, perceived isolation and health among older adults. *J Health Soc Behav* 2009;50(1):31–48. doi.org/10.1177/002214650905000103
9. Holt-Lunstad J, Smith TB, Baker M, Harris T, Stephenson D. Loneliness and social isolation as risk factors for mortality: A meta-analytic review. *Perspect Psychol Sci* 2015;10(2):227–237. doi.org/10.1177/1745691614568352
10. Brodaty H, Donkin M. Family carers of people with dementia. *Dialogues Clin Neurosci* 2009;11(2):217–228.
11. Alzheimer's Society. *Worst hit: Dementia during coronavirus.* London: Alzheimer's Society, 2020. https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf
12. Brooker D, Evans SC, Evans SB, *et al.* Evaluation of the implementation of the Meeting Centres Support Program in Italy, Poland, and the UK; exploration of the effects on people with dementia. *Int J Geriatr Psychiatry* 2018;33(7):883-892. doi: 10.1002/gps.4865.
13. Evans SB, Evans SC, Brooker D, *et al.* 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 Ment Health* 2018; doi: 10.1080/13607863.2018.1544207
14. Lord K, Beresford-Dent J, Rapaport P, *et al.* 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. *Soc Psychiatry Psychiatr Epidemiol* 2019; doi: 10.1007/s00127-019-01784-w
15. McDermott O, Charlesworth G, Hogervorst E, *et al.* Psychosocial interventions for people with dementia: a synthesis of systematic reviews. *Aging Ment Health* 2019;23(4):393–403. doi: 10.1080/13607863.2017.1423031
16. Van't Leven N, Prick AE, Groenewoud JG, et al. Dyadic interventions for community-dwelling people with dementia and their family caregivers: a systematic review. *Int Psychogeriatr* 2013;25(10):1581-1603.
17. Dröes RM, Van Mierlo LD, Meiland FJM, Van der Roest HG. Memory problems in dementia: Adaptation and coping strategies, and psychosocial treatments. *Expert Rev Neurother* 2011;11(12):1769-1782.
18. Dröes RM, Meiland F, Schmitz MJ, Van Tilburg W. 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 multi-centre implementation study. *Int J Geriatr Psychiatry* 2004;19(7):673-684.
19. Dröes RM, Meiland FJM, Schmitz MJ, Van Tilburg W. Effect of the Meeting Centres Support Program on informal carers of people with dementia: Results from a multi-centre study. *Aging Ment Health* 2006;10(2):112-124.

20. Wittenberg R, Hu B, Barraza-Araiza L, Rehill A. *Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019-2040 (CPEC Working Paper 50).* London: LSE, 2019. https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf
21. Dröes RM, Breebaart E, Meiland FJ, *et al.* Effect of Meeting Centres Support Program on feelings of competence of family carers and delay of institutionalization of people with dementia. *Aging Ment Health* 2004;8(3):201-211. doi.org/10.1080/13607860410001669732
22. Dröes RM, Meiland FJM, Schmitz M, van Tilburg W. 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. *Int J Geriatr Psychiatry* 2004;19:1-12.
23. Booth A, Clarke M, Ghersi D, *et al.* An international registry of systematic-review protocols. *Lancet* 2011;377:108–9.
24. Morton T, Atkinson T, Brooker D, *et al.* Sustainability of community-based interventions for people affected by dementia: a protocol for the SCI-Dem realist review. *BMJ Open* 2019;9:e032109. doi: 10.1136/bmjopen-2019-032109
25. Pawson R. *Evidence-based Policy: A Realist Perspective*. London: Sage Publications, 2006.
26. Pawson R, Greenhalgh T, Harvey G, Walshe K. Realist review – a new method of systematic review designed for complex policy interventions. *J Health Serv Res Policy* 2005;10(1):21-24.
27. Jagosh J, Macaulay AC, Salsberg J, *et al.* Uncovering the benefits of participatory research: implications of a realist review for health research and practice. *Milbank Q* 2012;90:311–46.
28. Astbury B, Leeuw F. Unpacking black boxes: mechanisms and theory building in evaluation. *Am J Eval* 2010;31:363–81.
29. Pawson R, Greenhalgh T, Harvey G, *et al. Realist Synthesis – An Introduction.* ESRC Working Paper Series. London: ESRC, 2004.
30. Wong G, Greenhalgh T, Westhorp G, Pawson R. Development of methodological guidance, publication standards and training materials for realist and meta-narrative reviews: the RAMESES (Realist And Meta-narrative Evidence Syntheses - Evolving Standards) project. *Health Serv Deliv Res* 2014;2(30):1-252.
31. DEEP. *DEEP: The UK Network of Dementia Voices* website. 2020. http://dementiavoices.org.uk
32. Greenhalgh T, Peacock R. Effectiveness and efficiency of search methods in systematic reviews of complex evidence: audit of primary sources. *BMJ* 2005;331:1064.
33. Booth A, Harris J, Croot E, *et al.* Towards a methodology for cluster searching to provide conceptual and contextual "richness" for systematic reviews of complex interventions: case study (CLUSTER). *BMC Med Res Methodol* 2013;13:118.
34. Wong G. Data gathering in realist reviews: Looking for needles in haystacks. In: Emmel, N, Greenhalgh J, Manzano A, *et al.* (eds.) *Doing Realist Research.* London: Sage Publications, 2018:131-145.
35. Pawson R. Digging for nuggets: How 'bad' research can yield 'good' evidence. *Int J Soc Res Methodol* 2006;9(2):127-142.
36. Actifcare. *Best practice recommendations from the Actifcare study: Access to community care services for home-dwelling people with dementia and their carers.* www.actifcare.eu. Bangor: Dementia Services Development Centre Wales, 2017. http://dsdc.bangor.ac.uk/documents/ShortversionBestPracticeRecommendationwithoutsupportingfindings_000.pdf
37. Alzheimer's Australia. *The benefits of physical activity and exercise for people living with dementia (Dicussion paper 11).* Sydney: Alzheimer's Australia, 2014. https://www.dementia.org.au/sites/default/files/NSW/documents/AANSW_DiscussionPaper11.pdf
38. Arkin SM, Morrow-Howell N. Elder Rehab: A student-supervised exercise program for Alzheimer's patients. *Gerontologist* 1999;39(6):729-735. doi:10.1093/geront/39.6.729
39. Arthur A, Buckner S, Buswell M, *et al. DEMCOM: National Evaluation of Dementia Friendly Communities (Executive Summary).* Cambridge: Applied Research Collaboration (ARC) East of England, 2020.
40. Bould E, McFayden S, Thomas C. *Dementia-friendly sport and physical activity guide.* London: Alzheimer's Society, 2019. https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/organisations/dementia-friendly-sports
41. Brataas HV, Bjugan H, Wille T, Hellzen O. Experiences of day care and collaboration among people with mild dementia. *J Clin Nurs* 2010;19(19-20):2839-2848. doi:10.1111/j.1365-2702.2010.03270.x
42. Brooker D, Evans SB, Evans SC, et al. *Meeting Centres Support Programme UK: Overview, evidence and getting started.* Worcester: Association for Dementia Studies, University of Worcester, 2017. https://www.worcester.ac.uk/documents/Meeting-Centres-Support-Progamme-Overview-evidence-and-getting-started-Conference-booklet.pdf

43. Cahill S, Pierce M, Bobersky A. *An evaluation report on flexible respite options of the Living Well With Dementia project in Stillorgan and Blackrock.* Dublin: Trinity College, 2014. http://dementia.ie/images/uploads/site-images/Evaluation_Flexible_Respite_Options.pdf
44. Carone L, Tischler V, Dening T. Football and dementia: A qualitative investigation of a community based sports group for men with early onset dementia. *Dementia* 2016;15(6):1358-1376. doi:10.1177/1471301214560239
45. Casey J. Early Onset Dementia: Getting Out and About. *Journal of Dementia Care* July/August 2004;12(4):12-13.
46. Clarke CL, Keyes SE, Wilkinson H, *et al.* Organisational space for partnership and sustainability: Lessons from the implementation of the National Dementia Strategy for England. *Health Soc Care Community* 2014;22(6):634-645. doi:10.1111/hsc.12134
47. Daykin N, Julier G, Tomlinson A, *et al. Review of the grey literature: music, singing and wellbeing.* London: What Works Wellbeing, 2016. https://whatworkswellbeing.files.wordpress.com/2016/11/grey-literature-review-music-singing-wellbeing-nov2016.pdf
48. Dean J, Silversides K, Crampton J, Wrigley J. *Evaluation of the Bradford Dementia Friendly Communities Programme.* York: Jospeh Rowntree Foundation, 2015. https://www.jrf.org.uk/report/evaluation-bradford-dementia-friendly-communities-programme
49. Dean J, Silversides K, Crampton J, Wrigley J. *Evaluation of the York Dementia Friendly Communities Programme*. York: Jospeh Rowntree Foundation, 2015. https://www.jrf.org.uk/report/evaluation-york-dementia-friendly-communities-programme
50. Gajardo J, Aravena JM, Budinich M, et al. The Kintun program for families with dementia: From novel experiment to national policy (innovative practice). *Dementia* 2017;19(2):488-495. doi:10.1177/1471301217721863
51. Glover C. *Running self-help groups in sheltered and extra care accommodation for people who live with dementia.* London: Mental Health Foundation, 2014. https://www.mentalhealth.org.uk/sites/default/files/dementia-self-help-guide.pdf
52. Gottleib-Tanaka D. *Creative expression, dementia and the therapeutic environment (PhD Thesis).* Vancouver: University of British Columbia, 2006. https://open.library.ubc.ca/cIRcle/collections/ubctheses/831/items/1.0076821
53. Green G, Lakey L. *Building dementia-friendly communities: a priority for everyone.* London: Alzheimer's Society, 2013. https://actonalz.org/sites/default/files/documents/Dementia_friendly_communities_full_report.pdf
54. Grinberg A, Lagunoff J, Phillips D, *et al.* Multidisciplinary design and implementation of a day program specialized for the frontotemporal dementias. *Am J Alzheimers Dis Other Demen* 2008;22(6):499-506. doi:10.1177/1533317507308780
55. Hayes R, Williamson M. *Men's Sheds: Exploring the Evidence for Best Practice.* Melbourne: La Trobe University, 2007. https://www.researchgate.net/publication/259313489
56. Health Innovation Network South London. *Peer Support for People with Dementia Resource Pack.* London: Health Innovation Network South London, 2015. https://dementiapartnerships.com/resource/dementia-peer-support-resource-pack/
57. Health Innovation Network South London. *Case Study: Dulwich Helpline and Southwark Churches Care (DH&SCC) – The Dementia Project, Southwark, South London.* London: Health Innovation Network South London, 2015. http://www.hin-southlondon.org/system/resources/resources/000/000/083/original/Case_Study_The_Healthy_Living_Club.pdf?1426083299
58. Health Innovation Network South London. *Case Study: The Healthy Living Club (HLC) – A self-directed, dementia-centred community group in Stockwell, London.* London: Health Innovation Network South London, 2015. http://www.hin-southlondon.org/system/resources/resources/000/000/084/original/Case_Study_The_Dulwich_Helpline_and_Southwark_Churches.pdf?1426083406
59. Hikichi H, Kondo K, Takeda T, Kawachi I. Social interaction and cognitive decline: Results of a 7-year community intervention. *Alzheimers Dement (N Y)* 2017;3:23-32. doi:10.1016/j.trci.2016.11.003
60. Hochgraeber I, Bartholomeyczik S, Holle B. Low-threshold support for families with dementia in Germany. *BMC Res Notes* 2012:5(1). doi:10.1186/1756-0500-5-317
61. Hochgraeber I, Kutzleben MV, Bartholomeyczik S, Holle B. Low-threshold support services for people with dementia within the scope of respite care in Germany – A qualitative study on different stakeholders' perspective. *Dementia* 2015;16(5):576-590. doi:10.1177/1471301215610234
62. Jackson L. *The Debenham Project: Project Blog and Catch-Up (August 2017).* Debenham, Suffolk: The Debenham Project, 2017. http://www.the-debenham-project.org.uk/downloads/newsletters/blogs/1708.pdf
63. Kelsey SG, Laditka SB. Evaluating best practices for social model programs for adults with Alzheimer's disease in South Carolina. *Home Health Care Serv Q* 2006;24(4):21-46. doi:10.1300/j027v24n04_02

64. La Rue A, Felten K, Duschene K, *et al*. Language-enriched exercise plus socialization for older adults with dementia: Translation to rural communities. *Semin Speech Lang* 2013;34(03):170-184. doi:10.1055/s-0033-1358370

65. La Rue A, Felten K, Turkstra L. Intervention of multi-modal activities for older adults with dementia translation to rural communities. *Am J Alzheimers Dis Other Demen* 2015;30(5):468-477. doi:10.1177/1533317514568888

66. LeBlanc LA. Integrating behavioral psychology services into adult day programming for individuals with dementia. *Behav Modif* 2010;34(5):443-458. doi:10.1177/0145445510383528

67. Lockwood S. *The Debenham Project: A case study of a unique community-led and owned project dedicated to the support of carers of those that have symptoms of dementia and those they care for.* Harrogate: Community Catalysts CIC, 2012. http://www.the-debenham-project.org.uk/downloads/articles/2012/121106report.pdf

68. Mangiaracina F, Chattat R, Farina E, *et al.* Not re-inventing the wheel: The adaptive implementation of the meeting centres support programme in four European countries. *Aging Ment Health* 2016;21(1):40-48. doi:10.1080/13607863.2016.1258540

69. Mapes N, Milton S, Nicholls V, Williamson T. *Is it nice outside? Consulting people living with dementia and their carers about engaging with the natural environment.* Natural England Commissioned Reports, Number211. York: Natural England, 2016. http://publications.naturalengland.org.uk/publication/5910641209507840

70. Marshall J, Jackson L. *Encouraging and supporting the growth of "dementia proactive communities".* Ipswich: Sue Ryder/The Debenham Project, 2015. http://www.the-debenham-project.org.uk/downloads/conference/Supplementary%20contributions/Lynden%20Jackson%20&%20Jo%20Marshall/Lynden%20Jackson%20&%20%20Jo%20Marshall%20-%20Supplementary%20Contribution.pdf

71. Mason T, Slack G. *The Debenham Project: Research into the dementia/memory loss journey for cared-for and carer, 2012-13.* Norwich: Norfolk & Suffolk Dementia Alliance, 2013. http://www.the-debenham-project.org.uk/downloads/articles/2014/DebProjResearch_Final_Report_311013.pdf

72. McAiney CA, Hillier LM, Stolee P, *et al.* 'Throwing a lifeline': The role of First Link™ in enhancing support for individuals with dementia and their caregivers. *Neurodegener Dis Manag* 2012;2(6);623-638. doi:10.2217/nmt.12.66

73. McDonald A, Heath B. Developing services for people with dementia. *Work Older People* 2009;13(3);18-21. doi:10.1108/13663666200900045

74. The Me Myself and I Club.*The Me, Myself and I Club, Briton Ferry: A case study in warm humanity and meaningful co-production.* Neath Port Talbot: The Me Myself and I Club, 2018. https://info.copronet.wales/me-myself-and-i-club-briton-ferry/

75. Meiland FJ, Dröes RM, Lange J, Vernooij-Dassen M. Development Of A Theoretical Model For Tracing Facilitators And Barriers In Adaptive Implementation Of Innovative Practices In Dementia Care. *Arch Gerontol Geriatr* 2004;38:279-290. doi:10.1016/j.archger.2004.04.038

76. Meiland FJ, Dröes RM, Lange JD, Vernooij-Dassen MJ. Facilitators and barriers in the implementation of the meeting centres model for people with dementia and their carers. *Health Policy* 2005;71(2):243-253. doi:10.1016/j.healthpol.2004.08.011

77. Mental Health Foundation. *An evaluation of the Standing Together project.* London: Mental Health Foundation, 2018. https://www.mentalhealth.org.uk/sites/default/files/standing-together-evaluation-WEB.pdf

78. Milligan C, Payne S, Bingley A, Cockshott Z. Place and wellbeing: Shedding light on activity interventions for older men. *Ageing Soc* 2013;35(1):124-149. doi:10.1017/s0144686x13000494

79. Moore KD. Observed affect in a dementia day center: Does the physical setting matter? *Alzheimers Care Q* 2002;3(1):67-73.

80. Noimuenwai P. *Effectiveness of adult day care programs on health outcomes of Thai family caregivers of persons with dementia (PhD Thesis).* Kansas: University of Kansas, 2012. https://kuscholarworks.ku.edu/bitstream/handle/1808/11440/Noimuenwai_ku_0099D_12475_DATA_1.pdf?sequence=1&isAllowed=y

81. NCVO. *How To Fundraise In Tough Times.* London: NCVO, 2019. https://knowhow.ncvo.org.uk/how-to/how-to-fundraise-in-tough-times

82. Older People's Commissioner for Wales. *Rethinking respite for people affected by dementia.* Cardiff: Older People's Commissioner for Wales, 2018. http://www.olderpeoplewales.com/en/Reviews/respite.aspx

83. Oliver-Watkins F, Kendall N, Matthews T. *Sow & Grow: Report from a two-year Social and Therapeutic Horticultural (STH) programme delivering table-top gardening courses to adults in the community aged 50 and over.* Reading: Thrive, 2016.

84. Reichet M, Wolter V. *Sport for People With Dementia – Implementing Physical Activity Programs (PAP) For People With Dementia: Results From A German Study (conference poster).* Dortmund: TU Dortmund University, 2017.
85. Reichet M, Wolter V. Implementing physical activity programs for people with dementia: Results from a German study. *Innov Aging* 2017;1(Suppl_1):340-340. doi:10.1093/geroni/igx004.1247
86. Rio R. A Community-Based Music Therapy Support Group for People With Alzheimer's Disease and Their Caregivers: A Sustainable Partnership Model. *Front Med* 2018;5. doi:10.3389/fmed.2018.00293
87. Shnall A, Agate A, Grinberg A, *et al.* Development of supportive services for frontotemporal dementias through community engagement. *Int Rev Psychiatry* 2013;25(2):246-252. doi:10.3109/09540261.2013.767780
88. Solutions Research. *Public perceptions and experiences of community-based end of life care initiatives: a qualitative research report.* London: Public Health England, 2016. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/569711/Public_Perceptions_of_Community_Based_End_of_Life_Care_Initiatives_Resea....pdf
89. Strandenæs MG, Lund A, Rokstad AM. Experiences of attending day care services designed for people with dementia – a qualitative study with individual interviews. *Aging Ment Health* 2017;22(6):764-772. doi:10.1080/13607863.2017.1304892
90. Thrive. *Growing4life - A Thrive Community Gardening Project: A practical guide to setting up a community gardening project for people affected by mental ill health.* Reading: Thrive, 2012. https://www.lumi.org.uk/assets/resources-toolkits/event-and-projects/G4L-Resource-Book.pdf
91. Tuppen J. The benefits of groups that provide cognitive stimulation for people with dementia. *Nurs Older People,* 2012;24(10):20-24. doi:10.7748/nop2012.12.24.10.20.c9437
92. Tuppen J, Burton-Jones J. Cogs Clubs: a helpful activity in early dementia. *Journal of Dementia Care* September/October 2015;23(5):20-21.
93. Van Haeften-Van Dijk A, Meiland F, Mierlo LV, Dröes RM. Transforming nursing home-based day care for people with dementia into socially integrated community day care: Process analysis of the transition of six day care centres. *Int J Nurs Stud* 2015;52(8), 1310-1322. doi:10.1016/j.ijnurstu.2015.04.009
94. Van Mierlo L, Chattat R, Evans S, *et al.* Facilitators and barriers to adaptive implementation of the Meeting Centers Support Program (MCSP) in three European countries; the process evaluation within the MEETINGDEM study. *Int Psychogeriatr* 2017;30(4):527-537. doi:10.1017/s1041610217001922
95. Williams B, Roberts P. Friends in passing: Social interaction at an adult day care center. *Int J Aging Hum Dev* 1995;41(1):63-78. doi:10.2190/ghhw-v1qr-nacx-vbcb
96. Wimo A, Wallin J, Lundgren K, *et al.* Impact of day care on dementia patients–costs, well-being and relatives' views. *Fam Pract* 1990;7(4):279-287. doi:10.1093/fampra/7.4.279
97. Powell M, Osborne SP. Social enterprises, marketing, and sustainable public service provision. *International Review of Administrative Sciences*. 2020;86(1):62-79. doi:10.1177/0020852317751244
98. Powell M, Gillett A, Doherty B. Sustainability in social enterprise: hybrid organizing in public services. *Public Management Review* 2019;21(2):159-186. doi:10.1080/14719037.2018.1438504
99. Oyebode JR, Parveen S. Psychosocial interventions for people with dementia: An overview and commentary on recent developments. *Dementia* 2019;18(1):8–35. doi: 10.1177/1471301216656096
100. Barbarino P, Lynch C, Bliss A, *et al. From Plan to Impact III: Maintaining dementia as a priority in unprecedented times.* London: Alzheimer's Disease International, 2020. https://www.alzint.org/u/from-plan-to-impact-2020.pdf
101. Canevelli M, Valletta M, Toccaceli Blasi M, *et al.* Facing Dementia During the COVID-19 Outbreak. *J Am Geriatr Soc* 2020;68(8):1673–1676. https://doi.org/10.1111/jgs.16644

Recommendation	CMOCs
Getting Members: **Ensure a warm, welcoming, non-stigmatising introduction, with strong staff interpersonal skills and an appealing venue**	CMOC 3: If facilitators are knowledgeable and empathetic, with good interpersonal skills (C), an initiative will be perceived as more welcoming and inclusive (O), as they will be better at understanding needs, engaging and building trust with potential members and their families (M).[36 47 61 73 89 94] CMOC 4: If an initiative has an informal, unrushed and warm welcome on first visit (C), then people are more likely to want to return (O), as they are more likely to find the experience relaxing and enjoyable, not uncomfortable and intimidating (M).[42 51 84 85 89] CMOC 5: If potential members have had poor previous experiences with groups or activities (dementia related or not) (C), they may not want to try another group or activity (O), because they think the experience will be similar and will want to avoid it (M).[47 74 82 94] CMOC 6: If time is taken for personal contact, home visits or taster sessions with potential members (C), then people are more likely to come (O), as they will feel more familiar with the initiative and more trusting of those running it (M).[36 40 53 61 70 82] CMOC 7: If an initiative is familiar and trusted, or local and well integrated with other organisations in the community (C), then people are more likely to come (O), as its links to familiar things that they trust will make it less intimidating (M).[40 42 46 47 57 65 71 75 88 94] CMOC 8: If an intervention is based in familiar surroundings in, and open to, the community (C), then people are more likely to come (O), because potential members will find the normalcy, lack of stigma and chance for social integration appealing (M).[40 43 44 50 54 57 61 76 86 94] CMOC 9: If a venue is dementia-friendly, comfortable and accessible (C), people are more likely to come (O), as they will not have concerns about comfort or access (M).[40 52 69 75]
Keeping Members: **Keep activities relaxed, loose and focussed on the social, and encourage friendships and peer support**	CMOC 47: If there is group cohesion and mutual trust between members (C), then a group is more likely to sustain (O), because members will feel more solidarity and investment in the group (M).[41] CMOC 48: If friendships between members are encouraged, recognised and supported by staff and activities (C), then people are likely to keep coming (O), as they will feel more supported, comfortable and engaged, and able to support each other (M).[45 51 71 83 95] CMOC 49: If an intervention is too focussed on agendas, rules and expectations (C), then people may stop coming (O), because they feel pressured, restricted and unable to relax and enjoy the social and emotional benefits important to them (M).[37 52 55 78 83 84 85] CMOC 50: If the pace of activity through the day/session is too fast and strict (C), then people may stop coming (O), because they will struggle to stay engaged and will not enjoy themselves (M).[40 43 51 76 91] CMOC 51: If ample informal time is made for socialising, peer support and feedback (C), then members are more likely to keep coming (O), as they will be more likely to feel comfortable and supported (M).[37 40 41 44 51 55 70 77 78 83 86 89 90 91 92] CMOC 52: If there is opportunity to have communal eating and relaxing in a "cozy" environment (C), then members are more likely to keep coming (O), as this will provide comfort and foster group cohesion (M).[41 89]

Table 1 Examples of CMOCs leading to recommendations

Getting Members	Keeping Members
Emphasise the social aspects of your intervention, including food and refreshments, for wide appeal CMOC 1 – CMOC 2 [26 27 36 38 41 46 56 57 59] **Ensure a warm, welcoming, non-stigmatising introduction, with strong staff interpersonal skills and an appealing venue** CMOC 3 – CMOC 9 [36 40 42 43 44 46 47 50 51 52 53 54 57 61 65 69 70 71 73 74 75 76 82 84 85 86 88 89 94] **Foster understanding and support from trusted friends, family and health professionals, as their encouragement can be key** CMOC 10 – CMOC 14 [36 40 41 42 44 48 49 61 71 77 80 82 86 88 92 93 94] **Provide meaningful activities that have resonance with people's interests and experience, personal history and culture** CMOC 15 – CMOC 20 [37 40 41 43 44 49 52 55 56 59 60 64 65 67 69 70 74 78 82 83 84 85 86 88 91 94] **Be sensitive to differences in abilities, ages and stages and aim to empower members rather than avoid challenges for them** CMOC 21 – CMOC 24 [37 40 44 47 51 52 54 69 77 86 93] **Offer information and advice to connect with a broad range of people who may be in need** CMOC 25 [42 58 71 77 84 85] **Ensure people can get there easily, safely, reliably and cheaply** CMOC 26 – CMOC 30 [36 40 41 47 48 49 50 53 54 58 60 61 68 69 76 77 80 82 84 85 88] **Stay in constant contact with potential referrers and keep them involved** CMOC 31 – CMOC 32 [46 71 74 75 76 90 92 93 94] **Your "public relations" strategy should focus on who the intervention is for and what people can expect, and use existing networks to spread your message** CMOC 33 – CMOC 41 [36 40 45 46 47 50 53 55 56 60 61 62 64 67 71 72 74 76 77 79 80 82 83 84 85 86 88 90 91 92 94] **Consider simple and easy self referral** CMOC43 – CMOC 46 [43 48 56 72 76 61 64 82 84 85 90 93]	**Keep activities relaxed, loose and focussed on the social, and encourage friendships and peer support** CMOC 47 – CMOC 52 [37 40 41 43 44 45 51 52 55 70 71 76 77 78 83 84 85 86 89 90 91 92 95] **Encourage normalised activities and social integration outside of the group to empower members and reduce stigma** CMOC 53 – CMOC 57 [39 40 43 44 45 47 48 50 53 57 61 71 74 76 78 82 83 86 94] **Be person-centred: Give members input into planning and decision-making, and respect their individual needs and autonomy** CMOC 58 – CMOC 63 [36 40 41 42 45 50 51 52 57 63 67 74 75 76 78 83 84 85 89 90 94] **Talk to family or care partners about what arrangements and support they need in place** CMOC 64 – CMOC 65 [40 43 53 54 61 70 71 76 77 80 82 84 85] **Be sensitive to differences in abilities, ages and stages and have strategies to differentiate and manage activities so needs don't clash** CMOC 66 – CMOC 70 [40 43 44 45 47 48 50 51 53 54 74 76 78 80 82 83 84 85 90 92 94] **Ensure your venue is comfortable, stable and familiar, with adequate facilities and multiple spaces for use** CMOC 71 – CMOC 72 [40 51 52 75 79] **Stability and reliability matters to members, so aim for structure and minimise disruption** CMOC 73 – CMOC 77 [36 40 41 45 47 51 61 76 77 82 83 89 91 92]
Getting Staff and Volunteers	**Keeping Staff and Volunteers**
Network proactively: Engage in outreach activities to boost visibility and awareness; approach other groups and organisations for help CMOC 78 – CMOC 83 [37 40 44 49 50 56 63 64 67 76 70 74 79 83 88] **Get to know potential stakeholder groups in the local population that may provide a reliable volunteer base, and consider how to reach out to them** CMOC 84 – CMOC 90 [38 41 59 63 64 65 66 86 88] **Not all personnel need expertise, but ensure facilitators have good interpersonal and leadership skills, and your volunteer workforce is reliable** CMOC 91 – CMOC 95 [44 46 61 70 76 77 78 91 92 93]	**Foster flexibility, collaboration and communication skills in personnel to create a healthy and effective working environment** CMOC 96 – CMOC 97 [48 50 54 66 93] **Plan strategies to maintain the satisfaction and enjoyment of staff and volunteers, and to avoid burnout** CMOC 98 – CMOC 104 [44 51 55 57 61 67 76 90 92] **If possible, have financial support in place for staff roles and volunteers activities, so they will feel secure and valued** CMOC 105 – CMOC 108 [46 62 67 77 83 93]
Getting Support of Other Organisations	**Keeping Support of Other Organisations**
Focus on raising awareness and communicating value both to professionals and the community, involving them where possible CMOC 110 – CMOC 114 [39 42 47 55 56 67 68 70 71 73 75 76 92 93 94]	**Maintain constant contact and information sharing with the organisations, services and referrers you work with, with a dedicated person responsible if possible**

Approach and ask other community organisations if they can help with venue, resources, training, volunteers or contacts CMOC 115 – CMOC 118 [37 38 40 41 44 49 56 57 66 74 78 83 86 91 92] **Use your physical location (venue or neighbourhood) as an opportunity to build links with others sharing that space** CMOC 119 – CMOC 121 [40 42 44 50 86 93 94] **Seek out like-minded groups to band together with and share knowledge, resources, contacts and strategy** CMOC 122 – CMOC 124 [42 49 83] **To avoid conflict with other organisations, minimise overlap, involve them or offer them something of benefit** CMOC 125 – CMOC 131 [42 46 54 55 67 68 72 74 76 83 91 93 94]	CMOC 138 – CMOC 142 [46 49 67 70 73 75 83 84 85 93 94] **Seek authoritative external advice on overcoming differences in culture with other organisations, and up-skilling staff for collaboration** CMOC 143 – CMOC 148 [46 48 49 50 54 55 68 93 94] **Take time to formally plan how collaboration will work, involving collaborators in that planning** CMOC 149 – CMOC 152 [46 55 76 84 85 94]
Getting Funding and Income	**Keeping Funding and Income**
Ensure communication is clear about what the intervention does and its value CMOC 153 – CMOC 163 [46 55 56 73 74 76 79 81 88 92 93 94] **Build "social capital" and forge partnerships with other community organisations to help with costs and boost the case for viability and value for money** CMOC 164 – CMOC 169 [48 54 55 56 62 66 76 80 81 88 92 93 96] **Learn how to effectively plan and network to find funding, through knowledge-sharing with like-minded groups and seeking external advice** CMOC 170 – CMOC 175 [47 54 56 63 68 74 75 76 81] **Initiatives in rural areas should make clear the particular challenges that they face when seeking funding** CMOC 176 – CMOC 179 [63 67 70] **Find out what the national priorities are for dementia, and see if you can tailor you activities to fit; if not, lobby to change the national agenda** CMOC 180 – CMOC 184 [42 46 48 49 50 56 62 63 67 68 70 73 75 87 94 96]	**Keep in touch with previous, current and potential funders on an ongoing basis, as this will help when applying in the future** CMOC 185 – CMOC 188 [55 74 75 76 81] **Pay attention to how money can be put to use most efficiently and effectively for the benefit of all by co-operating and sharing with other organisations** CMOC 189 – CMOC 190 [48 55 56 66 80 92] **Plan a long-term strategy to build a portfolio of multiple income streams, that are flexible in what they contribute to paying for** CMOC 191 – CMOC 194 [55 56 67 81 84 85] **Ensure someone has the time and expertise to continually seek and apply for funding** CMOC 195 – CMOC 197 [55 67 56] **Emphasise deep learning and experience as an asset when calling for longer term funding** CMOC 198 – CMOC 201 [46 48 49 62 68 70 73 87 93]

Table 2 Recommendations for practice (For a full list of CMOCs see Supplementary file 5)

Recommendations for commissioning/policy-making
Service users value the social side of an intervention highly, often more than the intervention or activity itself CMOC 1 – CMOC 2; CMOC 47 – CMOC 53 [26 27 36 37 38 40 41 43 44 45 46 50 51 52 53 55 56 57 59 61 70 71 76 77 78 82 83 84 85 86 89 90 91 92 94 95]
Service users need to feel an intervention is "for them" to want to attend and keep attending CMOC 15 – CMOC 24; CMOC 66 – CMOC 70 [37 40 41 43 44 45 47 48 49 50 51 52 53 54 55 56 59 60 64 65 67 69 70 74 76 77 78 80 82 83 84 85 86 88 90 91 92 93 94]
Lack of appropriate transport can be a major barrier to an intervention getting and keeping attendees CMOC 26 – CMOC 30; CMOC 65 [36 40 41 43 47 48 49 50 53 54 58 60 61 68 69 70 76 77 80 82 84 85 88]
Health and social care services that may refer to an intervention need incentive and guidance to do so CMOC 42 – CMOC 44; CMOC 134 – CMOC 135 [37 48 49 56 70 72 76 82 93]
To retain staff and volunteers there needs to be adequate financial support in place for roles and activities CMOC 105 – CMOC 109 [46 62 67 70 77 83 93]
Established community organisations, including local authorities, can offer help in a number of ways to enable small-scale interventions to flourish

CMOC 115 – CMOC 118 [37 38 40 41 44 49 56 57 66 74 78 83 86 91 92]
Access to advice on how to create partnerships, collaborate and overcome differences in culture with other organisations can help
CMOC 143 – CMOC 148 [46 48 49 50 54 55 68 93 94]
Access to advice on how to effectively plan and network to help find and manage funding and income can help
CMOC 170 – CMOC 175 [47 54 56 63 68 74 75 76 81]
Commissioners should be flexible and accommodating of the challenges facing small groups regarding evidence gathering
CMOC 176 – CMOC 179 [63 67 70]
Policy makers should ensure policy meets local needs with adequate, protected and accessible resources attached
CMOC 180 – CMOC 182; CMOC 184 [42 46 48 49 50 56 62 63 67 68 70 73 75 94 96]
Longer term funding, with simplified application processes, would help smaller initiatives with less capacity to continue
CMOC 195 –CMOC 197 [55 67 56]
Longer term funding to support what is already being done will help retain and develop learning and practice on how best to meet local need
CMOC 198 – CMOC 200 [46 48 49 62 68 70 73 93]
Authorities and national organisations can help create conditions that encourage support for small initiatives, though policy, leadership and commissioning
CMOC 132 – CMOC 137 [37 46 49 50 70 73 82]

Table 3 Recommendations for commissioning/policy-making (For a full list of CMOCs see Supplementary file 5)

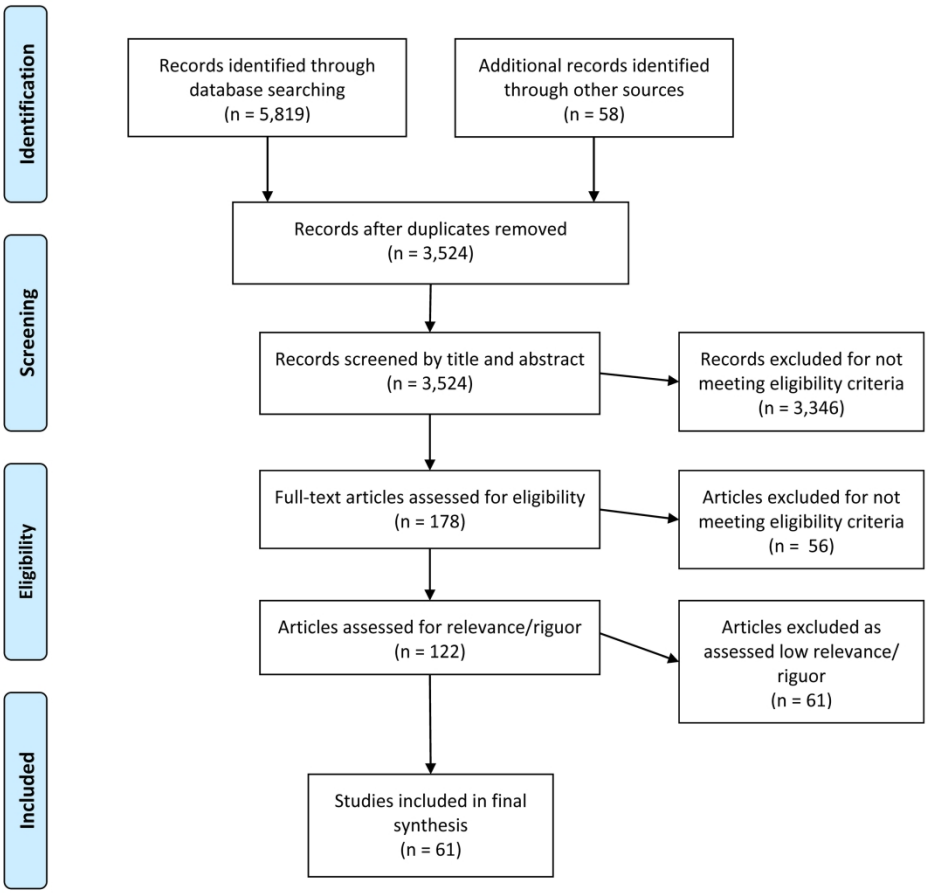


Figure 1 PRISMA flow diagram

133x130mm (600 x 600 DPI)

Figure 2 Factors affecting the sustainability of community-based groups and activities

164x106mm (600 x 600 DPI)

Supplementary file 1: Search strategy

Databases:

EBSCOhost: **Academic Search Complete, CINAHL, MEDLINE, PsychINFO**

Other health and social care databases: **AMED,Embase, PubMed, Social Care Online**

Interdisciplinary databases: **ProQuest, Scopus**

Systematic reviews: **Cochrane Library, Campbell Collaboration**

Other/general: **Google Scholar**

Limiters: Published 1990 to present

Key terms	String of related terms
Dementia	Dementia
Community	Commun* OR Local* OR Social*
Intervention	Intervention OR Program* OR Project OR Initiative OR Scheme OR Service OR Activit* OR Group OR Club OR Network OR Meeting OR Therapy
Sustainability	Sustain* OR Maint* OR Manag* OR Facilitat* OR Barrier*
Implementation and Engagement	Implement* OR Recruit* OR Engag*

Dementia AND (Commun* OR Local* OR Social*) AND (Intervention OR Program* OR Project OR Initiative OR Scheme OR Service OR Activit* OR Group OR Club OR Network OR Meeting OR Therapy) AND (Sustain* OR Maint* OR Manag* OR Facilitat* OR Barrier*)AND (Implement* OR Recruit* OR Engag*)

Supplementary file 2: Inclusion and assessment criteria

Inclusion and exclusion criteria for formal search:

Inclusion criteria Types of intervention for inclusion should:	**Exclusion criteria** Interventions will be excluded if they:
• Target people with mild to moderate dementia (whether exclusively or among others without dementia, but either way there is dementia-specific support) • Serve people living in the community, whether in their own homes or in extra-care housing • Are voluntary attendance (i.e. members have chosen to attend, not been told they must as part of treatment or respite care) • Are social and place-based (bringing people together physically) in a community setting (open to members of the public to attend) • Are designed as an intervention with meaningful activity aiming to improve quality of life for people with dementia and family carers, or to help them manage or lessen the challenging effects dementia • Meet at regular, pre-fixed times, at least weekly and for a substantial amount of time (i.e. a morning or afternoon) • Meet continuously, on an ongoing basis, or aim to do so	• Are only for those with severe dementia • Do not target, and have no plan to cater for, people with dementia • Are only for care home residents, hospital patients or those in a closed institutional setting • Are an online or at-a-distance networking scheme that does not involve meeting physically • Only involve individual participants alone (e.g. occupational therapy, counselling or medical) • Are only functional meetings solely for the purpose of administering medical treatment or carry out case management • Are focussed mainly upon respite for carers or nursing care only (i.e. not focussed upon social, meaningful and quality-of-life-raising activities for those attending) • Only take place monthly; or for a very short duration (e.g. one hour); or intermittently with no specified or timetabled meetings • Are fixed-term courses with a time/goal/session limit (e.g. an 8 week course)

Relevance and rigour assessment guidance:

Relevance	**Rigour**
An article should comply with the inclusion/exclusion criteria in the first instance, except where agreed by the team for inclusion for a specific reason e.g. containing data that is broadly transferable and of use to the programme theory.	This is an assessment of the likely validity and reliability only of the *relevant* data contained in an article, *not* an assessment of the rigour of a study or intervention programme as a whole. Useful questions might include: *Is this data likely to be biased? Is it dealt with critically? Is it from a real-world example or theoretical speculation? Was the data gathered in some depth over time or in a quick "snapshot"? Is it safe to generalise from this data?*

Reasons for rating must be recorded. For example:	Reasons for rating must be recorded. For example:
A **low rating** might mean the article that only contains a few relevant lines, with the bulk of the text focused on other, non-relevant matters A **medium rating** might mean an article has a lot of detail on one relevant issue (e.g. engaging people and keeping them engaged) which is pertinent to sustainability, but otherwise little on other important factors A **high rating** will mean an article has a direct focus on keeping an intervention sustainable long term, with a good level of detail	A **low rating** might mean data appears uncritically treated and at a high risk of bias (e.g. from a promotional article for a service) or simply descriptive and superficial in its reporting of basic facts from an intervention programme (e.g. from a short news article) A **medium rating** might mean data appears with some attempt at critical evaluation and is from a real-world example, but is limited in scope and generalisability, or in depth and detail A **high rating** might mean data is of good depth and detail and is from a critical evaluation of at least one real world example, gathered over a sustained period using range of robust measures and an appropriate sample of participants

Supplementary file 3: Full lists of included articles

Author(s)	Year	Article title	Type of intervention	Country of origin	Type of article/study	Publication	Reference list No.
Actifcare	2017	Best practice recommendations from the Actifcare study: Access to community care services for home-dwelling people with dementia and their carers	**community care services** in general	Netherlands, Germany, Sweden, UK, Norway, Ireland, Portugal, Italy	Recommendations report	www.actifcare.eu	**36**
Alzheimer's Australia	2014	The benefits of physical activity and exercise for people living with dementia (Dicussion paper 11)	**Exercise activities**	Australia	Report	Alzheimer's Australia	**37**
Arkin	1999	Elder rehab: A student-supervised exercise program for Alzheimer's patients	**Weekly exercise programme** pairing elders and student helpers at a college gym (caregivers also involved)	US	Journal paper - programme pilot	The Gerontologist	**38**
Arthur, Buckner, Buswell, Darlington, Killett, Lafortune, Mathie, Mayrhofer, Skedgel, Woodward & Goodman	2020	DEMCOM: National Evaluation of Dementia Friendly Communities (Executive Summary)	**Dementia Friendly Communities - various social and leisure activities**	UK	Evaluation report	Applied Research Collaboration (ARC) East of England	**39**

Bould, McFadyen & Thomas	2019	Dementia-friendly sport and physical activity guide	**Sport and excercise initiatives**	UK	Information booklet	Alzheimer's Society	**40**
Brataas, Bjugan, Wille & Hellzen	2010	Experiences of day care and collaboration among people with mild dementia	**Day care**	Norway	Journal paper - qual study of a trial programme	Journal of Clinical Nursing	**41**
Brooker, Evans, Evans, Watts & Droes	2017	Meeting Centres Support Programme UK: Overview, evidence and getting started	**Meeting Centres**	Netherlands, Italy, Poland, UK	Information/guide booklet	Association for Dementia Studies (University of Worcester)	**42**
Cahill, Pierce & Bobersky	2014	An evaluation report on flexible respite options of the Living Well With Dementia project in Stillorgan and Blackrock	**Day care/respite**	Ireland	Evaluation report	Trinity College Dublin	**43**

Carone, Tischler & Dening	2016	Football and dementia: A qualitative investigation of a community based sports group for men with early onset dementia	**Sport and excercise group**	UK	Journal paper - qualitative study	Dementia	**44**
Casey	2004	Early onset dementia: Getting out and about	**Small "out and about" social group**	UK	Specialist news article	Journal of Dementia Care	**45**
Clarke, Keyes, Wilkinson, Alexjuk, Wilcockson, Robinson, Corner & Cattan	2014	Organisational space for partnership and sustainability: lessons from the implementation of the National Dementia Strategy for England	**Peer support networks**	UK	Journal paper - stragtegy evaluation	Health & Social Care in the Community	**46**
Daykin, Julier, Tomlinson, Meads, Mansfield, Payne, Duffy, Lane, D'Innocenzo, Burnett, Kay, Dolan, Testoni & Victor	2016	Review of the grey literature: music, singing and wellbeing	**Singing and musical activities**	UK	Review/Report	What Works Wellbeing report	**47**

Dean, Silversides, Crampton & Wrigley	2015	Evaluation of the Bradford Dementia Friendly Communities Programme	**Activities and groups in the community**	UK	Evaluation report	Joseph Rowntree Foundation report	**48**
Dean, Silversides, Crampton & Wrigley	2015	Evaluation of the York Dementia Friendly Communities Programme	**Activities and groups in the community**	UK	Evaluation report	Joseph Rowntree Foundation report	**49**
Gajardo, Aravena, Budinich, Larrain, Fuentes & Gitlin	2017	The Kintun program for families with dementia: From novel experiment to national policy (innovative practice)	**Day centre** and dementia **community hub**	Chile	Journal article - program evaluation	Dementia	**50**
Glover	2014	Running self-help groups in sheltered and extra care accommodation for people who live with dementia	**Self-help social and activity groups**	UK	Information/guide booklet	Mental Health Foundation	**51**

Gottlieb-Tanaka	2006	Creative expression, dementia and the therapeutic environment	**Art/creative activities in a day centre environment**	Canada	Dissertation/Thesis		**52**
Green & Lakey (Alzheimer's Society)	2013	Building dementia-friendly communities: a priority for everyone	**Dementia Friendly Communities** - various social and leisure activities	UK	Report	Alzheimer's Society	**53**
Grinberg, Lagunoff, Phillips, Stern, Goodman & Chow	2007	Multidisciplinary design and implementation of a day program specialized for the frontotemporal dementias	**Day program** for people with FTD	Canada	Journal paper - program evaluation	American Journal of Alzheimer's Disease & Other Dementias	**54**
Hayes & Williamson	2007	Men's Sheds: Exploring the Evidence for Best Practice	**Men's Sheds**	Australia	Evaluation report	School of Public Health, La Trobe University	**55**

Health Innovation Network South London** (**see also linked films within document plus 2015 HIN Case Studies)	2015	Peer Support for People with Dementia Resource Pack	A range of **peer support groups and activities**	UK	Information/guide booklet	Health Innovation Network South London	**56**
Health Innovation Network South London	2015	Case Study: Dulwich Helpline and Southwark Churches Care (DH&SCC) – The Dementia Project, Southwark, South London.	**Peer support project**	UK	Information/guide booklet	Health Innovation Network South London	**57**
Health Innovation Network South London	2015	Case Study: The Healthy Living Club (HLC) – A self-directed, dementia-centred community group in Stockwell, London	**Peer support group**	UK	Information/guide booklet	Health Innovation Network South London	**58**
Hikichi, Kondo, Takeda & Kawachi	2017	Social interaction and cognitive decline: Results of a 7-year community intervention	**Community centres for older people**	Japan	Journal paper - longitudinal study	Alzheimer's & Dementia	**59**

Hochgraeber, Bartholomeyczik & Holle** (**See also Hochgraeber et al 2017)	2012	Low-threshold support for families with dementia in Germany	**"Low threshold" support services** including **social care groups**	Germany	Journal paper - survey protocol	BMC Research Notes	**60**
Hochgraeber, Von Kutzleben, Bartholomeyczik & Holle	2017	Low-threshold support services for people with dementia within the scope of respite care in Germany – A qualitative study on different stakeholders' perspective	**"Low threshold" support services** including **social care groups**	Germany	Journal paper - qualitative study	Dementia	**61**
Jackson	2017	The Debenham Project: Project Blog and Catch-Up	Range of local **support groups and activities**	UK	Project blog newsletter/report	Debenham Project	**62**
Kelsey & Laditka	2005	Evaluating best practices for social model programs for adults with Alzheimer's disease in South Carolina	**"Social model" day care**	US	Journal paper - review and survey of best practice	Home Health Care Services Quarterly	**63**

La Rue, Felten, Duschene, MacFarlane, Price, Zimmerman & Havez	2013	Language-enriched exercise plus socialization for older adults with dementia: Translation to rural communities	**Language, excercise and socialisation program**	US	Journal paper - trial progam in rural setting	Seminars in Speech and Language	**64**
La Rue, Felten & Turkstra	2015	Intervention of Multi-Modal Activities for Older Adults With Dementia Translation to Rural Communities	**Language, excercise and socialisation program**	US	Journal paper - trial progam in rural setting	American Journal of Alzheimer's Disease & Other Dementias	**65**
LeBlanc	2010	Integrating behavioral psychology services into adult day programming for individuals with dementia	**Day care** (for people with dementia exhibiting challenging behaviour)	US	Journal paper - program evaluation	Behavior Modification	**66**
Lockwood	2012	The Debenham Project: A case study of a unique community-led and owned project dedicated to the support of carers of those that have symptoms of dementia and those they care for	Range of local **support groups and activities**	UK	Case study report	Community Catalysts	**67**

Mangiaracina, Chattat, Farina, Saibene, Gamberini, Brooker, Evans, Evans, Szcześniak, Urbanska, Rymaszewska, Hendricks, Dröes & Meiland	2017	Not re-inventing the wheel: the adaptive implementation of the meeting centres support programme in four European countries	**Meeting Centres**	Netherlands, Italy, Poland, UK	Journal paper - project evaluation	Aging & Mental Health	**68**
Mapes, Milton, Nicholls & Williamson (Natural England)	2016	Is it nice outside? Consulting people living with dementia and their carers about engaging with the natural environment	**Outdoor activities**	UK	Report	Natural England report	**69**
Marshall & Jackson	2015	Encouraging and supporting the growth of "dementia proactive communities"	**Dementia proactive communities** (Range of local **support groups and activities**)	UK	Report	Debenham Project & Sue Ryder	**70**
Mason & Slack	2013	The Debenham Project: Research into the dementia/memory loss journey for cared-for and carer, 2012-13	Range of local **support groups and activities**	UK	Evaluation report - survey	Norfolk & Suffolk Dementia Alliance	**71**

McAiney, Hillier, Stolee, Harvey & Michael	2012	'Throwing a lifeline': the role of First Link in enhancing support for individuals with dementia and their caregivers	Information on and links between **support services (including groups and activities)**	Canada	Journal paper - evaluation	Neurodegenerative Disease Management (Future Medicine)	**72**
McDonald & Heath	2009	Developing services for people with dementia	**General dementia support services** in rural areas	UK	Journal short report feature - review of service provision	Working with Older People: Community Care Policy & Practice	**73**
The Me Myself and I Club	2018	The Me, Myself and I Club, Briton Ferry: A case study in warm humanity and meaningful co-production	**Friendship club and support services**	UK (Wales)	Programme/service report	Me Myself and I Club	**74**
Meiland, Dröes, De Lang & Vernooij-Dassen	2004	Development of a theoretical model for tracing facilitators and barriers in adaptive implementation of innovative practices in dementia care	**Meeting centres**	Netherlands	Journal paper - model development	Archives Of Gerontology And Geriatrics Supplement	**75**

Meiland, Dröes, De Lang & Vernooij-Dassen	2005	Facilitators and barriers in the implementation of the Meeting Centres model for people with dementia and their carers	**Meeting centres**	Netherlands	Journal paper - model test	Health Policy	**76**
The Mental Health Foundation	2018	An evaluation of the Standing Together project	**Peer support groups**	UK	Evaluation report	Mental Health Foundation report	**77**
Milligan, Payne, Bingley & Cockshott	2015	Place and wellbeing: shedding light on activity interventions for older men	**Men's Sheds**	UK	Journal paper - qualitative study of program	Ageing & Society	**78**
Moore	2002	Observed affect in a dementia day center: Does the physical setting matter?	**Day centre**	US	Journal paper - case study/field observation	Alzheimer's Care Quarterly	**79**

Noimuenwai	2012	Effectiveness of adult day care programs on health outcomes of Thai family caregivers of persons with dementia	**Day care (Thailand)**	Thailand	Dissertation/Thesis		**80**
NVCO	2019	How To Fundraise In Tough Times	**Third sector and non-profit organisations in general**	UK	Information guide	NCVO Knowhow website	**81**
Older People's Commissioner for Wales	2018	Rethinking respite for people affected by dementia	**Respite/day services**	UK (Wales)	Report	Older People's Commissioner for Wales report	**82**
Oliver-Watkins, Kendall & Matthews	2016	Sow & Grow: Report from a two-year Social and Therapeutic Horticultural (STH) programme delivering table-top gardening courses to adults in the community aged 50 and over	**Gardening groups**	UK	Evaluation report	Sow & Grow	**83**

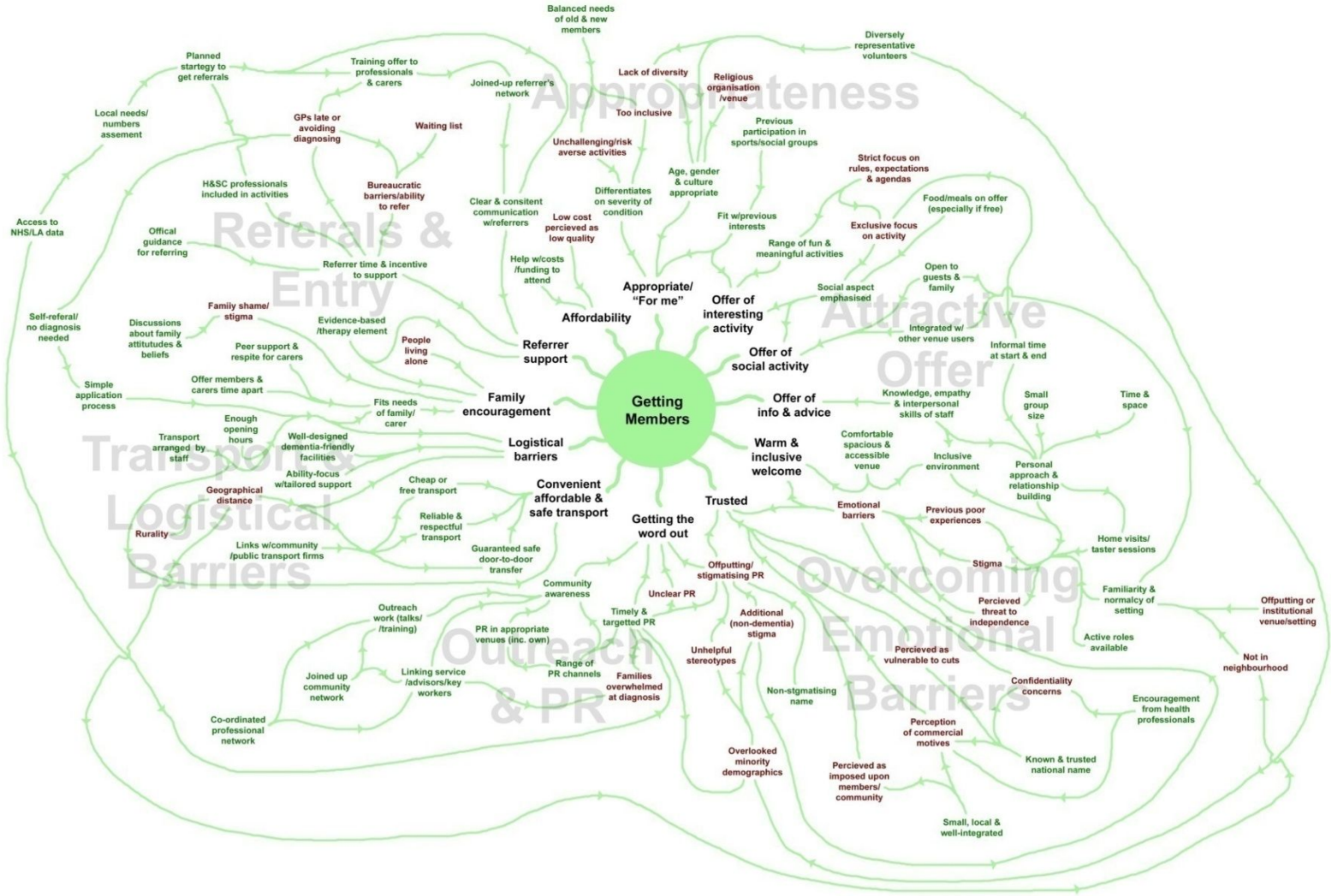
Reichet & Wolter	2017	Implementing physical activity programs for people with dementia: Results from a German study	**Sports club initiatives**	Germany	Poster presentation		**84**
Reichet & Wolter	2017	Implementing physical activity programs for people with dementia: Results from a German study	**Sports club initiatives**	Germany	Conference abstract	Innovation in Aging (Supplement)	**85**
Rio	2018	A Community-Based Music Therapy Support Group for People With Alzheimer's Disease and Their Caregivers: A Sustainable Partnership Model	**Music therapy group**	US	Journal paper - program evaluation	Frontiers In Medicine	**86**
Shnall, Agate, Grinberg, Huijbregts, Nguyen & Chow	2013	Development of supportive services for frontotemporal dementias through community engagement	**Day program for FTD** (plus online groups and resources for family carers)	Canada	Journal paper - review of initiatives	International Review of Psychiatry	**87**

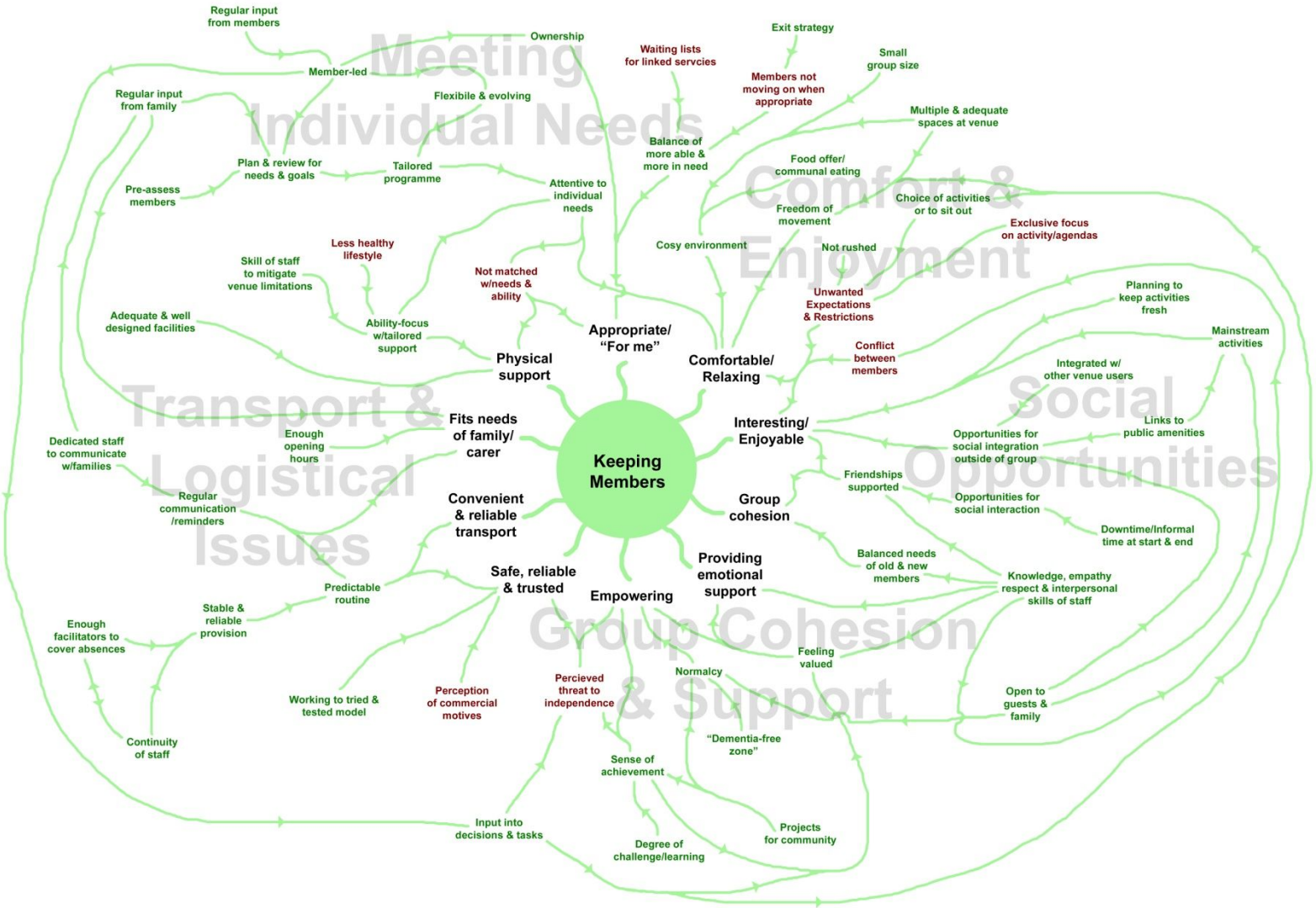
Solutions Research	2016	Public perceptions and experiences of community-based end of life care initiatives: a qualitative research report	**Community-based support initiatives** of all kinds	UK	Report	Public Health England report	**88**
Strandenæs, Lund & Rokstad	2018	Experiences of attending day care services designed for people with dementia - a qualitative study with individual interviews	**Day care**	Norway	Journal paper - qualitative study	Aging & Mental Health	**89**
Thrive	2012	Growing4life - A Thrive Community Gardening Project: A practical guide to setting up a community gardening project for people affected by mental ill health	**Gardening groups**	UK	Information/guide booklet	Thrive (The Society for Horticultural Therapy)	**90**
Tuppen	2012	The benefits of groups that provide cognitive stimulation for people with dementia	**Cognitive stimulation clubs**	UK	Journal article - overview of intervention	Nursing Older People	**91**

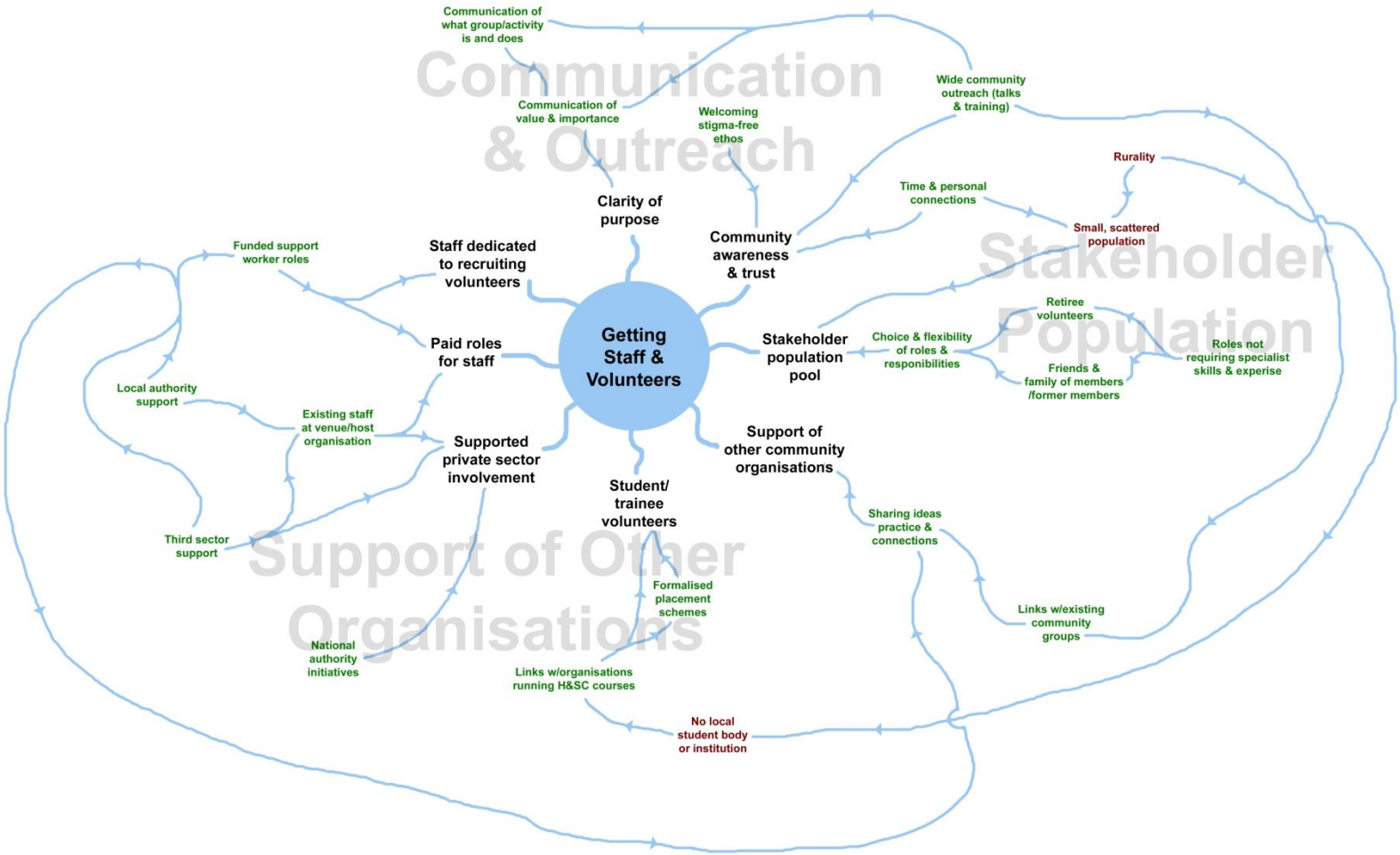
Tuppen & Jones	2015	Cogs Clubs: a helpful activity in early dementia	**Cognitive stimulation clubs**	UK	Specialist news article	Journal of Dementia Care	**92**
Van Haeften-van Dijk, Meiland, van Mierlo & Dröes	2015	Transforming nursing home-based day care for people with dementia into socially integrated community day care: Process analysis of the transition of six day care centres	**Meeting centres**	Netherlands	Journal paper - process evaluation	International Journal of Nursing Studies	**93**
Van Mierlo, Chattat, Evans, Brooker, Saibene, Gamberini, Farina, Scorolli, Szcześniak, Urbańska, Rymaszewska, Dröes & Meiland	2018	Facilitators and barriers to adaptive implementation of the Meeting Centers Support Program (MCSP) in three European countries; the process evaluation within the MEETINGDEM study	**Meeting centres**	Netherlands, Italy, Poland, UK	Journal paper - program evaluation	International Psychogeriatrics	**94**
Williams & Roberts	1995	Friends in passing: social interaction at an adult day care center	**Adult day care centre**	US	Journal paper - participant observation	International Journal Of Aging & Human Development	**95**

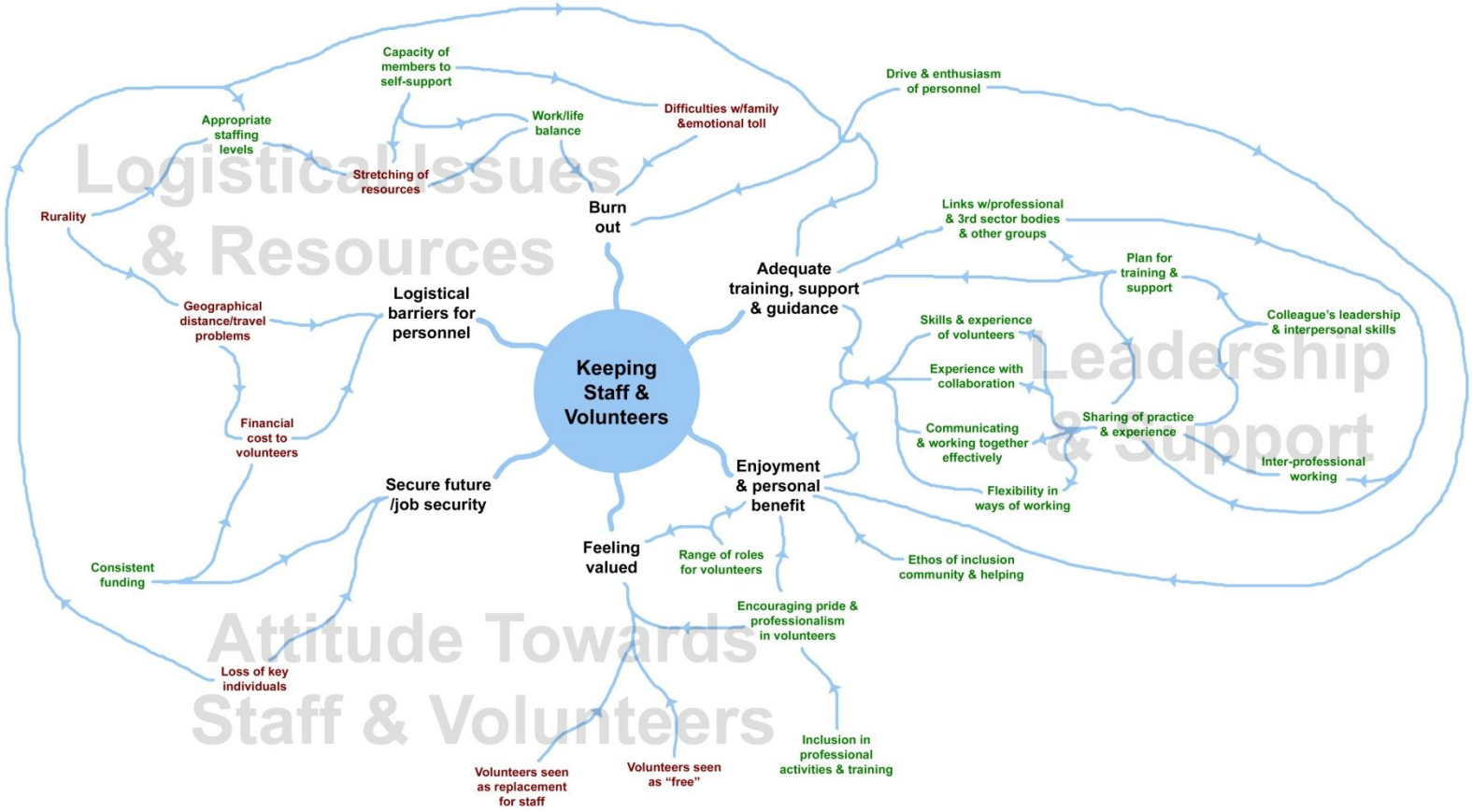
Wimo, Wallin, Lundgren, Ronnback, Asplund, Mattsson & Krakau (see also Clarkson et al 2017)	1990	Impact of Day Care on Dementia Patients—Costs, Well-being and Relatives' Views	**Specialist day care**	Sweden	Journal paper - cost analysis	Family Practice	**96**

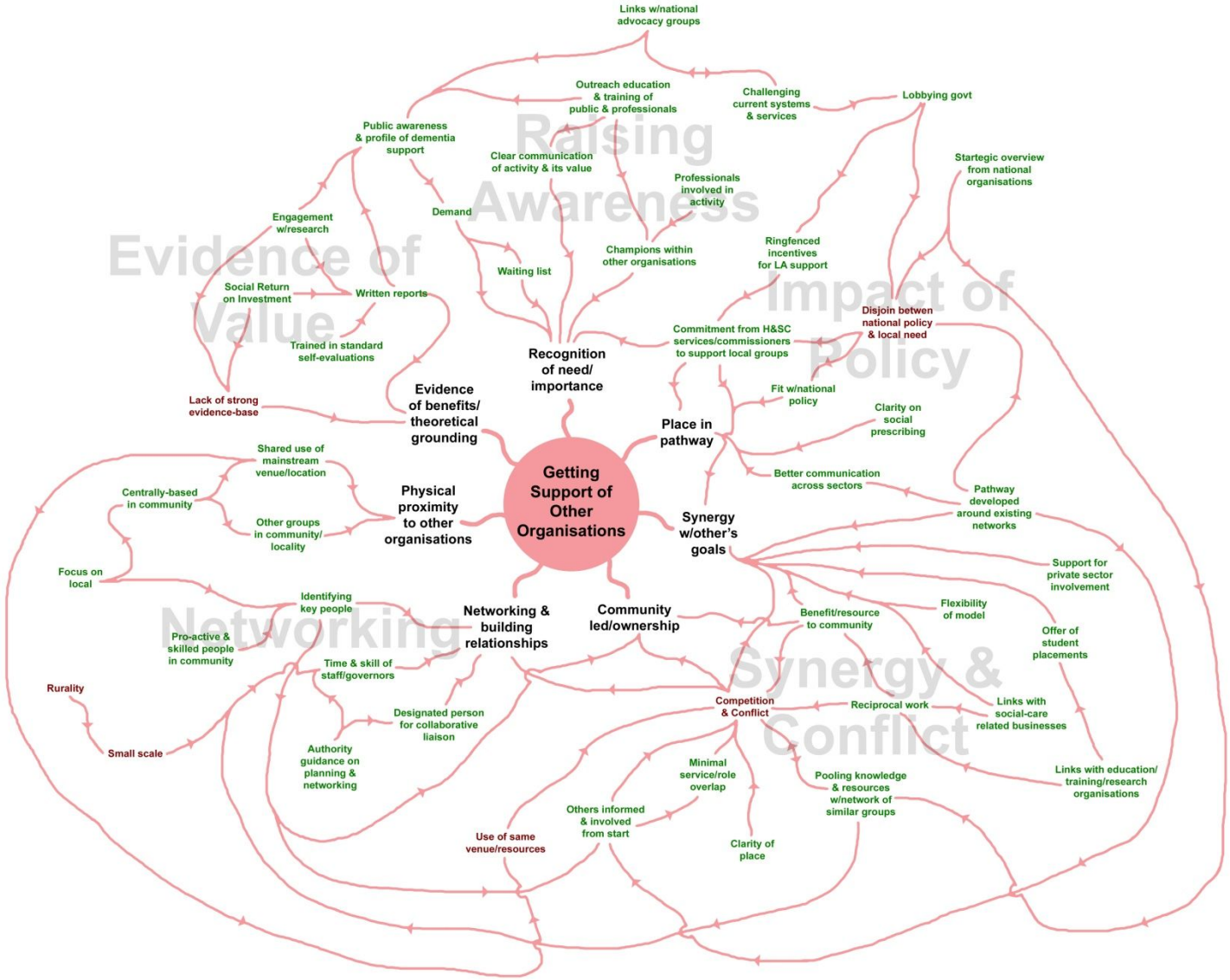
Supplementary file 4: Diagrams of factors involved in each critical sub-outcome area

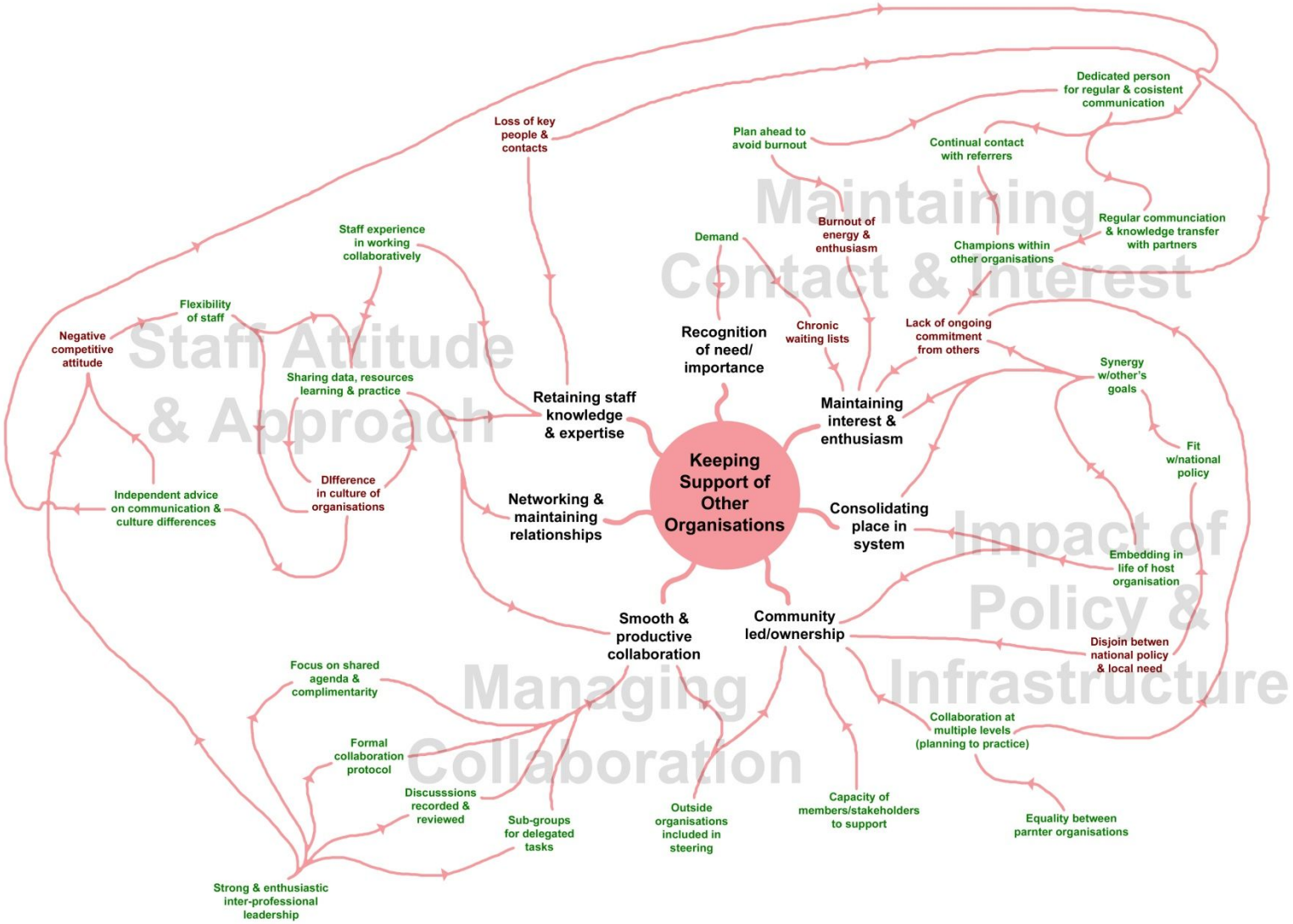



Keeping Members
Appropriate/ "For me"
Comfortable/ Relaxing
Interesting/ Enjoyable
Group cohesion
Providing emotional support
Empowering
Safe, reliable & trusted
Convenient & reliable transport
Fits needs of family/ carer
Physical support
Meeting Individual Needs
Comfort & Enjoyment
Social Opportunities
Group Cohesion & Support
Transport & Logistical Issues
Regular input from members
Ownership
Member-led
Regular input from family
Flexibile & evolving
Plan & review for needs & goals
Tailored programme
Pre-assess members
Attentive to individual needs
Waiting lists for linked servcies
Exit strategy
Small group size
Members not moving on when appropriate
Multiple & adequate spaces at venue
Balance of more able & more in need
Food offer/ communal eating
Freedom of movement
Choice of activities or to sit out
Exclusive focus on activity/agendas
Cosy environment
Not rushed
Unwanted Expectations & Restrictions
Planning to keep activities fresh
Mainstream activities
Conflict between members
Integrated w/ other venue users
Links to public amenities
Opportunities for social integration outside of group
Friendships supported
Opportunities for social interaction
Downtime/Informal time at start & end
Balanced needs of old & new members
Knowledge, empathy respect & interpersonal skills of staff
Feeling valued
Normalcy
Open to guests & family
"Dementia-free zone"
Sense of achievement
Projects for community
Degree of challenge/learning
Input into decisions & tasks
Percieved threat to independence
Perception of commercial motives
Working to tried & tested model
Predictable routine
Stable & reliable provision
Enough facilitators to cover absences
Continuity of staff
Dedicated staff to communicate w/families
Regular communication /reminders
Enough opening hours
Skill of staff to mitigate venue limitations
Less healthy lifestyle
Ability-focus w/tailored support
Adequate & well designed facilities
Not matched w/needs & ability

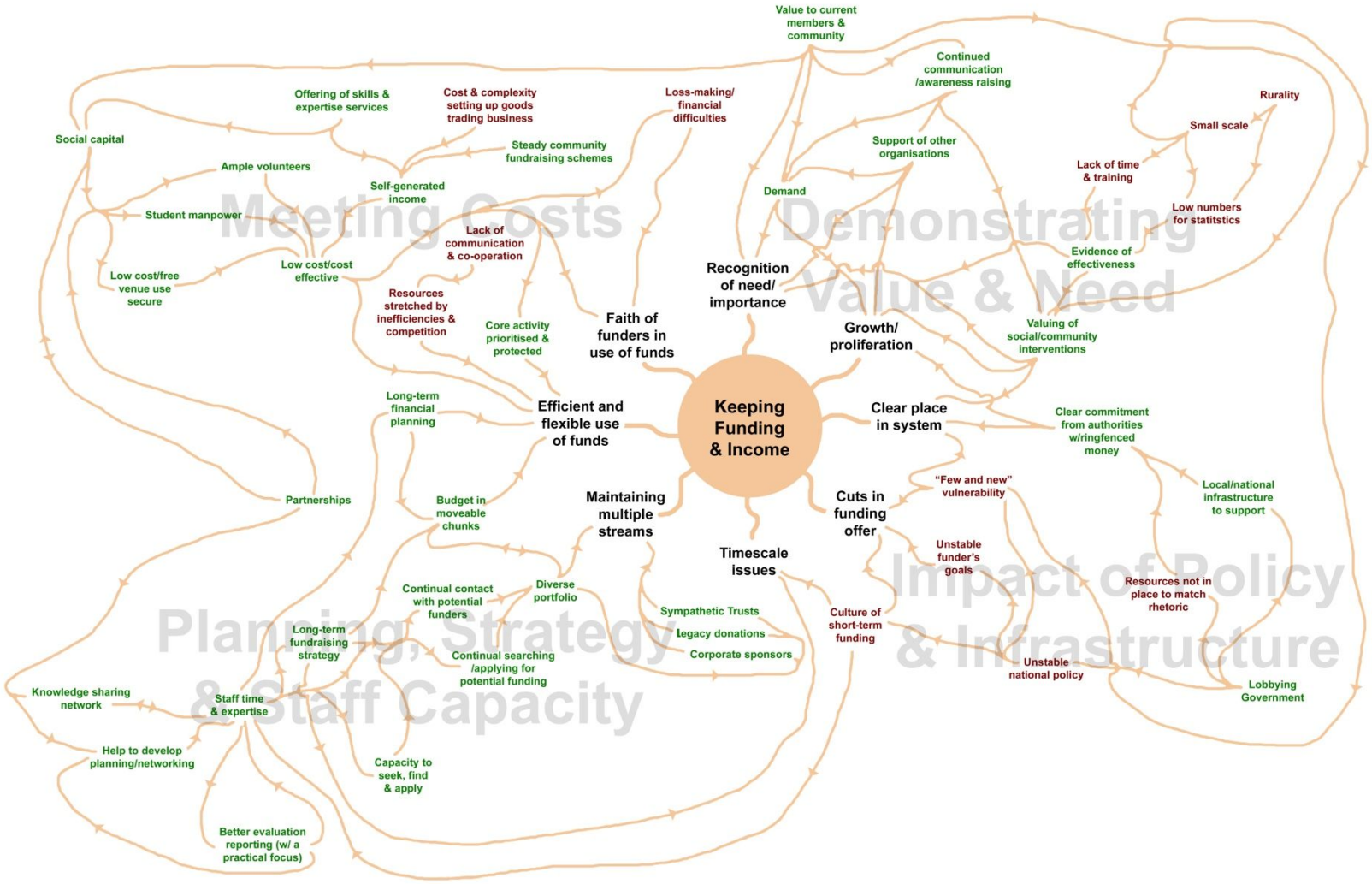

Communication & Outreach
Stakeholder Population
Support of Other Organisations
Getting Staff & Volunteers
Clarity of purpose
Staff dedicated to recruiting volunteers
Paid roles for staff
Supported private sector involvement
Student/ trainee volunteers
Support of other community organisations
Community awareness & trust
Stakeholder population pool
Communication of what group/activity is and does
Communication of value & importance
Welcoming stigma-free ethos
Wide community outreach (talks & training)
Time & personal connections
Rurality
Small, scattered population
Retiree volunteers
Choice & flexibility of roles & responibilities
Roles not requiring specialist skills & experise
Friends & family of members /former members
Funded support worker roles
Local authority support
Existing staff at venue/host organisation
Third sector support
National authority initiatives
Formalised placement schemes
Links w/organisations running H&SC courses
Sharing ideas practice & connections
Links w/existing community groups
No local student body or institution


Keeping Staff & Volunteers
Logistical barriers for personnel
Geographical distance/travel problems
Financial cost to volunteers
Rurality
Appropriate staffing levels
Capacity of members to self-support
Stretching of resources
Work/life balance
Difficulties w/family &emotional toll
Burn out
Secure future /job security
Consistent funding
Loss of key individuals
Feeling valued
Volunteers seen as replacement for staff
Volunteers seen as "free"
Encouraging pride & professionalism in volunteers
Inclusion in professional activities & training
Range of roles for volunteers
Adequate training, support & guidance
Drive & enthusiasm of personnel
Links w/professional & 3rd sector bodies & other groups
Plan for training & support
Skills & experience of volunteers
Experience with collaboration
Communicating & working together effectively
Sharing of practice & experience
Colleague's leadership & interpersonal skills
Inter-professional working
Flexibility in ways of working
Enjoyment & personal benefit
Ethos of inclusion community & helping
Logistical Issues & Resources
Leadership & Support
Attitude Towards Staff & Volunteers


Getting Support of Other Organisations
Recognition of need/ importance
Evidence of benefits/ theoretical grounding
Place in pathway
Physical proximity to other organisations
Synergy w/other's goals
Networking & building relationships
Community led/ownership
Raising Awareness
Evidence of Value
Impact of Policy
Networking
Synergy & Conflict
Links w/national advocacy groups
Outreach education & training of public & professionals
Challenging current systems & services
Lobbying govt
Public awareness & profile of dementia support
Clear communication of activity & its value
Professionals involved in activity
Startegic overview from national organisations
Engagement w/research
Demand
Champions within other organisations
Ringfenced incentives for LA support
Social Return on Investment
Written reports
Waiting list
Disjoin betwen national policy & local need
Trained in standard self-evaluations
Commitment from H&SC services/commissioners to support local groups
Lack of strong evidence-base
Fit w/national policy
Clarity on social prescribing
Shared use of mainstream venue/location
Better communication across sectors
Pathway developed around existing networks
Centrally-based in community
Other groups in community/ locality
Support for private sector involvement
Focus on local
Identifying key people
Flexibility of model
Benefit/resource to community
Offer of student placements
Pro-active & skilled people in community
Time & skill of staff/governors
Rurality
Competition & Conflict
Reciprocal work
Links with social-care related businesses
Designated person for collaborative liaison
Small scale
Authority guidance on planning & networking
Minimal service/role overlap
Pooling knowledge & resources w/network of similar groups
Links with education/ training/research organisations
Others informed & involved from start
Use of same venue/resources
Clarity of place


Keeping Support of Other Organisations
Retaining staff knowledge & expertise
Maintaining interest & enthusiasm
Networking & maintaining relationships
Consolidating place in system
Smooth & productive collaboration
Community led/ownership
Recognition of need/ importance
Loss of key people & contacts
Staff experience in working collaboratively
Flexibility of staff
Negative competitive attitude
Sharing data, resources learning & practice
Dlfference in culture of organisations
Independent advice on communication & culture differences
Staff Attitude & Approach
Demand
Burnout of energy & enthusiasm
Chronic waiting lists
Plan ahead to avoid burnout
Dedicated person for regular & cosistent communication
Continual contact with referrers
Champions within other organisations
Regular communciation & knowledge transfer with partners
Lack of ongoing commitment from others
Maintaining Contact & Interest
Synergy w/other's goals
Fit w/national policy
Embedding in life of host organisation
Disjoin betwen national policy & local need
Impact of Policy & Infrastructure
Focus on shared agenda & complimentarity
Formal collaboration protocol
Discusssions recorded & reviewed
Sub-groups for delegated tasks
Strong & enthusiastic inter-professional leadership
Outside organisations included in steering
Capacity of members/stakeholders to support
Collaboration at multiple levels (planning to practice)
Equality between parnter organisations
Managing Collaboration


Getting Funding
Recognition of need/ importance
Perception of viability
Perception of legitimacy
Value for money
Clear place in system
Capacity to seek, find & apply
Timescale issues
Fit with funder's goals
Clarity of communication /awareness of intervention
Ringfenced money for dementia
Funds must be diverted from other services
Acting as link/ gateway for others
Theoretical grounding
Trust of potential members
Demand
"Crowded market"/ Competition
Support of other organisations
Income from producing goods or services
Loss-making/ financial difficulties
Social capital
Ample volunteers
Student manpower
Low cost/free venue use secured
Low cost/cost effective
Partnerships
Rurality
Small scale
Lack of time & training
Low numbers for statitstics
Valuing of social/community interventions
Evidence of effectiveness
Financial incentives for referrers
Clear commitment from local/national authorities
Local/national infrastructure to support
"Falling between stools"
Misalign with local need
Fit with national agenda
Resources not in place to match rhetoric
Lobbying Government
Aims align with corporate sponsor
"Grey pound"
Sympathetic Trusts
Legacy donations
Formal plans & strategy ready
Knowledge sharing network
Help to develop planning/networking
Better evaluation reporting (w/practical focus)
Staff time
Staff expertise
Meeting Costs
Demonstrating Value & Need
Impact of Policy & Infrastructure
Planning, Strategy & Staff Capacity


Keeping Funding & Income
Efficient and flexible use of funds
Faith of funders in use of funds
Recognition of need/ importance
Growth/ proliferation
Clear place in system
Cuts in funding offer
Timescale issues
Maintaining multiple streams
Social capital
Offering of skills & expertise services
Cost & complexity setting up goods trading business
Loss-making/ financial difficulties
Steady community fundraising schemes
Ample volunteers
Self-generated income
Student manpower
Low cost/cost effective
Low cost/free venue use secure
Lack of communication & co-operation
Resources stretched by inefficiencies & competition
Core activity prioritised & protected
Long-term financial planning
Partnerships
Budget in moveable chunks
Value to current members & community
Continued communication /awareness raising
Support of other organisations
Demand
Rurality
Small scale
Lack of time & training
Low numbers for statitstics
Evidence of effectiveness
Valuing of social/community interventions
Clear commitment from authorities w/ringfenced money
Local/national infrastructure to support
"Few and new" vulnerability
Unstable funder's goals
Resources not in place to match rhetoric
Unstable national policy
Lobbying Government
Culture of short-term funding
Sympathetic Trusts
Legacy donations
Corporate sponsors
Diverse portfolio
Continual contact with potential funders
Continual searching /applying for potential funding
Long-term fundraising strategy
Capacity to seek, find & apply
Staff time & expertise
Knowledge sharing network
Help to develop planning/networking
Better evaluation reporting (w/ a practical focus)
Meeting Costs
Demonstrating Value & Need
Impact of Policy & Infrastructure
Planning, Strategy & Staff Capacity

Supplementary file 5: Full list of CMOCs

Getting Members

CMOC 1: If the social aspect of an intervention is emphasised (C), then a wider range of people are likely to be interested (O), as a desire for social connection and activity is more universal than interest in a niche and potentially intimidating activity (M). [40,43,44,69,70,86,89,92]

CMOC 2: If food is offered (C), then people are more likely to attend (O), because the enjoyment of good food is universal and communal eating is associated with comfort, relaxation and social connection (M). [50,89]

CMOC 3: If facilitators are knowledgeable and empathetic, with good interpersonal skills (C), an initiative will be perceived as more welcoming and inclusive (O), as they will be better at understanding needs, engaging and building trust with potential members and their families (M). [36,47,61,73,89,94]

CMOC 4: If an initiative has an informal, unrushed and warm welcome on first visit (C), then people are more likely to want to return (O), as they are more likely to find the experience relaxing and enjoyable, not uncomfortable and intimidating (M). [42,51,84/85,89]

CMOC 5: If potential members have had poor previous experiences with groups or activities (dementia related or not) (C), they may not want to try another group or activity (O), because they think the experience will be similar and will want to avoid it (M). [47,74,82,94]

CMOC 6: If time is taken for personal contact, home visits or taster sessions with potential members (C), then people are more likely to come (O), as they will feel more familiar with the initiative and more trusting of those running it (M). [36,40,53,61,70,82]

CMOC 7: If an initiative is familiar and trusted, or local and well integrated with other organisations in the community (C), then people are more likely to come (O), as its links to familiar things that they trust will make it less intimidating (M). [40,42,46,47,57,65,71,75,88,94]

CMOC 8: If an intervention is based in familiar surroundings in, and open to, the community (C), then people are more likely to come (O), because potential members will find the normalcy, lack of stigma and chance for social integration appealing (M). [40,43,44,50,54,57,61,76,86,94]

CMOC 9: If a venue is dementia-friendly, comfortable and accessible (C), people are more likely to come (O), as they will not have concerns about comfort or access (M). [40,52,69,75]

CMOC 10: If an intervention is recommended by trusted family members and health professionals (C) people are more likely to go (O), as they will trust their judgement that it will be of benefit to them (M). [41,71]

CMOC 11: If discussion/training is held with families, carers and health professionals about their attitudes and beliefs towards dementia (C), they may be more likely to successfully encourage the person they care for to try an intervention (O), because they will understand dementia and be better able to overcome stigma and emotional barriers(M). [36,41,71,88]

CMOC 12: If evidence of an intervention's therapeutic benefits is made clear to families and care partners (C), then people are more likely to attend (O) as families and care partners will have confidence in the intervention so be more likely to encourage them to go (M). [61,80,92,94]

CMOC 13: If there is support for family/care partners alongside the intervention (C) then people are more likely to attend (O), as family and care partners will feel more able and inclined to attend themselves and encourage those they care for (M). [40,42,44,48,49,88,93]

CMOC 14: If an initiative is in a close-knit community with where there is stigma about dementia (C), then people and their families may be put off coming (O), as they may be concerned about confidentially and word of their condition (or that of their family member) getting out (M). [77,82,86,88]

CMOC 15: If an initiative provides enjoyable, meaningful activities (C), then this is likely to attract members (O), as doing them will provide a reason and motive for many to attend initially, even if they stay on for other benefits (M). [55,64,69,70,78,83,84/85,91,94]

CMOC 16: If an initiative provides normalised, mainstream activities (C), then they are likely to attract members (O), as they will have resonance with people's previous interests, experience and history that would like to continue in some form (M). [40,41,43,44,59,74,78,83]

CMOC 17: If an initiative offers a range of different activities and services (C), then people are more likely to attend (O), as the initiative will appeal to a wider range of people with a range of needs (M). [40,67,82,86]

CMOC 18: If potential members' culture, ethnicity and language are acknowledged and catered for within the initiative (C), then they are more likely to come (O), as they will feel more comfortable and valued (M). [37,52,56,82,88]

CMOC 19: If there is a lack of diversity (of members and personnel) or pandering to stereotypes (C), then people may be put off coming (O), as they may have concerns about discrimination and stigma beyond dementia (M). [49,55,65,88]

CMOC 20: If the initiative is run by a religious organisation or in religious venue (C), then people may be put off coming (O), if they are not of that religion or cultural background (M). [60,88]

CMOC 21: If a group is too inclusive when not appropriate (C), this can alienate potential target members (O), as they will feel it will not be focussed on their specific needs (M). [47,54,86]

CMOC 22: If an initiative differentiates activities and roles for members by ability (C), then this can encourage potential members to attend (O), as they will feel there is an appropriate place for them rather than everyone being lumped in together (M). [40,93]

CMOC 23: If an intervention is risk averse or underestimates members' abilities and avoids challenge (C), then potential members will be put off (O), because they will see its activities as too easy, boring or not appropriate for them (M). [37,52,69,77]

CMOC 24: If an intervention is ability-focussed with tailored support and sensitive design of facilities (C), it is more likely to persuade potential members to attend (O) as they will be encouraged and supported to overcome physical impairments and negative attitudes (M). [37,44,51,69,86]

CMOC 25: When an intervention can offer practical advice, information and links to services that can help people (C), then it is more likely to attract members/service users (O), as they will be able to see that it has something to offer them that will meet their most immediate and pressing needs (M). [42,58,71,77,84/85]

CMOC 26: If safe, supported transfer from home to venue can be guaranteed (C), then people will be more likely to come (O), because they will be more likely to overcome any concerns about going out and getting to a group or activity session (M). [36,41,54,58,61,69,77,82,84/85]

CMOC 27: If the transport available isn't appropriate, reliable and respectful of people with dementia (C), then people will not come (O), as will not want to use that transport to get there (M). [47,48,49,53,60,69,82]

CMOC 28: If transport costs are significant and there is no financial support (C), then people will not come (O), as they will not be able to afford the transport costs (M). [36,48,50,60,61,69,80,88]

CMOC 29: If the venue is not in people's own neighbourhoods, is geographically distant or hard to reach (C) then people will not come (O), as they will find it difficult or intimidating to get there (M). [53,54,68,76]

CMOC 30: If an initiative forms links with community and public transport/taxi firms (C), then this will attract members (O), as they will find it less difficult or intimidating to travel to the venue (M). [40,48,49]

CMOC 31: If referrers are not made clearly aware of the added value, target population, ethos and activities of an intervention (C), then they will be less likely to refer appropriately (O), as they will not understand the value of it to their clients (M). [46,76,92,93,94]

CMOC 32: If there is constant contact and collaboration with potential referrers (C), then they are more likely to refer members (O), as they will build a relationship with the intervention that will mean they are better able to understand and remain alert to it (M). [46,71,74,75,90,92,93]

CMOC 33: If PR materials are not available in the right places or presented to people in the right circumstances (C), then they will not try an intervention (O), because they will not access those materials to find out about an intervention's potential value to them (M). [36,60,80,82,88]

CMOC 34: If PR materials are not in an understandable and appropriate format and tone (C), then people will not try an intervention (O), as they will find the materials too off-putting to engage with (M). [53,56,61,76,77,83,88,90]

CMOC 35: If PR materials do not make clear the specifics of an intervention, what to expect and how to attend (C), then people will be less likely to come (O), as they may be anxious due to uncertainties over what they will have to do and its value to them (M). [40,46,79,88,94]

CMOC 36: If an intervention has a stigma-free name that resonates with its target population (C), then people are more likely to come (O), as they will have confidence that they will be treated with respect and not suffer stigma when they go. [45,50,61,74,88,91]

CMOC 37: If the local community is fragmented with no local welfare organisation to distribute information (C), then people will be less likely to come (O), as it will be more difficult to get the word out to the right people in the community (M). [47,76,88]

CMOC 38: If in intervention forms links with existing groups, organisations and venues serving same demographic (C), then people will be more likely to come (O), as information and marketing materials will be more likely to reach them. [40,64,71,83,86]

CMOC 39: If all those involved in a person's care work together to collate and co-ordinate information (C), then people will be more likely to come (O) as information and marketing materials will reach them more efficiently (M). [36,76]

CMOC 40: If there is a dedicated linking, contact or health care adviser service (C) then people will be more likely to come (O) as information and marketing materials will reach them more efficiently. [36,56,61,72,82,84/85,88,92]

CMOC 41: If awareness of the needs of people dementia and of how an intervention can meet them is raised in the community in general (C), then people will be more likely to come (O), as stigma will be reduced and the value of the intervention communicated through word of mouth. [36,40,46,47,50,55,61,62,64,67,71,74,82,83,88]

CMOC 42: If GPs were given more incentive and guidance for social prescribing (C), then they would refer more people (O), because they would have a vested interest and confidence in doing so (M). [37,82]

CMOC 43: If there are significant bureaucratic problems with referring (such as chronic waiting lists, area border issues or the need for signed consent) (C), then professionals will be less likely to refer (O), as they will anticipate difficulties that will thwart their attempt to refer (M). [56,72,76,82]

CMOC 44: If GPs do not diagnose dementia until people are at later stages (C), then they will not refer people to community initiatives (O), as they will not see initiatives targeted towards those at earlier stages still able to live at home as appropriate for those they are diagnosing (M). [48,93]

CMOC 45: If an intervention waives the need for a diagnosis and accepts self-diagnosis (C), more people will come (O), as this will encourage a wider range of potential members and avoid excluding people who might benefit. [43,61,64,93]

CMOC 46: If an initiative's membership application process is not simple, clear, concise and easy (C), then people will not come (O), as the difficulty in applying will put them off joining. [61,84/85,90]

Keeping Members

CMOC 47: If there is group cohesion and mutual trust between members (C), then a group is more likely to sustain (O), because members will feel more solidarity and investment in the group. [41]

CMOC 48: If friendships between members are encouraged, recognised and supported by staff and activities (C), then people are likely to keep coming (O), as they will feel more supported, comfortable and engaged, and able to support each other (M). [45,51,71,83,95]

CMOC 49: If an intervention is too focussed on agendas, rules and expectations (C), then people may stop coming (O), because they feel pressured, restricted and unable to relax and enjoy the social and emotional benefits important to them. [37,52,55,78,83,84/85]

CMOC 50: If the pace of activity through the day/session is too fast and strict (C), then people may stop coming (O), because they will struggle to stay engaged and will not enjoy themselves (M). [40,43,51,76,91]

CMOC 51: If ample informal time is made for socialising, peer support and feedback (C), then members are more likely to keep coming (O), as they will be more likely to feel comfortable and supported. [37,40,41,44,51,55,70,77,78,83,86,89,90,91,92]

CMOC 52: If there is opportunity to have communal eating and relaxing in a "cozy" environment (C), then members are more likely to keep coming (O), as this will provide comfort and foster group cohesion. [41,89]

CMOC 53: If there is regular social integration with others outside of the group (C), then members are more likely to keep coming (O), as they will feel more connected and less stigmatised (M). [40,45,50,53,57,61,71,76,82,86,94]

CMOC 54: If activities are mainstream and involve others without dementia (e.g. family/carers or locals from the community) (C), then members are more likely to keep coming (O), as they will feel activities are more normalised, reducing stigma and increasing enjoyment (M). [40,43,47,48,71,74,76,82]

CMOC 55: If an intervention is treated as a "dementia free zone" where talk is not about a person's condition or medical issues (unless they want to raise them) (C), then people are more likely to keep coming (O), as they will find the environment more normalising and less stigmatising (M). [44,78]

CMOC 56: If an initiative contains projects which enable members to contribute to helping others in the community (C), then people are more likely to keep coming (O), because they will feel valued, useful and empowered (M). [82,83]

CMOC 57: If an initiative has links to existing mainstream public amenities (C), then people are more likely to keep coming (O), as they will recognise it gives them access to wider networks of support and friendship (M). [39]

CMOC 58: If members are involved in group decision-making and setting expectations (C), then people are more likely to keep coming (O), because they will feel ownership and investment in the group and confidence that the group is tailored towards their needs (M). [41,45,51,57,67,78,90]

CMOC 59: If regular feedback meetings are held to "tune" an intervention to the wants and needs of members (C), then people are more likely to keep coming (O), as activities will be kept appropriate and evolve to suit the membership (M). [40,63,75,83,84/85,94]

CMOC 60: If individuals are allowed to make their own decisions about what they do or don't do during a session (C), then they will be more likely to keep coming (O), as they will feel their independence and freedom is respected and their voice heard (M). [36,51,52,63,89]

CMOC 61: If staff treat people respectfully as equals and relate personally (C), then people are more likely to keep coming (O), because they will feel staff and the group as a whole understands them and their needs(M). [41,42,52,74,84/85,89]

CMOC 62: If strategies are planned to review individual progress and involvement (C), then people are more likely to keep coming (O), as they are more likely to remain engaged and feel part of the group as a whole (M). [50,51,90]

CMOC 63: If personnel listen to and act upon regular input from family and caregivers (C), then people are more likely to keep coming (O), as they will appreciate the increased personalisation and sensitivity to their needs (M). [50,52,63,76,94]

CMOC 64: If an initiative does not pay attention to the needs of family and care partners (C), then people are less likely to keep coming (O), because there may be unaddressed logistical difficulties for the family or carers such as fit with work or transport issues (M). [54,61,71,76,77,80,82,84/85]

CMOC 65: If an initiative can open for more hours and help arrange transport (C), then people are more likely to come (O), as this will take the pressure off family members and carers to be flexible and arrange things, and bypass logistical difficulties (M). [40,43,53,70,80,84/85]

CMOC 66: If members who are no longer the target for the intervention stay on because there is no exit strategy or onward service capacity (C), then this can discourage target members from continuing to attend (O), as they may feel the service is too stretched to meet their needs (M). [51,76,94]

CMOC 67: If an initiative does not cater equally both for new members and older members whose condition has progressed (C), then this can discourage one group or the other from continuing to attend (O), as they will feel the initiative is more focussed upon the other group hence not appropriate for them (M). [45,78,92]

CMOC 68: If a group or activity is not matched with members' interests and ability (C), then members may stop attending (O), as they will feel it is not appropriate for them or meeting their needs (M). [40,53,74,80]

CMOC 69: If activities involve a degree of challenge or learning (C), then members may be more likely to keep coming (O), as they will feel empowered and have a sense of achievement (M). [44,47,48,78,82,83]

CMOC 70: If an intervention pre-assesses members and plans strategies to meet their individual needs (C), then members are more likely to keep coming (O), because activities and support will be more likely to be appropriate for them (M). [43,50,51,54,84/85,90]

CMOC 71: If a venue is comfortable, familiar and stable, with adequate space and facilities (C), then people are more likely to keep coming (O), as they will feel relaxed, secure and at home there (M). [40,51,52,75]

CMOC 72: If a venue has multiple spaces within it (C), then people are more likely to feel comfortable there (O), as they will be able to move around and have a choice of activities, environments, social sub-groups or levels of involvement in activity (M). [52,79]

CMOC 73: If sessions are regular, routine and structured (C), then members will be more likely to keep coming (O), as they will feel comfortable and secure in the familiarity and reliability of proceedings (M). [40,41,51,61,77,82,89,91,92]

CMOC 74: If the venue and timings remain reliably the same (C) then members are more likely to keep coming (O), as it will become part of their routine (M). [40,51]

CMOC 75: If there is no continuity of staff or not enough staff to ensure reliable provision (C), then members may be less likely to keep coming (O), as they will find it difficult to have confidence and build trust in the intervention and its staff (M). [36,45,82]

CMOC 76: If an intervention works to a tried and tested model (C), then members are more likely to feel secure (O), as that model will provide a structure that works (M). [76]

CMOC 77: If there are not new ideas and some variety planned across the calendar (C), then members may stop coming (O), because they may feel the group/activities have become stale and boring (M). [47,51,83]

Getting Staff and Volunteers

CMOC 78: If an initiative engages in community outreach such as talks and training with other groups and at events (C), then this will help attract volunteers (O), because the initiative's profile will be raised with wide range of stakeholders in the community (M). [50,64,74]

CMOC 79: If awareness is raised in the community about the activities and benefits of a what an initiative does (C), then it will be more likely to attract appropriate personnel (O), as potential staff and volunteers will understand its value to service users and what they can do to help (M). [63,76,79,88]

CMOC 80: If an initiative has links with like-minded groups (C), then they may get help finding and training staff volunteers (O), as they will be able to share ideas and practice on what is successful (M). [63,70]

CMOC 81: If an initiative approaches established community organisations and authorities (third sector, faith or local authority) (C), they are more likely to get help with finding volunteers (O), as these organisations are likely to have access to an existing volunteer workforce or contacts that could help (M). [37,49]

CMOC 82: If an initiative has links with professional, third sector or educational bodies (C), they may help with creating a more skilled workforce (O), because they may have the remit provide training for staff and volunteers (M). [56,67]

CMOC 83: If an initiative is hosted by a public venue or local club (C), this may help with staffing (O), as the venue or club may have existing staff who can help with running things (M). [37,40,44,83]

CMOC 84: If a community has an educational establishment running a health and social-care course (C), this could be a source of volunteers (O), as students/trainees will have the drive and interest to work with social-care-related activities to gain experience (M). [38,41,63,66,86]

CMOC 85: If a formal partnership is agreed with an educational establishment (C), this will guarantee regular volunteers during term time (O), as work placements can be formalised as part of students' courses (M). [38,41,66]

CMOC 86: If the initiative is in a rural area (C), then it can be more difficult to recruit volunteers (O), as there may be no educational establishment or body of students/trainees to recruit from (M). [64,65]

CMOC 87: If the initiative is in a rural area (C), then it may take more time to recruit volunteers (O), as familiarity and personal contacts tend to be more important in small, close-knit communities (M). [64]

CMOC 88: If the initiative is in a rural area (C), then it may be more difficult to recruit staff and volunteers (O), as they may not live geographically near members or the venue, presenting extra logistical challenges (M). [64,65]

CMOC 89: If a community has a population of active retirees (C), this could be a source of volunteers (O), as they are likely to have time and experience conducive to volunteer work with older people (M). [88]

CMOC 90: If there are friends and family of current or previous members/service users that are available (C), this could be a source of volunteers (O), as they will understand the value of the intervention and already be invested in it (M). [59,88]

CMOC 91: If there are no specialist elements to the intervention or members with high care needs (C), then personnel do not need to have professional training or expertise (O), as they will still be able to understand and deliver the intervention for the benefit for service users (M). [44,91]

CMOC 92: If in intervention has more than one skilled facilitator (C), then it can benefit more members (O), as the workload can be split and more one-on-one support for members offered (M). [77,78,92]

CMOC 93: If an initiative's leaders/co-ordinators have good communication and interpersonal skills (C), then it is more likely to be successful (O), as they will engage and inspire other staff and volunteers (M). [46,61,76,93]

CMOC 94: If volunteers' availability and interpersonal skills are inconsistent (C), an initiative is less likely to be successful (O), as it will not have a reliable workforce to run it (M). [77]

CMOC 95: If funded support worker roles exist (C), then a reliable volunteer workforce is more likely (O), because they can help build a volunteer base (M). [70]

Keeping Staff and Volunteers

CMOC 96: If personnel are flexible and open to new ways of working (C), then they are more likely to work effectively (O), as they will be more likely to collaborate with others, sharing knowledge, experience, innovation, resources and effective working practices (M). [50,54,66,93]

CMOC 97: If personnel have advice or training to boost communication and collaboration skills (C), then they are more likely to work effectively (O), as they will be more able to share knowledge, experience, innovation, resources and effective working practices (both internally and externally) (M). [48,54]

CMOC 98: If personnel are driven and able to deal with stress (C), then they are more likely to continue (O), as they will be able to overcome the challenges and demands of running an intervention (M). [76]

CMOC 99: If facilitators are not able to take time for self-care (C), then they will burn out (O), as running an intervention can be challenging and emotionally demanding (M). [51,92]

CMOC 100: If time is taken to plan strategies for recruitment, training, support, retention and balance of personnel at the start (C), then personnel problems and burn out can be avoided (O), as planners will have thought through the challenges involved and put in place actions to tackle them (M). [55,90]

CMOC 101: If personnel have access to experienced tips and guidance (from materials or individuals) throughout an intervention's start-up period (C), they are more likely to continue (O), as they will be better informed to resolve problems and avoid common pitfalls (M). [47,88]

CMOC 102: If there is an ethos of inclusion, community, camaraderie and helping people (C), then personnel will be more likely to continue (O), as they will feel enjoyment and benefit from this ethos along with members/service users (M). [44,57,92]

CMOC 103: If there are a range of roles and levels of involvement for volunteers (C), they are more likely to be satisfied with volunteering (O), as they can do something that suits them and their abilities that they are comfortable with and interested in (M). [67]

CMOC 104: If volunteers are included in professional activities and training (C), they are more likely to be satisfied with volunteering (O), as they will feel their skills and development are valued by the initiative (M). [61]

CMOC 105: If there is limited and inconsistent funding (C), then an intervention is less likely to be able to retain paid staff (O), because their jobs and the long-term future of the intervention will not be secure (M). [67,77,93]

CMOC 106: If personnel roles are not secure (C), then an initiative is less likely to sustain (O), because turnover will be high and key individuals with key experience and contacts will be lost (M). [67,83,93]

CMOC 107: If volunteers are seen by authorities and commissioners as "coming for free" (C), then they are less likely to continue (O), as they will feel un-valued with their time and expertise taken for granted (M). [62]

CMOC 108: If unpaid volunteers are treated as a replacement for professional staff (C), then staff are less likely to continue (O), as they will feel their roles are undermined and un-valued (M). [46]

CMOC 109: If financial assistance is made available for volunteer groups (C), then they are more likely to continue (O), as they will have the resources and support to run more activities (M). [70]

Getting Support of Other Organisations

CMOC 110: If there is a higher public awareness and profile for people living with dementia (C), then dementia-targeted interventions are more likely to get support from other organisations, services and amenities (O), because there will be more recognition of their importance for society in general (M). [39,67,73]

CMOC 111: If the added value of an intervention is made clear to other organisations (C), then it is more likely to get support and find a place in the local care offer (O), because other organisations will understand it's value to their members/service users (M). [42,68,70,71,75,76,92,93,94]

CMOC 112: If an intervention engages with research and evaluation to gather evidence of benefits (C), then it is more likely to get support (O), because the resulting reports will lend it legitimacy in the eyes of other organisations (M). [47,55,56]

CMOC 113: If it is made clear that an intervention is based upon a strong evidence-based model (C), then it is more likely to get support (O), because that model will lend it legitimacy in the eyes of other organisations (M). [68,93,94]

CMOC 114: If an intervention involves the local community in its steering (C), then it likely to attract further community support (O), as key people and organisations in the community with wider links will feel a sense of ownership and investment (M). [67]

CMOC 115: When there are a range of organisations (e.g. local authority, third sector, faith, business and education) active in the community (C), they may be willing to offer support if asked (O), as they may have a remit to share resources such as venue space and facilities, equipment, training, staff, volunteers or contacts (M). [37,38,40,41,44,49,56,57,66,83,86]

CMOC 116: If an intervention model is flexible (C), then it has a better chance of finding support (O), as it can accommodate being run at a range of venue types in, a range of ways, by a range of host organisations (M). [37,78,91,92]

CMOC 117: If an existing social care business is approached (C), they may support, host or partner an intervention (O), as it may help them attract clients/customers (M). [92]

CMOC 118: If training and guidance is available from a public or third sector authority (C), this may help gain further support (O), as it will help an intervention develop its skills and expertise in marketing, networking and outreach (M). [74]

CMOC 119: If an intervention is based in a civic centre or public venue (C), then it is more likely to get support from other local organisations (O), because it will be visible to others sharing that space (M). [50,93]

CMOC 120: If an intervention focuses on building links with local organisations and services (C), it is more likely to get support (O), as it is easier to bring together a network of those who are already invested in the same community and some links will already exist (M). [42,86,94]

CMOC 121: If an intervention is run at a public venue or local club (C), then links with others in the community are easier to forge (O), as there will be an existing network of venue/club users and contacts that the intervention can access (M). [40,44,86,94]

CMOC 122: If a group or activity is small scale (C), then it can hard to get support (O), as it is more difficult for them to network with larger organisations, authorities, movers and shakers (M). [49]

CMOC 123: If struggling groups in the same area merge (C), they can support each other (O), because they can pool resources, personnel, knowledge and ideas (M). [83]

CMOC 124: If links are forged with a national network of similar interventions (C) then they can support each other (O), because they can pool resources, knowledge, contacts and strategy (M). [42]

CMOC 125: If a locality has other organisations working with the same target population (C), then in intervention may struggle to get support (O), as those other organisations and their supporters may perceive the intervention as competition (M). [93,94]

CMOC 126: If an intervention has a clear place in the local offer without service/role overlap (C), then it is more likely to get the support of others (O), because they will see it as complimenting their service not competing with it (M). [42,46]

CMOC 127: If other organisations are informed, invited to meetings and asked for help and advice early on (C), then an intervention is more likely to get the support (O), because they will feel respected and invested in the success of the new intervention (M). [46,67,76,93]

CMOC 128: If groups involve professionals already working with individual members (e.g. case workers, carers) in activities (C) then they are more likely to increase support from professional services (O), because professionals will understand the value of the intervention to their service-users and feel invested in its success (M). [93]

CMOC 129: If an intervention acts as a hub for/gate/link to other services and is tuned to dovetail with them (C), then it is more likely to get the support of those services (O), because they will see the intervention as being of help to them (M). [42,54,68,72,76,91]

CMOC 130: If an intervention offers a benefit or resource to the wider community (C), then it is more likely to get the support of other community organisations (O), as they will see it as benefiting their members/service users (M). [55,74,83,94]

CMOC 131: If an intervention offers to do reciprocal work, sharing knowledge and resources with other organisations (C), then it is more likely to get their support (O), as they will see the benefit to working together (M). [55,74,83,94]

CMOC 132: If there is a disjoin between national policy and local need (C), then initiatives can struggle to get and keep support (O), because by adhering to one they will neglect the other, alienating would-be supporters (M). [46]

CMOC 133: If there were ring-fenced funding to support dementia-targeted community initiatives as part of national policy (C), then small, local initiatives would get support (O), as there would be incentives for health services and LAs to help them (M). [37,50,73]

CMOC 134: If health and social care authorities commissioned services to work with community initiatives (C), then small, local initiatives would get support (O), because it would ensure the collaboration of services and organisations at different levels (M). [49,70,82]

CMOC 135: If health pathways were developed around existing social networks (C), then small, local initiatives would get support (O), as it would encourage more community collaboration and co-production with health services (M). [82]

CMOC 136: When national and official organisations take the lead in working with small, local initiatives (C), this helps more consistent provision of local services across regions (O), because there is more joined-up strategic direction of what is on offer and available (M). [70,73]

CMOC 137: When national and official organisations show support for the involvement of private sector partners (C), then small, local initiatives are more likely to get support (O), as it provides private sector organisations with the incentive, tools and guidance to work in partnership (M). [73]

Keeping Support of Other Organisations

CMOC 138: If communication is not maintained (C), then support of others can drop away (O), as interest and enthusiasm may dwindle in tandem with an intervention's contact and visibility to its collaborators (M). [75,94]

CMOC 139: If information sharing and knowledge transfer is not maintained (C), then support of others can drop away (O), as communication and administration problems may arise between collaborating parties (M). [49,84/85]

CMOC 140: If there is a designated person with responsibility for regular and consistent communication with other organisations (C), then continued support is more likely (O), as they will have the time to pay attention to maintaining collaborative working, and build experience and relationships with key people in doing so (M). [70,94]

CMOC 141: If relationships with key people in other organisations are maintained (C), then support of those organisations is more likely to continue (O), as an intervention will create "champions" within those organisations (M). [46,73]

CMOC 142: If staff turnover (internal and external) is high (C), then support can be lost (O), because communication and relationships with contacts and "champions" can suffer due to the loss of key personnel (M). [67,83,93]

CMOC 143: If there is a difference in culture between collaborating organisations (C), then effective support can be hindered (O), as personnel from each organisation will not be working with the same focus and goals (M). [46,93,94]

CMOC 144: If groups or sectors have a negative or competitive attitude towards each other (C), then effective support can be hindered (O), as it creates problems sharing data, learning and resources (M). [48,49,94]

CMOC 145: If an intervention makes effort to learn about and embed in the life of a supporting organisations (C), then it is more likely to maintain support (O), as it will understand that host organisation better and share the same goals (M). [55]

CMOC 146: If staff (internal and external) are experienced in working collaboratively (C), then an intervention is more likely to maintain support (O), as staff will be more skilled, flexible and understanding when working with those from another organisation (M). [93]

CMOC 147: If independent advice on communication (internal and external) and collaboration is available (C), then an intervention is more likely to maintain support (O), as leaders, staff and volunteers will become more skilled at networking and working together while overcoming differences in culture (M). [54,93]

CMOC 148: If there are multiple forms of strong inter-professional leadership (C), then collaboration is likely to be more successful (O), because there will be mutual learning with leaders setting an example for others to follow (M). [46,50,68,93]

CMOC 149: If time is taken to plan well early on (C), then support from others is more likely to be maintained (O), as personnel will have thought through the challenges involved in maintaining energy and enthusiasm and put in place actions to tackle them (M). [55]

CMOC 150: If there is a steering group including outside organisations (C), then support is more likely to be maintained (O), as steering will include a focus on shared agenda and complementarity with outside organisations (M). [46]

CMOC 151: If a partnership is not equal and collaborating at all stages, from planning to practice (C), then this could hinder support (O), as one party may feel the other is not contributing what it should while the other feels dictated to, creating friction (M). [84/85]

CMOC 152: If a collaboration protocol with supporting organisations is drafted and discussions logged and reviewed (C), then support is more likely to be maintained (O), because all parties will have the chance air and resolve issues and have clarity over expectations and mutual goals (M). [55,76,84/85,94]

Getting Funding and Income

CMOC 153: If potential funders are not clear on what a service/intervention is and does (C), then they will be less likely to fund it (O), because they do not understand its purpose or value (M). [79]

CMOC 154: If potential funders are made aware of the added value and benefit of an intervention (C), then they will be more likely to fund it (O), because they will recognise it has something uniquely valuable to offer service users (M). [55,76]

CMOC 155: If communication and publicity is regularly disseminated to potential funders (C), then they are more likely to fund in the future (O), as they will be familiar with and alert to the work of an intervention (M). [81]

CMOC 156: If recognised and standardised materials (e.g. Alzheimer's Society materials, PQASSO or Social Return on Investment evaluation) are used to gather and communicate evidence of worth (C) then funders are more likely to fund (O) as they will see that evidence as more legitimate than anecdotal accounts (M). [56]

CMOC 157: If potential funders are made aware of links with and support from other organisations (C), then they're more likely to fund (O) because they are likely to view the support of others as adding legitimacy to a community initiative (M). [55]

CMOC 158: If corporate organisations are made aware of how an intervention aligns with its aims (C), then they will be more likely to sponsor or donate (O), as they will feel supporting that intervention helps progress their goals (M). [81]

CMOC 159: If an intervention develops its skill in networking and communicating with other organisations (C), then it is more likely to find funding (O), as it will learn of funding opportunities through a wider network of support and contacts (M). [74]

CMOC 160: If awareness of the wants and needs of people with dementia is raised in society in general (C), then funders are more likely to support a dementia-targeted initiative (O), as they are more likely to recognise that it meets the needs of service-users (M). [73,74]

CMOC 161: If there is demand for an intervention from service users and referrers (C), then funders are more likely to fund (O), as they will recognise that it is meeting people's needs (M). [74]

CMOC 162: If potential members/service users are not clear on what a service/intervention is and does (C), then they will be less likely to try it (O), because they do not understand it's purpose or value to them (M). [46,79,88,94]

CMOC 163: If potential referrers are not clear on what a service/intervention is and does (C), then they will not refer people to it (O), because they do not understand it's purpose or value to their service users (M). [46,76,92,93,94]

CMOC 164: If an intervention is perceived as more expensive than alternatives on offer without offering significant added value (C), funders will be less likely to fund (O), as they will not see it as value for money (M). [56,62,93,96]

CMOC 165: If an initiative is perceived as having financial difficulties (C), potential funders are less likely to fund (O), as they will see it as a high risk funding decision (M). [76,88]

CMOC 166: If an initiative has co-operative working arrangements with other community organisations (C), then this can help keep costs low (O), as they can agree to share resources (venue, personnel, equipment, training etc.) (M). [48,55,56,66,80,92]

CMOC 167: If an initiative can generate some income through offeringservices to others(C), then funders are more likely to have confidence in it (O), as they will perceive it be to more viable (M). [81]

CMOC 168: If funders are made aware of the support from other organisations for a new initiative (C), they are more likely to fund (O), as they will perceive the initiative as being more viable due to that support (M). [55]

CMOC 169: If initiative can act as a gate/link for other services and community organisations (C), then it is more likely to get funding (O), as it will be seen as of value to enhancing existing services and organisations (M). [54,76]

CMOC 170: If intervention personnel have good, up-to-date knowledge of funding processes and policy (C), they are more likely to get funding (O), because they will understand how to plan and implement an effective strategy to seek and find it (M). [68,75,76]

CMOC 171: If like-minded groups share successful ideas (C), they are more likely to find funding solutions (O), because they will be able to learn from each other about what works or doesn't work (M). [56,63]

CMOC 172: If interventions include more practical detail on resources, costs and funding as part of standard reporting/evaluation (C), then others in the future will be more likely to find funding solutions (O), as they can learn from the experience of others about what works or doesn't work (M). [47]

CMOC 173: If authoritative help is available to develop personnel's expertise regarding business planning and networking (C), then an intervention is more likely to find funding solutions (O), because personnel will be better at developing and implementing a strategy to do so (M). [74]

CMOC 174: If an intervention has a realistic strategy to attract donations and grants (C), then it is more likely to find funding solutions (O), as personnel will have thought through the challenges involved and put in place actions to tackle them(M). [81]

CMOC 175: If an intervention has a business case ready (C), then it is more likely to secure funding (O), as it will be able to respond quickly when a window of opportunity opens with a potential funder (M). [54]

CMOC 176: When an initiative is in a more rural area (C), it is likely to be small scale with fewer members/service users (O), because the population is geographically diffuse without the infrastructure to gather together easily (M). [67]

CMOC 177: If an initiative is small-scale (C), it will not be able to robustly demonstrate demand, effectiveness and H&SC savings (O), because it's number or members/service users will not be enough to capture robust evidential statistics (M). [67]

CMOC 178: If funders demand robust statistical evidence before funding (C), then small and rural groups and activities will be disadvantaged (O), because they will not have the numbers and resources to produce this (M). [63,67,70]

CMOC 179: If an initiative is small-scale (C), it will be disadvantaged in securing funding (O), as it will have fewer personnel with more limited time and resources to continually apply (M). [67]

CMOC 180: If an intervention is aligned with national agenda (C), then it is more likely to get funding (O), because the policy and infrastructure will be in place to support it (M). [42,50,67,75]

CMOC 181: If national policy is not consistent with local need (C), then local groups serving those needs will struggle to attract funding (O), as funders will not see their cause as a priority (M). [46,67,94]

CMOC 182: If the national (and by extension funders') agenda focuses on medical needs and costs over social and emotional needs (C), then community-focussed groups and activities will struggle to get funding (O), as funders will not understand their benefits or see their cause as a priority (M). [49,56,63,68,96]

CMOC 183: If intervention providers, service users and families speak out about their needs (C), providers may be more likely to get funding for local community-focussed services (O), as authorities will feel pressure to change the national agenda to meet people's needs (M). [87]

CMOC 184: If resources are not allotted and ring-fenced to match changes in national or local policy (C), there will be no benefit to community interventions (O), as funders will not have the resources to invest in making a difference in practice (M). [48,62,70,73]

Keeping Funding and Income

CMOC 185: If communication and publicity is regularly disseminated to funders (C), then they are more likely to fund again in the future (O), as they will be kept informed and alert to the continuing work and benefits of an intervention (M). [81]

CMOC 186: If publicity and networking is pared back to cut costs (C), this could negatively impact changes of finding continued funding (O), as an intervention will drop off funders' "radar" and risk being forgotten or overlooked (M). [81]

CMOC 187: If funders are made aware of a growth in demand for an intervention from service users and referrers (C), then they are more likely to continue to fund (O), as they will recognise that it is meeting people's needs (M). [74,75]

CMOC 188: If funders are made aware of accruing evidence of the added value and benefit of an intervention (C), then they will be more likely to fund it (O), because they will recognise it has something uniquely valuable to offer service users (M). [55,76]

CMOC 189: If groups and organisations do not communicate and work together (C), then existing funds will not go as far (O), as available financial resources will be split and lost on inefficiencies and duplication of services (M). [48]

CMOC 190: If an initiative has co-operative working arrangements with other community organisations (C), then this can help keep costs low (O), as they can agree to share resources (venue, personnel, equipment, training etc.) (M). [48,55,56,66,80,92]

CMOC 191: If an initiative has multiple and diverse income streams (C), then it is more likely to maintain a proportion funding (O), because if one stream stops, others will still be available. [55,56,67]

CMOC 192: If an initiative's budget is broken down into identified parts (C), then it is more likely to be able to weather changes in funding (O), as what can be used to pay for what is more flexible, and core activity can be prioritised (M). [55,67,81]

CMOC 193: If financial planning is done with a focus on the long-term (C), then an initiative is more likely to weather changes in funding (O), as it will be able to spread existing funds more effectively by allotting spending carefully (M). [55,84/85]

CMOC 194: If an intervention has a realistic strategy to continually attract donations and grants (C), then it is more likely to find funding solutions (O), as personnel will have thought through the challenges involved and put in place actions to tackle them (M). [81]

CMOC 195: If there is no long-term funding available (C), this will place significant demands on the time and resources of personnel (O), because they will need to continually seek and apply for fresh funding (M). [67]

CMOC 196: If an initiative is small-scale (C), it will be disadvantaged in continuing to secure funding (O), as it will have fewer personnel with more limited time and resources to continually seek and apply (M). [67]

CMOC 197: If an initiative continually and systematically seeks new income streams (C), then it is more likely to maintain a proportion funding (O), because if one stream stops, it will be more likely to have multiple other streams available (M). [55,67,56]

CMOC 198: If funders objectives are always short-term and keep changing (C), then deep learning on what works for services users and communities will be lost (O), as "quick win" projects will be encouraged over support for existing and experienced initiatives (M). [46,93]

CMOC 199: If funders only support short-term or new projects (C), then initiatives will struggle to become established long-term (O), as they will be unable to plan ahead with confidence or have time to learn how activity can be supported sustainably (M). [49,62,68]

CMOC 200: If resources are not allotted and ring-fenced to match changes in national or local policy (C), there will be no benefit to community interventions (O), as funders will not have the resources to invest in making a difference in practice (M). [48,62,70,73]

CMOC 201: If intervention providers, service users and families speak out about their needs (C), providers may be more likely to get funding for local community-focussed services (O), as authorities will feel pressure to change the national agenda to meet people's needs (M). [87]

RAMESES publication standards (realist synthesis) checklist

(After BMC Medicine 2013, 11:21 http://www.biomedcentral.com/1741-7015/11/21)

Items required when reporting a realist synthesis			Reported on page(s)
1		In the title, identify the document as a realist synthesis or review	1,2
ABSTRACT			
2		While acknowledging publication requirements and house style, abstracts should ideally contain brief details of: the study's background, review question or objectives; search strategy; methods of selection, appraisal, analysis and synthesis of sources; main results; and implications for practice.	2
INTRODUCTION			
3	Rationale for review	Explain why the review is needed and what it is likely to contribute to existing understanding of the topic area.	4
4	Objectives and focus of review	State the objective(s) of the review and/or the review question(s). Define and provide a rationale for the focus of the review.	5
METHODS			
5	Changes in the review process	Any changes made to the review process that was initially planned should be briefly described and justified.	N/A
6	Rationale for using realist synthesis	Explain why realist synthesis was considered the most appropriate method to use.	6
7	Scoping the literature	Describe and justify the initial process of exploratory scoping of the literature.	6-7
8	Searching processes	While considering specific requirements of the journal or other publication outlet, state and provide a rationale for how the iterative searching was done. Provide details on all the sources accessed for information in the review. Where searching in electronic databases has taken place, the details should include, for example, name of database, search terms, dates of coverage and date last searched. If individuals familiar with the relevant literature and/or topic area were contacted, indicate how they were identified and selected.	7-8
9	Selection and appraisal of documents	Explain how judgements were made about including and excluding data from documents, and justify these.	8-9
10	Data extraction	Describe and explain which data or information were extracted from the included documents and justify this selection.	8-9
11	Analysis and synthesis processes	Describe the analysis and synthesis processes in detail. This section should include information on the constructs analyzed and describe the analytic process.	9
RESULTS			
12	Document flow diagram	Provide details on the number of documents assessed for eligibility and included in the review with reasons for exclusion at each stage as well as an indication of their source of origin (for example, from searching databases, reference lists and so on). You may consider using the example templates (which are likely to need modification	8

Items required when reporting a realist synthesis			Reported on page(s)
		to suit the data) that are provided.	
13	Document characteristics	Provide information on the characteristics of the documents included in the review.	10
14	Main findings	Present the key findings with a specific focus on theory building and testing.	10-14
DISCUSSION			
15	Summary of findings	Summarize the main findings, taking into account the review's objective(s), research question(s), focus and intended audience(s).	14-15
16	Strengths, limitations and future research directions	Discuss both the strengths of the review and its limitations. These should include (but need not be restricted to) (a) consideration of all the steps in the review process and (b) comment on the overall strength of evidence supporting the explanatory insights which emerged. The limitations identified may point to areas where further work is needed.	15-16, 17-18
17	Comparison with existing literature	Where applicable, compare and contrast the review's findings with the existing literature (for example, other reviews) on the same topic.	16-17
18	Conclusion and recommendations	List the main implications of the findings and place these in the context of other relevant literature. If appropriate, offer recommendations for policy and practice.	16-18
19	Funding	Provide details of funding source (if any) for the review, the role played by the funder (if any) and any conflicts of interests of the reviewers.	19-20

BMJ Open

Sustaining community-based interventions for people affected by dementia long term: The SCI-Dem realist review

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2020-047789.R1
Article Type:	Original research
Date Submitted by the Author:	22-Feb-2021
Complete List of Authors:	Morton, Thomas; University of Worcester, Association for Dementia Studies Wong, Geoff; Oxford University, Nuffield Department of Primary Care Health Sciences Atkinson, Teresa; University of Worcester, Association for Dementia Studies Brooker, Dawn; University of Worcester, Association for Dementia Studies
Primary Subject Heading:	Health services research
Secondary Subject Heading:	Geriatric medicine, Health policy, Mental health, Public health, Sociology
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Organisation of health services < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Dementia < NEUROLOGY, Old age psychiatry < PSYCHIATRY, SOCIAL MEDICINE

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Sustaining community-based interventions for people affected by dementia long term: The SCI-Dem realist review

Authors:

Thomas Morton, Association for Dementia Studies, University of Worcester, Worcester, UK.

Geoffrey Wong, Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK.

Teresa Atkinson, Association for Dementia Studies, University of Worcester, Worcester, UK.

Dawn Brooker, Association for Dementia Studies, University of Worcester, Worcester, UK.

Corresponding Author:

Professor Dawn Brooker, Director of the Association for Dementia Studies, School of Allied Health and Community, University of Worcester, Henwick Grove, Worcester WR2 6AJ.

Email: *d.brooker@worc.ac.uk*. Tel: 01905 855250

Sustaining community-based interventions for people affected by dementia long term: The SCI-Dem realist review

Thomas Morton[1] Geoffrey Wong[2] Teresa Atkinson[1] Dawn Brooker[1]

ABSTRACT

Objectives: Community-based support for people with ealier-stage dementia and their care partners, such as regularly-meeting groups and activities, can play an important part in post-diagnostic care. Typically delivered piecemeal in the UK by a variety of agencies with inconsistent funding, provision is fragmented and many such interventions struggle to continue after only a short start-up period. This realist review investigates what can promote or hinder them in being able to sustain long-term.

Methods: Key sources of evidence were gathered using formal searches of electronic databases and grey literature, together with informal search methods such as citation tracking and snowballing. No restrictions were made on type of article or study design, but only data pertaining to regularly-meeting, ongoing, community-based interventions for those affected by dementia were included. Data were extracted, assessed, organised and synthesised and a realist logic of analysis applied to trace context-mechanism-outcome configurations as part an overall programme theory. Consultation with stakeholders, involved with a variety of such interventions in various roles, informed this process throughout.

Results: Ability to continually get and keep members; staff and volunteers; the support of other services and organisations; and funding/income were found to be critical in long-term sustainability, with multiple mechanisms feeding into these sub-outcomes, sensitive to context. These included an emphasis on socialising and person-centredness; lowering stigma and logistical barriers; providing satisfaction, support and recognition for personnel; networking, raising awareness and sharing with other organisations, while avoiding conflict; and skilled financial planning and management. Challenges were especially acute for small-scale and rural groups.

Conclusions: This review presents a theoretical model of the factors and mechanisms involved in the long term sustainability of community-based interventions. While the data used predated the COVID-19 pandemic, it can provide a framework for new research to look at what sustainability-impacting elements might have been affected, and how.

Article Summary

- This review brings together transferrable learning from a wide range of intervention types on a topic that has received little formal, integrated research attention, to deepen our understanding on how such interventions could be implemented and supported to sustain more universally and consistently across the sector.
- This review's realist approach is well suited to accommodate and account for the complexity of such 'real life' intervention programmes, as implemented under different conditions in different settings, to extract transferable conclusions.
- This review was designed to gather evidence regarding how interventions can be sustained, not on the efficacy/effectiveness of interventions of this type, hence conclusions regarding the latter are beyond its scope.
- Literature was limited as this research question is not commonly the main focus of study in dementia care research.
- Not all of the data were of equal depth and detail or the highest empirical rigour, rather contributing together in a way that is useful to an overall programme theory that will benefit from further refinement and revision with empirical testing in subsequent research.

Keywords

Dementia; Post-diagnosis; Peer support; Psychosocial; Implementation

INTRODUCTION

Supporting people with dementia and their carers to live as well as possible in their communities, with timely psychosocial support, is a global public health goal,[1] though remains a challenging aspiration in many countries. In the UK, with an aging population[2] and increasing pressure on already-stretched health services[3] 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, support for family carers and 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.[4]

Support following a diagnosis of dementia is patchy,[4] however, with families in some areas lacking any formal proactive support for those with less severe symptoms, beyond occasional contact with primary care and third sector. There are significant gaps in social care for people affected by dementia across the UK.[5 6 7] 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[6] and in some areas has "broken down" creating "care deserts".[5] There is an associated reliance on informal carers (e.g. family members) to provide support but there is a growing recognition that informal carers' own health and wellbeing is often negatively impacted by their caring activities.[6] The detrimental health impact of social isolation and loneliness is also increasingly being recognised,[8 9] with survey data revealing nearly 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.[7] Family carers can also be subject to such loneliness and isolation.[10] This situation has only been exacerbated by the recent impact of COVID-19,[11] bringing the need for groups and activities that provide social connection and support for people and families affected by dementia into stark relief.

There have been various attempts to mitigate these challenges in communities across the country, in the form of groups and activities for people with dementia and family carers. These aim to serve a number of functions: peer support, companionship and help for people to reintegrate with their communities; delivery of professional support, psychosocial interventions and physical exercise; a point of contact, signposting and referral for other services; or raising awareness and acting as a dementia-friendly community hub. The benefits of such community-based initiatives are now being recognised.[12 13 14 15 16] There is evidence that regular social activity, where people are able to leave their homes and gather together in a communal setting on a frequent and ongoing basis, can be helpful both for people living with dementia and the people who care for them.[12 13 17 18 19] With care systems unprepared for the forecasted UK doubling of the number of people living with dementia (1.6 million) and tripling of social care costs by 2040,[20] improving provision of evidence-based community initiatives for people with dementia, and their families, is imperative.[12 13 14 15 16 21 22] However, even prior to the 2020 pandemic restrictions, such initiatives, groups and activities already faced a variety of challenges with long-term sustainability. 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.

This realist review aims to deepen our understanding of what can help or hinder the long-term sustainability of regularly meeting, place-based community interventions, such as groups and activities, for people affected by dementia. It aims to use data gathered as the basis of evidence-informed recommendations for policy and practice.

METHODS

This review was conducted from December 2018 to December 2020. A project protocol was registered with PROSPERO in March 2019[23] and the protocol was published in this journal in June 2019.[24]

The realist review is an interpretive, theory-driven approach to synthesising evidence from a range of sources, including qualitative, quantitative and mixed-methods research.[25] This approach is designed to accommodate and account for the complexity of 'real life' intervention programmes, as implemented under different conditions in different settings, aiming to explain how and why context can influence outcomes.[26] Hence it is well suited to extracting transferable lessons from reviewing the functioning and success (or otherwise) of a range of community-based interventions for people affected by dementia, as these are likely to involve a high level of complexity and be responsive to contextual factors which are likely to vary considerably from intervention to intervention. Data was gathered and synthesized, with a realist logic of analysis applied to identify causal chains involving different contexts, mechanisms and outcomes that can in turn affect an initiative's long-term sustainability. We define context as the conditions that trigger or modify the behaviour of mechanisms;[27] mechanisms are the usually-hidden processes that generate outcomes, defined as "underlying entities, processes, or structures which operate in particular contexts to generate outcomes of interest.";[28] outcomes can be "either intended or unintended and can be proximal, intermediate, or final"[27] and in this review refer to any identifiable result (of the interaction between contexts and mechanisms) that can directly have a bearing on an intervention's ability to sustain long-term.

Our review followed Pawson's five iterative stages[29] as outlined below.

Step 1: Locating existing theories

This initial step was to identify and gather existing ideas around what can help or hinder the sustainability of a group or activity, from those who have first-hand experience of them. In line with realist review guidelines (RAMESES),[30] stakeholders were contacted by TA and TM and consulted for input at points throughout the project. These stakeholders were lay experts involved with community-based interventions in various capacities, whether commissioning, leading, running, supporting or attending. In the first instance a workshop was held in March 2019 with a group of 13

invited stakeholders to gather their content expertise on barriers and facilitators to engagement and sustainability. Eight others were subsequently consulted by TM individually, in person, by telephone or by email. Input was also taken by TA and TM from members and facilitators of various local DEEP (Dementia Engagement and Empowerment Project)[31] groups at a national meeting in June 2019, and TM also visited three community groups in Herefordshire, Oxfordshire and Wolverhampton. In addition, an exploratory search of the literature was conducted by TM, using informal methods such as citation tracking and snow-balling[32] along with informal scoping searches[33] and the gathering of relevant publications and materials recommended by stakeholders. Together, this contributed towards the building of an initial theoretical model, or *programme theory*, with the guidance of GW, prior to our main search, both to inform our formal search strategy and to be tested and refined by the data subsequently found. This model began as two diagrams (one regarding engagement, one regarding sustainability) drawn up by TM and TA by batching issues raised at the March workshop, and possible links between them. These diagrams were then discussed, altered and added to iteratively over four months as new stakeholder input became available (these can be seen in Supplementary file 1). These diagrams were speculative so kept deliberately broad and fluid in focus, as a work in progress. Detailed analysis of possible context-mechanism-outcome configurations (CMOCs) was not considered appropriate at this stage, as: 1) Not enough data had been gathered; 2) This would be both labour intensive and too limiting for a model whose purpose was only as a steering guide to inform the review proper, yet to be undertaken.

Step 2: Search for evidence

Formal search

Formal searching activity took place between May and September 2019. A search strategy was designed, piloted and conducted by the research team with the guidance from an information specialist (CK) (see Supplementary file 2).The following databases were searched: Academic Search Complete; AMED; CINAHL; EMBASE; MEDLINE; ProQuest; PsycINFO; PubMed; Scopus and Social Care

Online. In keeping with RAMESES guidelines,[30] no restrictions were made on the type of article or study design eligible for inclusion, other than being more recent than 1990. Documents such as editorials, opinion pieces, information guides, publicity materials, newspaper and magazine articles, evaluation reports, PhD theses and research poster and slide presentations were included along with peer-reviewed journal articles, if found to be holding relevant information. Search terms were kept uniform across all databases and searching was carried out by looking for the occurrence of these within the title, abstract and key words of documents (or nearest equivalent) in each database. Database-specific defined keywords were not used as the types of intervention were not only very diverse but often without a common agreed terminology, hence using too narrowly-specified terms would have resulted in an unmanageably voluminous list of possible key words, without necessarily locating better targeted results, and could be limiting and misleading. In addition the nature of this review's research question is atypical in that it does not have an efficacy/effectiveness focus in common with many of its sources of data, hence manual screening was key in determining relevance. A disadvantage of this was that we had to accept a higher ratio of irrelevant search hits which then had to be excluded through manual screening of title and abstract.

After removing duplicates, records were screened by title and abstract by TM using the eligibility criteria, ensuring interventions covered were those targeted at people with dementia and their families living in the community, that brought people together physically and met on a frequent, regular and an on-going basis (these criteria are outlined in full detail in Supplementary file 3). Interventions exclusively for those with severe dementia at advanced stages were excluded as these were not the focus of this review. As those with severe dementia have high needs and are less likely to be living independently in the community, by their nature community-based interventions where people meet outside of their home are likely to serve those who are towards the start of their dementia journey rather than those at an advanced stage, and are distinct from more acute care.

Full text of documents were then obtained of the remaining records, and again screened by close reading against the eligibility criteria by TM. A 10% random subsample of was reviewed independently at each of these stages by a second reviewer (TA) with disagreements recorded and resolved by discussion. Informal searching continued iteratively alongside the formal search and in response to articles found in it, congruent with the realist review process which allows searching to be revised as necessary as the review progresses.[30] In certain cases, documents regarding on interventions that met only some, not all, of the inclusion criteria were included if found to contain information on hypothesised mechanisms, with reason to believe such mechanisms may function similarly or analogously in types of intervention that are closely related.[29]

Steps 3 and 4: Article selection, data extraction and organisation

Figure 1 shows a PRISMA diagram outlining the full screening and selection process.

[Figure 1 here]

Following screening and close-reading of full texts for eligibility, full texts of the remaining 122 articles were loaded into NVivo qualitative data analysis software to help locate and categorise (code) relevant sections of text containing data regarding contexts, mechanisms or outcomes pertinent to the long-term sustainability of the intervention they described. Coding was both inductive (codes created in response to data as found) and deductive (codes created in advance, informed by the initial programme theory) and carried out by TM (An overview of top-level 'parent' codes can also be seen in Supplementary file 1; deductive codes can be identified in that they mirror the headings of the initial model diagrams). The characteristics of the articles were also extracted separately into an EXCEL spreadsheet.

During this extraction and organisation process, more fine-grained assessments of relevance (to answering the research question) and rigour (the trustworthiness and credibility of the data and its source)[25 34] were made by TM, with a random sample of 10% of articles again selected, assessed

independently and discussed with TA. The data an article contained was assessed on its own merits, not on that of the paper or study as a whole. This is because it was recognised that poorly designed or conducted research may still contain good quality 'nuggets' of information for a realist review,[34 35] or a document meeting inclusion criteria may not contain any relevant data. Due to the variety and breadth of the type of article included in the review, a standardised relevance and rigour assessment tool that would be appropriate in all cases was impossible to design.[25] Rather a set of general principles was agreed to guide a 'traffic light' assessment system of low, medium and high relevance, and low, medium and high rigour (see Supplementary file 3 for detail). Reasons for each assessment were outlined and logged for each article, and compared with each other to ensure consistency. Ambiguous cases of relevance or rigour were discussed with the wider project team as they arose. A decision was made by the project team to exclude articles assessed to have data of low relevance or low rigour to ensure a more robust data-set with which to build the final programme theory and context-mechanism-outcome configurations.

Step 5: Synthesising the evidence and drawing conclusions

Once data from the remaining articles were extracted and categorised, key outcome themes were identified by discussion with the whole team. These themes and categories were presented to the stakeholders for comment and feedback, to determine what was most important to focus upon, if they felt anything had been overlooked and if any changes or refinements should be made. Four key outcome areas (getting and keeping members, personnel, support of other organisations and funding/income) were settled upon. Data were then organised under these headings in the form of "If-then" statements that provided initial explanations of how, why, for whom and in which contexts these outcomes might arise, initially by TM but with input from DB and TA. These were then further refined, with guidance from GW, using a realist logic of analysis to identify cause-and-effect chains in the data and finally elaborated into context-mechanism-outcome configurations (CMOCs).[30] Related CMOCs were then grouped together to create recommendations for practice or policy that also

acted as a summary of the CMOCs found. Diagrams of the factors found affecting sustainability, and how they are likely to relate to each other within an overall programme theory, were also designed through team discussion and drawn by TM.

Patient and public involvement

The research question was developed during the authors' previous work with community interventions (for example, but not limited to, Meeting Centres)[12 13] and the practical problems encountered with sustaining such interventions expressed both personnel and members of the public attending. This review mainly involved the gathering of secondary data so did not involve patients or public directly as study participants. However people with dementia, their family and friends, intervention staff and volunteers and other community stakeholders were consulted as content experts throughout, informing the search strategy, data synthesis, development of materials and channels for dissemination. More information on our stakeholder consultation process can be found under *Step 1: Locating existing theories* and *Step 5: Synthesising the evidence and drawing conclusions.*

RESULTS

In total, 61 articles were coded to develop the CMOCs used to refine and expand our initial programme theory (see Supplementary file 4 for a detailed list of included articles). They were published between 1990 and 2020, and ranged in type: most were either peer-reviewed journal articles (28) or formal reports/evaluations (18); information guides (8), news feature articles (3), doctoral theses (2) and conference presentation paraphernalia (2) were also analysed. About half of these articles (33) were authored (or co-authored) in the UK, consistent with a proportion being identified informally through UK-based stakeholders (see Figure 2).Four articles had international authorship. Other countries of origin (or co-origin) comprised the US (8), Netherlands (7), Germany

(5), Canada (4), Italy (4), Norway (3), Poland (3), Australia (2), Ireland (2), Sweden (2), Chile (1), Japan (1), Portugal (1) and Thailand (1).The type of intervention discussed in these articles varied broadly, including: day centres/day care, social activities, sports and exercise initiatives, peer support groups, arts and crafts groups, singing and music groups, cognitive stimulation, gardening activities and other outdoor activities. Many interventions had multiple and overlapping elements: for example a sports activity may have a social function, a drop-in day centre may have exercise and cognitive stimulation activities or a craft club may have peer support built in. When an article's remit was general (for example community support services, outdoor activities, social and leisure activities or third sector groups) the data included from the article was only that which was relevant to our programme theory and the kind of interventions outlined in the inclusion criteria (see Supplementary file 3).

Our analysis, together with stakeholder input, identified four critical areas affecting the sustainability of an intervention: members, staff and volunteers, support of other organisations and funding/income. These were each sub-divided into "getting" and "keeping" outcomes in recognition of changes in focus over time regarding these areas, and likely different contexts and mechanisms involved as an intervention continues. Figure 2 shows an overview of factors leading to the getting and keeping of members, staff and volunteers, support of other organisations and funding/income, found in the article data (individual diagrams tracing factors for each critical area can be found in Supplementary file 5).

[Figure 2 here]

Our analysis of the data produced 201 CMOCs (outlined in full in Supplementary file 6), all covered by the above eight sub-divisions. These CMOCs provide causal explanations relating to sustainability of community-based groups and activities either at the level of the individual, organisation or wider. Due to the high number of CMOCs, they were further organised by grouping them under practical recommendations that could follow. These recommendations are not simply

an end conclusion, but were also part of the data synthesizing process, as they act as a way in which to categorise and summarise the large number of CMOCs. Examples of how a number of grouped CMOCs were related to a recommendation can be seen in Table 1.

Recommendation	CMOCs
Getting Members: **Ensure a warm, welcoming, non-stigmatising introduction, with strong staff interpersonal skills and an appealing venue**	CMOC 3: If facilitators are knowledgeable and empathetic, with good interpersonal skills (C), an initiative will be perceived as more welcoming and inclusive (O), as they will be better at understanding needs, engaging and building trust with potential members and their families (M).[36 37 38 39 40 41] CMOC 4: If an initiative has an informal, unrushed and warm welcome on first visit (C), then people are more likely to want to return (O), as they are more likely to find the experience relaxing and enjoyable, not uncomfortable and intimidating (M).[40 42 43 44 45] CMOC 5: If potential members have had poor previous experiences with groups or activities (dementia related or not) (C), they may not want to try another group or activity (O), because they think the experience will be similar and will want to avoid it (M).[37 41 46 47] CMOC 6: If time is taken for personal contact, home visits or taster sessions with potential members (C), then people are more likely to come (O), as they will feel more familiar with the initiative and more trusting of those running it (M).[36 38 47 48 49 50] CMOC 7: If an initiative is familiar and trusted, or local and well integrated with other organisations in the community (C), then people are more likely to come (O), as its links to familiar things that they trust will make it less intimidating (M).[37 41 42 48 51 52 53 54 55 56] CMOC 8: If an intervention is based in familiar surroundings in, and open to, the community (C), then people are more likely to come (O), because potential members will find the normalcy, lack of stigma and chance for social integration appealing (M).[38 41 48 52 57 58 59 60 61 62] CMOC 9: If a venue is dementia-friendly, comfortable and accessible (C), people are more likely to come (O), as they will not have concerns about comfort or access (M).[48 55 63 64]
Keeping Members: **Keep activities relaxed, loose and focussed on the social, and encourage friendships and peer support**	CMOC 47: If there is group cohesion and mutual trust between members (C), then a group is more likely to sustain (O), because members will feel more solidarity and investment in the group (M).[65] CMOC 48: If friendships between members are encouraged, recognised and supported by staff and activities (C), then people are likely to keep coming (O), as they will feel more supported, comfortable and engaged, and able to support each other (M).[43 54 66 67 68] CMOC 49: If an intervention is too focussed on agendas, rules and expectations (C), then people may stop coming (O), because they feel pressured, restricted and unable to relax and enjoy the social and emotional benefits important to them (M).[44 45 63 67 69 70 71] CMOC 50: If the pace of activity through the day/session is too fast and strict (C), then people may stop coming (O), because they will struggle to stay engaged and will not enjoy themselves (M).[43 48 57 61 72] CMOC 51: If ample informal time is made for socialising, peer support and feedback (C), then members are more likely to keep coming (O), as they will be more likely to feel comfortable and supported (M).[40 43 48 50 58 62 65 67 69 70 71 72 73 74 75] CMOC 52: If there is opportunity to have communal eating and relaxing in a “cozy” environment (C), then members are more likely

	to keep coming (O), as this will provide comfort and foster group cohesion (M).[40 65]

Table 1 Examples of CMOCs leading to recommendations

Recommendations for practice

In total, 41 recommendations for practice were drawn from the CMOCs as can be seen in Table2.

Getting Members	Keeping Members
Emphasise the social aspects of your intervention, including food and refreshments, for wide appeal CMOC 1 – CMOC 2 [40 48 50 57 58 59 62 64 75] **Ensure a warm, welcoming, non-stigmatising introduction, with strong staff interpersonal skills and an appealing venue** CMOC 3 – CMOC 9 [36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60 61 62 63 64] **Foster understanding and support from trusted friends, family and health professionals, as their encouragement can be key** CMOC 10 – CMOC 14 [36 38 41 42 47 48 54 56 58 62 65 73 75 76 77 78 79] **Provide meaningful activities that have resonance with people's interests and experience, personal history and culture** CMOC 15 – CMOC 20 [41 44 45 47 48 50 53 56 57 58 62 63 64 65 67 69 70 71 72 77 80 81 82 83 84] **Be sensitive to differences in abilities, ages and stages and aim to empower members rather than avoid challenges for them** CMOC 21 – CMOC 24 [37 43 48 58 60 62 63 64 69 73 79] **Offer information and advice to connect with a broad range of people who may be in need** CMOC 25 [42 44 45 54 73 85] **Ensure people can get there easily, safely, reliably and cheaply** CMOC 26 – CMOC 30 [36 37 38 44 45 47 48 49 53 56 59 60 61 64 65 73 76 78 82 85 86] **Stay in constant contact with potential referrers and keep them involved** CMOC 31 – CMOC 32 [41 46 51 54 55 61 74 75 79] **Your "public relations" strategy should focus on who the intervention is for and what people can expect, and use existing networks to spread your message** CMOC 33 – CMOC 41 [36 37 38 41 44 45 46 47 48 49 51 54 56 59 61 62 66 67 70 72 73 74 75 78 80 82 83 84 87 88 89] **Consider simple and easy self referral** CMOC43 – CMOC 46 [38 44 45 47 57 61 74 76 79 80 83 88]	**Keep activities relaxed, loose and focussed on the social, and encourage friendships and peer support** CMOC 47 – CMOC 52 [40 43 44 45 48 50 54 57 58 61 62 63 65 66 67 68 69 70 71 72 73 74 75] **Encourage normalised activities and social integration outside of the group to empower members and reduce stigma** CMOC 53 – CMOC 57 [37 38 41 46 47 48 49 52 54 57 58 59 61 62 66 67 71 76 90] **Be person-centred: Give members input into planning and decision-making, and respect their individual needs and autonomy** CMOC 58 – CMOC 63 [36 40 41 42 43 44 45 46 48 52 55 59 61 63 65 66 67 71 74 84 91] **Talk to family or care partners about what arrangements and support they need in place** CMOC 64 – CMOC 65 [38 44 45 47 48 49 50 54 57 60 61 73 78] **Be sensitive to differences in abilities, ages and stages and have strategies to differentiate and manage activities so needs don't clash** CMOC 66 – CMOC 70 [37 41 43 44 45 46 47 48 49 57 58 59 60 61 66 67 71 74 75 76 78] **Ensure your venue is comfortable, stable and familiar, with adequate facilities and multiple spaces for use** CMOC 71 – CMOC 72 [43 48 55 63 89] **Stability and reliability matters to members, so aim for structure and minimise disruption** CMOC 73 – CMOC 77 [36 37 38 40 43 47 48 61 65 66 67 72 73 75]
Getting Staff and Volunteers	**Keeping Staff and Volunteers**
Network proactively: Engage in outreach activities to boost visibility and awareness; approach other groups and organisations for help CMOC 78 – CMOC 83 [46 48 50 56 58 59 61 67 69 77 80 83 84 89 91] **Get to know potential stakeholder groups in the local population that may provide a reliable volunteer base, and consider how to reach out to them** CMOC 84 – CMOC 90 [53 56 62 65 81 83 91 92 93]	**Foster flexibility, collaboration and communication skills in personnel to create a healthy and effective working environment** CMOC 96 – CMOC 97 [59 60 76 79 93] **Plan strategies to maintain the satisfaction and enjoyment of staff and volunteers, and to avoid burnout** CMOC 98 – CMOC 104 [38 43 52 58 61 70 74 75 84] **If possible, have financial support in place for staff roles and**

Not all personnel need expertise, but ensure facilitators have good interpersonal and leadership skills, and your volunteer workforce is reliable CMOC 91 – CMOC 95 [38 50 51 58 61 71 72 73 75 79]	**volunteers activities, so they will feel secure and valued** CMOC 105 – CMOC 108 [51 67 73 79 87 84]
Getting Support of Other Organisations	**Keeping Support of Other Organisations**
Focus on raising awareness and communicating value both to professionals and the community, involving them where possible CMOC 110 – CMOC 114 [37 39 41 42 50 54 55 61 70 75 79 80 84 86 90] **Approach and ask other community organisations if they can help with venue, resources, training, volunteers or contacts** CMOC 115 – CMOC 118 [46 48 52 58 62 65 67 69 71 72 75 77 80 92 93] **Use your physical location (venue or neighbourhood) as an opportunity to build links with others sharing that space** CMOC 119 – CMOC 121 [41 42 48 58 59 62 79] **Seek out like-minded groups to band together with and share knowledge, resources, contacts and strategy** CMOC 122 – CMOC 124 [42 67 77] **To avoid conflict with other organisations, minimise overlap, involve them or offer them something of benefit** CMOC 125 – CMOC 131 [41 42 46 51 60 61 67 70 72 79 84 86 88]	**Maintain constant contact and information sharing with the organisations, services and referrers you work with, with a dedicated person responsible if possible** CMOC 138 – CMOC 142 [39 41 44 45 50 51 55 67 77 79 84] **Seek authoritative external advice on overcoming differences in culture with other organisations, and up-skilling staff for collaboration** CMOC 143 – CMOC 148 [41 51 59 60 70 76 77 79 86] **Take time to formally plan how collaboration will work, involving collaborators in that planning** CMOC 149 – CMOC 152 [41 44 45 51 61 70]
Getting Funding and Income	**Keeping Funding and Income**
Ensure communication is clear about what the intervention does and its value CMOC 153 – CMOC 163 [39 41 46 51 56 61 70 75 79 80 89 94] **Build "social capital" and forge partnerships with other community organisations to help with costs and boost the case for viability and value for money** CMOC 164 – CMOC 169 [56 60 61 70 75 76 78 79 80 87 93 94 95] **Learn how to effectively plan and network to find funding, through knowledge-sharing with like-minded groups and seeking external advice** CMOC 170 – CMOC 175 [37 46 55 60 61 80 86 91 94] **Initiatives in rural areas should make clear the particular challenges that they face when seeking funding** CMOC 176 – CMOC 179 [50 84 91] **Find out what the national priorities are for dementia, and see if you can tailor you activities to fit; if not, lobby to change the national agenda** CMOC 180 – CMOC 184 [39 41 42 50 51 55 59 76 77 80 84 86 87 91 95 96]	**Keep in touch with previous, current and potential funders on an ongoing basis, as this will help when applying in the future** CMOC 185 – CMOC 188 [46 55 61 70 94] **Pay attention to how money can be put to use most efficiently and effectively for the benefit of all by co-operating and sharing with other organisations** CMOC 189 – CMOC 190 [70 75 76 78 80 93] **Plan a long-term strategy to build a portfolio of multiple income streams, that are flexible in what they contribute to paying for** CMOC 191 – CMOC 194 [44 45 70 80 84 94] **Ensure someone has the time and expertise to continually seek and apply for funding** CMOC 195 – CMOC 197 [70 80 84] **Emphasise deep learning and experience as an asset when calling for longer term funding** CMOC 198 – CMOC 201 [39 50 51 76 77 79 87 86 96]

Table 2 Recommendations for practice (For a full list of CMOCs see Supplementary file 6)

Data regarding getting and keeping members was the most abundant and showed most consensus. As may be expected, boosting the motivation and understanding of potential referrers, while lowering bureaucratic and logistical barriers, was important to getting members (CMOC 10-CMOC 14; CMOC 31-CMOC 46; CMOC64-CMOC 65). Transport from home to venue was particularly

key: not just its availability, but people's experiences of the accessibility, appropriateness and convenience of it (CMOC 10-CMOC 14). Other salient mechanisms involved how respected, valued and comfortable members felt, or perceived they would feel should they attend: both for overcoming initial anxiety and stigma and fostering a happy, cohesive group (CMOC 3-CMOC 9; CMOC 15-CMOC 24; CMOC 53-CMOC 63; CMOC 71-CMOC72). Staff attitudes and a comfortable, accessible venue play a role in this, but also planned practices, such as involving members in decision making (CMOC 58-CMOC 63), differentiating activities for need and ability (CMOC 21- CMOC24; CMOC 66-CMOC 70) and ensuring enough opportunity and time for socialising (reported to be of high importance to people no matter what the intervention or activity) (CMOC 1-CMOC 2; CMOC 47-CMOC 52). The stability and reliability of an intervention was also important, though often at odds with nature of groups run informally with few personnel and unstable income (CMOC 73-CMOC 77). Overall, ensuring individual wants and needs are met – that people they feel they are gaining something useful and appropriate to them in particular – was important to keeping members long-term (CMOC 47-CMOC 72).

Data regarding getting and keeping staff and volunteers was least abundant of the four critical outcome areas, though working with other organisations was frequently alluded to as helpful in finding personnel (CMOC 78-CMOC 83). Data regarding skills of personnel was largely around the role of communication and collaboration in creating an encouraging and effective environment for staff and volunteers (CMOC 84-CMOC 97). Context was key with regards to the availability of potential volunteers in the local population, as this could be very different depending on location (e.g. rural or urban), with different likely mechanisms requiring different approaches to finding and encouraging volunteers from different demographic groups (CMOC 84-CMOC 90). With regard to keeping volunteers, issues raised included the importance of maintaining work satisfaction and avoiding burnout, and having financial support available (CMOC 98-CMOC 108).

Getting and keeping support of other organisations, such as other community groups, health and social care services, third sector bodies, local authorities and local businesses was a widely recurring theme in the data. Actively involving other organisations, minimising overlap, sharing knowledge and resources and offering something of benefit were all ways to encourage them to feel invested in supporting an intervention rather than threatened or indifferent to it (CMOC 122-CMOC 131), in addition to pro-active awareness raising and networking (CMOC 110-CMOC 121). Good collaboration planning, with expert advice on collaborative working and continual attention to maintaining communication were strategies to avoid problems developing or loss of enthusiasm with partner organisations (CMOC 138-CMOC 152).

On getting and keeping funding and income, salient CMOCs again involved continual networking and communication, for the reason that this would support multiple mechanisms: by reducing costs through sharing and partnership; boosting visibility, legitimacy and value in the eyes of potential and existing funders; and helping to locate more funding and income opportunities (CMOC 153-CMOC 175; CMOC 185-CMOC 190). Data made some reference to the importance of strategic planning in finding and managing funds, with outside expertise and dedicated personnel helpful in carrying this out (CMOC 170-CMOC 175; CMOC 191-CMOC 197). While tailoring an intervention to national (and therefore funders') priorities may increase its chances of obtaining funding, this is not always possible or desirable for a group (CMOC 180-CMOC 184). Groups in rural areas particularly, or experienced groups unable to find anything but short-term solutions, may have to raise greater awareness with commissioners and policy-makers about the specific challenges that face them, and lobby for change to ensure better conditions for groups in their situation long term (CMOC 170-CMOC 179; CMOC 198-CMOC 201). For example rural groups with a small number of members and personnel can struggle to meet funders demands, especially if put in competition with larger, well-resourced organisations.

Recommendations for policy and commissioning

In addition, 13 recommendations for policy-making and commissioning were also drawn (see Table 3), for the most part mirroring those for practice and drawing on the same CMOCs.

Recommendations for commissioning/policy-making
Service users value the social side of an intervention highly, often more than the intervention or activity itself
CMOC 1 – CMOC 2; CMOC 47 – CMOC 53 [38 40 41 43 44 45 47 48 49 50 52 54 57 58 59 61 62 63 64 65 66 67 68 69 70 71 72 73 74 75]
Service users need to feel an intervention is "for them" to want to attend and keep attending
CMOC 15 – CMOC 24; CMOC 66 – CMOC 70 [37 41 43 44 45 46 47 48 49 50 53 56 57 58 59 60 61 62 63 64 65 66 67 69 70 71 72 73 74 75 76 77 78 79 80 81 82 83 84]
Lack of appropriate transport can be a major barrier to an intervention getting and keeping attendees
CMOC 26 – CMOC 30; CMOC 65 [36 37 38 44 45 47 48 49 50 56 57 59 60 61 64 65 73 76 77 78 82 85 86]
Health and social care services that may refer to an intervention need incentive and guidance to do so
CMOC 42 – CMOC 44; CMOC 134 – CMOC 135 [47 50 61 69 76 77 79 80 88]
To retain staff and volunteers there needs to be adequate financial support in place for roles and activities
CMOC 105 – CMOC 109 [50 51 67 73 79 84 87]
Established community organisations, including local authorities, can offer help in a number of ways to enable small-scale interventions to flourish
CMOC 115 – CMOC 118 [46 48 52 58 62 65 67 69 71 72 75 76 80 92 93]
Access to advice on how to create partnerships, collaborate and overcome differences in culture with other organisations can help
CMOC 143 – CMOC 148 [41 51 59 60 70 76 77 79 86]
Access to advice on how to effectively plan and network to help find and manage funding and income can help
CMOC 170 – CMOC 175 [37 46 55 60 61 80 86 91 94]
Commissioners should be flexible and accommodating of the challenges facing small groups regarding evidence gathering
CMOC 176 – CMOC 179 [50 84 91]
Policy makers should ensure policy meets local needs with adequate, protected and accessible resources attached
CMOC 180 – CMOC 182; CMOC 184 [39 41 42 50 51 55 59 76 77 80 84 86 87 91 95]
Longer term funding, with simplified application processes, would help smaller initiatives with less capacity to continue
CMOC 195 –CMOC 197 [70 80 84]
Longer term funding to support what is already being done will help retain and develop learning and practice on how best to meet local need
CMOC 198 – CMOC 200 [39 50 51 76 77 79 86 87]
Authorities and national organisations can help create conditions that encourage support for small initiatives, though policy, leadership and commissioning
CMOC 132 – CMOC 137 [39 47 50 51 59 69 77]

Table 3 Recommendations for commissioning/policy-making (For a full list of CMOCs see Supplementary file 6)

The final recommendation covers CMOCs unique to policy-making and commissioning, highlighting issues such as the detrimental effect of a disjoin between national policy and local need on an intervention finding support (as by adhering to one they will neglect the other) (CMOC 132). Practices that could benefit the sustainability of community interventions included ring-fencing

funding specifically for dementia-targeted community initiatives; commissioning health and social care services to work with community initiatives; and developing health pathways around existing community networks (CMOC 133-CMOC 135). National and official organisations can also encourage a more strategic, joined up direction regarding community-based dementia support by showing leadership in working with smaller, local initiatives and support for potential private sector partners (CMOC 136-CMOC 137).

DISCUSSION

Summary of findings

Being able to continually get and hold on to members, staff and volunteers, the support of other services and organisations, and funding/income are the key factors in the long-term sustainability of a community-based intervention for people affected by dementia. There are multiple mechanisms that feed into these sub-outcomes, sensitive to context. Ability to attract members was found to be driven by perceptions that a group or activity was “for them”, and expectations they would be welcomed, respected and supported without stigma once attending, as well as having motivated referrers and low logistical barriers including transport. Members are more likely to keep attending if feeling comfortable, at home, respected and empowered, with individual needs understood. Opportunity to socialising was found to be of high importance no matter what intervention type, with stability and reliability also important. Networking and outreach were found to be important in getting staff and volunteers; feeling satisfied, valued and supported (including financially) was important in keeping them. Proactive measures to raise awareness and involve other organisations, avoiding conflict and sharing knowledge and resources, were found to help in securing essential support, though requiring significant maintenance through skilled communication, planning and working practices. Such networking and collaboration was found to be helpful in finding and securing funding and income, with skilled planning and management of multiple income streams helpful in sustaining long term. However, the often short term nature of funding was found to be a

barrier to retaining deep learning and experience, and disjoins between national policy and local need a barrier to securing both funding and wider support. Challenges in meeting funders' requirements and overcoming logistical barriers were especially acute for small-scale and rural groups.

Strengths and limitations

This review was designed to gather evidence regarding how regularly-meeting community-based interventions for people affected by dementia can be sustained, not on the efficacy/effectiveness of interventions of this type, hence conclusions regarding the latter are beyond its scope. Literature was limited as this research question is not commonly the main focus of study in dementia care research. This meant some CMOCs arrived at were the result of abundant data sources, while others were not, hence the CMOCs here vary in robustness (see Supplementary file 6). While efforts were made to exclude data of low rigour (see Supplementary file 3), it is the nature of a realist review to include data from a variety of source types to build a theoretical model piecemeal; not all of the data were of equal depth and detail and many will not meet the highest level of empirical rigour, rather they contribute together in a way that is useful to the theoretical constructs that are the CMOCs and overall programme theory.[29] The results of this review therefore should be taken as theory and sit in relation to other research: SCI-Dem provides a theoretical framework which can be put to the test and further refines by subsequent empirical research.[29] The breadth of intervention types covered in this review is on the one hand a strength, as it has enabled the surfacing of commonalities in experience likely relevant to a wide range of real-world initiatives broadly in the same category; on the other hand, it means this review cannot be specific on certain details. An example is that little could be concluded on the cost-effectiveness or economic functioning of the interventions covered, because details were both too scant and too specific to draw robust CMOCs that might usefully be applicable to others.

The practice of one researcher carrying out the bulk of article selection and data analysis, with a second researcher independently checking 10% at each stage for consistency (along with regular input and discussion with other members of the research team) is common in realist review, but nevertheless can be seen as a limitation, as in Cochrane-style systematic reviews double-screening by two reviewers independently is recommended for greater reliability of results. However, it should be noted realist review is a theory-driven interpretive approach with significant differences to more traditional forms of systematic review;[30] i.e. the aim is to develop an evidence-informed theory rather than a comprehensive summation of all research data available on a particular research question.

Recommendations and comparison with existing literature

Recommendations for practice and policy are presented in Tables 2 and 3 in the results section. However, they also highlight some common problems for which there may be no easy solution: for example what to do in rural areas where public transport coverage is poor and potential members and volunteers are few and widespread, given that transport to venue is a key factor in getting and keeping members. The issue of whether interventions can be entirely self-sustaining or must rely on service-level agreements and grant funding is also a key one. This review suggests that costs can be reduced and income opportunities found by pro-active networking and collaborative working; though rather than removing the need for grant funding, this is more likely useful in leveraging it, adding to it and helping it to go further. Recent research into whether social enterprises delivering adult social care services (not dementia specific) could be self-sustaining suggests that marketing is key, but needs to focus upon building relationships with stakeholders at multiple levels rather than adopting an approach akin to selling a product:[97] networking and marketing are closely bound up with each other. Delivering social quality as well as service quality, having a hybrid workforce and diverse income streams to strengthen financial viability and reduce reliance on grants were also found to help.[98] This review echoes all of these points with regards to dementia-targeted

community-based interventions, in particular that interventions cannot sustain without a cultivated support network around them, as well as careful collaborative financial planning and management.

The emphasis found in this review on the value to members of social activity and a respectful, empowering person-centred approach, reinforces the benefits of community-based initiatives and regular social activity, both for people living with dementia and the people who care for them.[12 13 14 15 16 17 18 19] However, the time-limited nature of most research in this area is unhelpful when seeking data on the long-term sustainability of such interventions, with a large number of articles excluded from this review due to this. Recent systematic reviews have found that psychosocial interventions tend to be short term, with short-term trials only measuring short-term impact, and a pressing need for more longer-term studies with larger sample sizes.[14 99] However, there is a "chicken and egg" problem: if policy and commissioning is hesitant to support interventions unless there is evidence of robust statistical effects, then such interventions will struggle to sustain long enough, in enough abundance, to have the numbers to carry out the research required to produce that evidence. Equally, if research focuses only on efficacy/effectiveness without attention to the implementation process, and reporting of how costs were met and resources, personnel, and service users were found, then little can be learnt about sustaining them.

Future research directions

When drafting inclusion criteria for this review in 2018 it was decided to focus upon interventions that brought people together to meet physically and socially, as distinct from community services that go into people's homes. It did not take into account virtual community activities or communities at-a-distance, which at the time seemed like a distinct niche. In 2020, however, this kind of activity became much more important, and integrated with the activities of existing community groups that met physically prior to the COVID-19 pandemic. With COVID-19 the landscape for community-based

interventions has changed significantly, presenting further unprecedented challenges, but the need for groups that connect people socially remains acute. A recent study by the Alzheimer's Society[11] revealed COVID-19 restrictions have had particularly negative impacts on the health and well-being of people affected by dementia and their carers, a finding echoed by the Alzheimer's Disease International's update report for 2020.[100] Restrictions have forced changes to routine, causing anxiety and strain in relationships; led to a reduction in skills and confidence; and increased pressure on home carers, not least through the erosion of support systems.[101] Many support initiatives will have ceased operating either temporarily or permanently. As the effects of the pandemic continue to be felt, there is an urgent need for community-based interventions to find ways to keep going or re-establish quickly when emerging from COVID-19 restrictions. While the data used in this review predated the pandemic, it can provide a framework for new research to look at what sustainability-impacting elements have been affected and how. This review presents a theoretical model of the factors and mechanisms involved in the long term sustainability of community-based interventions. As such it is for further research to put this model to the test by comparing it empirically with real-world interventions going forward, which will further refine and add to this programme theory in a post-pandemic climate.

Word count: 5356

Figure legends

Figure 1 PRISMA flow diagram

Figure 2 Factors affecting the sustainability of community-based groups and activities

Author affiliations and email

1 Association for Dementia Studies, University of Worcester, Worcester, UK. *t.morton@worc.ac.uk*

2 Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK. *geoffrey.wong@phc.ox.ac.uk*

1 Association for Dementia Studies, University of Worcester, Worcester, UK. *t.atkinson@worc.ac.uk*

1 Association for Dementia Studies, University of Worcester, Worcester, UK. *d.brooker@worc.ac.uk*

Author Contributions DB and TA conceptualised the study along with Dr Shirley Evans (Association for Dementia Studies, University of Worcester) with input from GW, TM and Clive Kennard (Information specialist, University of Worcester). The study was conducted by DB as principal investigator, TA as project manager, TM research associate and GW providing methodological expertise. TM wrote the first draft of this manuscript. GW, DB and TA critically contributed to and refined this manuscript. All authors have read and approved the final manuscript.

Corresponding Author Professor Dawn Brooker, Director of the Association for Dementia Studies, School of Allied Health and Community, University of Worcester, Henwick Grove, Worcester WR2 6AJ. Email: *d.brooker@worc.ac.uk*. Tel: 01905 855250

Twitter Follow Thomas Morton @ThomasMortonADS

Original protocol: http://dx.doi.org/10.1136/bmjopen-2019-032109

Funding: This work was supported by The Alzheimer's Society, Grant No: 402, AS-PG-17b-023. Gold Open Access Article Processing Charges met by the University of Worcester.

Acknowledgements This project was funded by the Alzheimer's Society. Dr Shirley Evans (Association for Dementia Studies, University of Worcester) contributed to the writing of the protocol for this review. Clive Kennard (information specialist, University of Worcester), helped design, pilot and carry out the formal search. The authors would like to thank all those who shared their invaluable experience and contributed to advising and guiding this project as a stakeholder

consultant: Alzheimer's Society research monitors Sue Comely, Maggie Ewer and Mair Graham; Philly Hare, Rachael Litherland, Damian Murphy and Rachel Niblock of DEEP/Innovations in Dementia, and all who attended the national meeting of DEEP groups at Wooodbrooke, Birmingham, July 2019; Teresa 'Dory' Davies, James McKillop and Dreane Williams of DEEP; Judith Baron and the Face It Together DEEP group; Jill Turley and The Buddies DEEP group; the Friends for Life DEEP group; Kim Badcock of Kim's Cafe (Denmead, Havant and Waterlooville, Hampshire); Jo Barrow and the Forget Me Not Lunch and Friendship Club (Bicester, Oxfordshire); Elizabeth Bartlett of the Laverstock Memory Support Group (Wiltshire); Shirley Bradley of Friends of the Elderly (Worcester); David Budd of Our Connected Neighbourhoods (Stirling); Di Burbidge of Liverpool DAA Diversity Sub-Group and Chinese Wellbeing (Liverpool); Kishwar Butt of the South Asian Ladies' Milaap Group (Wolverhampton); Michelle Candlish of Ceartas Advocacy (Kirkintilloch, East Dunbartonshire); Annette Darby of Brierly Hill Health and Social Care Centre (West Midlands); Sue Denman of Solva Care (Haverfordwest); Gerry Fouracres of Scrubditch Farm (Cirencester); Graham Galloway of Kirrie Connections (Kirriemuir, Angus); Reinhard Guss; Deborah Harrold of Agewell CIC (Oldbury, West Midlands); June Hennell; Jacoba Huizenga of Health and Social Care in Communities, Utrecht (Netherlands); Lynden Jackson of the Debenham Project (Suffolk); Ghazal Mazloumi of Trent Dementia Services Development Centre; Cheryl Poole of Leominster Meeting Centre; Anita Tomaszewski and Jennifer Williams of Me, Myself and I (Briton Ferry, Neath Port Talbot); Dame Louise Robinson; Droitwich Meeting Centre; Leominster Meeting Centre; the members of the UKMCSP National Reference Group; and Jennifer Bray, Shirley Evans, Nicola Jacobson-Wright, Chris Russell and Mike Watts of the Association for Dementia Studies, University of Worcester.

Competing interests Geoffrey Wong is Deputy Chair of the National Institute for Health Research Health Technology Assessment Prioritisation Committee: Integrated Community Health and Social Care (A).

Disclaimer The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the Alzheimer's Society.

Ethics approval This project has been reviewed by the University of Worcester College of Health, Life and Environmental Sciences Research Ethics Panel.

PROSPERO registration number CRD42019125889.

Data availability statement This study was a qualitative review of secondary data, hence no new primary dataset was generated. However, we can share more information on what data was extracted and how it was analysed if requested. Please contact Thomas Morton at t.morton@worc.ac.uk, ORCID 0000-0001-8264-0834

REFERENCES

1. World Health Organisation. *Global action plan on the public health response to dementia 2017-2025.*Geneva: world Health Organisation, 2017.https://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/
2. Office for National Statistics (ONS). *Living longer: Caring in later life.* London: ONS, 2019. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/livinglongerhowourpopulationischangingandwhyitmatters/2019-03-15
3. Care Quality Commission. *The state of health care and adult social care in England 2018/19.*Newcastle-upon-Tyne: Care Quality Commission, 2019. https://www.cqc.org.uk/sites/default/files/20191015b_stateofcare1819_fullreport.pdf
4. Department of Health. *Prime Minister's challenge on dementia 2020.*London: Department of Health, 2015. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf
5. Incisive Health. *Care deserts: the impact of a dysfunctional market in adult social care provision.* London: Incisive Health, 2019: https://www.incisivehealth.com/wp-content/uploads/2019/05/care-deserts-age-uk-report.pdf
6. Age UK. *Briefing: Health and Care of Older People in England 2019.*London: Age UK, 2019. https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/health--wellbeing/age_uk_briefing_state_of_health_and_care_of_older_people_july2019.pdf

7. Alzheimer's Society. *A lonely future: 120,000 people with dementia living alone, set to double in the next 20 years.* London: Alzheimer's Society, 2019. https://www.alzheimers.org.uk/news/2019-05-15/lonely-future-120000-people-dementia-living-alone-set-double-next-20-years
8. Cornwell EY, Waite, LJ. Social disconnectedness, perceived isolation and health among older adults. *J Health Soc Behav* 2009;50(1):31–48. doi.org/10.1177/002214650905000103
9. Holt-Lunstad J, Smith TB, Baker M, Harris T, Stephenson D. Loneliness and social isolation as risk factors for mortality: A meta-analytic review. *Perspect Psychol Sci* 2015;10(2):227–237. doi.org/10.1177/1745691614568352
10. Brodaty H, Donkin M. Family carers of people with dementia. *Dialogues Clin Neurosci* 2009;11(2):217–228.
11. Alzheimer's Society. *Worst hit: Dementia during coronavirus.* London: Alzheimer's Society, 2020. https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf
12. Brooker D, Evans SC, Evans SB, *et al.* Evaluation of the implementation of the Meeting Centres Support Program in Italy, Poland, and the UK; exploration of the effects on people with dementia. *Int J Geriatr Psychiatry* 2018;33(7):883-892. doi: 10.1002/gps.4865.
13. Evans SB, Evans SC, Brooker D, *et al.* 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 Ment Health* 2018; doi: 10.1080/13607863.2018.1544207
14. Lord K, Beresford-Dent J, Rapaport P, *et al.* 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. *Soc Psychiatry Psychiatr Epidemiol* 2019;doi: 10.1007/s00127-019-01784-w
15. McDermott O, Charlesworth G, Hogervorst E, *et al.* Psychosocial interventions for people with dementia: a synthesis of systematic reviews. *Aging Ment Health* 2019;23(4):393–403. doi: 10.1080/13607863.2017.1423031
16. Van't Leven N, Prick AE, Groenewoud JG, et al. Dyadic interventions for community-dwelling people with dementia and their family caregivers: a systematic review. *Int Psychogeriatr* 2013;25(10):1581-1603.
17. Dröes RM, Van Mierlo LD, Meiland FJM, Van der Roest HG. Memory problems in dementia: Adaptation and coping strategies, and psychosocial treatments. *Expert Rev Neurother* 2011;11(12):1769-1782.
18. Dröes RM, Meiland F, Schmitz MJ, Van Tilburg W. 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 multi-centre implementation study. *Int J Geriatr Psychiatry* 2004;19(7):673-684.
19. Dröes RM, Meiland FJM, Schmitz MJ, Van Tilburg W. Effect of the Meeting Centres Support Program on informal carers of people with dementia: Results from a multi-centre study. *Aging Ment Health* 2006;10(2):112-124.
20. Wittenberg R, Hu B, Barraza-Araiza L, Rehill A. *Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019-2040 (CPEC Working Paper 50).* London: LSE, 2019.https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf
21. Dröes RM, Breebaart E, Meiland FJ, *et al.*Effect of Meeting Centres Support Program on feelings of competence of family carers and delay of institutionalization of people with dementia. *Aging Ment Health* 2004;8(3):201-211.doi.org/10.1080/13607860410001669732
22. Dröes RM, Meiland FJM, Schmitz M, van Tilburg W. 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. *Int J Geriatr Psychiatry* 2004;19:1-12.
23. Booth A, Clarke M, Ghersi D, *et al.* An international registry of systematic-review protocols. *Lancet* 2011;377:108–9.
24. Morton T, Atkinson T, Brooker D, *et al.* Sustainability of community-based interventions for people affected by dementia: a protocol for the SCI-Dem realist review. *BMJ Open* 2019;9:e032109. doi: 10.1136/bmjopen-2019-032109
25. Pawson R. *Evidence-based Policy: A Realist Perspective*. London: Sage Publications, 2006.
26. Pawson R, Greenhalgh T, Harvey G, Walshe K. Realist review – a new method of systematic review designed for complex policy interventions. *J Health Serv Res Policy* 2005;10(1):21-24.
27. Jagosh J, Macaulay AC, Salsberg J, *et al.* Uncovering the benefits of participatory research: implications of a realist review for health research and practice. *Milbank Q* 2012;90:311–46.
28. Astbury B, Leeuw F. Unpacking black boxes: mechanisms and theory building in evaluation. *Am J Eval* 2010;31:363–81.

29. Pawson R, Greenhalgh T, Harvey G, *et al. Realist Synthesis – An Introduction.* ESRC Working Paper Series. London: ESRC, 2004.
30. Wong G, Greenhalgh T, Westhorp G, Pawson R. Development of methodological guidance, publication standards and training materials for realist and meta-narrative reviews: the RAMESES (Realist And Meta-narrative Evidence Syntheses - Evolving Standards) project. *Health Serv Deliv Res* 2014;2(30):1-252.
31. DEEP. *DEEP: The UK Network of Dementia Voices* website. 2020.http://dementiavoices.org.uk
32. Greenhalgh T, Peacock R. Effectiveness and efficiency of search methods in systematic reviews of complex evidence: audit of primary sources. *BMJ* 2005;331:1064.
33. Booth A, Harris J, Croot E, *et al.* Towards a methodology for cluster searching to provide conceptual and contextual "richness" for systematic reviews of complex interventions: case study (CLUSTER). *BMC Med Res Methodol* 2013;13:118.
34. Wong G. Data gathering in realist reviews: Looking for needles in haystacks. In: Emmel, N, Greenhalgh J, Manzano A, *et al.* (eds.) *Doing Realist Research.* London: Sage Publications, 2018:131-145.
35. Pawson R. Digging for nuggets: How 'bad' research can yield 'good' evidence. *Int J Soc Res Methodol* 2006;9(2):127-142.
36. Actifcare. *Best practice recommendations from the Actifcare study: Access to community care services for home-dwelling people with dementia and their carers.*www.actifcare.eu. Bangor: Dementia Services Development Centre Wales, 2017.http://dsdc.bangor.ac.uk/documents/ShortversionBestPracticeRecommendationwithoutsupportingfindings_000.pdf
37. Daykin N, Julier G, Tomlinson A, *et al. Review of the grey literature: music, singing and wellbeing.* London: What Works Wellbeing, 2016. https://whatworkswellbeing.files.wordpress.com/2016/11/grey-literature-review-music-singing-wellbeing-nov2016.pdf
38. Hochgraeber I, Kutzleben MV, Bartholomeyczik S, Holle B. Low-threshold support services for people with dementia within the scope of respite care in Germany – A qualitative study on different stakeholders' perspective. *Dementia* 2015;16(5):576-590. doi:10.1177/1471301215610234
39. McDonald A, Heath B. Developing services for people with dementia. *Work Older People* 2009;13(3);18-21. doi:10.1108/13663666200900045
40. Strandenæs MG, Lund A, Rokstad AM. Experiences of attending day care services designed for people with dementia – a qualitative study with individual interviews. *Aging Ment Health* 2017;22(6):764-772. doi:10.1080/13607863.2017.1304892
41. Van Mierlo L, Chattat R, Evans S, *et al.* Facilitators and barriers to adaptive implementation of the Meeting Centers Support Program (MCSP) in three European countries; the process evaluation within the MEETINGDEM study. *Int Psychogeriatr* 2017;30(4):527-537. doi:10.1017/s1041610217001922
42. Brooker D, Evans SB, Evans SC, et al. *Meeting Centres Support Programme UK: Overview, evidence and getting started.*Worcester: Association for Dementia Studies, University of Worcester, 2017. https://www.worcester.ac.uk/documents/Meeting-Centres-Support-Progamme-Overview-evidence-and-getting-started-Conference-booklet.pdf
43. Glover C. *Running self-help groups in sheltered and extra care accommodation for people who live with dementia.* London: Mental Health Foundation, 2014. https://www.mentalhealth.org.uk/sites/default/files/dementia-self-help-guide.pdf
44. Reichet M, Wolter V. *Sport for People With Dementia – Implementing Physical Activity Programs (PAP) For People With Dementia: Results From A German Study (conference poster).* Dortmund: TU Dortmund University, 2017.
45. Reichet M, Wolter V. Implementing physical activity programs for people with dementia: Results from a German study. *Innov Aging* 2017;1(Suppl_1):340-340. doi:10.1093/geroni/igx004.1247
46. The Me Myself and I Club. *The Me, Myself and I Club, Briton Ferry: A case study in warm humanity and meaningful co-production.* Neath Port Talbot: The Me Myself and I Club, 2018. https://info.copronet.wales/me-myself-and-i-club-briton-ferry/
47. Older People's Commissioner for Wales. *Rethinking respite for people affected by dementia.* Cardiff: Older People's Commissioner for Wales, 2018. http://www.olderpeoplewales.com/en/Reviews/respite.aspx
48. Bould E, McFayden S, Thomas C.*Dementia-friendly sport and physical activity guide.*London: Alzheimer's Society, 2019. https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/organisations/dementia-friendly-sports
49. Green G, Lakey L. *Building dementia-friendly communities: a priority for everyone.* London: Alzheimer's Society, 2013.https://actonalz.org/sites/default/files/documents/Dementia_friendly_communities_full_report.pdf
50. Marshall J, Jackson L. *Encouraging and supporting the growth of "dementia proactive communities".* Ipswich: Sue Ryder/The Debenham Project, 2015. http://www.the-debenham-

project.org.uk/downloads/conference/Supplementary%20contributions/Lynden%20Jackson%20&%20Jo%20Marshall/Lynden%20Jackson%20&%20%20Jo%20Marshall%20-%20Supplementary%20Contribution.pdf

51. Clarke CL, Keyes SE, Wilkinson H, *et al.* Organisational space for partnership and sustainability: Lessons from the implementation of the National Dementia Strategy for England. *Health Soc Care Community* 2014;22(6):634-645. doi:10.1111/hsc.12134
52. Health Innovation Network South London. *Case Study: Dulwich Helpline and Southwark Churches Care (DH&SCC) – The Dementia Project, Southwark, South London.* London: Health Innovation Network South London, 2015.http://www.hin-southlondon.org/system/resources/resources/000/000/083/original/Case_Study_The_Healthy_Living_Club.pdf?1426083299
53. La Rue A, Felten K, Turkstra L. Intervention of multi-modal activities for older adults with dementia translation to rural communities. *Am J Alzheimers Dis Other Demen* 2015; 30(5):468-477. doi:10.1177/1533317514568888
54. Mason T, Slack G. *The Debenham Project: Research into the dementia/memory loss journey for cared-for and carer, 2012-13.* Norwich: Norfolk & Suffolk Dementia Alliance, 2013. http://www.the-debenham-project.org.uk/downloads/articles/2014/DebProjResearch_Final_Report_311013.pdf
55. Meiland FJ, Dröes RM, Lange J, Vernooij-Dassen M. Development Of A Theoretical Model For Tracing Facilitators And Barriers In Adaptive Implementation Of Innovative Practices In Dementia Care. *Arch Gerontol Geriatr* 2004;38:279-290. doi:10.1016/j.archger.2004.04.038
56. Solutions Research. *Public perceptions and experiences of community-based end of life care initiatives: a qualitative research report.* London: Public Health England, 2016. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/569711/Public_Perceptions_of_Community_Based_End_of_Life_Care_Initiatives_Resea....pdf
57. Cahill S, Pierce M, Bobersky A.*An evaluation report on flexible respite options of the Living Well With Dementia project in Stillorgan and Blackrock.* Dublin: Trinity College, 2014. http://dementia.ie/images/uploads/site-images/Evaluation_Flexible_Respite_Options.pdf
58. Carone L, Tischler V, Dening T. Football and dementia: A qualitative investigation of a community based sports group for men with early onset dementia. *Dementia* 2016;15(6):1358-1376. doi:10.1177/1471301214560239
59. Gajardo J, Aravena JM, Budinich M, et al. The Kintun program for families with dementia: From novel experiment to national policy (innovative practice). *Dementia* 2017;19(2):488-495. doi:10.1177/1471301217721863
60. Grinberg A, Lagunoff J, Phillips D, *et al.* Multidisciplinary design and implementation of a day program specialized for the frontotemporal dementias. *Am J Alzheimers Dis Other Demen* 2008;22(6):499-506. doi:10.1177/1533317507308780
61. Meiland FJ, Dröes RM, Lange JD, Vernooij-Dassen MJ. Facilitators and barriers in the implementation of the meeting centres model for people with dementia and their carers. *Health Policy* 2005;71(2):243-253. doi:10.1016/j.healthpol.2004.08.011
62. Rio R. A Community-Based Music Therapy Support Group for People With Alzheimer's Disease and Their Caregivers: A Sustainable Partnership Model. *Front Med* 2018;5. doi:10.3389/fmed.2018.00293
63. Gottleib-Tanaka D. *Creative expression, dementia and the therapeutic environment (PhD Thesis).* Vancouver: University of British Columbia, 2006. https://open.library.ubc.ca/cIRcle/collections/ubctheses/831/items/1.0076821
64. Mapes N, Milton S, Nicholls V, Williamson T. *Is it nice outside? Consulting people living with dementia and their carers about engaging with the natural environment.* Natural England Commissioned Reports, Number 211. York: Natural England, 2016.http://publications.naturalengland.org.uk/publication/5910641209507840
65. Brataas HV, Bjugan H, Wille T, Hellzen O. Experiences of day care and collaboration among people with mild dementia. *J Clin Nurs* 2010;19(19-20):2839-2848. doi:10.1111/j.1365-2702.2010.03270.x
66. Casey J. Early Onset Dementia: Getting Out and About. *Journal of Dementia Care* July/August 2004;12(4):12-13.
67. Oliver-Watkins F, Kendall N, Matthews T. *Sow & Grow: Report from a two-year Social and Therapeutic Horticultural (STH) programme delivering table-top gardening courses to adults in the community aged 50 and over.* Reading: Thrive, 2016.
68. Williams B, Roberts P. Friends in passing: Social interaction at an adult day care center. *Int J Aging Hum Dev* 1995;41(1):63-78. doi:10.2190/ghhw-v1qr-nacx-vbcb
69. Alzheimer's Australia.*The benefits of physical activity and exercise for people living with dementia (Dicussion paper 11).* Sydney: Alzheimer's Australia, 2014. https://www.dementia.org.au/sites/default/files/NSW/documents/AANSW_DiscussionPaper11.pdf

70. Hayes R, Williamson M. *Men's Sheds: Exploring the Evidence for Best Practice.* Melbourne: La Trobe University, 2007. https://www.researchgate.net/publication/259313489
71. Milligan C, Payne S, Bingley A, Cockshott Z. Place and wellbeing: Shedding light on activity interventions for older men. *Ageing Soc* 2013;35(1):124-149. doi:10.1017/s0144686x13000494
72. Tuppen J. The benefits of groups that provide cognitive stimulation for people with dementia. *Nurs Older People* 2012;24(10):20-24. doi:10.7748/nop2012.12.24.10.20.c9437
73. Mental Health Foundation. *An evaluation of the Standing Together project.* London: Mental Health Foundation, 2018. https://www.mentalhealth.org.uk/sites/default/files/standing-together-evaluation-WEB.pdf
74. Thrive. *Growing4life - A Thrive Community Gardening Project: A practical guide to setting up a community gardening project for people affected by mental ill health.* Reading: Thrive, 2012. https://www.lumi.org.uk/assets/resources-toolkits/event-and-projects/G4L-Resource-Book.pdf
75. Tuppen J, Burton-Jones J. Cogs Clubs: a helpful activity in early dementia. *Journal of Dementia Care* September/October 2015;23(5):20-21.
76. Dean J, Silversides K, Crampton J, Wrigley J. *Evaluation of the Bradford Dementia Friendly Communities Programme.* York: Jospeh Rowntree Foundation, 2015. https://www.jrf.org.uk/report/evaluation-bradford-dementia-friendly-communities-programme
77. Dean J, Silversides K, Crampton J, Wrigley J. *Evaluation of the York Dementia Friendly Communities Programme*. York: Jospeh Rowntree Foundation, 2015. https://www.jrf.org.uk/report/evaluation-york-dementia-friendly-communities-programme
78. Noimuenwai P. *Effectiveness of adult day care programs on health outcomes of Thai family caregivers of persons with dementia (PhD Thesis).* Kansas: University of Kansas, 2012. https://kuscholarworks.ku.edu/bitstream/handle/1808/11440/Noimuenwai_ku_0099D_12475_DATA_1.pdf?sequence=1&isAllowed=y
79. Van Haeften-Van Dijk A, Meiland F, Mierlo LV, Dröes RM. Transforming nursing home-based day care for people with dementia into socially integrated community day care: Process analysis of the transition of six day care centres. *Int J Nurs Stud* 2015;52(8), 1310-1322. doi:10.1016/j.ijnurstu.2015.04.009
80. Health Innovation Network South London. *Peer Support for People with Dementia Resource Pack.* London: Health Innovation Network South London, 2015.https://dementiapartnerships.com/resource/dementia-peer-support-resource-pack/
81. Hikichi H, Kondo K, Takeda T, Kawachi I. Social interaction and cognitive decline: Results of a 7-year community intervention. *Alzheimers Dement (N Y)* 2017;3:23-32. doi:10.1016/j.trci.2016.11.003
82. Hochgraeber I, Bartholomeyczik S, Holle B. Low-threshold support for families with dementia in Germany. *BMC Res Notes* 2012:5(1). doi:10.1186/1756-0500-5-317
83. La Rue A, Felten K, Duschene K, *et al*. Language-enriched exercise plus socialization for older adults with dementia: Translation to rural communities. *Semin Speech Lang* 2013;34(03):170-184. doi:10.1055/s-0033-1358370
84. Lockwood S. *The Debenham Project: A case study of a unique community-led and owned project dedicated to the support of carers of those that have symptoms of dementia and those they care for.* Harrogate: Community Catalysts CIC, 2012.http://www.the-debenham-project.org.uk/downloads/articles/2012/121106report.pdf
85. Health Innovation Network South London. *Case Study: The Healthy Living Club (HLC) – A self-directed, dementia-centred community group in Stockwell, London.* London: Health Innovation Network South London, 2015. http://www.hin-southlondon.org/system/resources/resources/000/000/084/original/Case_Study_The_Dulwich_Helpline_and_Southwark_Churches.pdf?1426083406
86. Mangiaracina F, Chattat R, Farina E, *et al.* Not re-inventing the wheel: The adaptive implementation of the meeting centres support programme in four European countries. *Aging Ment Health* 2016;21(1):40-48. doi:10.1080/13607863.2016.1258540
87. Jackson L. *The Debenham Project: Project Blog and Catch-Up (August 2017).* Debenham, Suffolk: The Debenham Project, 2017. http://www.the-debenham-project.org.uk/downloads/newsletters/blogs/1708.pdf
88. McAiney CA, Hillier LM, Stolee P, *et al.* 'Throwing a lifeline': The role of First Link™ in enhancing support for individuals with dementia and their caregivers. *Neurodegener Dis Manag* 2012;2(6);623-638. doi:10.2217/nmt.12.66
89. Moore KD. Observed affect in a dementia day center: Does the physical setting matter? *Alzheimers Care Q* 2002;3(1):67-73.

90. Arthur A, Buckner S, Buswell M, *et al. DEMCOM: National Evaluation of Dementia Friendly Communities (Executive Summary).* Cambridge: Applied Research Collaboration (ARC) East of England, 2020.
91. Kelsey SG, Laditka SB. Evaluating best practices for social model programs for adults with Alzheimer's disease in South Carolina. *Home Health Care Serv Q* 2006;24(4):21-46. doi:10.1300/j027v24n04_02
92. Arkin SM, Morrow-Howell N. Elder Rehab: A student-supervised exercise program for Alzheimer's patients. *Gerontologist* 1999;39(6):729-735. doi:10.1093/geront/39.6.729
93. LeBlanc LA. Integrating behavioral psychology services into adult day programming for individuals with dementia. *BehavModif* 2010;34(5):443-458. doi:10.1177/0145445510383528
94. NCVO. *How To Fundraise In Tough Times.* London: NCVO, 2019. https://knowhow.ncvo.org.uk/how-to/how-to-fundraise-in-tough-times
95. Wimo A, Wallin J, Lundgren K, *et al.* Impact of day care on dementia patients–costs, well-being and relatives' views. *Fam Pract* 1990;7(4):279-287. doi:10.1093/fampra/7.4.279
96. Shnall A, Agate A, Grinberg A, *et al.* Development of supportive services for frontotemporal dementias through community engagement. *Int Rev Psychiatry* 2013;25(2):246-252. doi:10.3109/09540261.2013.767780
97. Powell M, Osborne SP. Social enterprises, marketing, and sustainable public service provision. *International Review of Administrative Sciences* 2020;86(1):62-79. doi:10.1177/0020852317751244
98. Powell M, Gillett A, Doherty B. Sustainability in social enterprise: hybrid organizing in public services. *Public Management Review* 2019;21(2):159-186. doi:10.1080/14719037.2018.1438504
99. Oyebode JR, Parveen S. Psychosocial interventions for people with dementia: An overview and commentary on recent developments. *Dementia* 2019;18(1):8–35. doi: 10.1177/1471301216656096
100. Barbarino P, Lynch C, Bliss A, *et al. From Plan to Impact III: Maintaining dementia as a priority in unprecedented times.* London: Alzheimer's Disease International, 2020. https://www.alzint.org/u/from-plan-to-impact-2020.pdf
101. Canevelli M, Valletta M, Toccaceli Blasi M, *et al.* Facing Dementia During the COVID-19 Outbreak. *J Am Geriatr Soc* 2020;68(8):1673–1676. https://doi.org/10.1111/jgs.16644

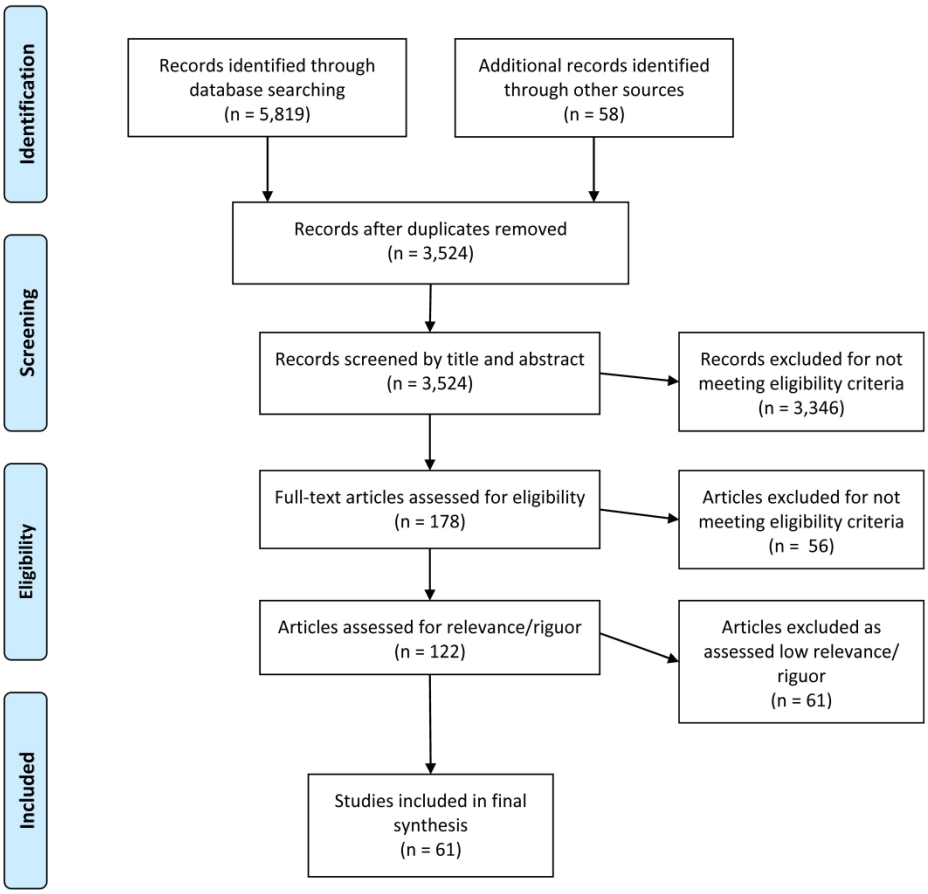


Figure 1 PRISMA flow diagram

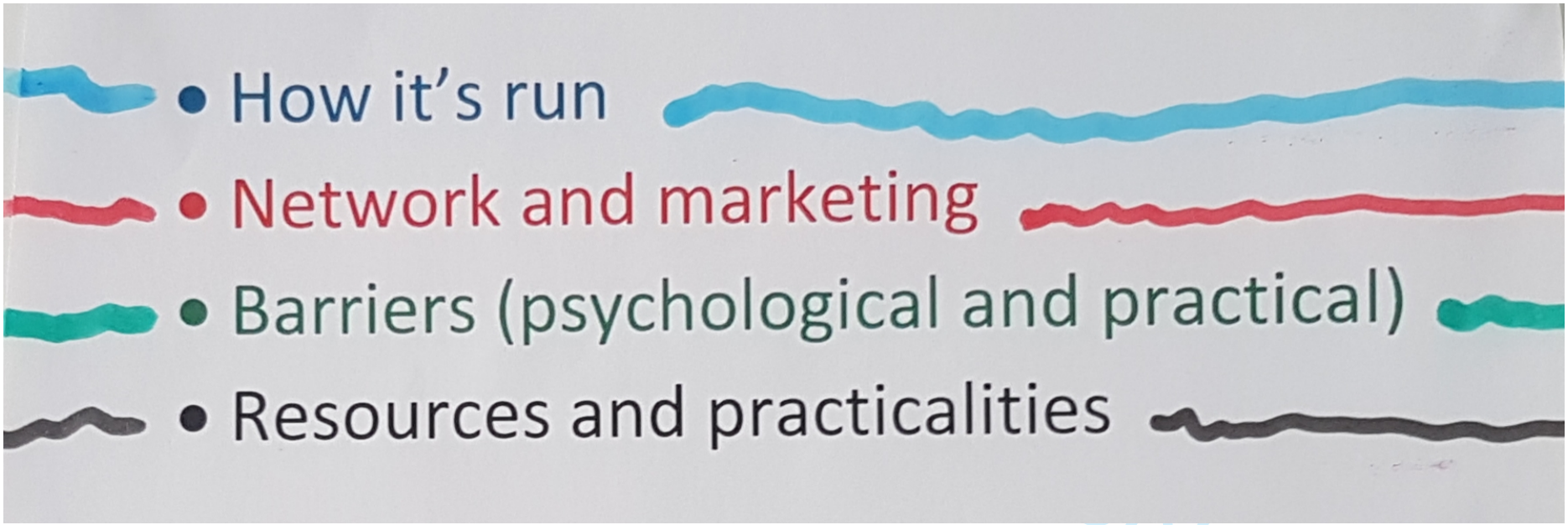
133x130mm (1200 x 1200 DPI)

Figure 2 Factors affecting the sustainability of community-based groups and activities

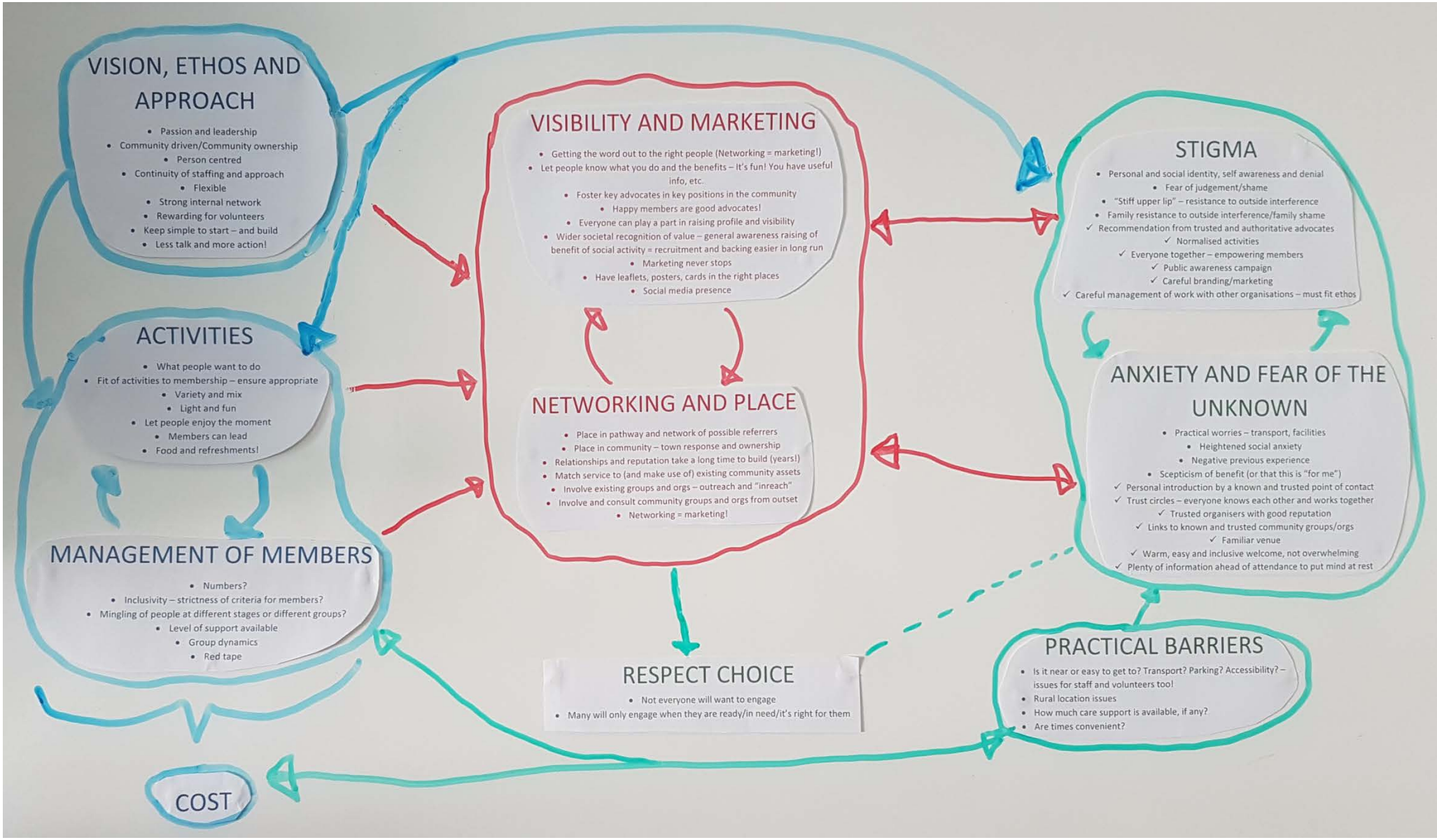
164x106mm (1200 x 1200 DPI)

Supplementary file 1: Initial programme theory diagrams and coding themes

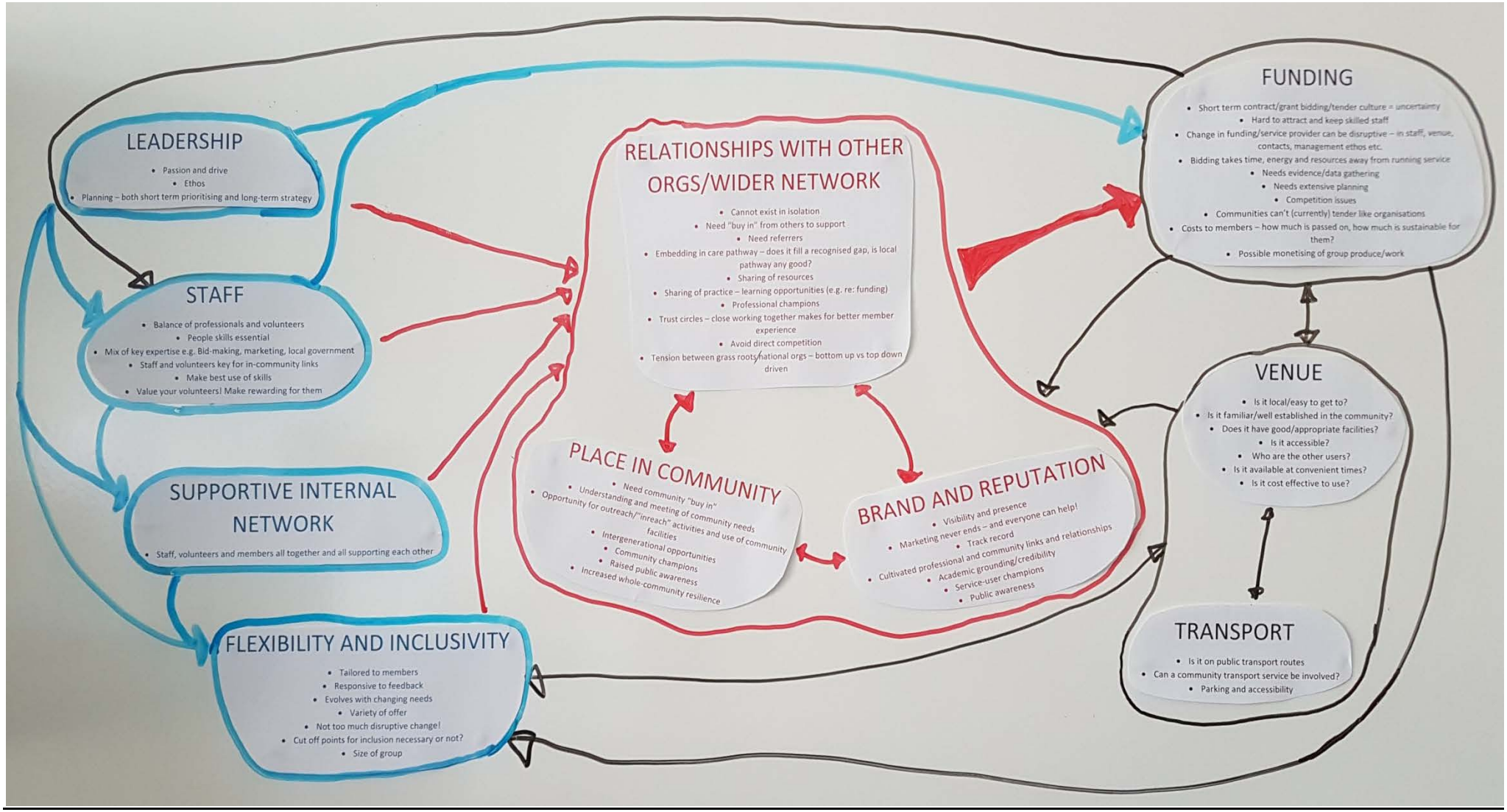
Key to colour coding:



Barriers and facilitators to <u>engagement</u>



Barriers and facilitators to <u>sustainability</u>



Top-level "parent" coding categories in NVivo analysis of the data

Name	Files	References	
Leadership	54	226	"How it's run"
Management of members (inc flexibility and inclusivity)	66	219	
Staff and volunteer issues	71	196	
Activities	94	577	
Ethos and approach	92	556	
Stability and reliabiltiy of provision	14	23	
Anxiety and fear of unknown	65	321	Barriers to engagement
Transport and geography	39	87	
Venue issues	60	203	
Attendee characteristics	62	216	
Difficulty becoming a member	23	50	
Visibility and marketing	76	365	Networking & marketing
Place in the community	67	295	
Relationships with other organisations	71	567	
Funding issues	64	327	Money & resources
Cost effectiveness issues	35	68	

Supplementary file 2: Search strategy

Databases:

EBSCOhost: **Academic Search Complete, CINAHL, MEDLINE, PsychINFO**

Other health and social care databases: **AMED,Embase, PubMed, Social Care Online**

Interdisciplinary databases: **ProQuest, Scopus**

Systematic reviews: **Cochrane Library, Campbell Collaboration**

Other/general: **Google Scholar**

Limiters: Published 1990 to present

Key terms	String of related terms
Dementia	Dementia
Community	Commun* OR Local* OR Social*
Intervention	Intervention OR Program* OR Project OR Initiative OR Scheme OR Service OR Activit* OR Group OR Club OR Network OR Meeting OR Therapy
Sustainability	Sustain* OR Maint* OR Manag* OR Facilitat* OR Barrier*
Implementation and Engagement	Implement* OR Recruit* OR Engag*

Dementia AND (Commun* OR Local* OR Social*) AND (Intervention OR Program* OR Project OR Initiative OR Scheme OR Service OR Activit* OR Group OR Club OR Network OR Meeting OR Therapy) AND (Sustain* OR Maint* OR Manag* OR Facilitat* OR Barrier*)AND (Implement* OR Recruit* OR Engag*)

NOTES:

Search terms were kept uniform across all databases and searching was carried out by looking for the occurrence of these terms within the title, abstract and key words of documents in each database. If a database did not allow for this, the strategy was altered slightly to the closest option (e.g. in ProQuest this was searching everywhere in a document except full text; in PubMed this was by carrying out three separate searches by title content, by abstract content and key word content, then combining the results).

Supplementary file 3: Inclusion and assessment criteria

Inclusion and exclusion criteria for formal search:

Inclusion criteria Types of intervention for inclusion should:	**Exclusion criteria** Interventions will be excluded if they:
• Target people with mild to moderate dementia (whether exclusively or among others without dementia, but either way there is dementia-specific support) • Serve people living in the community, whether in their own homes or in extra-care housing • Are voluntary attendance (i.e. members have chosen to attend, not been told they must as part of treatment or respite care) • Are social and place-based (bringing people together physically) in a community setting (open to members of the public to attend) • Are designed as an intervention with meaningful activity aiming to improve quality of life for people with dementia and family carers, or to help them manage or lessen the challenging effects dementia • Meet at regular, pre-fixed times, at least weekly and for a substantial amount of time (i.e. a morning or afternoon) • Meet continuously, on an ongoing basis, or aim to do so	• Are only for those with severe dementia • Do not target, and have no plan to cater for, people with dementia • Are only for care home residents, hospital patients or those in a closed institutional setting • Are an online or at-a-distance networking scheme that does not involve meeting physically • Only involve individual participants alone (e.g. occupational therapy, counselling or medical) • Are only functional meetings solely for the purpose of administering medical treatment or carry out case management • Are focussed mainly upon respite for carers or nursing care only (i.e. not focussed upon social, meaningful and quality-of-life-raising activities for those attending) • Only take place monthly; or for a very short duration (e.g. one hour); or intermittently with no specified or timetabled meetings • Are fixed-term courses with a time/goal/session limit (e.g. an 8 week course)

Relevance and rigour assessment guidance:

Relevance	**Rigour**
An article should comply with the inclusion/exclusion criteria in the first instance, except where agreed by the team for inclusion for a specific reason e.g. containing data that is broadly transferable and of use to the programme theory.	This is an assessment of the likely validity and reliability only of the *relevant* data contained in an article, *not* an assessment of the rigour of a study or intervention programme as a whole. Useful questions might include: *Is this data likely to be biased? Is it dealt with critically? Is it from a real-world example or theoretical speculation? Was the data gathered in some depth over time or in a quick "snapshot"? Is it safe to generalise from this data?*

Reasons for rating must be recorded. For example:	Reasons for rating must be recorded. For example:
A **low rating** might mean the article only contains a few relevant lines, with the bulk of the text focused on other, non-relevant matters A **medium rating** might mean an article has a lot of detail on one relevant issue (e.g. engaging people and keeping them engaged) which is pertinent to sustainability, but otherwise little on other important factors A **high rating** will mean an article has a direct focus on keeping an intervention sustainable long term, with a good level of detail	A **low rating** might mean data appears uncritically treated and at a high risk of bias (e.g. from a promotional article for a service) or simply descriptive and superficial in its reporting of basic facts from an intervention programme (e.g. from a short news article) A **medium rating** might mean data appears with some attempt at critical evaluation and is from a real-world example, but is limited in scope and generalisability, or in depth and detail A **high rating** might mean data is of good depth and detail and is from a critical evaluation of at least one real world example, gathered over a sustained period using range of robust measures and an appropriate sample of participants

Supplementary file 4: Full lists of included articles

Author(s)	Year	Article title	Type of intervention	Country of origin	Type of article/study	Publication	Reference list No.
Actifcare	2017	Best practice recommendations from the Actifcare study: Access to community care services for home-dwelling people with dementia and their carers	**community care services** in general	Netherlands, Germany, Sweden, UK, Norway, Ireland, Portugal, Italy	Recommendations report	www.actifcare.eu	**36**
Alzheimer's Australia	2014	The benefits of physical activity and exercise for people living with dementia (Dicussion paper 11)	**Exercise activities**	Australia	Report	Alzheimer's Australia	**69**
Arkin	1999	Elder rehab: A student-supervised exercise program for Alzheimer's patients	**Weekly exercise programme** pairing elders and student helpers at a college gym (caregivers also involved)	US	Journal paper - programme pilot	The Gerontologist	**92**
Arthur, Buckner, Buswell, Darlington, Killett, Lafortune, Mathie, Mayrhofer, Skedgel, Woodward & Goodman	2020	DEMCOM: National Evaluation of Dementia Friendly Communities (Executive Summary)	**Dementia Friendly Communities - various social and leisure activities**	UK	Evaluation report	Applied Research Collaboration (ARC) East of England	**90**

Bould, McFadyen & Thomas	2019	Dementia-friendly sport and physical activity guide	**Sport and excercise initiatives**	UK	Information booklet	Alzheimer's Society	**48**
Brataas, Bjugan, Wille & Hellzen	2010	Experiences of day care and collaboration among people with mild dementia	**Day care**	Norway	Journal paper - qual study of a trial programme	Journal of Clinical Nursing	**65**
Brooker, Evans, Evans, Watts & Droes	2017	Meeting Centres Support Programme UK: Overview, evidence and getting started	**Meeting Centres**	Netherlands, Italy, Poland, UK	Information/guide booklet	Association for Dementia Studies (University of Worcester)	**42**
Cahill, Pierce & Bobersky	2014	An evaluation report on flexible respite options of the Living Well With Dementia project in Stillorgan and Blackrock	**Day care/respite**	Ireland	Evaluation report	Trinity College Dublin	**57**

Carone, Tischler & Dening	2016	Football and dementia: A qualitative investigation of a community based sports group for men with early onset dementia	**Sport and excercise group**	UK	Journal paper - qualitative study	Dementia	**58**
Casey	2004	Early onset dementia: Getting out and about	**Small "out and about" social group**	UK	Specialist news article	Journal of Dementia Care	**66**
Clarke, Keyes, Wilkinson, Alexjuk, Wilcockson, Robinson, Corner & Cattan	2014	Organisational space for partnership and sustainability: lessons from the implementation of the National Dementia Strategy for England	**Peer support networks**	UK	Journal paper - stragtegy evaluation	Health & Social Care in the Community	**51**
Daykin, Julier, Tomlinson, Meads, Mansfield, Payne, Duffy, Lane, D'Innocenzo, Burnett, Kay, Dolan, Testoni & Victor	2016	Review of the grey literature: music, singing and wellbeing	**Singing and musical activities**	UK	Review/Report	What Works Wellbeing report	**37**

Dean, Silversides, Crampton & Wrigley	2015	Evaluation of the Bradford Dementia Friendly Communities Programme	**Activities and groups in the community**	UK	Evaluation report	Joseph Rowntree Foundation report	**76**
Dean, Silversides, Crampton & Wrigley	2015	Evaluation of the York Dementia Friendly Communities Programme	**Activities and groups in the community**	UK	Evaluation report	Joseph Rowntree Foundation report	**77**
Gajardo, Aravena, Budinich, Larrain, Fuentes & Gitlin	2017	The Kintun program for families with dementia: From novel experiment to national policy (innovative practice)	**Day centre** and dementia **community hub**	Chile	Journal article - program evaluation	Dementia	**59**
Glover	2014	Running self-help groups in sheltered and extra care accommodation for people who live with dementia	**Self-help social and activity groups**	UK	Information/guide booklet	Mental Health Foundation	**43**

Gottlieb-Tanaka	2006	Creative expression, dementia and the therapeutic environment	**Art/creative activities in a day centre environment**	Canada	Dissertation/Thesis		**63**
Green & Lakey (Alzheimer's Society)	2013	Building dementia-friendly communities: a priority for everyone	**Dementia Friendly Communities** - various social and leisure activities	UK	Report	Alzheimer's Society	**49**
Grinberg, Lagunoff, Phillips, Stern, Goodman & Chow	2007	Multidisciplinary design and implementation of a day program specialized for the frontotemporal dementias	**Day program** for people with FTD	Canada	Journal paper - program evaluation	American Journal of Alzheimer's Disease & Other Dementias	**60**
Hayes & Williamson	2007	Men's Sheds: Exploring the Evidence for Best Practice	**Men's Sheds**	Australia	Evaluation report	School of Public Health, La Trobe University	**70**

Health Innovation Network South London** (**see also linked films within document plus 2015 HIN Case Studies)	2015	Peer Support for People with Dementia Resource Pack	A range of **peer support groups and activities**	UK	Information/guide booklet	Health Innovation Network South London	**80**
Health Innovation Network South London	2015	Case Study: Dulwich Helpline and Southwark Churches Care (DH&SCC) – The Dementia Project, Southwark, South London.	**Peer support project**	UK	Information/guide booklet	Health Innovation Network South London	**52**
Health Innovation Network South London	2015	Case Study: The Healthy Living Club (HLC) – A self-directed, dementia-centred community group in Stockwell, London	**Peer support group**	UK	Information/guide booklet	Health Innovation Network South London	**85**
Hikichi, Kondo, Takeda & Kawachi	2017	Social interaction and cognitive decline: Results of a 7-year community intervention	**Community centres for older people**	Japan	Journal paper - longitudinal study	Alzheimer's & Dementia	**81**

Hochgraeber, Bartholomeyczik & Holle** (**See also Hochgraeber et al 2017)	2012	Low-threshold support for families with dementia in Germany	**"Low threshold" support services** including **social care groups**	Germany	Journal paper - survey protocol	BMC Research Notes	**82**
Hochgraeber, Von Kutzleben, Bartholomeyczik & Holle	2017	Low-threshold support services for people with dementia within the scope of respite care in Germany – A qualitative study on different stakeholders' perspective	**"Low threshold" support services** including **social care groups**	Germany	Journal paper - qualitative study	Dementia	**38**
Jackson	2017	The Debenham Project: Project Blog and Catch-Up	Range of local **support groups and activities**	UK	Project blog newsletter/report	Debenham Project	**87**
Kelsey & Laditka	2005	Evaluating best practices for social model programs for adults with Alzheimer's disease in South Carolina	**"Social model" day care**	US	Journal paper - review and survey of best practice	Home Health Care Services Quarterly	**91**

La Rue, Felten, Duschene, MacFarlane, Price, Zimmerman & Havez	2013	Language-enriched exercise plus socialization for older adults with dementia: Translation to rural communities	**Language, excercise and socialisation program**	US	Journal paper - trial progam in rural setting	Seminars in Speech and Language	**83**
La Rue, Felten & Turkstra	2015	Intervention of Multi-Modal Activities for Older Adults With Dementia Translation to Rural Communities	**Language, excercise and socialisation program**	US	Journal paper - trial progam in rural setting	American Journal of Alzheimer's Disease & Other Dementias	**53**
LeBlanc	2010	Integrating behavioral psychology services into adult day programming for individuals with dementia	**Day care** (for people with dementia exhibiting challenging behaviour)	US	Journal paper - program evaluation	Behavior Modification	**93**
Lockwood	2012	The Debenham Project: A case study of a unique community-led and owned project dedicated to the support of carers of those that have symptoms of dementia and those they care for	Range of local **support groups and activities**	UK	Case study report	Community Catalysts	**84**

Mangiaracina, Chattat, Farina, Saibene, Gamberini, Brooker, Evans, Evans, Szcześniak, Urbanska, Rymaszewska, Hendricks, Dröes & Meiland	2017	Not re-inventing the wheel: the adaptive implementation of the meeting centres support programme in four European countries	**Meeting Centres**	Netherlands, Italy, Poland, UK	Journal paper - project evaluation	Aging & Mental Health	**86**
Mapes, Milton, Nicholls & Williamson (Natural England)	2016	Is it nice outside? Consulting people living with dementia and their carers about engaging with the natural environment	**Outdoor activities**	UK	Report	Natural England report	**64**
Marshall & Jackson	2015	Encouraging and supporting the growth of "dementia proactive communities"	**Dementia proactive communities** (Range of local **support groups and activities**)	UK	Report	Debenham Project & Sue Ryder	**50**
Mason & Slack	2013	The Debenham Project: Research into the dementia/memory loss journey for cared-for and carer, 2012-13	Range of local **support groups and activities**	UK	Evaluation report - survey	Norfolk & Suffolk Dementia Alliance	**54**

McAiney, Hillier, Stolee, Harvey & Michael	2012	'Throwing a lifeline': the role of First Link in enhancing support for individuals with dementia and their caregivers	Information on and links between **support services (including groups and activities)**	Canada	Journal paper - evaluation	Neurodegenerative Disease Management (Future Medicine)	**88**
McDonald & Heath	2009	Developing services for people with dementia	**General dementia support services** in rural areas	UK	Journal short report feature - review of service provision	Working with Older People: Community Care Policy & Practice	**39**
The Me Myself and I Club	2018	The Me, Myself and I Club, Briton Ferry: A case study in warm humanity and meaningful co-production	**Friendship club and support services**	UK (Wales)	Programme/service report	Me Myself and I Club	**46**
Meiland, Dröes, De Lang & Vernooij-Dassen	2004	Development of a theoretical model for tracing facilitators and barriers in adaptive implementation of innovative practices in dementia care	**Meeting centres**	Netherlands	Journal paper - model development	Archives Of Gerontology And Geriatrics Supplement	**55**

Meiland, Dröes, De Lang & Vernooij-Dassen	2005	Facilitators and barriers in the implementation of the Meeting Centres model for people with dementia and their carers	**Meeting centres**	Netherlands	Journal paper - model test	Health Policy	**61**
The Mental Health Foundation	2018	An evaluation of the Standing Together project	**Peer support groups**	UK	Evaluation report	Mental Health Foundation report	**73**
Milligan, Payne, Bingley & Cockshott	2015	Place and wellbeing: shedding light on activity interventions for older men	**Men's Sheds**	UK	Journal paper - qualitative study of program	Ageing & Society	**71**
Moore	2002	Observed affect in a dementia day center: Does the physical setting matter?	**Day centre**	US	Journal paper - case study/field observation	Alzheimer's Care Quarterly	**89**

Noimuenwai	2012	Effectiveness of adult day care programs on health outcomes of Thai family caregivers of persons with dementia	**Day care (Thailand)**	Thailand	Dissertation/Thesis		**78**
NVCO	2019	How To Fundraise In Tough Times	**Third sector and non-profit organisations in general**	UK	Information guide	NCVO Knowhow website	**94**
Older People's Commissioner for Wales	2018	Rethinking respite for people affected by dementia	**Respite/day services**	UK (Wales)	Report	Older People's Commissioner for Wales report	**47**
Oliver-Watkins, Kendall & Matthews	2016	Sow & Grow: Report from a two-year Social and Therapeutic Horticultural (STH) programme delivering table-top gardening courses to adults in the community aged 50 and over	**Gardening groups**	UK	Evaluation report	Sow & Grow	**67**

Reichet & Wolter	2017	Implementing physical activity programs for people with dementia: Results from a German study	**Sports club initiatives**	Germany	Poster presentation		**44**
Reichet & Wolter	2017	Implementing physical activity programs for people with dementia: Results from a German study	**Sports club initiatives**	Germany	Conference abstract	Innovation in Aging (Supplement)	**45**
Rio	2018	A Community-Based Music Therapy Support Group for People With Alzheimer's Disease and Their Caregivers: A Sustainable Partnership Model	**Music therapy group**	US	Journal paper - program evaluation	Frontiers In Medicine	**62**
Shnall, Agate, Grinberg, Huijbregts, Nguyen & Chow	2013	Development of supportive services for frontotemporal dementias through community engagement	**Day program for FTD** (plus online groups and resources for family carers)	Canada	Journal paper - review of initiatives	International Review of Psychiatry	**96**

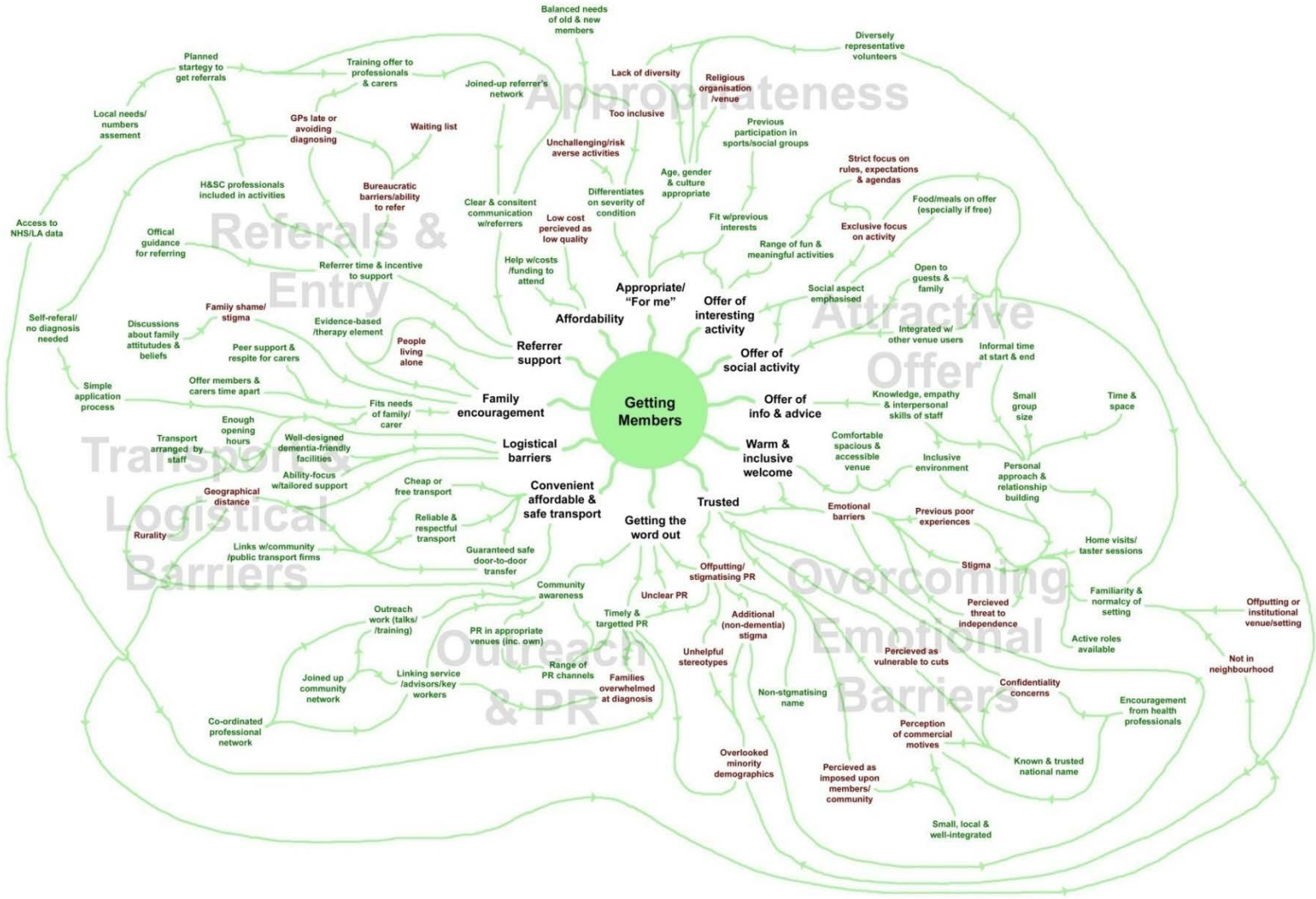
Solutions Research	2016	Public perceptions and experiences of community-based end of life care initiatives: a qualitative research report	**Community-based support initiatives** of all kinds	UK	Report	Public Health England report	**56**
Strandenæs, Lund & Rokstad	2018	Experiences of attending day care services designed for people with dementia - a qualitative study with individual interviews	**Day care**	Norway	Journal paper - qualitative study	Aging & Mental Health	**40**
Thrive	2012	Growing4life - A Thrive Community Gardening Project: A practical guide to setting up a community gardening project for people affected by mental ill health	**Gardening groups**	UK	Information/guide booklet	Thrive (The Society for Horticultural Therapy)	**74**
Tuppen	2012	The benefits of groups that provide cognitive stimulation for people with dementia	**Cognitive stimulation clubs**	UK	Journal article - overview of intervention	Nursing Older People	**72**

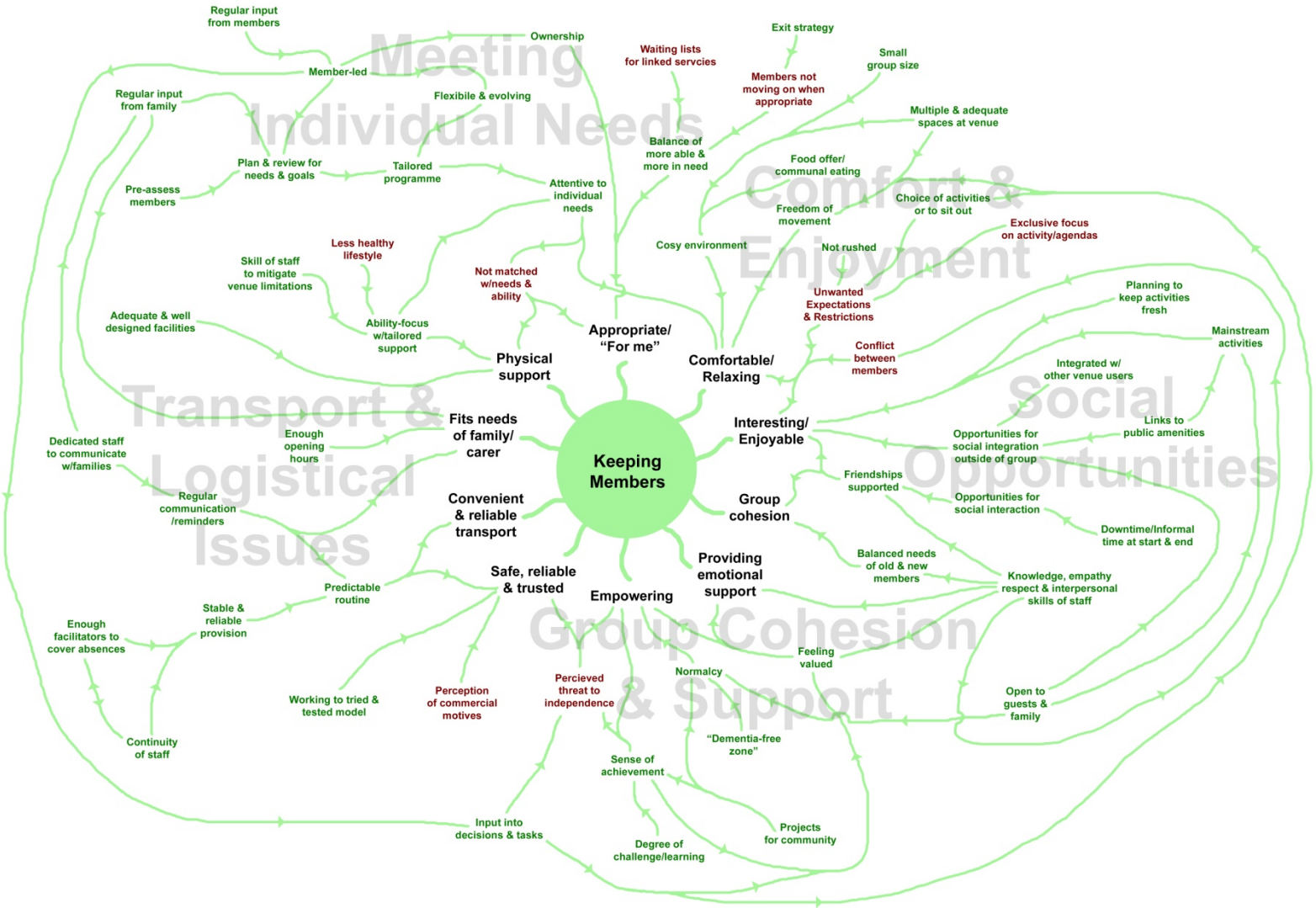
Tuppen & Jones	2015	Cogs Clubs: a helpful activity in early dementia	**Cognitive stimulation clubs**	UK	Specialist news article	Journal of Dementia Care	**75**
Van Haeften-van Dijk, Meiland, van Mierlo & Dröes	2015	Transforming nursing home-based day care for people with dementia into socially integrated community day care: Process analysis of the transition of six day care centres	**Meeting centres**	Netherlands	Journal paper - process evaluation	International Journal of Nursing Studies	**79**
Van Mierlo, Chattat, Evans, Brooker, Saibene, Gamberini, Farina, Scorolli, Szcześniak, Urbańska, Rymaszewska, Dröes & Meiland	2018	Facilitators and barriers to adaptive implementation of the Meeting Centers Support Program (MCSP) in three European countries; the process evaluation within the MEETINGDEM study	**Meeting centres**	Netherlands, Italy, Poland, UK	Journal paper - program evaluation	International Psychogeriatrics	**41**
Williams & Roberts	1995	Friends in passing: social interaction at an adult day care center	**Adult day care centre**	US	Journal paper - participant observation	International Journal Of Aging & Human Development	**68**

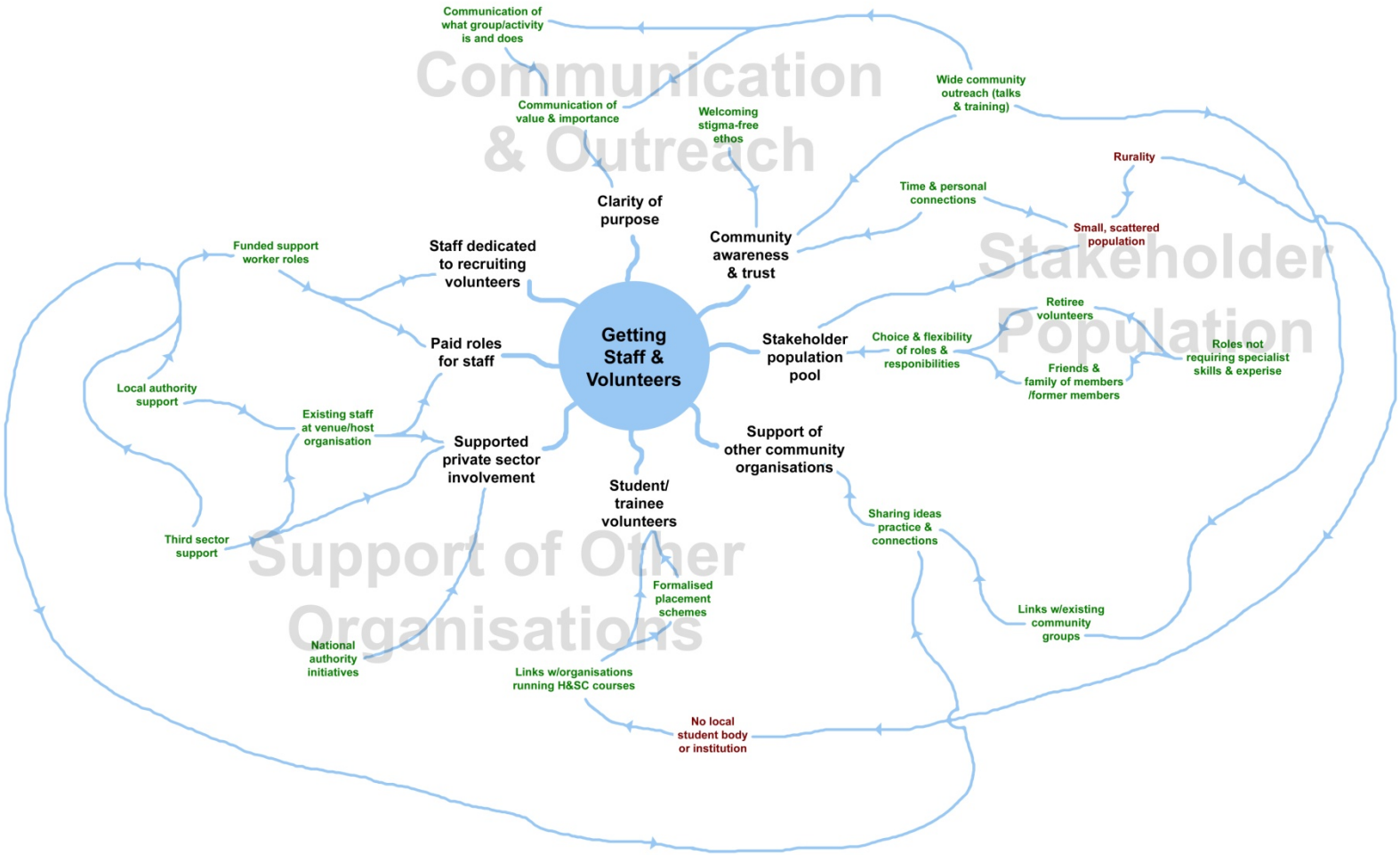
Wimo, Wallin, Lundgren, Ronnback, Asplund, Mattsson & Krakau (see also Clarkson et al 2017)	1990	Impact of Day Care on Dementia Patients—Costs, Well-being and Relatives' Views	**Specialist day care**	Sweden	Journal paper - cost analysis	Family Practice	**95**

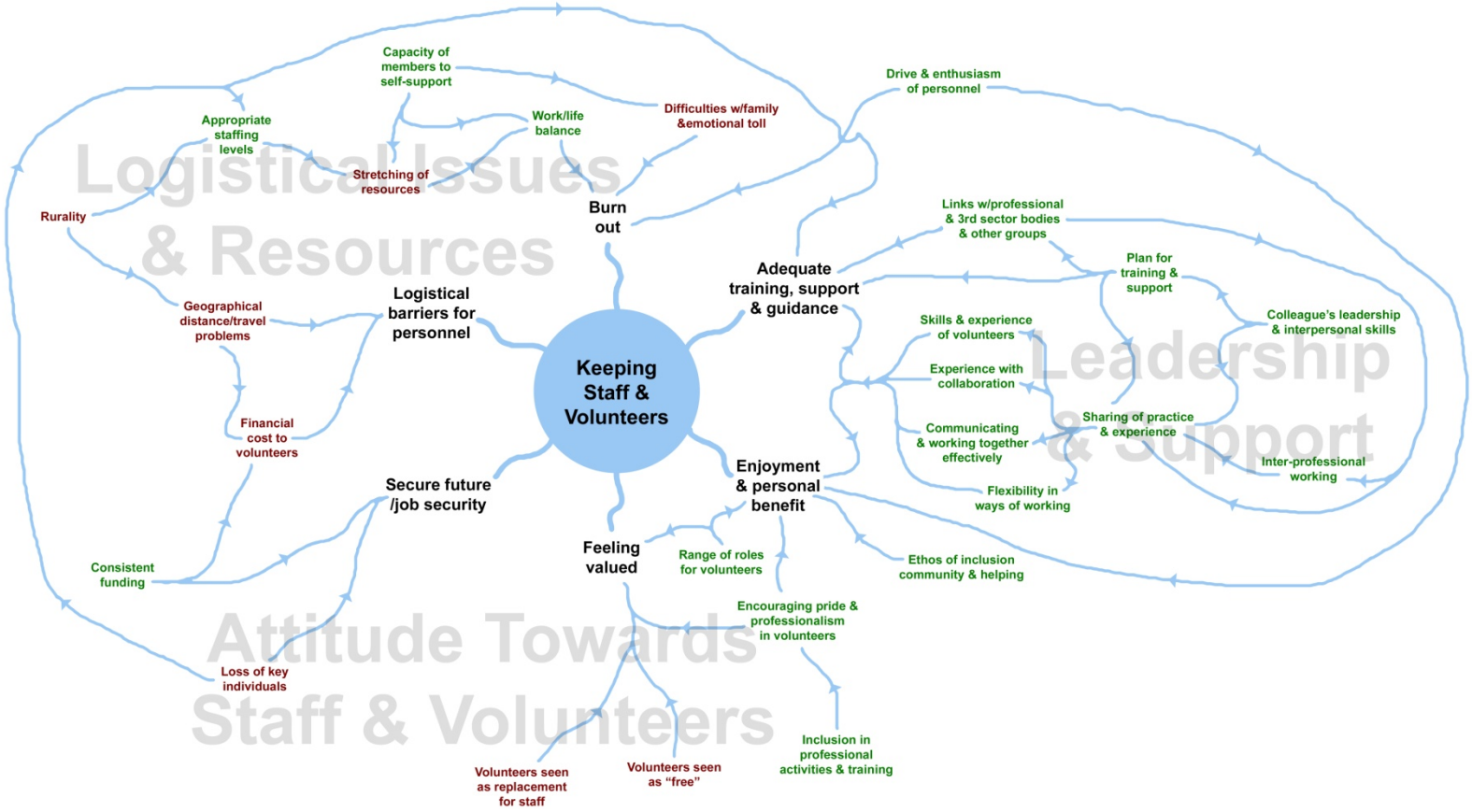
Supplementary file 5: Diagrams of factors involved in each critical area

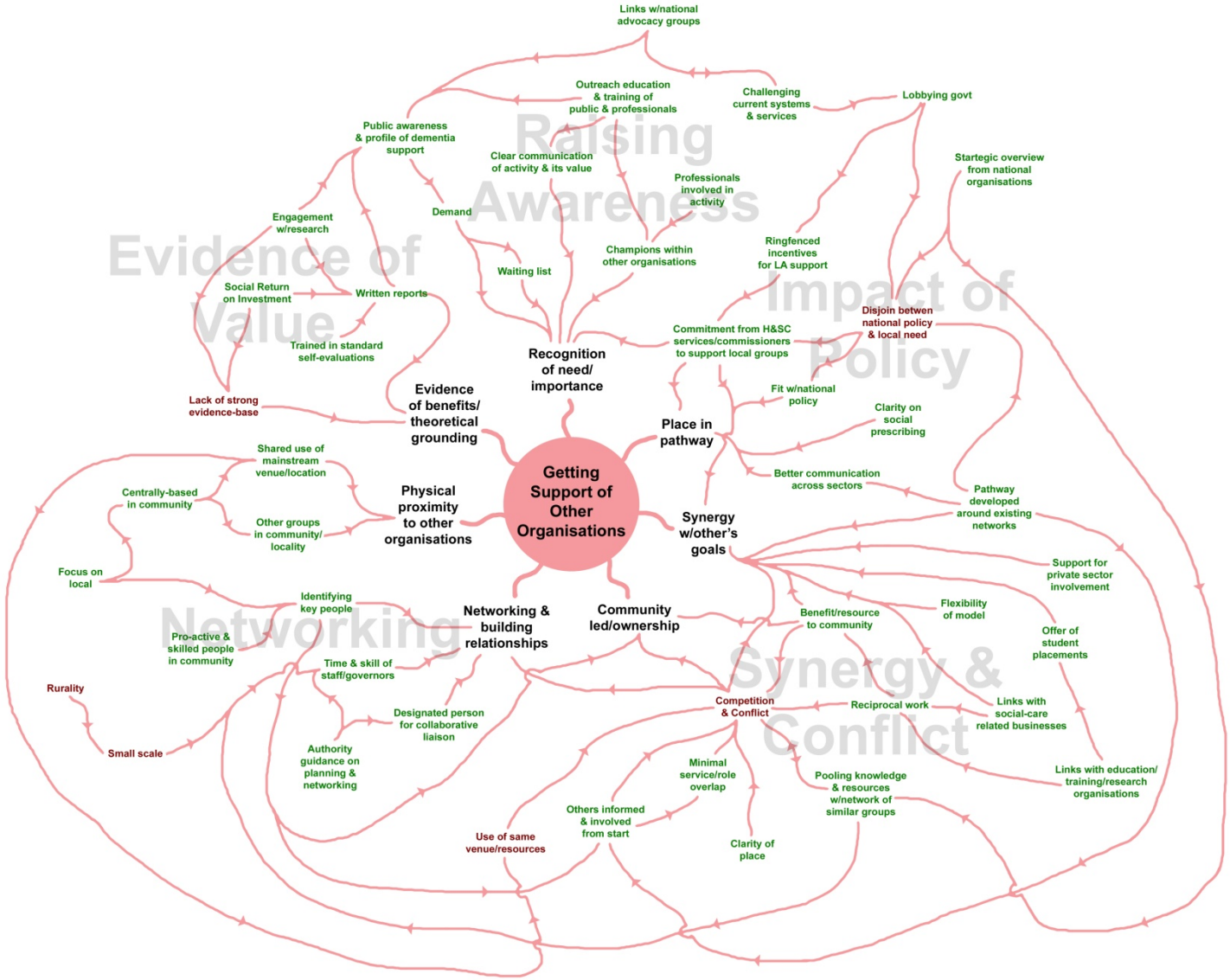
Text colour key: **Black text** = sub-outcome directly impacting upon "getting/keeping" **Green text** = likely to help sub-outcome **Red text** = likely to hinder sub-outcome

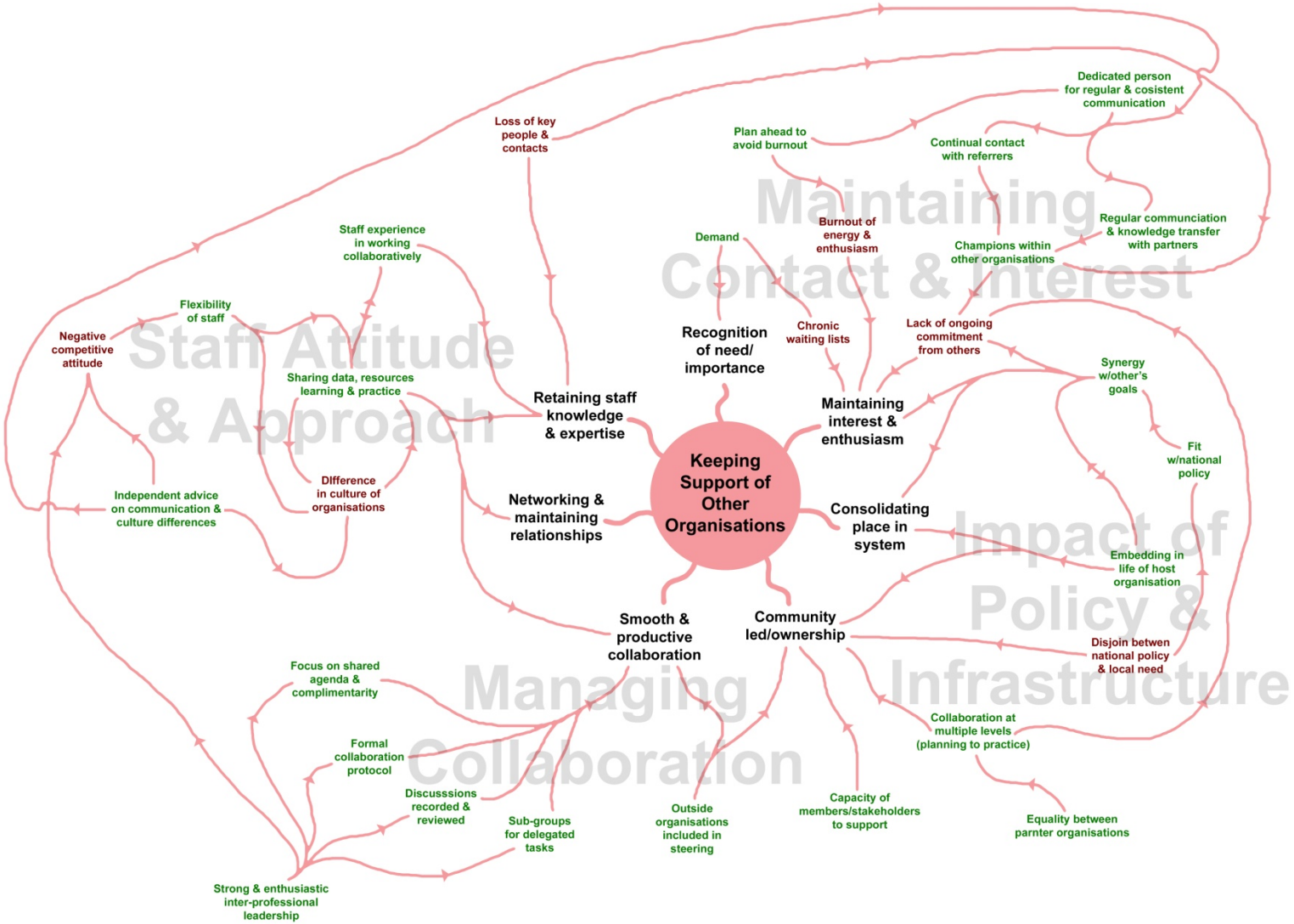



Keeping Members
Meeting Individual Needs
Comfort & Enjoyment
Social Opportunities
Group Cohesion & Support
Transport & Logistical Issues
Appropriate/ "For me"
Comfortable/ Relaxing
Interesting/ Enjoyable
Group cohesion
Providing emotional support
Empowering
Safe, reliable & trusted
Convenient & reliable transport
Fits needs of family/ carer
Physical support
Regular input from members
Ownership
Member-led
Regular input from family
Flexibile & evolving
Plan & review for needs & goals
Tailored programme
Pre-assess members
Attentive to individual needs
Waiting lists for linked servcies
Exit strategy
Small group size
Members not moving on when appropriate
Multiple & adequate spaces at venue
Balance of more able & more in need
Food offer/ communal eating
Freedom of movement
Choice of activities or to sit out
Exclusive focus on activity/agendas
Cosy environment
Not rushed
Unwanted Expectations & Restrictions
Planning to keep activities fresh
Mainstream activities
Conflict between members
Integrated w/ other venue users
Opportunities for social integration outside of group
Links to public amenities
Friendships supported
Opportunities for social interaction
Downtime/Informal time at start & end
Balanced needs of old & new members
Knowledge, empathy respect & interpersonal skills of staff
Feeling valued
Normalcy
Open to guests & family
"Dementia-free zone"
Sense of achievement
Projects for community
Degree of challenge/learning
Input into decisions & tasks
Percieved threat to independence
Perception of commercial motives
Working to tried & tested model
Predictable routine
Stable & reliable provision
Enough facilitators to cover absences
Continuity of staff
Enough opening hours
Dedicated staff to communicate w/families
Regular communication /reminders
Less healthy lifestyle
Skill of staff to mitigate venue limitations
Ability-focus w/tailored support
Not matched w/needs & ability
Adequate & well designed facilities

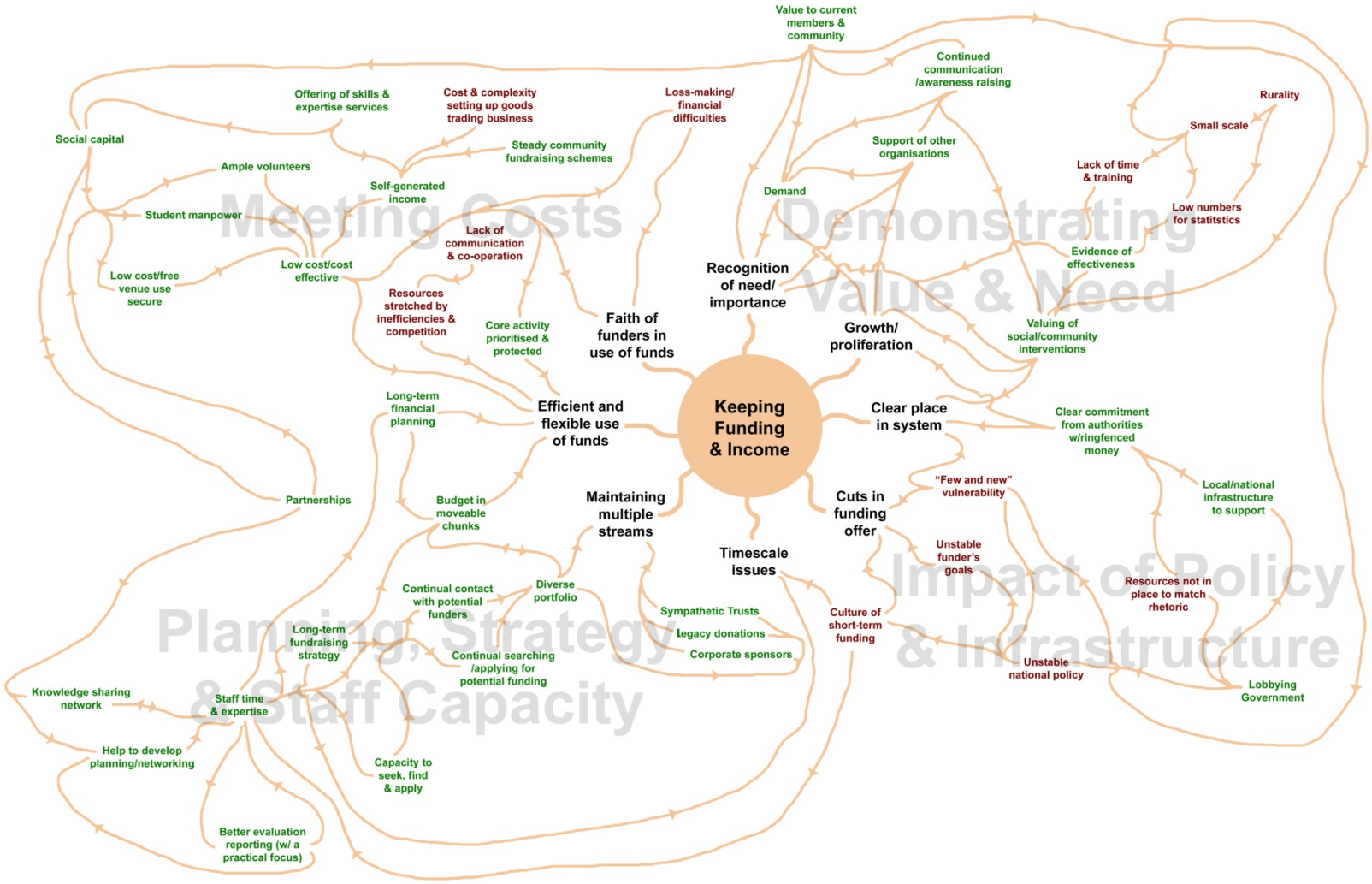

Communication & Outreach
Stakeholder Population
Support of Other Organisations
Getting Staff & Volunteers
Clarity of purpose
Staff dedicated to recruiting volunteers
Paid roles for staff
Supported private sector involvement
Student/ trainee volunteers
Support of other community organisations
Community awareness & trust
Stakeholder population pool
Communication of what group/activity is and does
Communication of value & importance
Welcoming stigma-free ethos
Wide community outreach (talks & training)
Time & personal connections
Rurality
Small, scattered population
Retiree volunteers
Choice & flexibility of roles & responibilities
Roles not requiring specialist skills & experise
Friends & family of members /former members
Funded support worker roles
Local authority support
Existing staff at venue/host organisation
Third sector support
National authority initiatives
Formalised placement schemes
Links w/organisations running H&SC courses
Sharing ideas practice & connections
Links w/existing community groups
No local student body or institution


Keeping Staff & Volunteers
Logistical barriers for personnel
Geographical distance/travel problems
Financial cost to volunteers
Rurality
Appropriate staffing levels
Capacity of members to self-support
Stretching of resources
Work/life balance
Difficulties w/family &emotional toll
Burn out
Secure future /job security
Consistent funding
Loss of key individuals
Feeling valued
Volunteers seen as replacement for staff
Volunteers seen as "free"
Encouraging pride & professionalism in volunteers
Inclusion in professional activities & training
Range of roles for volunteers
Adequate training, support & guidance
Drive & enthusiasm of personnel
Links w/professional & 3rd sector bodies & other groups
Plan for training & support
Skills & experience of volunteers
Experience with collaboration
Communicating & working together effectively
Sharing of practice & experience
Colleague's leadership & interpersonal skills
Inter-professional working
Flexibility in ways of working
Enjoyment & personal benefit
Ethos of inclusion community & helping
Logistical Issues & Resources
Leadership & Support
Attitude Towards Staff & Volunteers


Getting Support of Other Organisations
Evidence of benefits/ theoretical grounding
Recognition of need/ importance
Place in pathway
Physical proximity to other organisations
Synergy w/other's goals
Networking & building relationships
Community led/ownership
Competition & Conflict
Raising Awareness
Evidence of Value
Impact of Policy
Networking
Synergy & Conflict
Links w/national advocacy groups
Outreach education & training of public & professionals
Challenging current systems & services
Lobbying govt
Public awareness & profile of dementia support
Clear communication of activity & its value
Professionals involved in activity
Startegic overview from national organisations
Engagement w/research
Demand
Champions within other organisations
Ringfenced incentives for LA support
Social Return on Investment
Written reports
Waiting list
Disjoin betwen national policy & local need
Trained in standard self-evaluations
Commitment from H&SC services/commissioners to support local groups
Lack of strong evidence-base
Fit w/national policy
Clarity on social prescribing
Shared use of mainstream venue/location
Better communication across sectors
Pathway developed around existing networks
Centrally-based in community
Other groups in community/ locality
Support for private sector involvement
Focus on local
Identifying key people
Flexibility of model
Benefit/resource to community
Offer of student placements
Pro-active & skilled people in community
Time & skill of staff/governors
Rurality
Designated person for collaborative liaison
Reciprocal work
Links with social-care related businesses
Small scale
Authority guidance on planning & networking
Minimal service/role overlap
Pooling knowledge & resources w/network of similar groups
Links with education/ training/research organisations
Others informed & involved from start
Use of same venue/resources
Clarity of place


Keeping Support of Other Organisations
Retaining staff knowledge & expertise
Maintaining interest & enthusiasm
Networking & maintaining relationships
Consolidating place in system
Smooth & productive collaboration
Community led/ownership
Recognition of need/ importance
Loss of key people & contacts
Demand
Burnout of energy & enthusiasm
Chronic waiting lists
Plan ahead to avoid burnout
Dedicated person for regular & cosistent communication
Continual contact with referrers
Champions within other organisations
Regular communciation & knowledge transfer with partners
Lack of ongoing commitment from others
Synergy w/other's goals
Fit w/national policy
Embedding in life of host organisation
Disjoin betwen national policy & local need
Staff experience in working collaboratively
Flexibility of staff
Negative competitive attitude
Sharing data, resources learning & practice
DIfference in culture of organisations
Independent advice on communication & culture differences
Focus on shared agenda & complimentarity
Formal collaboration protocol
Discusssions recorded & reviewed
Sub-groups for delegated tasks
Strong & enthusiastic inter-professional leadership
Outside organisations included in steering
Capacity of members/stakeholders to support
Collaboration at multiple levels (planning to practice)
Equality between parnter organisations
Maintaining Contact & Interest
Staff Attitude & Approach
Impact of Policy & Infrastructure
Managing Collaboration


Getting Funding
Recognition of need/ importance
Perception of viability
Perception of legitimacy
Value for money
Clear place in system
Capacity to seek, find & apply
Timescale issues
Fit with funder's goals
Clarity of communication /awareness of intervention
Ringfenced money for dementia
Funds must be diverted from other services
Acting as link/ gateway for others
Theoretical grounding
Trust of potential members
Demand
"Crowded market"/ Competition
Support of other organisations
Income from producing goods or services
Loss-making/ financial difficulties
Social capital
Ample volunteers
Student manpower
Low cost/free venue use secured
Low cost/cost effective
Partnerships
Rurality
Small scale
Lack of time & training
Low numbers for statitstics
Valuing of social/community interventions
Evidence of effectiveness
Financial incentives for referrers
Clear commitment from local/national authorities
Local/national infrastructure to support
"Falling between stools"
Misalign with local need
Fit with national agenda
Resources not in place to match rhetoric
Lobbying Government
Aims align with corporate sponsor
"Grey pound"
Sympathetic Trusts
Legacy donations
Formal plans & strategy ready
Knowledge sharing network
Help to develop planning/networking
Better evaluation reporting (w/practical focus)
Staff time
Staff expertise
Meeting Costs
Demonstrating Value & Need
Impact of Policy & Infrastructure
Planning, Strategy & Staff Capacity


Keeping Funding & Income
Efficient and flexible use of funds
Faith of funders in use of funds
Recognition of need/ importance
Growth/ proliferation
Clear place in system
Cuts in funding offer
Timescale issues
Maintaining multiple streams
Social capital
Offering of skills & expertise services
Cost & complexity setting up goods trading business
Loss-making/ financial difficulties
Steady community fundraising schemes
Ample volunteers
Self-generated income
Student manpower
Low cost/cost effective
Low cost/free venue use secure
Lack of communication & co-operation
Resources stretched by inefficiencies & competition
Core activity prioritised & protected
Long-term financial planning
Budget in moveable chunks
Partnerships
Value to current members & community
Continued communication /awareness raising
Support of other organisations
Demand
Rurality
Small scale
Lack of time & training
Low numbers for statitstics
Evidence of effectiveness
Valuing of social/community interventions
Clear commitment from authorities w/ringfenced money
Local/national infrastructure to support
"Few and new" vulnerability
Unstable funder's goals
Resources not in place to match rhetoric
Unstable national policy
Lobbying Government
Culture of short-term funding
Sympathetic Trusts
Legacy donations
Corporate sponsors
Diverse portfolio
Continual contact with potential funders
Long-term fundraising strategy
Continual searching /applying for potential funding
Capacity to seek, find & apply
Knowledge sharing network
Staff time & expertise
Help to develop planning/networking
Better evaluation reporting (w/ a practical focus)
Meeting Costs
Demonstrating Value & Need
Impact of Policy & Infrastructure
Planning, Strategy & Staff Capacity

Supplementary file 6: Full list of CMOCs

Getting Members

CMOC 1: If the social aspect of an intervention is emphasised (C), then a wider range of people are likely to be interested (O), as a desire for social connection and activity is more universal than interest in a niche and potentially intimidating activity (M). [40,48,50,57,58,62,64,75]

CMOC 2: If food is offered (C), then people are more likely to attend (O), because the enjoyment of good food is universal and communal eating is associated with comfort, relaxation and social connection (M). [40,59]

CMOC 3: If facilitators are knowledgeable and empathetic, with good interpersonal skills (C), an initiative will be perceived as more welcoming and inclusive (O), as they will be better at understanding needs, engaging and building trust with potential members and their families (M). [36,37,38,39,40,41]

CMOC 4: If an initiative has an informal, unrushed and warm welcome on first visit (C), then people are more likely to want to return (O), as they are more likely to find the experience relaxing and enjoyable, not uncomfortable and intimidating (M). [40,42,43,44,45]

CMOC 5: If potential members have had poor previous experiences with groups or activities (dementia related or not) (C), they may not want to try another group or activity (O), because they think the experience will be similar and will want to avoid it (M). [37,41,46,47]

CMOC 6: If time is taken for personal contact, home visits or taster sessions with potential members (C), then people are more likely to come (O), as they will feel more familiar with the initiative and more trusting of those running it (M). [36,38,47,48,49,50]

CMOC 7: If an initiative is familiar and trusted, or local and well integrated with other organisations in the community (C), then people are more likely to come (O), as its links to familiar things that they trust will make it less intimidating (M). [37,41,42,48,51,52,53,54,55,56]

CMOC 8: If an intervention is based in familiar surroundings in, and open to, the community (C), then people are more likely to come (O), because potential members will find the normalcy, lack of stigma and chance for social integration appealing (M). [38,41,48,52,57,58,59,60,61,62]

CMOC 9: If a venue is dementia-friendly, comfortable and accessible (C), people are more likely to come (O), as they will not have concerns about comfort or access (M). [48,55,63,64]

CMOC 10: If an intervention is recommended by trusted family members and health professionals (C) people are more likely to go (O), as they will trust their judgement that it will be of benefit to them (M). [54,65]

CMOC 11: If discussion/training is held with families, carers and health professionals about their attitudes and beliefs towards dementia (C), they may be more likely to successfully encourage the person they care for to try an intervention (O), because they will understand dementia and be better able to overcome stigma and emotional barriers (M). [36,54,56,65]

CMOC 12: If evidence of an intervention's therapeutic benefits is made clear to families and care partners (C), then people are more likely to attend (O) as families and care partners will have confidence in the intervention so be more likely to encourage them to go (M). [38,41,75,78]

CMOC 13: If there is support for family/care partners alongside the intervention (C) then people are more likely to attend (O), as family and care partners will feel more able and inclined to attend themselves and encourage those they care for (M). [42,48,56,58,76,77,79]

CMOC 14: If an initiative is in a close-knit community with where there is stigma about dementia (C), then people and their families may be put off coming (O), as they may be concerned about confidentially and word of their condition (or that of their family member) getting out (M). [47,56,62,73]

CMOC 15: If an initiative provides enjoyable, meaningful activities (C), then this is likely to attract members (O), as doing them will provide a reason and motive for many to attend initially, even if they stay on for other benefits (M). [41,44,45,50,64,67,70,71,72,83]

CMOC 16: If an initiative provides normalised, mainstream activities (C), then they are likely to attract members (O), as they will have resonance with people's previous interests, experience and history that would like to continue in some form (M). [46,48,57,58,65,67,71,81]

CMOC 17: If an initiative offers a range of different activities and services (C), then people are more likely to attend (O), as the initiative will appeal to a wider range of people with a range of needs (M). [47,48,62,84]

CMOC 18: If potential members' culture, ethnicity and language are acknowledged and catered for within the initiative (C), then they are more likely to come (O), as they will feel more comfortable and valued (M). [47,56,63,69,80]

CMOC 19: If there is a lack of diversity (of members and personnel) or pandering to stereotypes (C), then people may be put off coming (O), as they may have concerns about discrimination and stigma beyond dementia (M). [53,56,70,77]

CMOC 20: If the initiative is run by a religious organisation or in religious venue (C), then people may be put off coming (O), if they are not of that religion or cultural background (M). [56,82]

CMOC 21: If a group is too inclusive when not appropriate (C), this can alienate potential target members (O), as they will feel it will not be focussed on their specific needs (M). [37,60,62]

CMOC 22: If an initiative differentiates activities and roles for members by ability (C), then this can encourage potential members to attend (O), as they will feel there is an appropriate place for them rather than everyone being lumped in together (M). [48,79]

CMOC 23: If an intervention is risk averse or underestimates members' abilities and avoids challenge (C), then potential members will be put off (O), because they will see its activities as too easy, boring or not appropriate for them (M). [63,64,69,73]

CMOC 24: If an intervention is ability-focussed with tailored support and sensitive design of facilities (C), it is more likely to persuade potential members to attend (O) as they will be encouraged and supported to overcome physical impairments and negative attitudes (M). [43,58,62,64,69]

CMOC 25: When an intervention can offer practical advice, information and links to services that can help people (C), then it is more likely to attract members/service users (O), as they will be able to see that it has something to offer them that will meet their most immediate and pressing needs (M). [42,44,45,54,73,85]

CMOC 26: If safe, supported transfer from home to venue can be guaranteed (C), then people will be more likely to come (O), because they will be more likely to overcome any concerns about going out and getting to a group or activity session (M). [36,38,44,45,47,60,64,65,85,73]

CMOC 27: If the transport available isn't appropriate, reliable and respectful of people with dementia (C), then people will not come (O), as will not want to use that transport to get there (M). [37,47,49,64,76,77,82]

CMOC 28: If transport costs are significant and there is no financial support (C), then people will not come (O), as they will not be able to afford the transport costs (M). [36,38,56,59,64,76,78,82]

CMOC 29: If the venue is not in people's own neighbourhoods, is geographically distant or hard to reach (C) then people will not come (O), as they will find it difficult or intimidating to get there (M). [49,60,61,86]

CMOC 30: If an initiative forms links with community and public transport/taxi firms (C), then this will attract members (O), as they will find it less difficult or intimidating to travel to the venue (M). [48,76,77]

CMOC 31: If referrers are not made clearly aware of the added value, target population, ethos and activities of an intervention (C), then they will be less likely to refer appropriately (O), as they will not understand the value of it to their clients (M). [41,51,61,75,79]

CMOC 32: If there is constant contact and collaboration with potential referrers (C), then they are more likely to refer members (O), as they will build a relationship with the intervention that will mean they are better able to understand and remain alert to it (M). [46,51,54,55,74,75,79]

CMOC 33: If PR materials are not available in the right places or presented to people in the right circumstances (C), then they will not try an intervention (O), because they will not access those materials to find out about an intervention's potential value to them (M). [36,47,56,78,82]

CMOC 34: If PR materials are not in an understandable and appropriate format and tone (C), then people will not try an intervention (O), as they will find the materials too off-putting to engage with (M). [38,49,56,61,67,73,74,80]

CMOC 35: If PR materials do not make clear the specifics of an intervention, what to expect and how to attend (C), then people will be less likely to come (O), as they may be anxious due to uncertainties over what they will have to do and its value to them (M). [41,48,51,56,89]

CMOC 36: If an intervention has a stigma-free name that resonates with its target population (C), then people are more likely to come (O), as they will have confidence that they will be treated with respect and not suffer stigma when they go (M). [38,46,56,59,66,72]

CMOC 37: If the local community is fragmented with no local welfare organisation to distribute information (C), then people will be less likely to come (O), as it will be more difficult to get the word out to the right people in the community (M). [37,56,61]

CMOC 38: If in intervention forms links with existing groups, organisations and venues serving same demographic (C), then people will be more likely to come (O), as information and marketing materials will be more likely to reach them (M). [48,54,62,67,83]

CMOC 39: If all those involved in a person's care work together to collate and co-ordinate information (C), then people will be more likely to come (O) as information and marketing materials will reach them more efficiently (M). [36,61]

CMOC 40: If there is a dedicated linking, contact or health care adviser service (C) then people will be more likely to come (O) as information and marketing materials will reach them more efficiently (M). [36,38,44,45,47,56,75,80,88]

CMOC 41: If awareness of the needs of people dementia and of how an intervention can meet them is raised in the community in general (C), then people will be more likely to come (O), as stigma will be reduced and the value of the intervention communicated through word of mouth (M). [36,37,38,46,47,48,51,54,56,59,67,70,83,84,87]

CMOC 42: If GPs were given more incentive and guidance for social prescribing (C), then they would refer more people (O), because they would have a vested interest and confidence in doing so (M). [47,69]

CMOC 43: If there are significant bureaucratic problems with referring (such as chronic waiting lists, area border issues or the need for signed consent) (C), then professionals will be less likely to refer (O), as they will anticipate difficulties that will thwart their attempt to refer (M). [47,61,80,88]

CMOC 44: If GPs do not diagnose dementia until people are at later stages (C), then they will not refer people to community initiatives (O), as they will not see initiatives targeted towards those at earlier stages still able to live at home as appropriate for those they are diagnosing (M). [76,79]

CMOC 45: If an intervention waives the need for a diagnosis and accepts self-diagnosis (C), more people will come (O), as this will encourage a wider range of potential members and avoid excluding people who might benefit (M). [38,57,79,83]

CMOC 46: If an initiative's membership application process is not simple, clear, concise and easy (C), then people will not come (O), as the difficulty in applying will put them off joining (M). [38,44,45,74]

Keeping Members

CMOC 47: If there is group cohesion and mutual trust between members (C), then a group is more likely to sustain (O), because members will feel more solidarity and investment in the group (M). [65]

CMOC 48: If friendships between members are encouraged, recognised and supported by staff and activities (C), then people are likely to keep coming (O), as they will feel more supported, comfortable and engaged, and able to support each other (M). [43,54,66,67,68]

CMOC 49: If an intervention is too focussed on agendas, rules and expectations (C), then people may stop coming (O), because they feel pressured, restricted and unable to relax and enjoy the social and emotional benefits important to them (M). [44,45,63,67,69,70,71]

CMOC 50: If the pace of activity through the day/session is too fast and strict (C), then people may stop coming (O), because they will struggle to stay engaged and will not enjoy themselves (M). [43,48,57,61,72]

CMOC 51: If ample informal time is made for socialising, peer support and feedback (C), then members are more likely to keep coming (O), as they will be more likely to feel comfortable and supported (M). [40,43,48,50,58,62,65,67,69,70,71,72,73,74,75]

CMOC 52: If there is opportunity to have communal eating and relaxing in a "cozy" environment (C), then members are more likely to keep coming (O), as this will provide comfort and foster group cohesion. [40,65]

CMOC 53: If there is regular social integration with others outside of the group (C), then members are more likely to keep coming (O), as they will feel more connected and less stigmatised (M). [38,41,47,48,49,52,54,59,61,62,66]

CMOC 54: If activities are mainstream and involve others without dementia (e.g. family/carers or locals from the community) (C), then members are more likely to keep coming (O), as they will feel activities are more normalised, reducing stigma and increasing enjoyment (M). [37,46,47,48,54,57,61,76]

CMOC 55: If an intervention is treated as a "dementia free zone" where talk is not about a person's condition or medical issues (unless they want to raise them) (C), then people are more likely to keep coming (O), as they will find the environment more normalising and less stigmatising (M). [58,71]

CMOC 56: If an initiative contains projects which enable members to contribute to helping others in the community (C), then people are more likely to keep coming (O), because they will feel valued, useful and empowered (M). [47,67]

CMOC 57: If an initiative has links to existing mainstream public amenities (C), then people are more likely to keep coming (O), as they will recognise it gives them access to wider networks of support and friendship (M). [90]

CMOC 58: If members are involved in group decision-making and setting expectations (C), then people are more likely to keep coming (O), because they will feel ownership and investment in the group and confidence that the group is tailored towards their needs (M). [43,52,65,66,71,74,84]

CMOC 59: If regular feedback meetings are held to "tune" an intervention to the wants and needs of members (C), then people are more likely to keep coming (O), as activities will be kept appropriate and evolve to suit the membership (M). [41,44,45,48,55,67,91]

CMOC 60: If individuals are allowed to make their own decisions about what they do or don't do during a session (C), then they will be more likely to keep coming (O), as they will feel their independence and freedom is respected and their voice heard (M). [36,40,43,63,91]

CMOC 61: If staff treat people respectfully as equals and relate personally (C), then people are more likely to keep coming (O), because they will feel staff and the group as a whole understands them and their needs(M). [40,42,44,45,46,63,65]

CMOC 62: If strategies are planned to review individual progress and involvement (C), then people are more likely to keep coming (O), as they are more likely to remain engaged and feel part of the group as a whole (M). [43,59,74]

CMOC 63: If personnel listen to and act upon regular input from family and caregivers (C), then people are more likely to keep coming (O), as they will appreciate the increased personalisation and sensitivity to their needs (M). [41,59,61,63,91]

CMOC 64: If an initiative does not pay attention to the needs of family and care partners (C), then people are less likely to keep coming (O), because there may be unaddressed logistical difficulties for the family or carers such as fit with work or transport issues (M). [38,44,45,47,54,60,61,73,78]

CMOC 65: If an initiative can open for more hours and help arrange transport (C), then people are more likely to come (O), as this will take the pressure off family members and carers to be flexible and arrange things, and bypass logistical difficulties (M). [44,45,48,49,50,57,78]

CMOC 66: If members who are no longer the target for the intervention stay on because there is no exit strategy or onward service capacity (C), then this can discourage target members from continuing to attend (O), as they may feel the service is too stretched to meet their needs (M). [41,43,61]

CMOC 67: If an initiative does not cater equally both for new members and older members whose condition has progressed (C), then this can discourage one group or the other from continuing to attend (O), as they will feel the initiative is more focussed upon the other group hence not appropriate for them (M). [66,71,75]

CMOC 68: If a group or activity is not matched with members' interests and ability (C), then members may stop attending (O), as they will feel it is not appropriate for them or meeting their needs (M). [46,48,49,78]

CMOC 69: If activities involve a degree of challenge or learning (C), then members may be more likely to keep coming (O), as they will feel empowered and have a sense of achievement (M). [37,47,58,67,71,76]

CMOC 70: If an intervention pre-assesses members and plans strategies to meet their individual needs (C), then members are more likely to keep coming (O), because activities and support will be more likely to be appropriate for them (M). [43,44,45,57,59,60,74]

CMOC 71: If a venue is comfortable, familiar and stable, with adequate space and facilities (C), then people are more likely to keep coming (O), as they will feel relaxed, secure and at home there (M). [43,48,55,63]

CMOC 72: If a venue has multiple spaces within it (C), then people are more likely to feel comfortable there (O), as they will be able to move around and have a choice of activities, environments, social sub-groups or levels of involvement in activity (M). [63,89]

CMOC 73: If sessions are regular, routine and structured (C), then members will be more likely to keep coming (O), as they will feel comfortable and secure in the familiarity and reliability of proceedings (M). [38,40,43,47,48,65,72,73,75]

CMOC 74: If the venue and timings remain reliably the same (C) then members are more likely to keep coming (O), as it will become part of their routine (M). [43,48]

CMOC 75: If there is no continuity of staff or not enough staff to ensure reliable provision (C), then members may be less likely to keep coming (O), as they will find it difficult to have confidence and build trust in the intervention and its staff (M). [36,47,66]

CMOC 76: If an intervention works to a tried and tested model (C), then members are more likely to feel secure (O), as that model will provide a structure that works (M). [61]

CMOC 77: If there are not new ideas and some variety planned across the calendar (C), then members may stop coming (O), because they may feel the group/activities have become stale and boring (M). [37,43,67]

Getting Staff and Volunteers

CMOC78: If an initiative engages in community outreach such as talks and training with other groups and at events (C), then this will help attract volunteers (O), because the initiative's profile will be raised with wide range of stakeholders in the community (M). [46,59,83]

CMOC79: If awareness is raised in the community about the activities and benefits of a what an initiative does (C), then it will be more likely to attract appropriate personnel (O), as potential staff and volunteers will understand its value to service users and what they can do to help (M). [56,61,89,91]

CMOC80: If an initiative has links with like-minded groups (C), then they may get help finding and training staff volunteers (O), as they will be able to share ideas and practice on what is successful (M). [50,91]

CMOC81: If an initiative approaches established community organisations and authorities (third sector, faith or local authority) (C), they are more likely to get help with finding volunteers (O), as these organisations are likely to have access to an existing volunteer workforce or contacts that could help (M). [69,77]

CMOC82: If an initiative has links with professional, third sector or educational bodies (C), they may help with creating a more skilled workforce (O), because they may have the remit provide training for staff and volunteers (M). [80,84]

CMOC83: If an initiative is hosted by a public venue or local club (C), this may help with staffing (O), as the venue or club may have existing staff who can help with running things (M). [48,58,67,69]

CMOC84: If a community has an educational establishment running a health and social-care course (C), this could be a source of volunteers (O), as students/trainees will have the drive and interest to work with social-care-related activities to gain experience (M). [62,65,91,92,93]

CMOC85: If a formal partnership is agreed with an educational establishment (C), this will guarantee regular volunteers during term time (O), as work placements can be formalised as part of students' courses (M). [65,92,93]

CMOC86: If the initiative is in a rural area (C), then it can be more difficult to recruit volunteers (O), as there may be no educational establishment or body of students/trainees to recruit from (M). [53,83]

CMOC87: If the initiative is in a rural area (C), then it may take more time to recruit volunteers (O), as familiarity and personal contacts tend to be more important in small, close-knit communities (M). [83]

CMOC88: If the initiative is in a rural area (C), then it may be more difficult to recruit staff and volunteers (O), as they may not live geographically near members or the venue, presenting extra logistical challenges (M). [53,83]

CMOC89: If a community has a population of active retirees (C), this could be a source of volunteers (O), as they are likely to have time and experience conducive to volunteer work with older people (M). [56]

CMOC90: If there are friends and family of current or previous members/service users that are available (C), this could be a source of volunteers (O), as they will understand the value of the intervention and already be invested in it (M). [56,81]

CMOC91: If there are no specialist elements to the intervention or members with high care needs (C), then personnel do not need to have professional training or expertise (O), as they will still be able to understand and deliver the intervention for the benefit for service users (M). [58,72]

CMOC92: If in intervention has more than one skilled facilitator (C), then it can benefit more members (O), as the workload can be split and more one-on-one support for members offered (M). [71,73,75]

CMOC93: If an initiative's leaders/co-ordinators have good communication and interpersonal skills (C), then it is more likely to be successful (O), as they will engage and inspire other staff and volunteers (M). [38,51,61,79]

CMOC94: If volunteers' availability and interpersonal skills are inconsistent (C), an initiative is less likely to be successful (O), as it will not have a reliable workforce to run it (M). [73]

CMOC95: If funded support worker roles exist (C), then a reliable volunteer workforce is more likely (O), because they can help build a volunteer base (M). [50]

Keeping Staff and Volunteers

CMOC 96: If personnel are flexible and open to new ways of working (C), then they are more likely to work effectively (O), as they will be more likely to collaborate with others, sharing knowledge, experience, innovation, resources and effective working practices (M). [59,60,79,93]

CMOC 97: If personnel have advice or training to boost communication and collaboration skills (C), then they are more likely to work effectively (O), as they will be more able to share knowledge, experience, innovation, resources and effective working practices (both internally and externally) (M). [60,76]

CMOC 98: If personnel are driven and able to deal with stress (C), then they are more likely to continue (O), as they will be able to overcome the challenges and demands of running an intervention (M). [61]

CMOC 99: If facilitators are not able to take time for self-care (C), then they will burn out (O), as running an intervention can be challenging and emotionally demanding (M). [43,75]

CMOC 100: If time is taken to plan strategies for recruitment, training, support, retention and balance of personnel at the start (C), then personnel problems and burn out can be avoided (O), as planners will have thought through the challenges involved and put in place actions to tackle them (M). [70,74]

CMOC 101: If personnel have access to experienced tips and guidance (from materials or individuals) throughout an intervention's start-up period (C), they are more likely to continue (O), as they will be better informed to resolve problems and avoid common pitfalls (M). [37,56]

CMOC 102: If there is an ethos of inclusion, community, camaraderie and helping people (C), then personnel will be more likely to continue (O), as they will feel enjoyment and benefit from this ethos along with members/service users (M). [52,58,75]

CMOC 103: If there are a range of roles and levels of involvement for volunteers (C), they are more likely to be satisfied with volunteering (O), as they can do something that suits them and their abilities that they are comfortable with and interested in (M). [84]

CMOC 104: If volunteers are included in professional activities and training (C), they are more likely to be satisfied with volunteering (O), as they will feel their skills and development are valued by the initiative (M). [38]

CMOC 105: If there is limited and inconsistent funding (C), then an intervention is less likely to be able to retain paid staff (O), because their jobs and the long-term future of the intervention will not be secure (M). [73,79,84]

CMOC 106: If personnel roles are not secure (C), then an initiative is less likely to sustain (O), because turnover will be high and key individuals with key experience and contacts will be lost (M). [67,79,84]

CMOC 107: If volunteers are seen by authorities and commissioners as "coming for free" (C), then they are less likely to continue (O), as they will feel un-valued with their time and expertise taken for granted (M). [87]

CMOC 108: If unpaid volunteers are treated as a replacement for professional staff (C), then staff are less likely to continue (O), as they will feel their roles are undermined and un-valued (M). [51]

CMOC 109: If financial assistance is made available for volunteer groups (C), then they are more likely to continue (O), as they will have the resources and support to run more activities (M). [50]

Getting Support of Other Organisations

CMOC 110: If there is a higher public awareness and profile for people living with dementia (C), then dementia-targeted interventions are more likely to get support from other organisations, services and amenities (O), because there will be more recognition of their importance for society in general (M). [39,84,90]

CMOC 111: If the added value of an intervention is made clear to other organisations (C), then it is more likely to get support and find a place in the local care offer (O), because other organisations will understand it's value to their members/service users (M). [41,42,50,54,55,61,75,79,86]

CMOC 112: If an intervention engages with research and evaluation to gather evidence of benefits (C), then it is more likely to get support (O), because the resulting reports will lend it legitimacy in the eyes of other organisations (M). [37,70,80]

CMOC 113: If it is made clear that an intervention is based upon a strong evidence-based model (C), then it is more likely to get support (O), because that model will lend it legitimacy in the eyes of other organisations (M). [41,79,86]

CMOC 114: If an intervention involves the local community in its steering (C), then it likely to attract further community support (O), as key people and organisations in the community with wider links will feel a sense of ownership and investment (M). [84]

CMOC 115: When there are a range of organisations (e.g. local authority, third sector, faith, business and education) active in the community (C), they may be willing to offer support if asked (O), as they may have a remit to share resources such as venue space and facilities, equipment, training, staff, volunteers or contacts (M). [48,52,58,62,65,67,69,77,80,92,93]

CMOC 116: If an intervention model is flexible (C), then it has a better chance of finding support (O), as it can accommodate being run at a range of venue types in, a range of ways, by a range of host organisations (M). [69,71,72,75]

CMOC 117: If an existing social care business is approached (C), they may support, host or partner an intervention (O), as it may help them attract clients/customers (M). [75]

CMOC 118: If training and guidance is available from a public or third sector authority (C), this may help gain further support (O), as it will help an intervention develop its skills and expertise in marketing, networking and outreach (M). [46]

CMOC 119: If an intervention is based in a civic centre or public venue (C), then it is more likely to get support from other local organisations (O), because it will be visible to others sharing that space (M). [59,79]

CMOC 120: If an intervention focuses on building links with local organisations and services (C), it is more likely to get support (O), as it is easier to bring together a network of those who are already invested in the same community and some links will already exist (M). [41,42,62]

CMOC 121: If an intervention is run at a public venue or local club (C), then links with others in the community are easier to forge (O), as there will be an existing network of venue/club users and contacts that the intervention can access (M). [41,48,58,62]

CMOC 122: If a group or activity is small scale (C), then it can be hard to get support (O), as it is more difficult for them to network with larger organisations, authorities, movers and shakers (M). [77]

CMOC 123: If struggling groups in the same area merge (C), they can support each other (O), because they can pool resources, personnel, knowledge and ideas (M). [67]

CMOC 124: If links are forged with a national network of similar interventions (C) then they can support each other (O), because they can pool resources, knowledge, contacts and strategy (M). [42]

CMOC 125: If a locality has other organisations working with the same target population (C), then in intervention may struggle to get support (O), as those other organisations and their supporters may perceive the intervention as competition (M). [41,79]

CMOC 126: If an intervention has a clear place in the local offer without service/role overlap (C), then it is more likely to get the support of others (O), because they will see it as complimenting their service not competing with it (M). [42,51]

CMOC 127: If other organisations are informed, invited to meetings and asked for help and advice early on (C), then an intervention is more likely to get the support (O), because they will feel respected and invested in the success of the new intervention (M). [51,61,79,84]

CMOC 128: If groups involve professionals already working with individual members (e.g. case workers, carers) in activities (C) then they are more likely to increase support from professional services (O), because professionals will understand the value of the intervention to their service-users and feel invested in its success (M). [79]

CMOC 129: If an intervention acts as a hub for/gate/link to other services and is tuned to dovetail with them (C), then it is more likely to get the support of those services (O), because they will see the intervention as being of help to them (M). [42,60,61,72,86,88]

CMOC 130: If an intervention offers a benefit or resource to the wider community (C), then it is more likely to get the support of other community organisations (O), as they will see it as benefiting their members/service users (M). [41,46,67,70]

CMOC 131: If an intervention offers to do reciprocal work, sharing knowledge and resources with other organisations (C), then it is more likely to get their support (O), as they will see the benefit to working together (M). [41,46,67,70]

CMOC 132: If there is a disjoin between national policy and local need (C), then initiatives can struggle to get and keep support (O), because by adhering to one they will neglect the other, alienating would-be supporters (M). [51]

CMOC 133: If there were ring-fenced funding to support dementia-targeted community initiatives as part of national policy (C), then small, local initiatives would get support (O), as there would be incentives for health services and LAs to help them (M). [39,59,69]

CMOC 134: If health and social care authorities commissioned services to work with community initiatives (C), then small, local initiatives would get support (O), because it would ensure the collaboration of services and organisations at different levels (M). [47,50,77]

CMOC 135: If health pathways were developed around existing social networks (C), then small, local initiatives would get support (O), as it would encourage more community collaboration and co-production with health services (M). [47]

CMOC 136: When national and official organisations take the lead in working with small, local initiatives (C), this helps more consistent provision of local services across regions (O), because there is more joined-up strategic direction of what is on offer and available (M). [39,50]

CMOC 137: When national and official organisations show support for the involvement of private sector partners (C), then small, local initiatives are more likely to get support (O), as it provides private sector organisations with the incentive, tools and guidance to work in partnership (M). [39]

Keeping Support of Other Organisations

CMOC 138: If communication is not maintained (C), then support of others can drop away (O), as interest and enthusiasm may dwindle in tandem with an intervention's contact and visibility to its collaborators (M). [41,55]

CMOC 139: If information sharing and knowledge transfer is not maintained (C), then support of others can drop away (O), as communication and administration problems may arise between collaborating parties (M). [44,45,77]

CMOC 140: If there is a designated person with responsibility for regular and consistent communication with other organisations (C), then continued support is more likely (O), as they will have the time to pay attention to maintaining collaborative working, and build experience and relationships with key people in doing so (M). [41,50]

CMOC 141: If relationships with key people in other organisations are maintained (C), then support of those organisations is more likely to continue (O), as an intervention will create "champions" within those organisations (M). [39,51]

CMOC 142: If staff turnover (internal and external) is high (C), then support can be lost (O), because communication and relationships with contacts and "champions" can suffer due to the loss of key personnel (M). [67,79,84]

CMOC 143: If there is a difference in culture between collaborating organisations (C), then effective support can be hindered (O), as personnel from each organisation will not be working with the same focus and goals (M). [41,51,79]

CMOC 144: If groups or sectors have a negative or competitive attitude towards each other (C), then effective support can be hindered (O), as it creates problems sharing data, learning and resources (M). [41,76,77]

CMOC 145: If an intervention makes effort to learn about and embed in the life of a supporting organisations (C), then it is more likely to maintain support (O), as it will understand that host organisation better and share the same goals (M). [70]

CMOC 146: If staff (internal and external) are experienced in working collaboratively (C), then an intervention is more likely to maintain support (O), as staff will be more skilled, flexible and understanding when working with those from another organisation (M). [79]

CMOC 147: If independent advice on communication (internal and external) and collaboration is available (C), then an intervention is more likely to maintain support (O), as leaders, staff and volunteers will become more skilled at networking and working together while overcoming differences in culture (M). [60,79]

CMOC 148: If there are multiple forms of strong inter-professional leadership (C), then collaboration is likely to be more successful (O), because there will be mutual learning with leaders setting an example for others to follow (M). [51,59,79,86]

CMOC 149: If time is taken to plan well early on (C), then support from others is more likely to be maintained (O), as personnel will have thought through the challenges involved in maintaining energy and enthusiasm and put in place actions to tackle them (M). [70]

CMOC 150: If there is a steering group including outside organisations (C), then support is more likely to be maintained (O), as steering will include a focus on shared agenda and complementarity with outside organisations (M). [51]

CMOC 151: If a partnership is not equal and collaborating at all stages, from planning to practice (C), then this could hinder support (O), as one party may feel the other is not contributing what it should while the other feels dictated to, creating friction (M). [44,45]

CMOC 152: If a collaboration protocol with supporting organisations is drafted and discussions logged and reviewed (C), then support is more likely to be maintained (O), because all parties will have the chance air and resolve issues and have clarity over expectations and mutual goals (M). [41,44,45,61,70]

Getting Funding and Income

CMOC 153: If potential funders are not clear on what a service/intervention is and does (C), then they will be less likely to fund it (O), because they do not understand its purpose or value (M). [89]

CMOC 154: If potential funders are made aware of the added value and benefit of an intervention (C), then they will be more likely to fund it (O), because they will recognise it has something uniquely valuable to offer service users (M). [61,70]

CMOC 155: If communication and publicity is regularly disseminated to potential funders (C), then they are more likely to fund in the future (O), as they will be familiar with and alert to the work of an intervention (M). [94]

CMOC 156: If recognised and standardised materials (e.g. Alzheimer's Society materials, PQASSO or Social Return on Investment evaluation) are used to gather and communicate evidence of worth (C) then funders are more likely to fund (O) as they will see that evidence as more legitimate than anecdotal accounts (M). [80]

CMOC 157: If potential funders are made aware of links with and support from other organisations (C), then they're more likely to fund (O) because they are likely to view the support of others as adding legitimacy to a community initiative (M). [70]

CMOC 158: If corporate organisations are made aware of how an intervention aligns with its aims (C), then they will be more likely to sponsor or donate (O), as they will feel supporting that intervention helps progress their goals (M). [94]

CMOC 159: If an intervention develops its skill in networking and communicating with other organisations (C), then it is more likely to find funding (O), as it will learn of funding opportunities through a wider network of support and contacts (M). [46]

CMOC 160: If awareness of the wants and needs of people with dementia is raised in society in general (C), then funders are more likely to support a dementia-targeted initiative (O), as they are more likely to recognise that it meets the needs of service-users (M). [39,46]

CMOC 161: If there is demand for an intervention from service users and referrers (C), then funders are more likely to fund (O), as they will recognise that it is meeting people's needs (M). [46]

CMOC 162: If potential members/service users are not clear on what a service/intervention is and does (C), then they will be less likely to try it (O), because they do not understand it's purpose or value to them (M). [41,51,56,89]

CMOC 163: If potential referrers are not clear on what a service/intervention is and does (C), then they will not refer people to it (O), because they do not understand its purpose or value to their service users (M). [41,51,61,75,79]

CMOC 164: If an intervention is perceived as more expensive than alternatives on offer without offering significant added value (C), funders will be less likely to fund (O), as they will not see it as value for money (M). [79,80,87,95]

CMOC 165: If an initiative is perceived as having financial difficulties (C), potential funders are less likely to fund (O), as they will see it as a high risk funding decision (M). [56,61]

CMOC 166: If an initiative has co-operative working arrangements with other community organisations (C), then this can help keep costs low (O), as they can agree to share resources (venue, personnel, equipment, training etc.) (M). [70,75,76,78,80,93]

CMOC 167: If an initiative can generate some income through offering services to others(C), then funders are more likely to have confidence in it (O), as they will perceive it be to more viable (M). [94]

CMOC 168: If funders are made aware of the support from other organisations for a new initiative (C), they are more likely to fund (O), as they will perceive the initiative as being more viable due to that support (M). [70]

CMOC 169: If initiative can act as a gate/link for other services and community organisations (C), then it is more likely to get funding (O), as it will be seen as of value to enhancing existing services and organisations (M). [60,61]

CMOC 170: If intervention personnel have good, up-to-date knowledge of funding processes and policy (C), they are more likely to get funding (O), because they will understand how to plan and implement an effective strategy to seek and find it (M). [55,61,86]

CMOC 171: If like-minded groups share successful ideas (C), they are more likely to find funding solutions (O), because they will be able to learn from each other about what works or doesn't work (M). [80,91]

CMOC 172: If interventions include more practical detail on resources, costs and funding as part of standard reporting/evaluation (C), then others in the future will be more likely to find funding solutions (O), as they can learn from the experience of others about what works or doesn't work (M). [37]

CMOC 173: If authoritative help is available to develop personnel's expertise regarding business planning and networking (C), then an intervention is more likely to find funding solutions (O), because personnel will be better at developing and implementing a strategy to do so (M). [46]

CMOC 174: Ifan intervention has a realistic strategy to attract donations and grants (C), then it is more likely to find funding solutions (O), as personnel will have thought through the challenges involved and put in place actions to tackle them (M). [94]

CMOC 175: If an intervention has a business case ready (C), then it is more likely to secure funding (O), as it will be able to respond quickly when a window of opportunity opens with a potential funder (M). [60]

CMOC 176: When an initiative is in a more rural area (C), it is likely to be small scale with fewer members/service users (O), because the population is geographically diffuse without the infrastructure to gather together easily (M). [84]

CMOC 177: If an initiative is small-scale (C), it will not be able to robustly demonstrate demand, effectiveness and H&SC savings (O), because it's number or members/service users will not be enough to capture robust evidential statistics (M). [84]

CMOC 178: If funders demand robust statistical evidence before funding (C), then small and rural groups and activities will be disadvantaged (O), because they will not have the numbers and resources to produce this (M). [50,84,91]

CMOC 179: If an initiative is small-scale (C), it will be disadvantaged in securing funding (O), as it will have fewer personnel with more limited time and resources to continually apply (M). [84]

CMOC 180: If an intervention is aligned with national agenda (C), then it is more likely to get funding (O), because the policy and infrastructure will be in place to support it (M). [42,55,59,84]

CMOC 181: If national policy is not consistent with local need (C), then local groups serving those needs will struggle to attract funding (O), as funders will not see their cause as a priority (M). [41,51,84]

CMOC182: If the national (and by extension funders') agenda focuses on medical needs and costs over social and emotional needs (C), then community-focussed groups and activities will struggle to get funding (O), as funders will not understand their benefits or see their cause as a priority (M). [77,80,86,91,95]

CMOC 183: If intervention providers, service users and families speak out about their needs (C), providers may be more likely to get funding for local community-focussed services (O), as authorities will feel pressure to change the national agenda to meet people's needs (M). [96]

CMOC 184: If resources are not allotted and ring-fenced to match changes in national or local policy (C), there will be no benefit to community interventions (O), as funders will not have the resources to invest in making a difference in practice (M). [39,50,76,87]

Keeping Funding and Income

CMOC 185: If communication and publicity is regularly disseminated to funders (C), then they are more likely to fund again in the future (O), as they will be kept informed and alert to the continuing work and benefits of an intervention (M). [94]

CMOC 186: If publicity and networking is pared back to cut costs (C), this could negatively impact changes of finding continued funding (O), as an intervention will drop off funders' "radar" and risk being forgotten or overlooked (M). [94]

CMOC 187: If funders are made aware of a growth in demand for an intervention from service users and referrers (C), then they are more likely to continue to fund (O), as they will recognise that it is meeting people's needs (M). [46,55]

CMOC 188: If funders are made aware of accruing evidence of the added value and benefit of an intervention (C), then they will be more likely to fund it (O), because they will recognise it has something uniquely valuable to offer service users (M). [61,70]

CMOC 189: If groups and organisations do not communicate and work together (C), then existing funds will not go as far (O), as available financial resources will be split and lost on inefficiencies and duplication of services (M). [76]

CMOC 190: If an initiative has co-operative working arrangements with other community organisations (C), then this can help keep costs low (O), as they can agree to share resources (venue, personnel, equipment, training etc.) (M). [70,75,76,78,80,93]

CMOC 191: If an initiative has multiple and diverse income streams (C), then it is more likely to maintain a proportion funding (O), because if one stream stops, others will still be available. [70,80,84]

CMOC 192: If an initiative's budget is broken down into identified parts (C), then it is more likely to be able to weather changes in funding (O), as what can be used to pay for what is more flexible, and core activity can be prioritised (M). [70,84,94]

CMOC 193: If financial planning is done with a focus on the long-term (C), then an initiative is more likely to weather changes in funding (O), as it will be able to spread existing funds more effectively by allotting spending carefully (M). [44,45,70]

CMOC194: If an intervention has a realistic strategy to continually attract donations and grants (C), then it is more likely to find funding solutions (O), as personnel will have thought through the challenges involved and put in place actions to tackle them (M). [94]

CMOC 195: If there is no long-term funding available (C), this will place significant demands on the time and resources of personnel (O), because they will need to continually seek and apply for fresh funding (M). [84]

CMOC 196: If an initiative is small-scale (C), it will be disadvantaged in continuing to secure funding (O), as it will have fewer personnel with more limited time and resources to continually seek and apply (M). [84]

CMOC 197: If an initiative continually and systematically seeks new income streams (C), then it is more likely to maintain a proportion funding (O), because if one stream stops, it will be more likely to have multiple other streams available (M). [70,80,84]

CMOC 198: If funders objectives are always short-term and keep changing (C), then deep learning on what works for services users and communities will be lost (O), as "quick win" projects will be encouraged over support for existing and experienced initiatives (M). [51,79]

CMOC 199: If funders only support short-term or new projects (C), then initiatives will struggle to become established long-term (O), as they will be unable to plan ahead with confidence or have time to learn how activity can be supported sustainably (M). [77,86,87]

CMOC 200: If resources are not allotted and ring-fenced to match changes in national or local policy (C), there will be no benefit to community interventions (O), as funders will not have the resources to invest in making a difference in practice (M). [39,50,76,87]

CMOC 201: If intervention providers, service users and families speak out about their needs (C), providers may be more likely to get funding for local community-focussed services (O), as authorities will feel pressure to change the national agenda to meet people's needs (M). [96]

RAMESES publication standards (realist synthesis) checklist

(After BMC Medicine 2013, 11:21 http://www.biomedcentral.com/1741-7015/11/21)

Items required when reporting a realist synthesis			Reported on page(s)
1		In the title, identify the document as a realist synthesis or review	1,2
ABSTRACT			
2		While acknowledging publication requirements and house style, abstracts should ideally contain brief details of: the study's background, review question or objectives; search strategy; methods of selection, appraisal, analysis and synthesis of sources; main results; and implications for practice.	2
INTRODUCTION			
3	Rationale for review	Explain why the review is needed and what it is likely to contribute to existing understanding of the topic area.	4
4	Objectives and focus of review	State the objective(s) of the review and/or the review question(s). Define and provide a rationale for the focus of the review.	5
METHODS			
5	Changes in the review process	Any changes made to the review process that was initially planned should be briefly described and justified.	N/A
6	Rationale for using realist synthesis	Explain why realist synthesis was considered the most appropriate method to use.	6
7	Scoping the literature	Describe and justify the initial process of exploratory scoping of the literature.	6-7
8	Searching processes	While considering specific requirements of the journal or other publication outlet, state and provide a rationale for how the iterative searching was done. Provide details on all the sources accessed for information in the review. Where searching in electronic databases has taken place, the details should include, for example, name of database, search terms, dates of coverage and date last searched. If individuals familiar with the relevant literature and/or topic area were contacted, indicate how they were identified and selected.	7-8
9	Selection and appraisal of documents	Explain how judgements were made about including and excluding data from documents, and justify these.	8-9
10	Data extraction	Describe and explain which data or information were extracted from the included documents and justify this selection.	8-9
11	Analysis and synthesis processes	Describe the analysis and synthesis processes in detail. This section should include information on the constructs analyzed and describe the analytic process.	9
RESULTS			
12	Document flow diagram	Provide details on the number of documents assessed for eligibility and included in the review with reasons for exclusion at each stage as well as an indication of their source of origin (for example, from searching databases, reference lists and so on). You may consider using the example templates (which are likely to need modification	8

Items required when reporting a realist synthesis			Reported on page(s)
		to suit the data) that are provided.	
13	Document characteristics	Provide information on the characteristics of the documents included in the review.	10
14	Main findings	Present the key findings with a specific focus on theory building and testing.	10-14
DISCUSSION			
15	Summary of findings	Summarize the main findings, taking into account the review's objective(s), research question(s), focus and intended audience(s).	14-15
16	Strengths, limitations and future research directions	Discuss both the strengths of the review and its limitations. These should include (but need not be restricted to) (a) consideration of all the steps in the review process and (b) comment on the overall strength of evidence supporting the explanatory insights which emerged. The limitations identified may point to areas where further work is needed.	15-16, 17-18
17	Comparison with existing literature	Where applicable, compare and contrast the review's findings with the existing literature (for example, other reviews) on the same topic.	16-17
18	Conclusion and recommendations	List the main implications of the findings and place these in the context of other relevant literature. If appropriate, offer recommendations for policy and practice.	16-18
19	Funding	Provide details of funding source (if any) for the review, the role played by the funder (if any) and any conflicts of interests of the reviewers.	19-20

BMJ Open

Sustaining community-based interventions for people affected by dementia long term: The SCI-Dem realist review

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2020-047789.R2
Article Type:	Original research
Date Submitted by the Author:	30-Mar-2021
Complete List of Authors:	Morton, Thomas; University of Worcester, Association for Dementia Studies Wong, Geoff; Oxford University, Nuffield Department of Primary Care Health Sciences Atkinson, Teresa; University of Worcester, Association for Dementia Studies Brooker, Dawn; University of Worcester, Association for Dementia Studies
Primary Subject Heading:	Health services research
Secondary Subject Heading:	Geriatric medicine, Health policy, Mental health, Public health, Sociology
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Organisation of health services < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Dementia < NEUROLOGY, Old age psychiatry < PSYCHIATRY, SOCIAL MEDICINE

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Sustaining community-based interventions for people affected by dementia long term: The SCI-Dem realist review

Authors:

Thomas Morton, Association for Dementia Studies, University of Worcester, Worcester, UK.

Geoffrey Wong, Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK.

Teresa Atkinson, Association for Dementia Studies, University of Worcester, Worcester, UK.

Dawn Brooker, Association for Dementia Studies, University of Worcester, Worcester, UK.

Corresponding Author:

Professor Dawn Brooker, Director of the Association for Dementia Studies, School of Allied Health and Community, University of Worcester, Henwick Grove, Worcester WR2 6AJ.

Email: *d.brooker@worc.ac.uk*. Tel: 01905 855250

Sustaining community-based interventions for people affected by dementia long term: The SCI-Dem realist review

Thomas Morton[1] Geoffrey Wong[2] Teresa Atkinson[1] Dawn Brooker[1]

ABSTRACT

Objectives: Community-based support for people with earlier-stage dementia and their care partners, such as regularly-meeting groups and activities, can play an important part in post-diagnostic care. Typically delivered piecemeal in the UK, by a variety of agencies with inconsistent funding, provision is fragmented and many such interventions struggle to continue after only a short start-up period. This realist review investigates what can promote or hinder such interventions in being able to sustain long term.

Methods: Key sources of evidence were gathered using formal searches of electronic databases and grey literature, together with informal search methods such as citation tracking. No restrictions were made on article type or study design; only data pertaining to regularly-meeting, ongoing, community-based interventions were included. Data were extracted, assessed, organised and synthesised and a realist logic of analysis applied to trace context-mechanism-outcome configurations as part an overall programme theory. Consultation with stakeholders, involved with a variety of such interventions, informed this process throughout.

Results: Ability to continually get and keep members; staff and volunteers; the support of other services and organisations; and funding/income were found to be critical, with multiple mechanisms feeding into these sub-outcomes, sensitive to context. These included an emphasis on socialising and person-centredness; lowering stigma and logistical barriers; providing support and recognition for personnel; networking, raising awareness and sharing with other organisations, while avoiding conflict; and skilled financial planning and management.

Conclusions: This review presents a theoretical model of what is involved in the long-term sustainability of community-based interventions. Alongside the need for longer-term funding and skilled financial management, key factors include the need for stigma-free, person-centred provision, sensitive to members' diversity and social needs, as well as the need for a robust support network including the local community, health and care services. Challenges were especially acute for small-scale and rural groups.

Article Summary

- This review brings together transferrable learning from a wide range of intervention types on a topic that has received little formal, integrated research attention, to deepen our understanding on how such interventions could be implemented and supported to sustain more universally and consistently across the sector.
- This review's realist approach is well suited to accommodate and account for the complexity of such 'real life' intervention programmes, as implemented under different conditions in different settings, to extract transferable conclusions.
- This review was designed to gather evidence regarding how interventions can be sustained, not on the efficacy/effectiveness of interventions of this type, hence conclusions regarding the latter are beyond its scope.
- Literature was limited as this research question is not commonly the main focus of study in dementia care research.
- Not all data were equal in depth and detail or the highest empirical rigour, rather they contributed together in a way that was useful to an overall programme theory that will benefit from further refinement and revision with empirical testing in subsequent research.

Keywords

Dementia; Post-diagnosis; Peer support; Psychosocial; Implementation

INTRODUCTION

Supporting people with dementia and their carers to live as well as possible in their communities, with timely psychosocial support, is a global public health goal,[1] though remains a challenging aspiration in many countries. In the UK, with an aging population[2] and increasing pressure on already-stretched health services[3] 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, support for family carers and better integrated care (involving the voluntary and independent sectors) – all in a more dementia-friendly community environment – are contemporary UK Government priorities for dementia care.[4]

Support following a diagnosis of dementia is patchy,[4] however, with families in some areas lacking any formal proactive support for those with less severe symptoms beyond occasional contact with primary care and third sector. There are significant gaps in social care for people affected by dementia across the UK.[5 6 7] 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[6] and in some areas has "broken down" creating "care deserts".[5] There is an associated reliance on informal carers (e.g. family members) but there is a growing recognition that informal carers' own health and wellbeing is often negatively impacted by their caring activities.[6] The detrimental health impact of social isolation and loneliness is also increasingly being recognised,[8 9] with survey data revealing nearly 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.[7] Family carers can also be subject to such loneliness and isolation.[10] This situation has only been exacerbated by the recent impact of COVID-19,[11] bringing the need for groups and activities that provide social connection and support for people and families affected by dementia into stark relief.

There have been various attempts to mitigate these challenges in communities across the country, in the form of groups and activities for people with dementia and family carers. These aim to serve a number of functions: peer support, companionship and help for people to reintegrate with their communities; delivery of professional support, psychosocial interventions and physical exercise; a point of contact, signposting and referral for other services; or raising awareness and acting as a dementia-friendly community hub. The benefits of such community-based initiatives are now being recognised.[12 13 14 15 16] There is evidence that regular social activity, where people are able to leave their homes and gather together in a communal setting on a frequent and ongoing basis, can be helpful both for people living with dementia and the people who care for them.[12 13 17 18 19] With care systems unprepared for the forecasted UK doubling of the number of people living with dementia (1.6 million) and tripling of social care costs by 2040,[20] improving provision of evidence-based community initiatives for people with dementia, and their families, is imperative.[12 13 14 15 16 21 22] However, even prior to the 2020 pandemic restrictions, such initiatives, groups and activities already faced a variety of challenges with long-term sustainability. 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.

This realist review aims to deepen our understanding of what can help or hinder the long-term sustainability of regularly meeting, place-based community interventions, such as groups and activities, for people affected by dementia. It aims to use data gathered as the basis of evidence-informed recommendations for policy and practice.

METHODS

This review was conducted from December 2018 to December 2020. A project protocol was registered with PROSPERO in March 2019[23] and the protocol was published in this journal in June 2019.[24]

The realist review is an interpretive, theory-driven approach to synthesising evidence from a range of sources, including qualitative, quantitative and mixed-methods research.[25] This approach is designed to accommodate and account for the complexity of 'real life' intervention programmes, as implemented under different conditions in different settings, aiming to explain how and why context can influence outcomes.[26] Hence it is well suited to extracting transferable lessons from reviewing the functioning and success (or otherwise) of a range of community-based interventions for people affected by dementia, as these are likely to involve a high level of complexity and be responsive to contextual factors which are likely to vary considerably from intervention to intervention. Data was gathered and synthesized, with a realist logic of analysis applied to identify causal chains involving different contexts, mechanisms and outcomes that can in turn affect an initiative's long-term sustainability. We define context as the conditions that trigger or modify the behaviour of mechanisms;[27] mechanisms are the usually-hidden processes that generate outcomes, defined as "underlying entities, processes, or structures which operate in particular contexts to generate outcomes of interest.";[28] outcomes can be "either intended or unintended and can be proximal, intermediate, or final"[27] and in this review refer to any identifiable result (of the interaction between contexts and mechanisms) that can directly have a bearing on an intervention's ability to sustain long term.

Our review followed Pawson's five iterative stages[29] as outlined below.

Step 1: Locating existing theories

This initial step was to identify and gather existing ideas around what can help or hinder the sustainability of a group or activity, from those who have first-hand experience of them. In line with realist review guidelines (RAMESES),[30] stakeholders were contacted by TA and TM and consulted for input at points throughout the project. These stakeholders were lay experts involved with community-based interventions in various capacities, whether commissioning, leading, running, supporting or attending. In the first instance a workshop was held in March 2019 with a group of 13

invited stakeholders to gather their content expertise on barriers and facilitators to engagement and sustainability. Eight others were subsequently consulted by TM individually, in person, by telephone or by email. Input was also taken by TA and TM from members and facilitators of various local DEEP (Dementia Engagement and Empowerment Project)[31] groups at a national meeting in June 2019, and TM also visited three community groups in Herefordshire, Oxfordshire and Wolverhampton. In addition, an exploratory search of the literature was conducted by TM, using informal methods such as citation tracking and snow-balling[32] along with informal scoping searches[33] and the gathering of relevant publications and materials recommended by stakeholders. Together, this contributed towards the building of an initial theoretical model, or *programme theory*, with the guidance of GW, prior to our main search, both to inform our formal search strategy and to be tested and refined by the data subsequently found. This model began as two diagrams (one regarding engagement, one regarding sustainability), drawn up by TM and TA by batching issues raised at the March workshop, and possible links between them. These diagrams were then discussed, altered and added to iteratively over four months as new stakeholder input became available (these can be seen in Supplementary file 1). These diagrams were speculative so kept deliberately broad and fluid in focus, as a work in progress. Detailed analysis of possible context-mechanism-outcome configurations (CMOCs) was not considered appropriate at this stage, as: 1) Not enough data had been gathered; 2) This would be both labour intensive and too limiting for a model whose purpose was only as a steering guide to inform the review proper, yet to be undertaken.

Step 2: Search for evidence

Formal search

Formal searching activity took place between May and September 2019. A search strategy was designed, piloted and conducted by the research team with the guidance from an information specialist (CK) (see Supplementary file 2). The following databases were searched: Academic Search Complete; AMED; CINAHL; EMBASE; MEDLINE; ProQuest; PsycINFO; PubMed; Scopus and Social Care

Online. In keeping with RAMESES guidelines,[30] no restrictions were made on the type of article or study design eligible for inclusion, other than being more recent than 1990. Documents such as editorials, opinion pieces, information guides, publicity materials, newspaper and magazine articles, evaluation reports, PhD theses and research poster and slide presentations were included along with peer-reviewed journal articles, if found to be holding relevant information. Search terms were kept uniform across all databases and searching was carried out by looking for the occurrence of these within the title, abstract and key words of documents (or nearest equivalent) in each database. Database-specific defined keywords were not used as the types of intervention were not only very diverse but often without a common agreed terminology, hence using too narrowly-specified terms would have resulted in an unmanageably voluminous list of possible key words, without necessarily locating better-targeted results, and could be limiting and misleading. In addition the nature of this review's research question is atypical in that it does not have an efficacy/effectiveness focus in common with many of its sources of data, hence manual screening was key in determining relevance. A disadvantage of this was that we had to accept a higher ratio of irrelevant search hits which then had to be excluded through manual screening of title and abstract.

After removing duplicates, records were screened by title and abstract by TM using the eligibility criteria, ensuring interventions covered were those targeted towards people with dementia and their families living in the community, that brought people together physically and met on a frequent, regular and an on-going basis (these criteria are outlined in full detail in Supplementary file 3). Interventions exclusively for those with severe dementia at advanced stages were excluded as these were not the focus of this review. Those with severe dementia have high needs and are less likely to be living independently in the community, hence by their nature community-based interventions where people meet outside of their home are likely to serve those who are towards the start of their dementia journey rather than those at an advanced stage, and are distinct from more acute care.

Full text of documents were then obtained of the remaining records, and again screened by close reading against the eligibility criteria by TM. A 10% random subsample of was reviewed independently at each of these stages by a second reviewer (TA) with disagreements recorded and resolved by discussion. Informal searching continued iteratively alongside the formal search and in response to articles found in it, congruent with the realist review process which allows searching to be revised as necessary as the review progresses.[30] In certain cases, documents regarding on interventions that met only some, not all, of the inclusion criteria were included, if found to contain information on hypothesised mechanisms with reason to believe such mechanisms may function similarly or analogously in types of intervention that are closely related.[29]

Steps 3 and 4: Article selection, data extraction and organisation

Figure 1 shows a PRISMA diagram outlining the full screening and selection process.

[Figure 1 here]

Following screening and close-reading of full texts for eligibility, full texts of the remaining 122 articles were loaded into NVivo qualitative data analysis software to help locate and categorise (code) relevant sections of text containing data regarding contexts, mechanisms or outcomes pertinent to the long-term sustainability of the intervention they described. Coding was both inductive (codes created in response to data as found) and deductive (codes created in advance, informed by the initial programme theory) and carried out by TM (An overview of top-level 'parent' codes can also be seen in Supplementary file 1; deductive codes can be identified in that they mirror the headings of the initial model diagrams). The characteristics of the articles were also extracted separately into an EXCEL spreadsheet.

During this extraction and organisation process, more fine-grained assessments of relevance (to answering the research question) and rigour (the trustworthiness and credibility of the data and its source)[25 34] were made by TM, with a random sample of 10% of articles again selected, assessed

independently and discussed with TA. The data contained in an article was assessed on its own merits, not on the merits of the paper or study as a whole. This is because it was recognised that poorly designed or conducted research may still contain good quality 'nuggets' of information for a realist review,[34 35] or a document meeting inclusion criteria may not contain any relevant data. Due to the variety and breadth of the type of article included in the review, a standardised relevance and rigour assessment tool that would be appropriate in all cases was impossible to design.[25] Rather a set of general principles was agreed to guide a 'traffic light' assessment system of low, medium and high relevance, and low, medium and high rigour (see Supplementary file 3 for detail). Reasons for each assessment were outlined and logged for each article and compared with each other to ensure consistency. Ambiguous cases of relevance or rigour were discussed with the wider project team as they arose. A decision was made by the project team to exclude articles assessed to have data of low relevance or low rigour to ensure a more robust dataset with which to build the final programme theory and context-mechanism-outcome configurations.

Step 5: Synthesising the evidence and drawing conclusions

Once data from the remaining articles were extracted and categorised, key outcome themes were identified by discussion with the whole team. These themes and categories were presented to the stakeholders for comment and feedback, to determine what was most important to focus upon, if they felt anything had been overlooked and if any changes or refinements should be made. Four key outcome areas (getting and keeping members, personnel, support of other organisations and funding/income) were settled upon. Data were then organised under these headings in the form of "If-then" statements that provided initial explanations of how, why, for whom and in which contexts these outcomes might arise, initially by TM but with input from DB and TA. These were then further refined, with guidance from GW, using a realist logic of analysis to identify cause-and-effect chains in the data and finally elaborated into context-mechanism-outcome configurations (CMOCs).[30] Related CMOCs were then grouped together to create recommendations for practice or policy that also

acted as a summary of the CMOCs found. Diagrams of the factors found affecting sustainability, and how they are likely to relate to each other within an overall programme theory, were also designed through team discussion and drawn by TM.

Patient and public involvement

The research question was developed during the authors' previous work with community interventions (for example, but not limited to, Meeting Centres)[12 13] and the practical problems encountered with sustaining such interventions expressed both by personnel and by members of the public attending. This review mainly involved the gathering of secondary data so did not involve patients or public directly as study participants. However, people with dementia, their family and friends, intervention staff and volunteers, and other community stakeholders were consulted as content experts throughout, informing the search strategy, data synthesis, development of materials and channels for dissemination. More information on our stakeholder consultation process can be found under *Step 1: Locating existing theories* and *Step 5: Synthesising the evidence and drawing conclusions.*

RESULTS

In total, 61 articles were coded to develop the CMOCs used to refine and expand our initial programme theory (see Supplementary file 4 for a detailed list of included articles). They were published between 1990 and 2020, and ranged in type: most were either peer-reviewed journal articles (28) or formal reports/evaluations (18); information guides (8), news feature articles (3), doctoral theses (2) and conference presentation paraphernalia (2) were also analysed. About half of these articles (33) were authored (or co-authored) in the UK, consistent with a proportion being identified informally through UK-based stakeholders (see Figure 2). Four articles had international authorship. Other countries of origin (or co-origin) comprised the US (8), Netherlands (7), Germany

(5), Canada (4), Italy (4), Norway (3), Poland (3), Australia (2), Ireland (2), Sweden (2), Chile (1), Japan (1), Portugal (1) and Thailand (1). The type of intervention discussed in these articles varied broadly, including: day centres/day care, social activities, sports and exercise initiatives, peer support groups, arts and crafts groups, singing and music groups, cognitive stimulation, gardening activities and other outdoor activities. Many interventions had multiple and overlapping elements: for example, a sports activity may have a social function, a drop-in day centre may have exercise and cognitive stimulation activities, or a craft club may have peer support built in. When an article's remit was general (for example community support services, outdoor activities, social and leisure activities or third sector groups), data was included from the article only if it was relevant to our programme theory and the kind of interventions outlined in the inclusion criteria (see Supplementary file 3).

Our analysis, together with stakeholder input, identified four critical areas affecting the sustainability of an intervention: members, staff and volunteers, support of other organisations and funding/income. These were each sub-divided into "getting" and "keeping" outcomes in recognition of changes in focus over time regarding these areas, and likely different contexts and mechanisms involved as an intervention continues. Figure 2 shows an overview of factors leading to the getting and keeping of members, staff and volunteers, support of other organisations and funding/income, found in the article data (individual diagrams tracing factors for each critical area can be found in Supplementary file 5).

[Figure 2 here]

Our analysis of the data produced 201 CMOCs (outlined in full in Supplementary file 6), all covered by the above eight sub-divisions. These CMOCs provide causal explanations relating to sustainability of community-based groups and activities either at the level of the individual, organisation or wider. Due to the high number of CMOCs, they were further organised by grouping them under practical recommendations that could follow. These recommendations are not simply an end conclusion, but were also part of the data synthesizing process, as they act as a way in which

to categorise and summarise the large number of CMOCs. Examples of how several grouped CMOCs were related to a recommendation can be seen in Table 1.

Recommendation	CMOCs
Getting Members: **Ensure a warm, welcoming, non-stigmatising introduction, with strong staff interpersonal skills and an appealing venue**	CMOC 3: If facilitators are knowledgeable and empathetic, with good interpersonal skills (C), an initiative will be perceived as more welcoming and inclusive (O), as they will be better at understanding needs, engaging and building trust with potential members and their families (M).[36 37 38 39 40 41] CMOC 4: If an initiative has an informal, unrushed and warm welcome on first visit (C), then people are more likely to want to return (O), as they are more likely to find the experience relaxing and enjoyable, not uncomfortable and intimidating (M).[40 42 43 44 45] CMOC 5: If potential members have had poor previous experiences with groups or activities (dementia related or not) (C), they may not want to try another group or activity (O), because they think the experience will be similar and will want to avoid it (M).[37 41 46 47] CMOC 6: If time is taken for personal contact, home visits or taster sessions with potential members (C), then people are more likely to come (O), as they will feel more familiar with the initiative and more trusting of those running it (M).[36 38 47 48 49 50] CMOC 7: If an initiative is familiar and trusted, or local and well-integrated with other organisations in the community (C), then people are more likely to come (O), as its links to familiar things that they trust will make it less intimidating (M).[37 41 42 48 51 52 53 54 55 56] CMOC 8: If an intervention is based in familiar surroundings in, and open to, the community (C), then people are more likely to come (O), because potential members will find the normalcy, lack of stigma and chance for social integration appealing (M).[38 41 48 52 57 58 59 60 61 62] CMOC 9: If a venue is dementia-friendly, comfortable and accessible (C), people are more likely to come (O), as they will not have concerns about comfort or access (M).[48 55 63 64]
Keeping Members: **Keep activities relaxed, loose and focussed on the social, and encourage friendships and peer support**	CMOC 47: If there is group cohesion and mutual trust between members (C), then a group is more likely to sustain (O), because members will feel more solidarity and investment in the group (M).[65] CMOC 48: If friendships between members are encouraged, recognised and supported by staff and activities (C), then people are likely to keep coming (O), as they will feel more supported, comfortable and engaged, and able to support each other (M).[43 54 66 67 68] CMOC 49: If an intervention is too focussed on agendas, rules and expectations (C), then people may stop coming (O), because they feel pressured, restricted and unable to relax and enjoy the social and emotional benefits important to them (M).[44 45 63 67 69 70 71] CMOC 50: If the pace of activity through the day/session is too fast and strict (C), then people may stop coming (O), because they will struggle to stay engaged and will not enjoy themselves (M).[43 48 57 61 72] CMOC 51: If ample informal time is made for socialising, peer support and feedback (C), then members are more likely to keep coming (O), as they will be more likely to feel comfortable and supported (M).[40 43 48 50 58 62 65 67 69 70 71 72 73 74 75] CMOC 52: If there is opportunity to have communal eating and relaxing in a "cozy" environment (C), then members are more likely to keep coming (O), as this will provide comfort and foster group cohesion (M).[40 65]

Table 1 Examples of CMOCs leading to recommendations

Recommendations for practice

In total, 41 recommendations for practice were drawn from the CMOCs as can be seen in Table2.

Getting Members	Keeping Members
Emphasise the social aspects of your intervention, including food and refreshments, for wide appeal CMOC 1 – CMOC 2 [40 48 50 57 58 59 62 64 75] **Ensure a warm, welcoming, non-stigmatising introduction, with strong staff interpersonal skills and an appealing venue** CMOC 3 – CMOC 9 [36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60 61 62 63 64] **Foster understanding and support from trusted friends, family and health professionals, as their encouragement can be key** CMOC 10 – CMOC 14 [36 38 41 42 47 48 54 56 58 62 65 73 75 76 77 78 79] **Provide meaningful activities that have resonance with people's interests and experience, personal history and culture** CMOC 15 – CMOC 20 [41 44 45 47 48 50 53 56 57 58 62 63 64 65 67 69 70 71 72 77 80 81 82 83 84] **Be sensitive to differences in abilities, ages and stages and aim to empower members rather than avoid challenges for them** CMOC 21 – CMOC 24 [37 43 48 58 60 62 63 64 69 73 79] **Offer information and advice to connect with a broad range of people who may be in need** CMOC 25 [42 44 45 54 73 85] **Ensure people can get there easily, safely, reliably and cheaply** CMOC 26 – CMOC 30 [36 37 38 44 45 47 48 49 53 56 59 60 61 64 65 73 76 78 82 85 86] **Stay in constant contact with potential referrers and keep them involved** CMOC 31 – CMOC 32 [41 46 51 54 55 61 74 75 79] **Your "public relations" strategy should focus on who the intervention is for and what people can expect, and use existing networks to spread your message** CMOC 33 – CMOC 41 [36 37 38 41 44 45 46 47 48 49 51 54 56 59 61 62 66 67 70 72 73 74 75 78 80 82 83 84 87 88 89] **Consider simple and easy self referral** CMOC43 – CMOC 46 [38 44 45 47 57 61 74 76 79 80 83 88]	**Keep activities relaxed, loose and focussed on the social, and encourage friendships and peer support** CMOC 47 – CMOC 52 [40 43 44 45 48 50 54 57 58 61 62 63 65 66 67 68 69 70 71 72 73 74 75] **Encourage normalised activities and social integration outside of the group to empower members and reduce stigma** CMOC 53 – CMOC 57 [37 38 41 46 47 48 49 52 54 57 58 59 61 62 66 67 71 76 90] **Be person-centred: Give members input into planning and decision-making, and respect their individual needs and autonomy** CMOC 58 – CMOC 63 [36 40 41 42 43 44 45 46 48 52 55 59 61 63 65 66 67 71 74 84 91] **Talk to family or care partners about what arrangements and support they need in place** CMOC 64 – CMOC 65 [38 44 45 47 48 49 50 54 57 60 61 73 78] **Be sensitive to differences in abilities, ages and stages and have strategies to differentiate and manage activities so needs don't clash** CMOC 66 – CMOC 70 [37 41 43 44 45 46 47 48 49 57 58 59 60 61 66 67 71 74 75 76 78] **Ensure your venue is comfortable, stable and familiar, with adequate facilities and multiple spaces for use** CMOC 71 – CMOC 72 [43 48 55 63 89] **Stability and reliability matters to members, so aim for structure and minimise disruption** CMOC 73 – CMOC 77 [36 37 38 40 43 47 48 61 65 66 67 72 73 75]
Getting Staff and Volunteers	**Keeping Staff and Volunteers**
Network proactively: Engage in outreach activities to boost visibility and awareness; approach other groups and organisations for help CMOC 78 – CMOC 83 [46 48 50 56 58 59 61 67 69 77 80 83 84 89 91] **Get to know potential stakeholder groups in the local population that may provide a reliable volunteer base, and consider how to reach out to them** CMOC 84 – CMOC 90 [53 56 62 65 81 83 91 92 93] **Not all personnel need expertise, but ensure facilitators have good interpersonal and leadership skills, and your volunteer workforce is reliable**	**Foster flexibility, collaboration and communication skills in personnel to create a healthy and effective working environment** CMOC 96 – CMOC 97 [59 60 76 79 93] **Plan strategies to maintain the satisfaction and enjoyment of staff and volunteers, and to avoid burnout** CMOC 98 – CMOC 104 [38 43 52 58 61 70 74 75 84] **If possible, have financial support in place for staff roles and volunteers activities, so they will feel secure and valued** CMOC 105 – CMOC 108 [51 67 73 79 87 84]

CMOC 91 – CMOC 95 [38 50 51 58 61 71 72 73 75 79]	
Getting Support of Other Organisations	**Keeping Support of Other Organisations**
Focus on raising awareness and communicating value both to professionals and the community, involving them where possible CMOC 110 – CMOC 114 [37 39 41 42 50 54 55 61 70 75 79 80 84 86 90] **Approach and ask other community organisations if they can help with venue, resources, training, volunteers or contacts** CMOC 115 – CMOC 118 [46 48 52 58 62 65 67 69 71 72 75 77 80 92 93] **Use your physical location (venue or neighbourhood) as an opportunity to build links with others sharing that space** CMOC 119 – CMOC 121 [41 42 48 58 59 62 79] **Seek out like-minded groups to band together with and share knowledge, resources, contacts and strategy** CMOC 122 – CMOC 124 [42 67 77] **To avoid conflict with other organisations, minimise overlap, involve them or offer them something of benefit** CMOC 125 – CMOC 131 [41 42 46 51 60 61 67 70 72 79 84 86 88]	**Maintain constant contact and information sharing with the organisations, services and referrers you work with, with a dedicated person responsible if possible** CMOC 138 – CMOC 142 [39 41 44 45 50 51 55 67 77 79 84] **Seek authoritative external advice on overcoming differences in culture with other organisations, and up-skilling staff for collaboration** CMOC 143 – CMOC 148 [41 51 59 60 70 76 77 79 86] **Take time to formally plan how collaboration will work, involving collaborators in that planning** CMOC 149 – CMOC 152 [41 44 45 51 61 70]
Getting Funding and Income	**Keeping Funding and Income**
Ensure communication is clear about what the intervention does and its value CMOC 153 – CMOC 163 [39 41 46 51 56 61 70 75 79 80 89 94] **Build "social capital" and forge partnerships with other community organisations to help with costs and boost the case for viability and value for money** CMOC 164 – CMOC 169 [56 60 61 70 75 76 78 79 80 87 93 94 95] **Learn how to effectively plan and network to find funding, through knowledge-sharing with like-minded groups and seeking external advice** CMOC 170 – CMOC 175 [37 46 55 60 61 80 86 91 94] **Initiatives in rural areas should make clear the particular challenges that they face when seeking funding** CMOC 176 – CMOC 179 [50 84 91] **Find out what the national priorities are for dementia, and see if you can tailor your activities to fit; if not, lobby to change the national agenda** CMOC 180 – CMOC 184 [39 41 42 50 51 55 59 76 77 80 84 86 87 91 95 96]	**Keep in touch with previous, current and potential funders on an ongoing basis, as this will help when applying in the future** CMOC 185 – CMOC 188 [46 55 61 70 94] **Pay attention to how money can be put to use most efficiently and effectively for the benefit of all by co-operating and sharing with other organisations** CMOC 189 – CMOC 190 [70 75 76 78 80 93] **Plan a long-term strategy to build a portfolio of multiple income streams, that are flexible in what they contribute to paying for** CMOC 191 – CMOC 194 [44 45 70 80 84 94] **Ensure someone has the time and expertise to continually seek and apply for funding** CMOC 195 – CMOC 197 [70 80 84] **Emphasise deep learning and experience as an asset when calling for longer term funding** CMOC 198 – CMOC 201 [39 50 51 76 77 79 87 86 96]

Table 2 Recommendations for practice (For a full list of CMOCs see Supplementary file 6)

Data regarding getting and keeping members was the most abundant and showed most consensus. As may be expected, boosting the motivation and understanding of potential referrers, while lowering bureaucratic and logistical barriers, was important to getting members (CMOC 10-CMOC 14; CMOC 31-CMOC 46; CMOC 64-CMOC 65). Transport from home to venue was particularly key: not just its availability, but people's experiences of the accessibility, appropriateness and

convenience of it (CMOC 10-CMOC 14). Other salient mechanisms involved how respected, valued and comfortable members felt, or perceived they would feel should they attend: both for overcoming initial anxiety and stigma and fostering a happy, cohesive group (CMOC 3-CMOC 9; CMOC 15-CMOC 24; CMOC 53-CMOC 63; CMOC 71-CMOC 72). Staff attitudes and a comfortable, accessible venue play a role in this, but also planned practices, such as involving members in decision making (CMOC 58-CMOC 63), differentiating activities for need and ability (CMOC 21- CMOC 24; CMOC 66-CMOC 70) and ensuring enough opportunity and time for socialising (reported to be of high importance to people no matter what the intervention or activity) (CMOC 1-CMOC 2; CMOC 47-CMOC 52). The stability and reliability of an intervention was also important, though often at odds with nature of groups run informally with few personnel and unstable income (CMOC 73-CMOC 77). Overall, ensuring individual wants and needs are met – that people they feel they are gaining something useful and appropriate to them in particular – was important to keeping members long term (CMOC 47-CMOC 72).

Data regarding getting and keeping staff and volunteers was least abundant of the four critical outcome areas, though working with other organisations was frequently alluded to as helpful in finding personnel (CMOC 78-CMOC 83). Data regarding skills of personnel was largely around the role of communication and collaboration in creating an encouraging and effective environment for staff and volunteers (CMOC 84-CMOC 97). Context was key with regards to the availability of potential volunteers in the local population, as this could be very different depending on location (e.g. rural or urban), with different likely mechanisms requiring different approaches to finding and encouraging volunteers from different demographic groups (CMOC 84-CMOC 90). With regard to keeping volunteers, issues raised included the importance of maintaining work satisfaction and avoiding burnout, and having financial support available (CMOC 98-CMOC 108).

Getting and keeping support of other organisations, such as other community groups, health and social care services, third sector bodies, local authorities and local businesses was a widely

recurring theme in the data. Actively involving other organisations, minimising overlap, sharing knowledge and resources and offering something of benefit were all ways to encourage them to feel invested in supporting an intervention rather than threatened or indifferent to it (CMOC 122-CMOC 131), in addition to pro-active awareness raising and networking (CMOC 110-CMOC 121). Good collaboration planning, with expert advice on collaborative working and continual attention to maintaining communication were strategies to avoid problems developing or loss of enthusiasm with partner organisations (CMOC 138-CMOC 152).

On getting and keeping funding and income, salient CMOCs again involved continual networking and communication, for the reason that this would support multiple mechanisms: by reducing costs through sharing and partnership; boosting visibility, legitimacy and value in the eyes of potential and existing funders; and helping to locate more funding and income opportunities (CMOC 153-CMOC 175; CMOC 185-CMOC 190). Data made some reference to the importance of strategic planning in finding and managing funds, with outside expertise and dedicated personnel helpful in carrying this out (CMOC 170-CMOC 175; CMOC 191-CMOC 197). While tailoring an intervention to national (and therefore funders') priorities may increase its chances of obtaining funding, this is not always possible or desirable for a group (CMOC 180-CMOC 184). Groups in rural areas particularly, or experienced groups unable to find anything but short-term solutions, may have to raise greater awareness with commissioners and policy-makers about the specific challenges that face them, and lobby for change to ensure better conditions for groups in their situation long term (CMOC 170-CMOC 179; CMOC 198-CMOC 201). For example rural groups with a small number of members and personnel can struggle to meet funders demands, especially if put in competition with larger, well-resourced organisations.

Recommendations for policy and commissioning

In addition, 13 recommendations for policy-making and commissioning were also drawn (see Table 3), for the most part mirroring those for practice and drawing on the same CMOCs.

Recommendations for commissioning/policy-making
Service users value the social side of an intervention highly, often more than the intervention or activity itself
CMOC 1 – CMOC 2; CMOC 47 – CMOC 53 [38 40 41 43 44 45 47 48 49 50 52 54 57 58 59 61 62 63 64 65 66 67 68 69 70 71 72 73 74 75]
Service users need to feel an intervention is "for them" to want to attend and keep attending
CMOC 15 – CMOC 24; CMOC 66 – CMOC 70 [37 41 43 44 45 46 47 48 49 50 53 56 57 58 59 60 61 62 63 64 65 66 67 69 70 71 72 73 74 75 76 77 78 79 80 81 82 83 84]
Lack of appropriate transport can be a major barrier to an intervention getting and keeping attendees
CMOC 26 – CMOC 30; CMOC 65 [36 37 38 44 45 47 48 49 50 56 57 59 60 61 64 65 73 76 77 78 82 85 86]
Health and social care services that may refer to an intervention need incentive and guidance to do so
CMOC 42 – CMOC 44; CMOC 134 – CMOC 135 [47 50 61 69 76 77 79 80 88]
To retain staff and volunteers there needs to be adequate financial support in place for roles and activities
CMOC 105 – CMOC 109 [50 51 67 73 79 84 87]
Established community organisations, including local authorities, can offer help in a number of ways to enable small-scale interventions to flourish
CMOC 115 – CMOC 118 [46 48 52 58 62 65 67 69 71 72 75 76 80 92 93]
Access to advice on how to create partnerships, collaborate and overcome differences in culture with other organisations can help
CMOC 143 – CMOC 148 [41 51 59 60 70 76 77 79 86]
Access to advice on how to effectively plan and network to help find and manage funding and income can help
CMOC 170 – CMOC 175 [37 46 55 60 61 80 86 91 94]
Commissioners should be flexible and accommodating of the challenges facing small groups regarding evidence gathering
CMOC 176 – CMOC 179 [50 84 91]
Policy makers should ensure policy meets local needs with adequate, protected and accessible resources attached
CMOC 180 – CMOC 182; CMOC 184 [39 41 42 50 51 55 59 76 77 80 84 86 87 91 95]
Longer term funding, with simplified application processes, would help smaller initiatives with less capacity to continue
CMOC 195 –CMOC 197 [70 80 84]
Longer term funding to support what is already being done will help retain and develop learning and practice on how best to meet local need
CMOC 198 – CMOC 200 [39 50 51 76 77 79 86 87]
Authorities and national organisations can help create conditions that encourage support for small initiatives, though policy, leadership and commissioning
CMOC 132 – CMOC 137 [39 47 50 51 59 69 77]

Table 3 Recommendations for commissioning/policy-making (For a full list of CMOCs see Supplementary file 6)

The final recommendation covers CMOCs unique to policy-making and commissioning, highlighting issues such as the detrimental effect of a disjoin between national policy and local need on an intervention finding support (as by adhering to one they will neglect the other) (CMOC 132). Practices that could benefit the sustainability of community interventions included ring-fencing funding specifically for dementia-targeted community initiatives; commissioning health and social care services to work with community initiatives; and developing health pathways around existing

community networks (CMOC 133-CMOC 135). National and official organisations can also encourage a more strategic, joined up direction regarding community-based dementia support by showing leadership in working with smaller, local initiatives and support for potential private sector partners (CMOC 136-CMOC 137).

DISCUSSION

Summary of findings

Being able to continually get and hold on to members, staff and volunteers, the support of other services and organisations, and funding/income are the key factors in the long-term sustainability of a community-based intervention for people affected by dementia. There are multiple mechanisms that feed into these sub-outcomes, sensitive to context. Ability to attract members was found to be driven by perceptions that a group or activity was "for them", and expectations they would be welcomed, respected and supported without stigma once attending, as well as having motivated referrers and low logistical barriers including transport. Members are more likely to keep attending if they feel comfortable, at home, respected and empowered, with individual needs understood. Opportunity for socialising was found to be of high importance no matter what intervention type, with stability and reliability also important. Networking and outreach were found to be important in getting staff and volunteers; feeling satisfied, valued and supported (including financially) was important in keeping them. Proactive measures to raise awareness and involve other organisations, avoiding conflict and sharing knowledge and resources, were found to help in securing essential support, though requiring significant maintenance through skilled communication, planning and working practices. Such networking and collaboration were found to be helpful in finding and securing funding and income, with skilled planning and management of multiple income streams helpful in sustaining long term. However, the often short term nature of funding was found to be a barrier to retaining deep learning and experience, and disjoins between national policy and local need a barrier to securing both funding and wider support. Challenges in meeting funders'

requirements and overcoming logistical barriers were especially acute for small-scale and rural groups.

Strengths and limitations

This review was designed to gather evidence regarding how regularly-meeting community-based interventions for people affected by dementia can be sustained, not on the efficacy/effectiveness of interventions of this type, hence conclusions regarding the latter are beyond its scope. Literature was limited as this research question is not commonly the main focus of study in dementia care research. This meant some CMOCs arrived at were the result of abundant data sources, while others were not, hence the CMOCs here vary in robustness (see Supplementary file 6). While efforts were made to exclude data of low rigour (see Supplementary file 3), it is the nature of a realist review to include data from a variety of source types to build a theoretical model piecemeal; not all of the data were of equal depth and detail and many will not meet the highest level of empirical rigour, rather they contribute together in a way that is useful to the theoretical constructs that are the CMOCs and overall programme theory.[29] The results of this review therefore should be taken as theory and sit in relation to other research: SCI-Dem provides a theoretical framework which can be put to the test and further refines by subsequent empirical research.[29] The breadth of intervention types covered in this review is on the one hand a strength, as it has enabled the surfacing of commonalities in experience likely relevant to a wide range of real-world initiatives broadly in the same category; on the other hand, it means this review cannot be specific on certain details. An example is that little could be concluded on the cost-effectiveness or economic functioning of the interventions covered, because details were both too scant and too specific to draw robust CMOCs that might usefully be applicable to others.

The practice of one researcher carrying out the bulk of article selection and data analysis, with a second researcher independently checking 10% at each stage for consistency (along with regular input and discussion with other members of the research team) is common in realist review,

but nevertheless can be seen as a limitation, as in Cochrane-style systematic reviews double-screening by two reviewers independently is recommended for greater reliability of results. However, it should be noted realist review is a theory-driven interpretive approach with significant differences to more traditional forms of systematic review;[30] i.e. the aim is to develop an evidence-informed theory rather than a comprehensive summation of all research data available on a particular research question.

Recommendations and comparison with existing literature

Recommendations for practice and policy are presented in Tables 2 and 3 in the results section. However, they also highlight some common problems for which there may be no easy solution: for example what to do in rural areas where public transport coverage is poor and potential members and volunteers are few and widespread, given that transport to venue is a key factor in getting and keeping members. The issue of whether interventions can be entirely self-sustaining or must rely on service-level agreements and grant funding is also a key one. This review suggests that costs can be reduced and income opportunities found by pro-active networking and collaborative working; though rather than removing the need for grant funding, this is more likely useful in leveraging it, adding to it and helping it to go further. Recent research into whether social enterprises delivering adult social care services (not dementia specific) could be self-sustaining suggests that marketing is key but needs to focus upon building relationships with stakeholders at multiple levels rather than adopting an approach akin to selling a product:[97] networking and marketing are closely bound up with each other. Delivering social quality as well as service quality, having a hybrid workforce and diverse income streams to strengthen financial viability and reduce reliance on grants were also found to help.[98] This review echoes all of these points with regards to dementia-targeted community-based interventions, in particular that interventions cannot sustain without a cultivated support network around them, as well as careful collaborative financial planning and management.

The emphasis found in this review on the value to members of social activity and a respectful, empowering person-centred approach, reinforces the benefits of community-based initiatives and regular social activity, both for people living with dementia and the people who care for them.[12 13 14 15 16 17 18 19] However, the time-limited nature of most research in this area is unhelpful when seeking data on the long-term sustainability of such interventions, with a large number of articles excluded from this review due to this. Recent systematic reviews have found that psychosocial interventions tend to be short term, with short-term trials only measuring short-term impact, and a pressing need for more longer-term studies with larger sample sizes.[14 99] However, there is a "chicken and egg" problem: if policy and commissioning is hesitant to support interventions unless there is evidence of robust statistical effects, then such interventions will struggle to sustain long enough, in enough abundance, to have the numbers to carry out the research required to produce that evidence. Equally, if research focuses only on efficacy/effectiveness without attention to the implementation process, and reporting of how costs were met and resources, personnel, and service users were found, then little can be learnt about sustaining them.

Future research directions

When drafting inclusion criteria for this review in 2018 it was decided to focus upon interventions that brought people together to meet physically and socially, as distinct from community services that go into people's homes. It did not take into account virtual community activities or communities at-a-distance, which at the time seemed like a distinct niche. In 2020, however, this kind of activity became much more important, and integrated with the activities of existing community groups that met physically prior to the COVID-19 pandemic. With COVID-19 the landscape for community-based interventions has changed significantly, presenting further unprecedented challenges, but the need for groups that connect people socially remains acute. A recent study by the Alzheimer's Society[11] revealed COVID-19 restrictions have had particularly negative impacts on the health and well-being

of people affected by dementia and their carers, a finding echoed by the Alzheimer's Disease International's update report for 2020.[100] Restrictions have forced changes to routine, causing anxiety and strain in relationships; led to a reduction in skills and confidence; and increased pressure on home carers, not least through the erosion of support systems.[101] Many support initiatives will have ceased operating either temporarily or permanently. As the effects of the pandemic continue to be felt, there is an urgent need for community-based interventions to find ways to keep going or re-establish quickly when emerging from COVID-19 restrictions. While the data used in this review predated the pandemic, it can provide a framework for new research to look at what sustainability-impacting elements have been affected and how. This review presents a theoretical model of the factors and mechanisms involved in the long-term sustainability of community-based interventions. As such it is for further research to put this model to the test by comparing it empirically with real-world interventions going forward, which will further refine and add to this programme theory in a post-pandemic climate.

Word count: 5363

Figure legends

Figure 1 PRISMA flow diagram

Figure 2 Factors affecting the sustainability of community-based groups and activities

Author affiliations and email

1 Association for Dementia Studies, University of Worcester, Worcester, UK. *t.morton@worc.ac.uk*

2 Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK. *geoffrey.wong@phc.ox.ac.uk*

1 Association for Dementia Studies, University of Worcester, Worcester, UK. *t.atkinson@worc.ac.uk*

1 Association for Dementia Studies, University of Worcester, Worcester, UK. *d.brooker@worc.ac.uk*

Author Contributions Authors Dawn Brooker and Teresa Atkinson conceptualised the study (along with Dr Shirley Evans of the University of Worcester, who co-wrote the protocol but does not meet the ICMJE criteria for authorship of this paper). Authors Geoffrey Wong and Thomas Morton had input into developing the study (along with information specialist Clive Kennard of the University of Worcester, who helped design the search strategy but does not meet the ICMJE criteria for authorship of this paper). The study was conducted by Dawn Brooker as principal investigator, Teresa Atkinson as project manager, Thomas Morton research associate and Geoffrey Wong providing methodological expertise. Thomas Morton wrote the first draft of this manuscript. Geoffrey Wong, Dawn Brooker and Teresa Atkinson critically contributed to and refined the originally submitted manuscript, as well as responses to reviewers' comments and the revised manuscript. All authors have read and approved the final manuscript.

Corresponding Author Professor Dawn Brooker, Director of the Association for Dementia Studies, School of Allied Health and Community, University of Worcester, Henwick Grove, Worcester WR2 6AJ. Email: *d.brooker@worc.ac.uk*. Tel: 01905 855250

Twitter Follow Thomas Morton @ThomasMortonADS

Original protocol: http://dx.doi.org/10.1136/bmjopen-2019-032109

Funding: This work was supported by The Alzheimer's Society, Grant No: 402, AS-PG-17b-023. Gold Open Access Article Processing Charges met by the University of Worcester.

Acknowledgements This project was funded by the Alzheimer's Society. Dr Shirley Evans (Association for Dementia Studies, University of Worcester) contributed to the writing of the protocol for this review. Clive Kennard (information specialist, University of Worcester), helped design, pilot and carry out the formal search. The authors would like to thank all those who shared

their invaluable experience and contributed to advising and guiding this project as a stakeholder consultant: Alzheimer's Society research monitors Sue Comely, Maggie Ewer and Mair Graham; Philly Hare, Rachael Litherland, Damian Murphy and Rachel Niblock of DEEP/Innovations in Dementia, and all who attended the national meeting of DEEP groups at Wooodbrooke, Birmingham, July 2019; Teresa 'Dory' Davies, James McKillop and Dreane Williams of DEEP; Judith Baron and the Face It Together DEEP group; Jill Turley and The Buddies DEEP group; the Friends for Life DEEP group; Kim Badcock of Kim's Cafe (Denmead, Havant and Waterlooville, Hampshire); Jo Barrow and the Forget Me Not Lunch and Friendship Club (Bicester, Oxfordshire); Elizabeth Bartlett of the Laverstock Memory Support Group (Wiltshire); Shirley Bradley of Friends of the Elderly (Worcester); David Budd of Our Connected Neighbourhoods (Stirling); Di Burbidge of Liverpool DAA Diversity Sub-Group and Chinese Wellbeing (Liverpool); Kishwar Butt of the South Asian Ladies' Milaap Group (Wolverhampton); Michelle Candlish of Ceartas Advocacy (Kirkintilloch, East Dunbartonshire); Annette Darby of Brierly Hill Health and Social Care Centre (West Midlands); Sue Denman of Solva Care (Haverfordwest); Gerry Fouracres of Scrubditch Farm (Cirencester); Graham Galloway of Kirrie Connections (Kirriemuir, Angus); Reinhard Guss; Deborah Harrold of Agewell CIC (Oldbury, West Midlands); June Hennell; Jacoba Huizenga of Health and Social Care in Communities, Utrecht (Netherlands); Lynden Jackson of the Debenham Project (Suffolk); Ghazal Mazloumi of Trent Dementia Services Development Centre; Cheryl Poole of Leominster Meeting Centre; Anita Tomaszewski and Jennifer Williams of Me, Myself and I (Briton Ferry, Neath Port Talbot); Dame Louise Robinson; Droitwich Meeting Centre; Leominster Meeting Centre; the members of the UKMCSP National Reference Group; and Jennifer Bray, Shirley Evans, Nicola Jacobson-Wright, Chris Russell and Mike Watts of the Association for Dementia Studies, University of Worcester.

Competing interests Geoffrey Wong is Deputy Chair of the National Institute for Health Research Health Technology Assessment Prioritisation Committee: Integrated Community Health and Social Care (A).

Disclaimer The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the Alzheimer's Society.

Ethics approval Not applicable.

PROSPERO registration number CRD42019125889.

Data availability statement This study was a qualitative review of secondary data, hence no new primary dataset was generated. However, we can share more information on what data was extracted and how it was analysed if requested. Please contact Thomas Morton at t.morton@worc.ac.uk, ORCID 0000-0001-8264-0834

REFERENCES

1. World Health Organisation. *Global action plan on the public health response to dementia 2017-2025.* Geneva: world Health Organisation, 2017. https://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/
2. Office for National Statistics (ONS). *Living longer: Caring in later life.* London: ONS, 2019. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/livinglongerhowourpopulationischangingandwhyitmatters/2019-03-15
3. Care Quality Commission. *The state of health care and adult social care in England 2018/19.*Newcastle-upon-Tyne: Care Quality Commission, 2019. https://www.cqc.org.uk/sites/default/files/20191015b_stateofcare1819_fullreport.pdf
4. Department of Health. *Prime Minister's challenge on dementia 2020.* London: Department of Health, 2015. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf
5. Incisive Health. *Care deserts: the impact of a dysfunctional market in adult social care provision.* London: Incisive Health, 2019: https://www.incisivehealth.com/wp-content/uploads/2019/05/care-deserts-age-uk-report.pdf
6. Age UK. *Briefing: Health and Care of Older People in England 2019.* London: Age UK, 2019. https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/health--wellbeing/age_uk_briefing_state_of_health_and_care_of_older_people_july2019.pdf
7. Alzheimer's Society. *A lonely future: 120,000 people with dementia living alone, set to double in the next 20 years.* London: Alzheimer's Society, 2019. https://www.alzheimers.org.uk/news/2019-05-15/lonely-future-120000-people-dementia-living-alone-set-double-next-20-years

8. Cornwell EY, Waite, LJ. Social disconnectedness, perceived isolation and health among older adults. *J Health Soc Behav* 2009; 50(1):31–48. doi.org/10.1177/002214650905000103
9. Holt-Lunstad J, Smith TB, Baker M, Harris T, Stephenson D. Loneliness and social isolation as risk factors for mortality: A meta-analytic review. *Perspect Psychol Sci* 2015; 10(2):227–237. doi.org/10.1177/1745691614568352
10. Brodaty H, Donkin M. Family carers of people with dementia. *Dialogues Clin Neurosci* 2009; 11(2):217–228.
11. Alzheimer's Society. *Worst hit: Dementia during coronavirus.* London: Alzheimer's Society, 2020. https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf
12. Brooker D, Evans SC, Evans SB, *et al.* Evaluation of the implementation of the Meeting Centres Support Program in Italy, Poland, and the UK; exploration of the effects on people with dementia. *Int J Geriatr Psychiatry* 2018; 33(7):883-892. doi: 10.1002/gps.4865.
13. Evans SB, Evans SC, Brooker D, *et al.* 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 Ment Health* 2018; doi: 10.1080/13607863.2018.1544207
14. Lord K, Beresford-Dent J, Rapaport P, *et al.* 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. *Soc Psychiatry Psychiatr Epidemiol* 2019; doi: 10.1007/s00127-019-01784-w
15. McDermott O, Charlesworth G, Hogervorst E, *et al.* Psychosocial interventions for people with dementia: a synthesis of systematic reviews. *Aging Ment Health* 2019; 23(4):393–403. doi: 10.1080/13607863.2017.1423031
16. Van't Leven N, Prick AE, Groenewoud JG, et al. Dyadic interventions for community-dwelling people with dementia and their family caregivers: a systematic review. *Int Psychogeriatr* 2013; 25(10):1581-1603.
17. Dröes RM, Van Mierlo LD, Meiland FJM, Van der Roest HG. Memory problems in dementia: Adaptation and coping strategies, and psychosocial treatments. *Expert Rev Neurother* 2011; 11(12):1769-1782.
18. Dröes RM, Meiland F, Schmitz MJ, Van Tilburg W. 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 multi-centre implementation study. *Int J Geriatr Psychiatry* 2004; 19(7):673-684.
19. Dröes RM, Meiland FJM, Schmitz MJ, Van Tilburg W. Effect of the Meeting Centres Support Program on informal carers of people with dementia: Results from a multi-centre study. *Aging Ment Health* 2006; 10(2):112-124.
20. Wittenberg R, Hu B, Barraza-Araiza L, Rehill A. *Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019-2040 (CPEC Working Paper 50).* London: LSE, 2019.https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf
21. Dröes RM, Breebaart E, Meiland FJ, *et al.*Effect of Meeting Centres Support Program on feelings of competence of family carers and delay of institutionalization of people with dementia. *Aging Ment Health* 2004; 8(3):201-211. doi.org/10.1080/13607860410001669732
22. Dröes RM, Meiland FJM, Schmitz M, van Tilburg W. 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. *Int J Geriatr Psychiatry* 2004; 19:1-12.
23. Booth A, Clarke M, Ghersi D, *et al.* An international registry of systematic-review protocols. *Lancet* 2011; 377:108–9.
24. Morton T, Atkinson T, Brooker D, *et al.* Sustainability of community-based interventions for people affected by dementia: a protocol for the SCI-Dem realist review. *BMJ Open* 2019; 9:e032109. doi: 10.1136/bmjopen-2019-032109
25. Pawson R. *Evidence-based Policy: A Realist Perspective*. London: Sage Publications, 2006.
26. Pawson R, Greenhalgh T, Harvey G, Walshe K. Realist review – a new method of systematic review designed for complex policy interventions. *J Health Serv Res Policy* 2005; 10(1):21-24.
27. Jagosh J, Macaulay AC, Salsberg J, *et al.* Uncovering the benefits of participatory research: implications of a realist review for health research and practice. *Milbank Q* 2012; 90:311–46.
28. Astbury B, Leeuw F. Unpacking black boxes: mechanisms and theory building in evaluation. *Am J Eval* 2010; 31:363–81.
29. Pawson R, Greenhalgh T, Harvey G, *et al. Realist Synthesis – An Introduction.* ESRC Working Paper Series. London: ESRC, 2004.

30. Wong G, Greenhalgh T, Westhorp G, Pawson R. Development of methodological guidance, publication standards and training materials for realist and meta-narrative reviews: the RAMESES (Realist And Meta-narrative Evidence Syntheses - Evolving Standards) project. *Health Serv Deliv Res* 2014; 2(30):1-252.
31. DEEP. *DEEP: The UK Network of Dementia Voices* website. 2020. http://dementiavoices.org.uk
32. Greenhalgh T, Peacock R. Effectiveness and efficiency of search methods in systematic reviews of complex evidence: audit of primary sources. *BMJ* 2005; 331:1064.
33. Booth A, Harris J, Croot E, *et al.* Towards a methodology for cluster searching to provide conceptual and contextual "richness" for systematic reviews of complex interventions: case study (CLUSTER). *BMC Med Res Methodol* 2013; 13:118.
34. Wong G. Data gathering in realist reviews: Looking for needles in haystacks. In: Emmel, N, Greenhalgh J, Manzano A, *et al.* (eds.) *Doing Realist Research.* London: Sage Publications, 2018:131-145.
35. Pawson R. Digging for nuggets: How 'bad' research can yield 'good' evidence. *Int J Soc Res Methodol* 2006; 9(2):127-142.
36. Actifcare. *Best practice recommendations from the Actifcare study: Access to community care services for home-dwelling people with dementia and their carers.*www.actifcare.eu. Bangor: Dementia Services Development Centre Wales, 2017.http://dsdc.bangor.ac.uk/documents/ShortversionBestPracticeRecommendationwithoutsupportingfindings_000.pdf
37. Daykin N, Julier G, Tomlinson A, *et al. Review of the grey literature: music, singing and wellbeing.* London: What Works Wellbeing, 2016. https://whatworkswellbeing.files.wordpress.com/2016/11/grey-literature-review-music-singing-wellbeing-nov2016.pdf
38. Hochgraeber I, Kutzleben MV, Bartholomeyczik S, Holle B. Low-threshold support services for people with dementia within the scope of respite care in Germany – A qualitative study on different stakeholders' perspective. *Dementia* 2015; 16(5):576-590. doi:10.1177/1471301215610234
39. McDonald A, Heath B. Developing services for people with dementia. *Work Older People* 2009; 13(3);18-21. doi:10.1108/13663666200900045
40. Strandenæs MG, Lund A, Rokstad AM. Experiences of attending day care services designed for people with dementia – a qualitative study with individual interviews. *Aging Ment Health* 2017; 22(6):764-772. doi:10.1080/13607863.2017.1304892
41. Van Mierlo L, Chattat R, Evans S, *et al.* Facilitators and barriers to adaptive implementation of the Meeting Centers Support Program (MCSP) in three European countries; the process evaluation within the MEETINGDEM study. *Int Psychogeriatr* 2017; 30(4):527-537. doi:10.1017/s1041610217001922
42. Brooker D, Evans SB, Evans SC, et al. *Meeting Centres Support Programme UK: Overview, evidence and getting started.*Worcester: Association for Dementia Studies, University of Worcester, 2017. https://www.worcester.ac.uk/documents/Meeting-Centres-Support-Progamme-Overview-evidence-and-getting-started-Conference-booklet.pdf
43. Glover C. *Running self-help groups in sheltered and extra care accommodation for people who live with dementia.* London: Mental Health Foundation, 2014. https://www.mentalhealth.org.uk/sites/default/files/dementia-self-help-guide.pdf
44. Reichet M, Wolter V. *Sport for People With Dementia – Implementing Physical Activity Programs (PAP) For People With Dementia: Results From A German Study (conference poster).* Dortmund: TU Dortmund University, 2017.
45. Reichet M, Wolter V. Implementing physical activity programs for people with dementia: Results from a German study. *Innov Aging* 2017; 1(Suppl_1):340-340. doi:10.1093/geroni/igx004.1247
46. The Me Myself and I Club. *The Me, Myself and I Club, Briton Ferry: A case study in warm humanity and meaningful co-production.* Neath Port Talbot: The Me Myself and I Club, 2018. https://info.copronet.wales/me-myself-and-i-club-briton-ferry/
47. Older People's Commissioner for Wales. *Rethinking respite for people affected by dementia.* Cardiff: Older People's Commissioner for Wales, 2018. http://www.olderpeoplewales.com/en/Reviews/respite.aspx
48. Bould E, McFayden S, Thomas C.*Dementia-friendly sport and physical activity guide.* London: Alzheimer's Society, 2019. https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/organisations/dementia-friendly-sports
49. Green G, Lakey L. *Building dementia-friendly communities: a priority for everyone.* London: Alzheimer's Society, 2013.https://actonalz.org/sites/default/files/documents/Dementia_friendly_communities_full_report.pdf
50. Marshall J, Jackson L. *Encouraging and supporting the growth of "dementia proactive communities".* Ipswich: Sue Ryder/The Debenham Project, 2015. http://www.the-debenham-project.org.uk/downloads/conference/Supplementary%20contributions/Lynden%20Jackson%20&%20Jo%20Marshall/Lynden%20Jackson%20&%20%20Jo%20Marshall%20-%20Supplementary%20Contribution.pdf

51. Clarke CL, Keyes SE, Wilkinson H, *et al.* Organisational space for partnership and sustainability: Lessons from the implementation of the National Dementia Strategy for England. *Health Soc Care Community* 2014; 22(6):634-645. doi:10.1111/hsc.12134
52. Health Innovation Network South London. *Case Study: Dulwich Helpline and Southwark Churches Care (DH&SCC) – The Dementia Project, Southwark, South London.* London: Health Innovation Network South London, 2015. http://www.hin-southlondon.org/system/resources/resources/000/000/083/original/Case_Study_The_Healthy_Living_Club.pdf?1426083299
53. La Rue A, Felten K, Turkstra L. Intervention of multi-modal activities for older adults with dementia translation to rural communities. *Am J Alzheimers Dis Other Demen* 2015; 30(5):468-477. doi:10.1177/1533317514568888
54. Mason T, Slack G. *The Debenham Project: Research into the dementia/memory loss journey for cared-for and carer, 2012-13.* Norwich: Norfolk & Suffolk Dementia Alliance, 2013. http://www.the-debenham-project.org.uk/downloads/articles/2014/DebProjResearch_Final_Report_311013.pdf
55. Meiland FJ, Dröes RM, Lange J, Vernooij-Dassen M. Development Of A Theoretical Model For Tracing Facilitators And Barriers In Adaptive Implementation Of Innovative Practices In Dementia Care. *Arch Gerontol Geriatr* 2004; 38:279-290. doi:10.1016/j.archger.2004.04.038
56. Solutions Research. *Public perceptions and experiences of community-based end of life care initiatives: a qualitative research report.* London: Public Health England, 2016. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/569711/Public_Perceptions_of_Community_Based_End_of_Life_Care_Initiatives_Resea....pdf
57. Cahill S, Pierce M, Bobersky A.*An evaluation report on flexible respite options of the Living Well With Dementia project in Stillorgan and Blackrock.* Dublin: Trinity College, 2014. http://dementia.ie/images/uploads/site-images/Evaluation_Flexible_Respite_Options.pdf
58. Carone L, Tischler V, Dening T. Football and dementia: A qualitative investigation of a community based sports group for men with early onset dementia. *Dementia* 2016; 15(6):1358-1376. doi:10.1177/1471301214560239
59. Gajardo J, Aravena JM, Budinich M, et al. The Kintun program for families with dementia: From novel experiment to national policy (innovative practice). *Dementia* 2017; 19(2):488-495. doi:10.1177/1471301217721863
60. Grinberg A, Lagunoff J, Phillips D, *et al.* Multidisciplinary design and implementation of a day program specialized for the frontotemporal dementias. *Am J Alzheimers Dis Other Demen* 2008; 22(6):499-506. doi:10.1177/1533317507308780
61. Meiland FJ, Dröes RM, Lange JD, Vernooij-Dassen MJ. Facilitators and barriers in the implementation of the meeting centres model for people with dementia and their carers. *Health Policy* 2005; 71(2):243-253. doi:10.1016/j.healthpol.2004.08.011
62. Rio R. A Community-Based Music Therapy Support Group for People With Alzheimer's Disease and Their Caregivers: A Sustainable Partnership Model. *Front Med* 2018; 5. doi:10.3389/fmed.2018.00293
63. Gottleib-Tanaka D. *Creative expression, dementia and the therapeutic environment (PhD Thesis).* Vancouver: University of British Columbia, 2006. https://open.library.ubc.ca/cIRcle/collections/ubctheses/831/items/1.0076821
64. Mapes N, Milton S, Nicholls V, Williamson T. *Is it nice outside? Consulting people living with dementia and their carers about engaging with the natural environment.* Natural England Commissioned Reports, Number 211. York: Natural England, 2016. http://publications.naturalengland.org.uk/publication/5910641209507840
65. Brataas HV, Bjugan H, Wille T, Hellzen O. Experiences of day care and collaboration among people with mild dementia. *J Clin Nurs* 2010; 19(19-20):2839-2848. doi:10.1111/j.1365-2702.2010.03270.x
66. Casey J. Early Onset Dementia: Getting Out and About. *Journal of Dementia Care* July/August 2004; 12(4):12-13.
67. Oliver-Watkins F, Kendall N, Matthews T. *Sow & Grow: Report from a two-year Social and Therapeutic Horticultural (STH) programme delivering table-top gardening courses to adults in the community aged 50 and over.* Reading: Thrive, 2016.
68. Williams B, Roberts P. Friends in passing: Social interaction at an adult day care center. *Int J Aging Hum Dev* 1995; 41(1):63-78. doi:10.2190/ghhw-v1qr-nacx-vbcb
69. Alzheimer's Australia.*The benefits of physical activity and exercise for people living with dementia (Dicussion paper 11).* Sydney: Alzheimer's Australia, 2014. https://www.dementia.org.au/sites/default/files/NSW/documents/AANSW_DiscussionPaper11.pdf
70. Hayes R, Williamson M. *Men's Sheds: Exploring the Evidence for Best Practice.* Melbourne: La Trobe University, 2007. https://www.researchgate.net/publication/259313489

71. Milligan C, Payne S, Bingley A, Cockshott Z. Place and wellbeing: Shedding light on activity interventions for older men. *Ageing Soc* 2013; 35(1):124-149. doi:10.1017/s0144686x13000494
72. Tuppen J. The benefits of groups that provide cognitive stimulation for people with dementia. *Nurs Older People* 2012; 24(10):20-24. doi:10.7748/nop2012.12.24.10.20.c9437
73. Mental Health Foundation. *An evaluation of the Standing Together project.* London: Mental Health Foundation, 2018. https://www.mentalhealth.org.uk/sites/default/files/standing-together-evaluation-WEB.pdf
74. Thrive. *Growing4life - A Thrive Community Gardening Project: A practical guide to setting up a community gardening project for people affected by mental ill health.* Reading: Thrive, 2012. https://www.lumi.org.uk/assets/resources-toolkits/event-and-projects/G4L-Resource-Book.pdf
75. Tuppen J, Burton-Jones J. Cogs Clubs: a helpful activity in early dementia. *Journal of Dementia Care* September/October 2015; 23(5):20-21.
76. Dean J, Silversides K, Crampton J, Wrigley J. *Evaluation of the Bradford Dementia Friendly Communities Programme.* York: Jospeh Rowntree Foundation, 2015. https://www.jrf.org.uk/report/evaluation-bradford-dementia-friendly-communities-programme
77. Dean J, Silversides K, Crampton J, Wrigley J. *Evaluation of the York Dementia Friendly Communities Programme*. York: Jospeh Rowntree Foundation, 2015. https://www.jrf.org.uk/report/evaluation-york-dementia-friendly-communities-programme
78. Noimuenwai P. *Effectiveness of adult day care programs on health outcomes of Thai family caregivers of persons with dementia (PhD Thesis).* Kansas: University of Kansas, 2012. https://kuscholarworks.ku.edu/bitstream/handle/1808/11440/Noimuenwai_ku_0099D_12475_DATA_1.pdf?sequence=1&isAllowed=y
79. Van Haeften-Van Dijk A, Meiland F, Mierlo LV, Dröes RM. Transforming nursing home-based day care for people with dementia into socially integrated community day care: Process analysis of the transition of six day care centres. *Int J Nurs Stud* 2015; 52(8), 1310-1322. doi:10.1016/j.ijnurstu.2015.04.009
80. Health Innovation Network South London. *Peer Support for People with Dementia Resource Pack.* London: Health Innovation Network South London, 2015. https://dementiapartnerships.com/resource/dementia-peer-support-resource-pack/
81. Hikichi H, Kondo K, Takeda T, Kawachi I. Social interaction and cognitive decline: Results of a 7-year community intervention. *Alzheimers Dement (N Y)* 2017; 3:23-32. doi:10.1016/j.trci.2016.11.003
82. Hochgraeber I, Bartholomeyczik S, Holle B. Low-threshold support for families with dementia in Germany. *BMC Res Notes* 2012; 5(1). doi:10.1186/1756-0500-5-317
83. La Rue A, Felten K, Duschene K, *et al*. Language-enriched exercise plus socialization for older adults with dementia: Translation to rural communities. *Semin Speech Lang* 2013; 34(03):170-184. doi:10.1055/s-0033-1358370
84. Lockwood S. *The Debenham Project: A case study of a unique community-led and owned project dedicated to the support of carers of those that have symptoms of dementia and those they care for.* Harrogate: Community Catalysts CIC, 2012.http://www.the-debenham-project.org.uk/downloads/articles/2012/121106report.pdf
85. Health Innovation Network South London. *Case Study: The Healthy Living Club (HLC) – A self-directed, dementia-centred community group in Stockwell, London.* London: Health Innovation Network South London, 2015. http://www.hin-southlondon.org/system/resources/resources/000/000/084/original/Case_Study_The_Dulwich_Helpline_and_Southwark_Churches.pdf?1426083406
86. Mangiaracina F, Chattat R, Farina E, *et al.* Not re-inventing the wheel: The adaptive implementation of the meeting centres support programme in four European countries. *Aging Ment Health* 2016; 21(1):40-48. doi:10.1080/13607863.2016.1258540
87. Jackson L. *The Debenham Project: Project Blog and Catch-Up (August 2017).* Debenham, Suffolk: The Debenham Project, 2017. http://www.the-debenham-project.org.uk/downloads/newsletters/blogs/1708.pdf
88. McAiney CA, Hillier LM, Stolee P, *et al.* 'Throwing a lifeline': The role of First Link™ in enhancing support for individuals with dementia and their caregivers. *Neurodegener Dis Manag* 2012; 2(6):623-638. doi:10.2217/nmt.12.66
89. Moore KD. Observed affect in a dementia day center: Does the physical setting matter? *Alzheimers Care Q* 2002; 3(1):67-73.
90. Arthur A, Buckner S, Buswell M, *et al. DEMCOM: National Evaluation of Dementia Friendly Communities (Executive Summary).* Cambridge: Applied Research Collaboration (ARC) East of England, 2020.

91. Kelsey SG, Laditka SB. Evaluating best practices for social model programs for adults with Alzheimer's disease in South Carolina. *Home Health Care Serv Q* 2006; 24(4):21-46. doi:10.1300/j027v24n04_02

92. Arkin SM, Morrow-Howell N. Elder Rehab: A student-supervised exercise program for Alzheimer's patients. *Gerontologist* 1999; 39(6):729-735. doi:10.1093/geront/39.6.729

93. LeBlanc LA. Integrating behavioral psychology services into adult day programming for individuals with dementia. *BehavModif* 2010; 34(5):443-458. doi:10.1177/0145445510383528

94. NCVO. *How To Fundraise In Tough Times.* London: NCVO, 2019. https://knowhow.ncvo.org.uk/how-to/how-to-fundraise-in-tough-times

95. Wimo A, Wallin J, Lundgren K, *et al.* Impact of day care on dementia patients–costs, well-being and relatives' views. *Fam Pract* 1990; 7(4):279-287. doi:10.1093/fampra/7.4.279

96. Shnall A, Agate A, Grinberg A, *et al.* Development of supportive services for frontotemporal dementias through community engagement. *Int Rev Psychiatry* 2013; 25(2):246-252. doi:10.3109/09540261.2013.767780

97. Powell M, Osborne SP. Social enterprises, marketing, and sustainable public service provision. *International Review of Administrative Sciences* 2020; 86(1):62-79. doi:10.1177/0020852317751244

98. Powell M, Gillett A, Doherty B. Sustainability in social enterprise: hybrid organizing in public services. *Public Management Review* 2019; 21(2):159-186. doi:10.1080/14719037.2018.1438504

99. Oyebode JR, Parveen S. Psychosocial interventions for people with dementia: An overview and commentary on recent developments. *Dementia* 2019; 18(1):8–35. doi: 10.1177/1471301216656096

100. Barbarino P, Lynch C, Bliss A, *et al. From Plan to Impact III: Maintaining dementia as a priority in unprecedented times.* London: Alzheimer's Disease International, 2020. https://www.alzint.org/u/from-plan-to-impact-2020.pdf

101. Canevelli M, Valletta M, Toccaceli Blasi M, *et al.* Facing Dementia During the COVID-19 Outbreak. *J Am Geriatr Soc* 2020; 68(8):1673–1676. https://doi.org/10.1111/jgs.16644

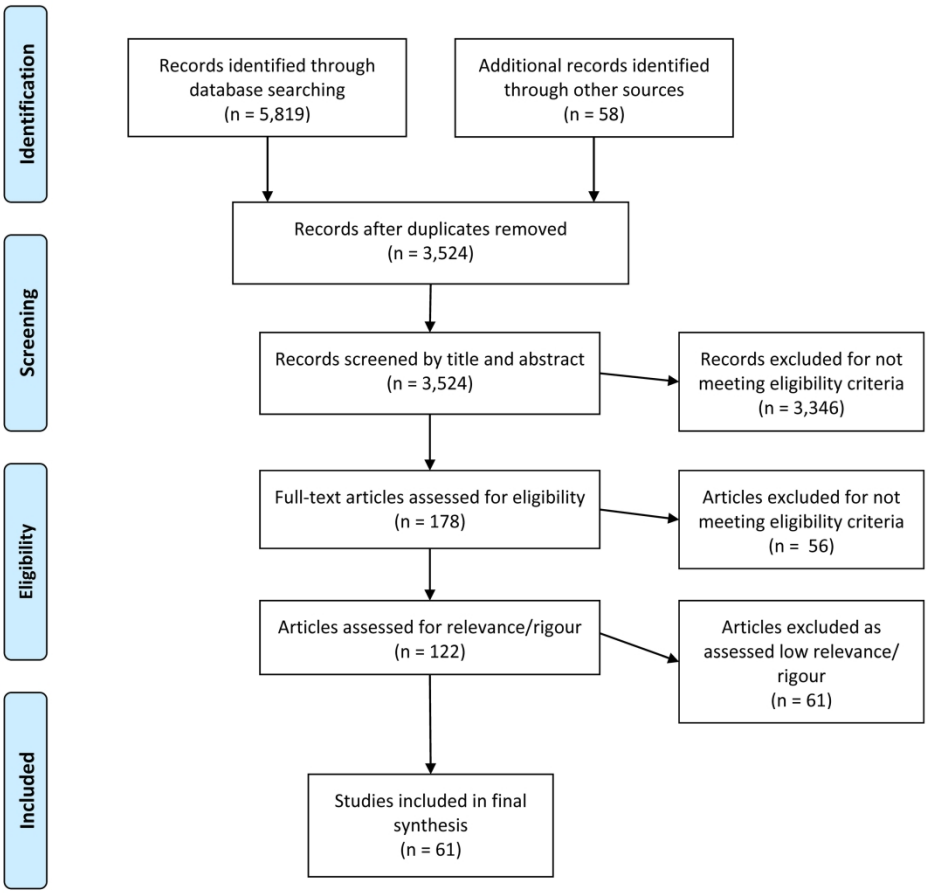


Figure 1 PRISMA flow diagram

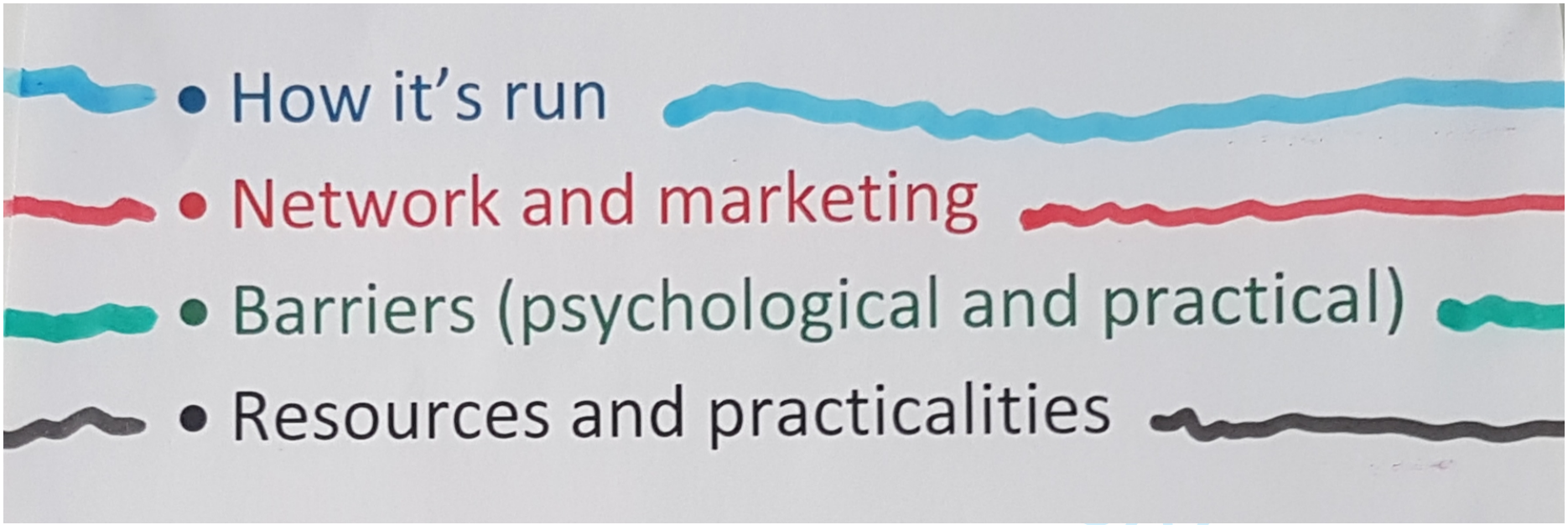
133x130mm (600 x 600 DPI)

Figure 2 Factors affecting the sustainability of community-based groups and activities

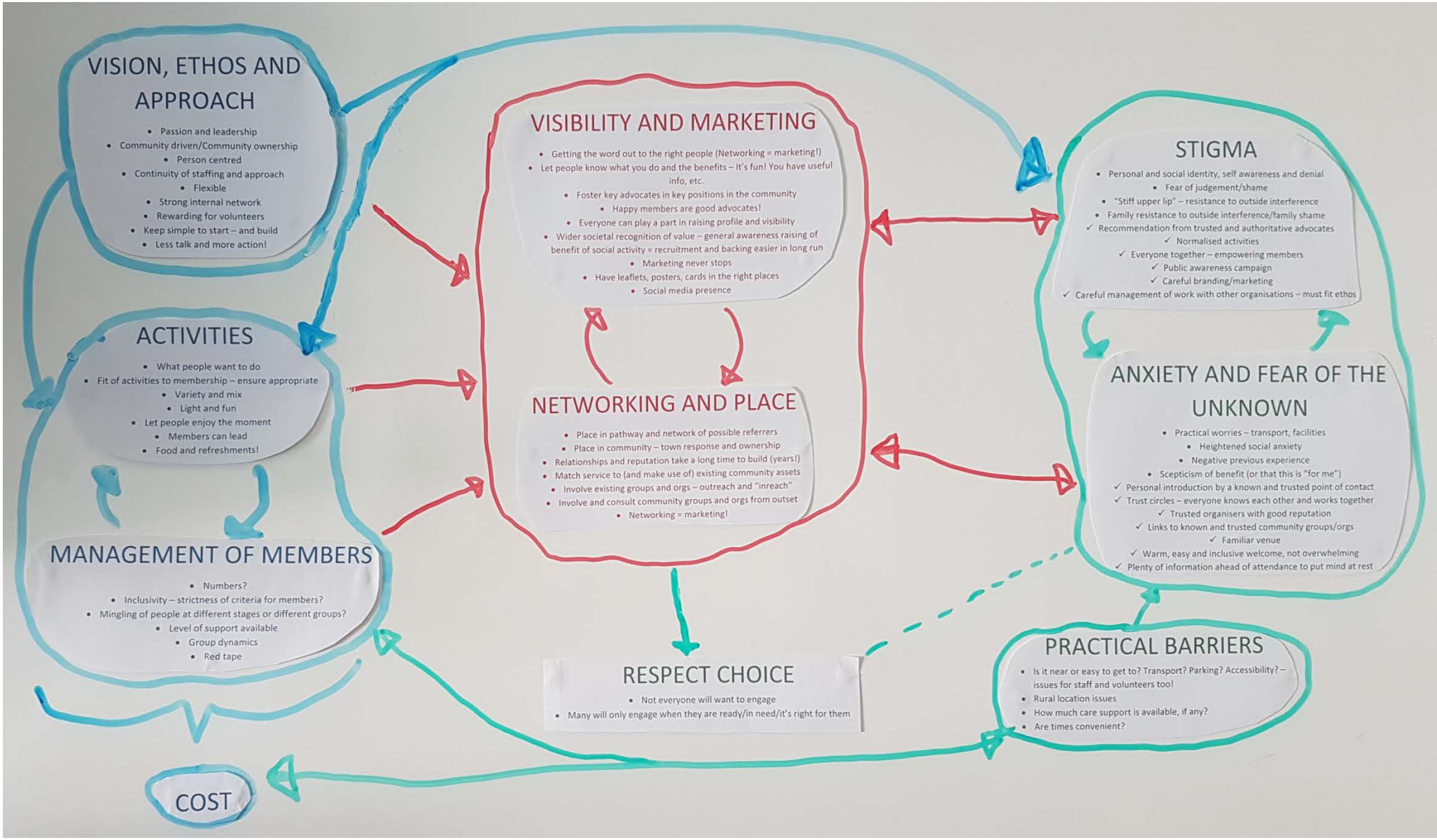
164x106mm (1200 x 1200 DPI)

Supplementary file 1: Initial programme theory diagrams and coding themes

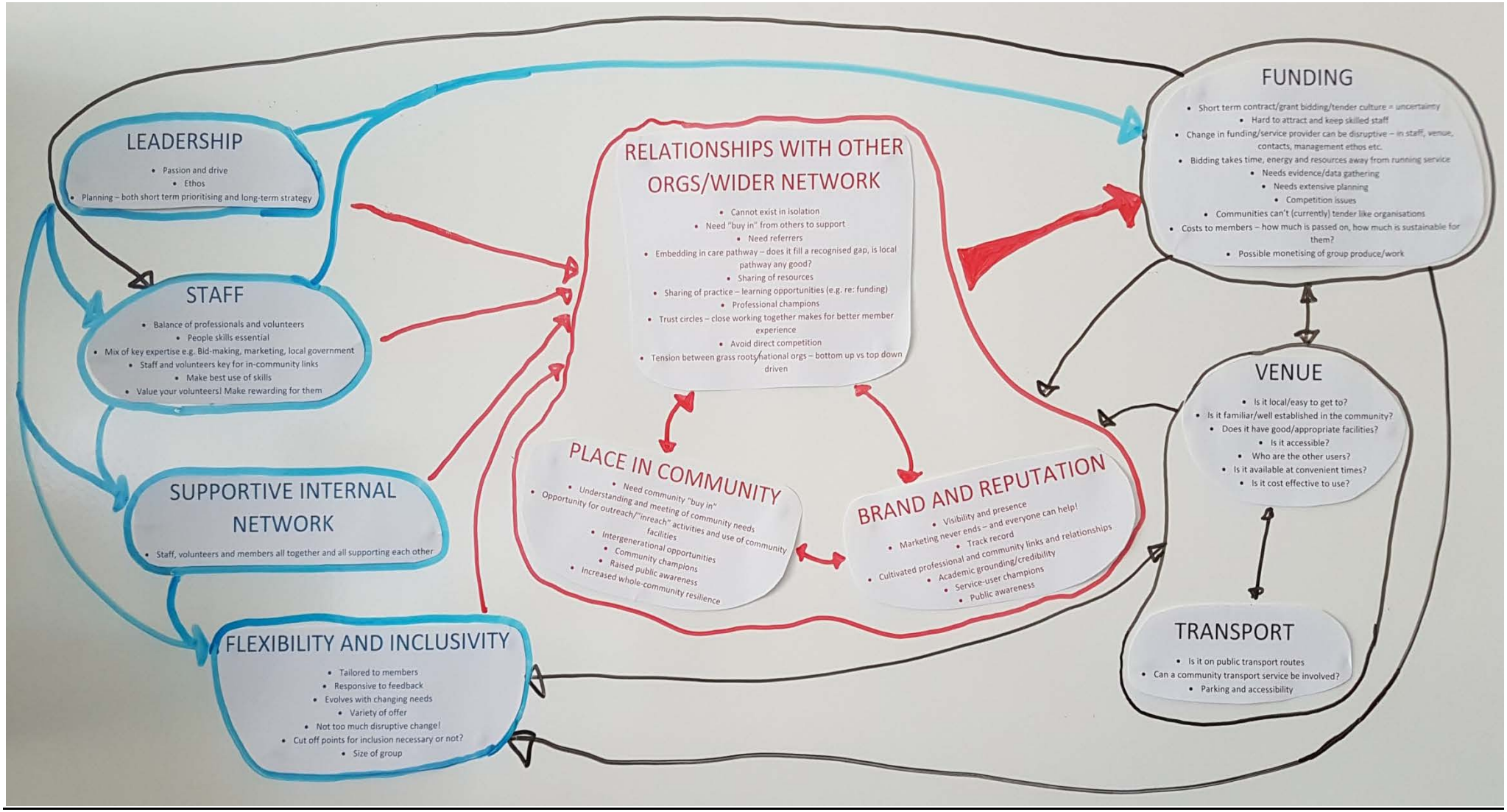
Key to colour coding:



Barriers and facilitators to <u>engagement</u>



Barriers and facilitators to <u>sustainability</u>



Top-level "parent" coding categories in NVivo analysis of the data

Name	Files	References	
Leadership	54	226	"How it's run"
Management of members (inc flexibility and inclusivity)	66	219	
Staff and volunteer issues	71	196	
Activities	94	577	
Ethos and approach	92	556	
Stability and reliabiltiy of provision	14	23	
Anxiety and fear of unknown	65	321	Barriers to engagement
Transport and geography	39	87	
Venue issues	60	203	
Attendee characteristics	62	216	
Difficulty becoming a member	23	50	
Visibility and marketing	76	365	Networking & marketing
Place in the community	67	295	
Relationships with other organisations	71	567	
Funding issues	64	327	Money & resources
Cost effectiveness issues	35	68	

Supplementary file 2: Search strategy

Databases:

EBSCOhost: **Academic Search Complete, CINAHL, MEDLINE, PsychINFO**

Other health and social care databases: **AMED,Embase, PubMed, Social Care Online**

Interdisciplinary databases: **ProQuest, Scopus**

Systematic reviews: **Cochrane Library, Campbell Collaboration**

Other/general: **Google Scholar**

Limiters: Published 1990 to present

Key terms	String of related terms
Dementia	Dementia
Community	Commun* OR Local* OR Social*
Intervention	Intervention OR Program* OR Project OR Initiative OR Scheme OR Service OR Activit* OR Group OR Club OR Network OR Meeting OR Therapy
Sustainability	Sustain* OR Maint* OR Manag* OR Facilitat* OR Barrier*
Implementation and Engagement	Implement* OR Recruit* OR Engag*

Dementia AND (Commun* OR Local* OR Social*) AND (Intervention OR Program* OR Project OR Initiative OR Scheme OR Service OR Activit* OR Group OR Club OR Network OR Meeting OR Therapy) AND (Sustain* OR Maint* OR Manag* OR Facilitat* OR Barrier*)AND (Implement* OR Recruit* OR Engag*)

NOTES:

Search terms were kept uniform across all databases and searching was carried out by looking for the occurrence of these terms within the title, abstract and key words of documents in each database. If a database did not allow for this, the strategy was altered slightly to the closest option (e.g. in ProQuest this was searching everywhere in a document except full text; in PubMed this was by carrying out three separate searches by title content, by abstract content and key word content, then combining the results).

Supplementary file 3: Inclusion and assessment criteria

Inclusion and exclusion criteria for formal search:

Inclusion criteria Types of intervention for inclusion should:	**Exclusion criteria** Interventions will be excluded if they:
• Target people with mild to moderate dementia (whether exclusively or among others without dementia, but either way there is dementia-specific support) • Serve people living in the community, whether in their own homes or in extra-care housing • Are voluntary attendance (i.e. members have chosen to attend, not been told they must as part of treatment or respite care) • Are social and place-based (bringing people together physically) in a community setting (open to members of the public to attend) • Are designed as an intervention with meaningful activity aiming to improve quality of life for people with dementia and family carers, or to help them manage or lessen the challenging effects dementia • Meet at regular, pre-fixed times, at least weekly and for a substantial amount of time (i.e. a morning or afternoon) • Meet continuously, on an ongoing basis, or aim to do so	• Are only for those with severe dementia • Do not target, and have no plan to cater for, people with dementia • Are only for care home residents, hospital patients or those in a closed institutional setting • Are an online or at-a-distance networking scheme that does not involve meeting physically • Only involve individual participants alone (e.g. occupational therapy, counselling or medical) • Are only functional meetings solely for the purpose of administering medical treatment or carry out case management • Are focussed mainly upon respite for carers or nursing care only (i.e. not focussed upon social, meaningful and quality-of-life-raising activities for those attending) • Only take place monthly; or for a very short duration (e.g. one hour); or intermittently with no specified or timetabled meetings • Are fixed-term courses with a time/goal/session limit (e.g. an 8 week course)

Relevance and rigour assessment guidance:

Relevance	**Rigour**
An article should comply with the inclusion/exclusion criteria in the first instance, except where agreed by the team for inclusion for a specific reason e.g. containing data that is broadly transferable and of use to the programme theory.	This is an assessment of the likely validity and reliability only of the *relevant* data contained in an article, *not* an assessment of the rigour of a study or intervention programme as a whole. Useful questions might include: *Is this data likely to be biased? Is it dealt with critically? Is it from a real-world example or theoretical speculation? Was the data gathered in some depth over time or in a quick "snapshot"? Is it safe to generalise from this data?*

Reasons for rating must be recorded. For example:	Reasons for rating must be recorded. For example:
A **low rating** might mean the article only contains a few relevant lines, with the bulk of the text focused on other, non-relevant matters A **medium rating** might mean an article has a lot of detail on one relevant issue (e.g. engaging people and keeping them engaged) which is pertinent to sustainability, but otherwise little on other important factors A **high rating** will mean an article has a direct focus on keeping an intervention sustainable long term, with a good level of detail	A **low rating** might mean data appears uncritically treated and at a high risk of bias (e.g. from a promotional article for a service) or simply descriptive and superficial in its reporting of basic facts from an intervention programme (e.g. from a short news article) A **medium rating** might mean data appears with some attempt at critical evaluation and is from a real-world example, but is limited in scope and generalisability, or in depth and detail A **high rating** might mean data is of good depth and detail and is from a critical evaluation of at least one real world example, gathered over a sustained period using range of robust measures and an appropriate sample of participants

Supplementary file 4: Full lists of included articles

Author(s)	Year	Article title	Type of intervention	Country of origin	Type of article/study	Publication	Reference list No.
Actifcare	2017	Best practice recommendations from the Actifcare study: Access to community care services for home-dwelling people with dementia and their carers	**community care services** in general	Netherlands, Germany, Sweden, UK, Norway, Ireland, Portugal, Italy	Recommendations report	www.actifcare.eu	**36**
Alzheimer's Australia	2014	The benefits of physical activity and exercise for people living with dementia (Dicussion paper 11)	**Exercise activities**	Australia	Report	Alzheimer's Australia	**69**
Arkin	1999	Elder rehab: A student-supervised exercise program for Alzheimer's patients	**Weekly exercise programme** pairing elders and student helpers at a college gym (caregivers also involved)	US	Journal paper - programme pilot	The Gerontologist	**92**
Arthur, Buckner, Buswell, Darlington, Killett, Lafortune, Mathie, Mayrhofer, Skedgel, Woodward & Goodman	2020	DEMCOM: National Evaluation of Dementia Friendly Communities (Executive Summary)	**Dementia Friendly Communities - various social and leisure activities**	UK	Evaluation report	Applied Research Collaboration (ARC) East of England	**90**

Bould, McFadyen & Thomas	2019	Dementia-friendly sport and physical activity guide	**Sport and excercise initiatives**	UK	Information booklet	Alzheimer's Society	**48**
Brataas, Bjugan, Wille & Hellzen	2010	Experiences of day care and collaboration among people with mild dementia	**Day care**	Norway	Journal paper - qual study of a trial programme	Journal of Clinical Nursing	**65**
Brooker, Evans, Evans, Watts & Droes	2017	Meeting Centres Support Programme UK: Overview, evidence and getting started	**Meeting Centres**	Netherlands, Italy, Poland, UK	Information/guide booklet	Association for Dementia Studies (University of Worcester)	**42**
Cahill, Pierce & Bobersky	2014	An evaluation report on flexible respite options of the Living Well With Dementia project in Stillorgan and Blackrock	**Day care/respite**	Ireland	Evaluation report	Trinity College Dublin	**57**

Carone, Tischler & Dening	2016	Football and dementia: A qualitative investigation of a community based sports group for men with early onset dementia	**Sport and excercise group**	UK	Journal paper - qualitative study	Dementia	**58**
Casey	2004	Early onset dementia: Getting out and about	**Small "out and about" social group**	UK	Specialist news article	Journal of Dementia Care	**66**
Clarke, Keyes, Wilkinson, Alexjuk, Wilcockson, Robinson, Corner & Cattan	2014	Organisational space for partnership and sustainability: lessons from the implementation of the National Dementia Strategy for England	**Peer support networks**	UK	Journal paper - stragtegy evaluation	Health & Social Care in the Community	**51**
Daykin, Julier, Tomlinson, Meads, Mansfield, Payne, Duffy, Lane, D'Innocenzo, Burnett, Kay, Dolan, Testoni & Victor	2016	Review of the grey literature: music, singing and wellbeing	**Singing and musical activities**	UK	Review/Report	What Works Wellbeing report	**37**

Dean, Silversides, Crampton & Wrigley	2015	Evaluation of the Bradford Dementia Friendly Communities Programme	**Activities and groups in the community**	UK	Evaluation report	Joseph Rowntree Foundation report	**76**
Dean, Silversides, Crampton & Wrigley	2015	Evaluation of the York Dementia Friendly Communities Programme	**Activities and groups in the community**	UK	Evaluation report	Joseph Rowntree Foundation report	**77**
Gajardo, Aravena, Budinich, Larrain, Fuentes & Gitlin	2017	The Kintun program for families with dementia: From novel experiment to national policy (innovative practice)	**Day centre** and dementia **community hub**	Chile	Journal article - program evaluation	Dementia	**59**
Glover	2014	Running self-help groups in sheltered and extra care accommodation for people who live with dementia	**Self-help social and activity groups**	UK	Information/guide booklet	Mental Health Foundation	**43**

Gottlieb-Tanaka	2006	Creative expression, dementia and the therapeutic environment	**Art/creative activities in a day centre environment**	Canada	Dissertation/Thesis		**63**
Green & Lakey (Alzheimer's Society)	2013	Building dementia-friendly communities: a priority for everyone	**Dementia Friendly Communities** - various social and leisure activities	UK	Report	Alzheimer's Society	**49**
Grinberg, Lagunoff, Phillips, Stern, Goodman & Chow	2007	Multidisciplinary design and implementation of a day program specialized for the frontotemporal dementias	**Day program** for people with FTD	Canada	Journal paper - program evaluation	American Journal of Alzheimer's Disease & Other Dementias	**60**
Hayes & Williamson	2007	Men's Sheds: Exploring the Evidence for Best Practice	**Men's Sheds**	Australia	Evaluation report	School of Public Health, La Trobe University	**70**

Health Innovation Network South London** (**see also linked films within document plus 2015 HIN Case Studies)	2015	Peer Support for People with Dementia Resource Pack	A range of **peer support groups and activities**	UK	Information/guide booklet	Health Innovation Network South London	**80**
Health Innovation Network South London	2015	Case Study: Dulwich Helpline and Southwark Churches Care (DH&SCC) – The Dementia Project, Southwark, South London.	**Peer support project**	UK	Information/guide booklet	Health Innovation Network South London	**52**
Health Innovation Network South London	2015	Case Study: The Healthy Living Club (HLC) – A self-directed, dementia-centred community group in Stockwell, London	**Peer support group**	UK	Information/guide booklet	Health Innovation Network South London	**85**
Hikichi, Kondo, Takeda & Kawachi	2017	Social interaction and cognitive decline: Results of a 7-year community intervention	**Community centres for older people**	Japan	Journal paper - longitudinal study	Alzheimer's & Dementia	**81**

Hochgraeber, Bartholomeyczik & Holle** (**See also Hochgraeber et al 2017)	2012	Low-threshold support for families with dementia in Germany	**"Low threshold" support services** including **social care groups**	Germany	Journal paper - survey protocol	BMC Research Notes	**82**
Hochgraeber, Von Kutzleben, Bartholomeyczik & Holle	2017	Low-threshold support services for people with dementia within the scope of respite care in Germany – A qualitative study on different stakeholders' perspective	**"Low threshold" support services** including **social care groups**	Germany	Journal paper - qualitative study	Dementia	**38**
Jackson	2017	The Debenham Project: Project Blog and Catch-Up	Range of local **support groups and activities**	UK	Project blog newsletter/report	Debenham Project	**87**
Kelsey & Laditka	2005	Evaluating best practices for social model programs for adults with Alzheimer's disease in South Carolina	**"Social model" day care**	US	Journal paper - review and survey of best practice	Home Health Care Services Quarterly	**91**

La Rue, Felten, Duschene, MacFarlane, Price, Zimmerman & Havez	2013	Language-enriched exercise plus socialization for older adults with dementia: Translation to rural communities	**Language, excercise and socialisation program**	US	Journal paper - trial progam in rural setting	Seminars in Speech and Language	**83**
La Rue, Felten & Turkstra	2015	Intervention of Multi-Modal Activities for Older Adults With Dementia Translation to Rural Communities	**Language, excercise and socialisation program**	US	Journal paper - trial progam in rural setting	American Journal of Alzheimer's Disease & Other Dementias	**53**
LeBlanc	2010	Integrating behavioral psychology services into adult day programming for individuals with dementia	**Day care** (for people with dementia exhibiting challenging behaviour)	US	Journal paper - program evaluation	Behavior Modification	**93**
Lockwood	2012	The Debenham Project: A case study of a unique community-led and owned project dedicated to the support of carers of those that have symptoms of dementia and those they care for	Range of local **support groups and activities**	UK	Case study report	Community Catalysts	**84**

Mangiaracina, Chattat, Farina, Saibene, Gamberini, Brooker, Evans, Evans, Szcześniak, Urbanska, Rymaszewska, Hendricks, Dröes & Meiland	2017	Not re-inventing the wheel: the adaptive implementation of the meeting centres support programme in four European countries	**Meeting Centres**	Netherlands, Italy, Poland, UK	Journal paper - project evaluation	Aging & Mental Health	**86**
Mapes, Milton, Nicholls & Williamson (Natural England)	2016	Is it nice outside? Consulting people living with dementia and their carers about engaging with the natural environment	**Outdoor activities**	UK	Report	Natural England report	**64**
Marshall & Jackson	2015	Encouraging and supporting the growth of "dementia proactive communities"	**Dementia proactive communities** (Range of local **support groups and activities**)	UK	Report	Debenham Project & Sue Ryder	**50**
Mason & Slack	2013	The Debenham Project: Research into the dementia/memory loss journey for cared-for and carer, 2012-13	Range of local **support groups and activities**	UK	Evaluation report - survey	Norfolk & Suffolk Dementia Alliance	**54**

McAiney, Hillier, Stolee, Harvey & Michael	2012	'Throwing a lifeline': the role of First Link in enhancing support for individuals with dementia and their caregivers	Information on and links between **support services (including groups and activities)**	Canada	Journal paper - evaluation	Neurodegenerative Disease Management (Future Medicine)	**88**
McDonald & Heath	2009	Developing services for people with dementia	**General dementia support services** in rural areas	UK	Journal short report feature - review of service provision	Working with Older People: Community Care Policy & Practice	**39**
The Me Myself and I Club	2018	The Me, Myself and I Club, Briton Ferry: A case study in warm humanity and meaningful co-production	**Friendship club and support services**	UK (Wales)	Programme/service report	Me Myself and I Club	**46**
Meiland, Dröes, De Lang & Vernooij-Dassen	2004	Development of a theoretical model for tracing facilitators and barriers in adaptive implementation of innovative practices in dementia care	**Meeting centres**	Netherlands	Journal paper - model development	Archives Of Gerontology And Geriatrics Supplement	**55**

Meiland, Dröes, De Lang & Vernooij-Dassen	2005	Facilitators and barriers in the implementation of the Meeting Centres model for people with dementia and their carers	**Meeting centres**	Netherlands	Journal paper - model test	Health Policy	**61**
The Mental Health Foundation	2018	An evaluation of the Standing Together project	**Peer support groups**	UK	Evaluation report	Mental Health Foundation report	**73**
Milligan, Payne, Bingley & Cockshott	2015	Place and wellbeing: shedding light on activity interventions for older men	**Men's Sheds**	UK	Journal paper - qualitative study of program	Ageing & Society	**71**
Moore	2002	Observed affect in a dementia day center: Does the physical setting matter?	**Day centre**	US	Journal paper - case study/field observation	Alzheimer's Care Quarterly	**89**

Noimuenwai	2012	Effectiveness of adult day care programs on health outcomes of Thai family caregivers of persons with dementia	**Day care (Thailand)**	Thailand	Dissertation/Thesis		**78**
NVCO	2019	How To Fundraise In Tough Times	**Third sector and non-profit organisations in general**	UK	Information guide	NCVO Knowhow website	**94**
Older People's Commissioner for Wales	2018	Rethinking respite for people affected by dementia	**Respite/day services**	UK (Wales)	Report	Older People's Commissioner for Wales report	**47**
Oliver-Watkins, Kendall & Matthews	2016	Sow & Grow: Report from a two-year Social and Therapeutic Horticultural (STH) programme delivering table-top gardening courses to adults in the community aged 50 and over	**Gardening groups**	UK	Evaluation report	Sow & Grow	**67**

Reichet & Wolter	2017	Implementing physical activity programs for people with dementia: Results from a German study	**Sports club initiatives**	Germany	Poster presentation		**44**
Reichet & Wolter	2017	Implementing physical activity programs for people with dementia: Results from a German study	**Sports club initiatives**	Germany	Conference abstract	Innovation in Aging (Supplement)	**45**
Rio	2018	A Community-Based Music Therapy Support Group for People With Alzheimer's Disease and Their Caregivers: A Sustainable Partnership Model	**Music therapy group**	US	Journal paper - program evaluation	Frontiers In Medicine	**62**
Shnall, Agate, Grinberg, Huijbregts, Nguyen & Chow	2013	Development of supportive services for frontotemporal dementias through community engagement	**Day program for FTD** (plus online groups and resources for family carers)	Canada	Journal paper - review of initiatives	International Review of Psychiatry	**96**

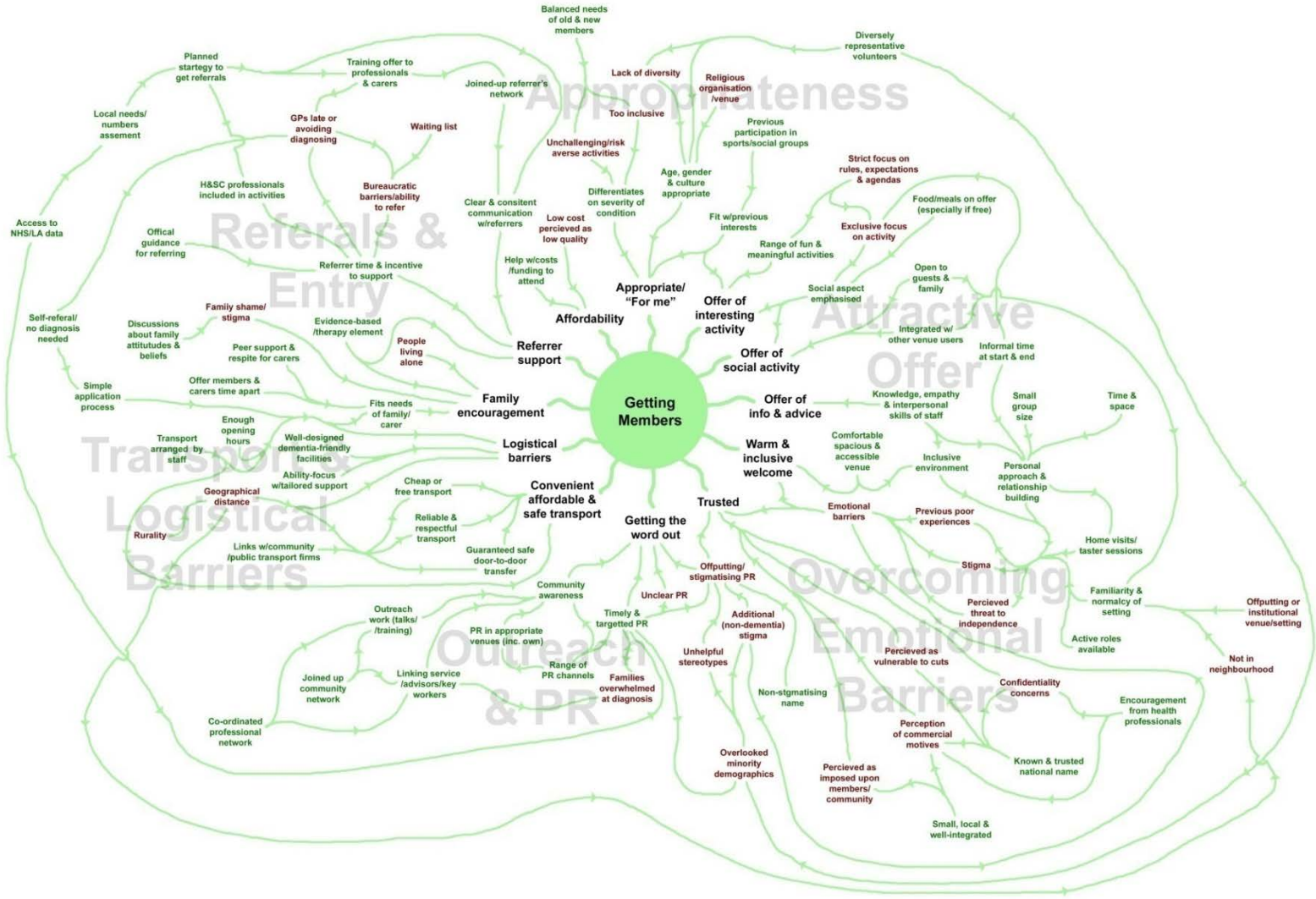
Solutions Research	2016	Public perceptions and experiences of community-based end of life care initiatives: a qualitative research report	**Community-based support initiatives** of all kinds	UK	Report	Public Health England report	**56**
Strandenæs, Lund & Rokstad	2018	Experiences of attending day care services designed for people with dementia - a qualitative study with individual interviews	**Day care**	Norway	Journal paper - qualitative study	Aging & Mental Health	**40**
Thrive	2012	Growing4life - A Thrive Community Gardening Project: A practical guide to setting up a community gardening project for people affected by mental ill health	**Gardening groups**	UK	Information/guide booklet	Thrive (The Society for Horticultural Therapy)	**74**
Tuppen	2012	The benefits of groups that provide cognitive stimulation for people with dementia	**Cognitive stimulation clubs**	UK	Journal article - overview of intervention	Nursing Older People	**72**

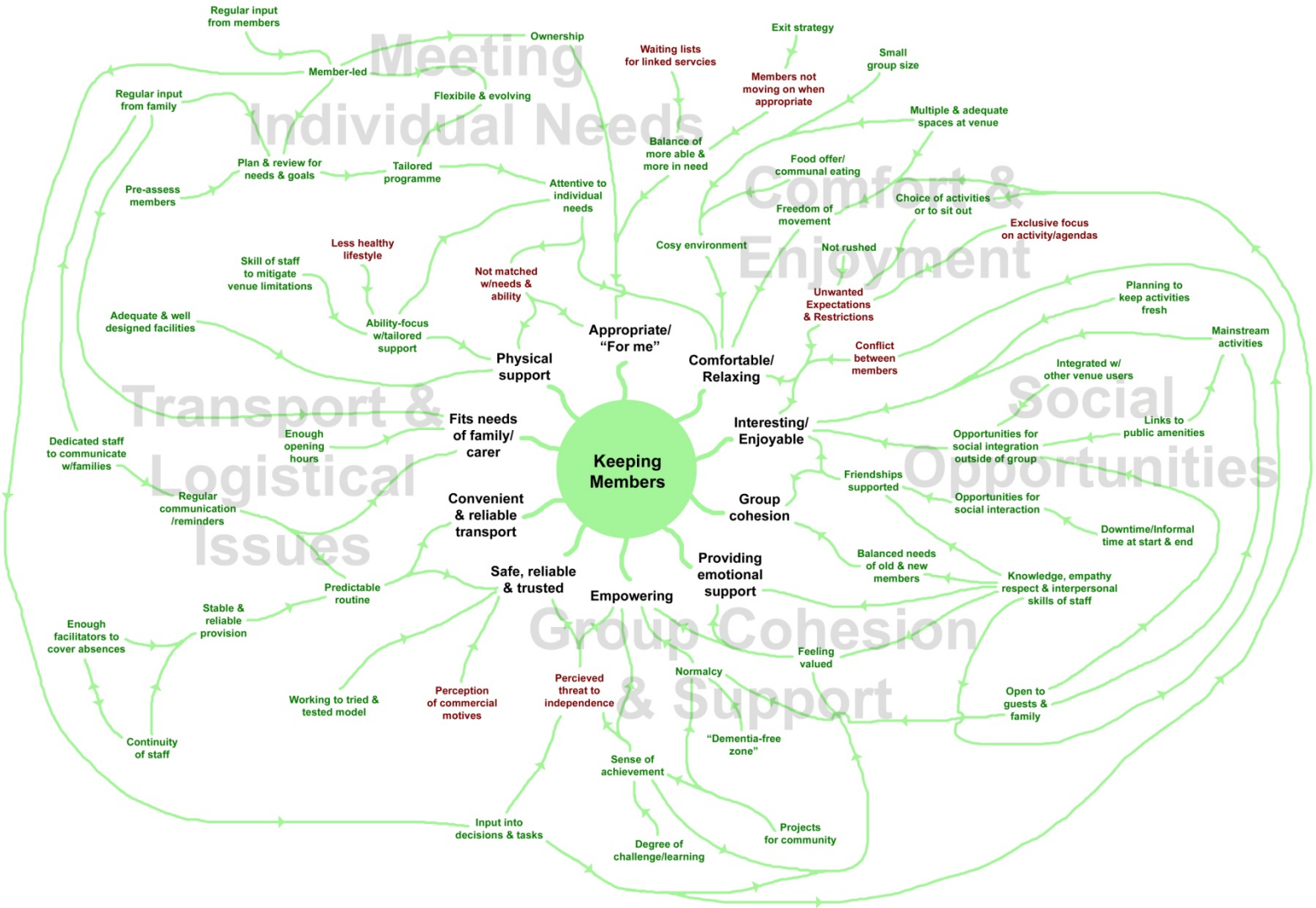
Tuppen & Jones	2015	Cogs Clubs: a helpful activity in early dementia	**Cognitive stimulation clubs**	UK	Specialist news article	Journal of Dementia Care	**75**
Van Haeften-van Dijk, Meiland, van Mierlo & Dröes	2015	Transforming nursing home-based day care for people with dementia into socially integrated community day care: Process analysis of the transition of six day care centres	**Meeting centres**	Netherlands	Journal paper - process evaluation	International Journal of Nursing Studies	**79**
Van Mierlo, Chattat, Evans, Brooker, Saibene, Gamberini, Farina, Scorolli, Szcześniak, Urbańska, Rymaszewska, Dröes & Meiland	2018	Facilitators and barriers to adaptive implementation of the Meeting Centers Support Program (MCSP) in three European countries; the process evaluation within the MEETINGDEM study	**Meeting centres**	Netherlands, Italy, Poland, UK	Journal paper - program evaluation	International Psychogeriatrics	**41**
Williams & Roberts	1995	Friends in passing: social interaction at an adult day care center	**Adult day care centre**	US	Journal paper - participant observation	International Journal Of Aging & Human Development	**68**

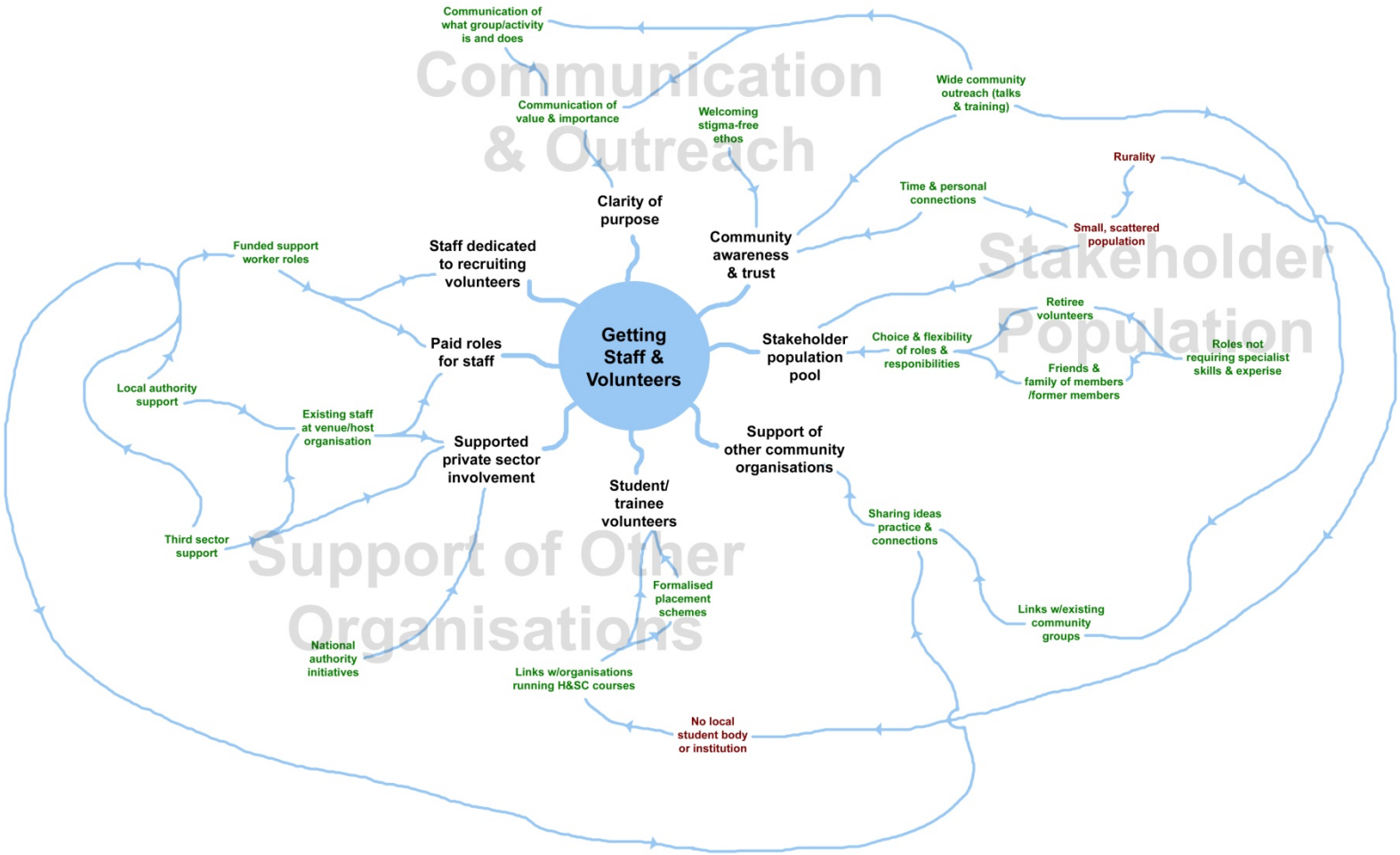
Wimo, Wallin, Lundgren, Ronnback, Asplund, Mattsson & Krakau (see also Clarkson et al 2017)	1990	Impact of Day Care on Dementia Patients—Costs, Well-being and Relatives' Views	**Specialist day care**	Sweden	Journal paper - cost analysis	Family Practice	**95**

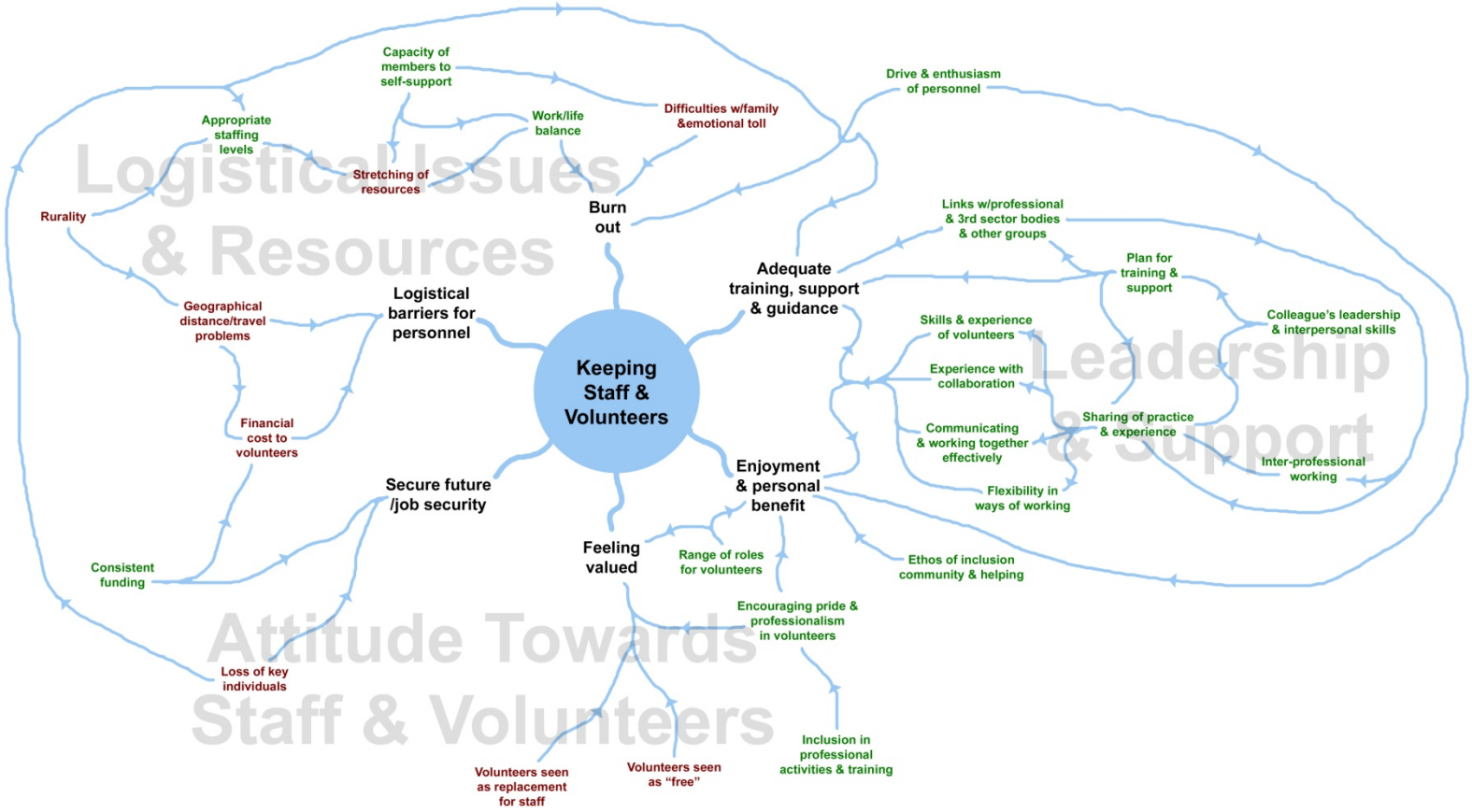
Supplementary file 5: Diagrams of factors involved in each critical area

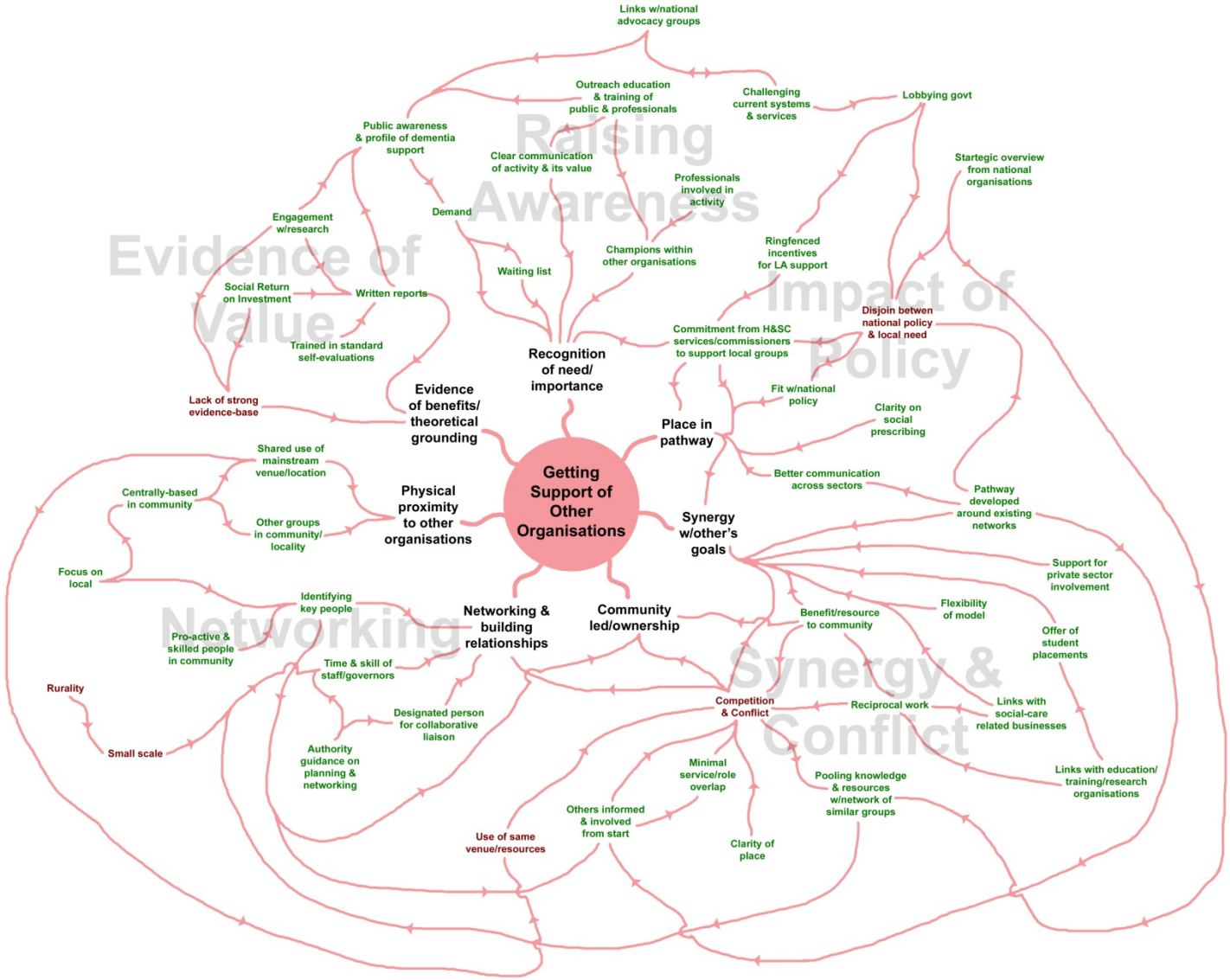
Text colour key: **Black text** = sub-outcome directly impacting upon "getting/keeping" **Green text** = likely to help sub-outcome **Red text** = likely to hinder sub-outcome

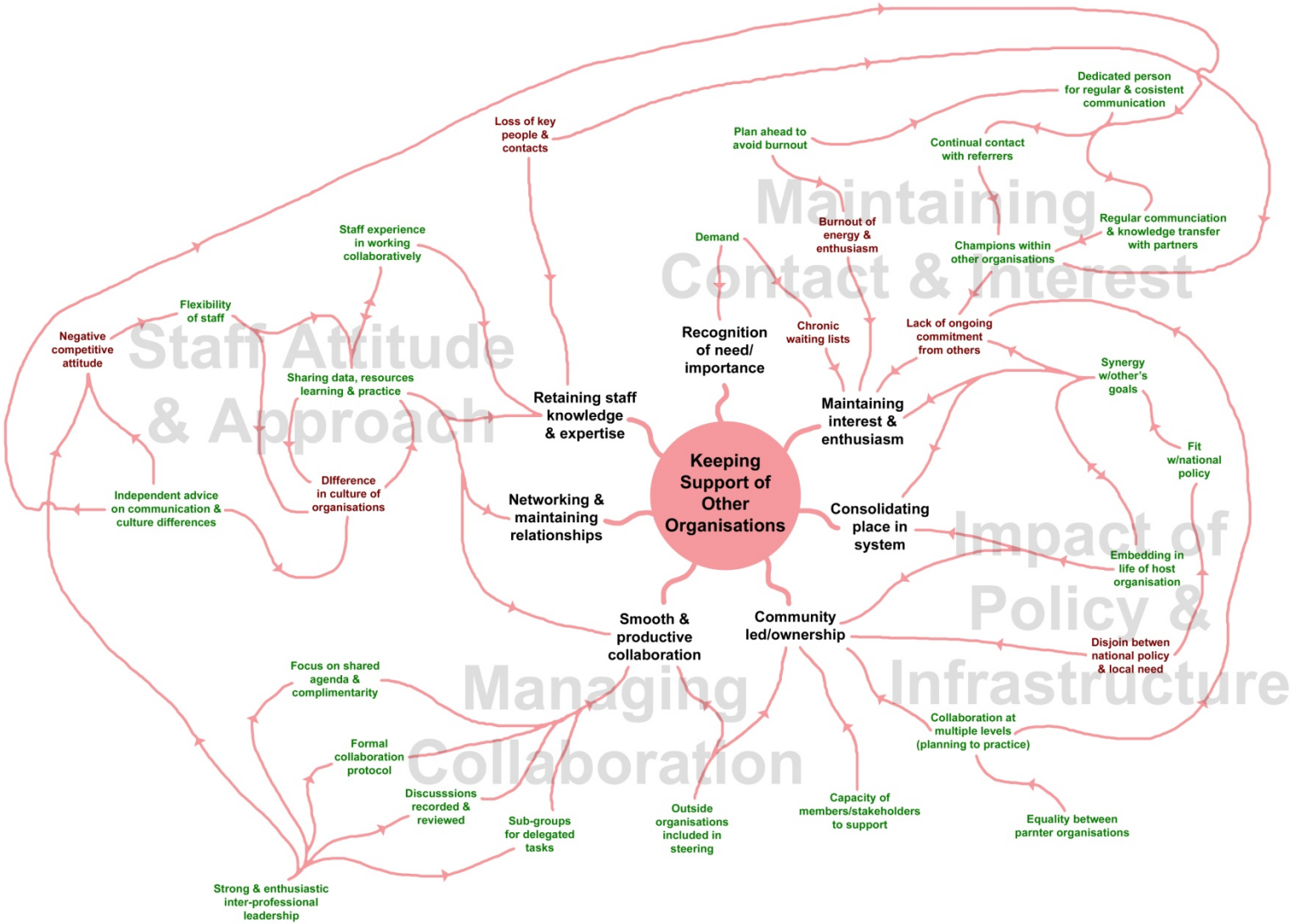



Keeping Members
Meeting Individual Needs
Comfort & Enjoyment
Social Opportunities
Group Cohesion & Support
Transport & Logistical Issues
Appropriate/ "For me"
Comfortable/ Relaxing
Interesting/ Enjoyable
Group cohesion
Providing emotional support
Empowering
Safe, reliable & trusted
Convenient & reliable transport
Fits needs of family/ carer
Physical support
Regular input from members
Ownership
Member-led
Regular input from family
Flexibile & evolving
Plan & review for needs & goals
Tailored programme
Pre-assess members
Attentive to individual needs
Waiting lists for linked servcies
Exit strategy
Small group size
Members not moving on when appropriate
Multiple & adequate spaces at venue
Balance of more able & more in need
Food offer/ communal eating
Freedom of movement
Choice of activities or to sit out
Exclusive focus on activity/agendas
Cosy environment
Not rushed
Unwanted Expectations & Restrictions
Planning to keep activities fresh
Mainstream activities
Conflict between members
Integrated w/ other venue users
Opportunities for social integration outside of group
Links to public amenities
Friendships supported
Opportunities for social interaction
Downtime/Informal time at start & end
Balanced needs of old & new members
Knowledge, empathy respect & interpersonal skills of staff
Feeling valued
Normalcy
Open to guests & family
"Dementia-free zone"
Sense of achievement
Projects for community
Degree of challenge/learning
Input into decisions & tasks
Percieved threat to independence
Perception of commercial motives
Working to tried & tested model
Predictable routine
Stable & reliable provision
Enough facilitators to cover absences
Continuity of staff
Enough opening hours
Dedicated staff to communicate w/families
Regular communication /reminders
Less healthy lifestyle
Skill of staff to mitigate venue limitations
Ability-focus w/tailored support
Not matched w/needs & ability
Adequate & well designed facilities

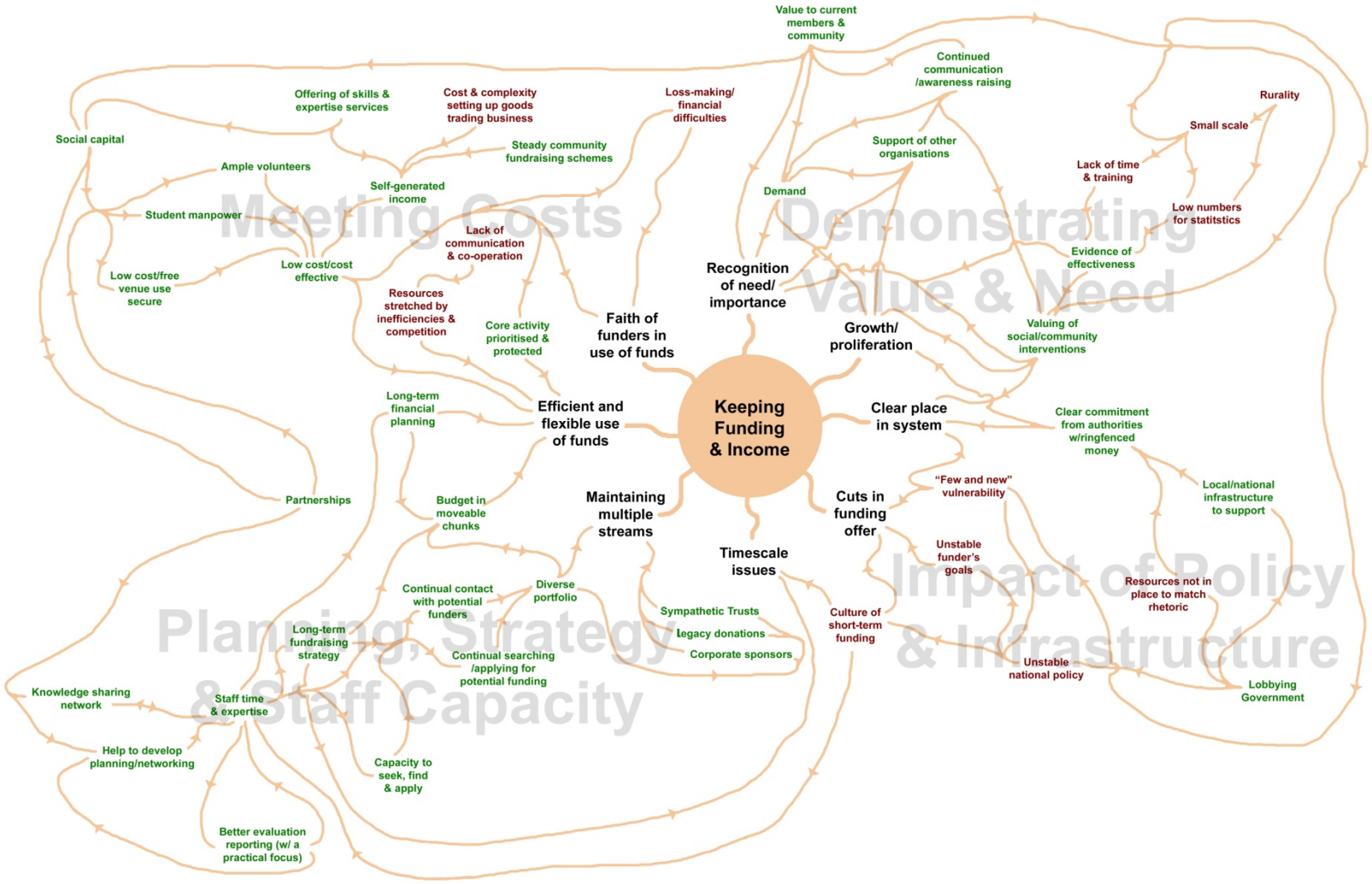

Communication & Outreach
Stakeholder Population
Support of Other Organisations
Getting Staff & Volunteers
Clarity of purpose
Staff dedicated to recruiting volunteers
Paid roles for staff
Supported private sector involvement
Student/ trainee volunteers
Support of other community organisations
Community awareness & trust
Stakeholder population pool
Communication of what group/activity is and does
Communication of value & importance
Welcoming stigma-free ethos
Wide community outreach (talks & training)
Time & personal connections
Rurality
Small, scattered population
Retiree volunteers
Choice & flexibility of roles & responibilities
Roles not requiring specialist skills & experise
Friends & family of members /former members
Funded support worker roles
Local authority support
Existing staff at venue/host organisation
Third sector support
National authority initiatives
Formalised placement schemes
Links w/organisations running H&SC courses
Sharing ideas practice & connections
Links w/existing community groups
No local student body or institution


Keeping Staff & Volunteers
Logistical barriers for personnel
Geographical distance/travel problems
Financial cost to volunteers
Rurality
Appropriate staffing levels
Capacity of members to self-support
Stretching of resources
Work/life balance
Difficulties w/family &emotional toll
Burn out
Secure future /job security
Consistent funding
Loss of key individuals
Feeling valued
Volunteers seen as replacement for staff
Volunteers seen as "free"
Encouraging pride & professionalism in volunteers
Inclusion in professional activities & training
Range of roles for volunteers
Adequate training, support & guidance
Drive & enthusiasm of personnel
Links w/professional & 3rd sector bodies & other groups
Plan for training & support
Skills & experience of volunteers
Experience with collaboration
Communicating & working together effectively
Sharing of practice & experience
Colleague's leadership & interpersonal skills
Inter-professional working
Flexibility in ways of working
Enjoyment & personal benefit
Ethos of inclusion community & helping
Logistical Issues & Resources
Leadership & Support
Attitude Towards Staff & Volunteers


Getting Support of Other Organisations
Evidence of benefits/ theoretical grounding
Recognition of need/ importance
Place in pathway
Physical proximity to other organisations
Synergy w/other's goals
Networking & building relationships
Community led/ownership
Competition & Conflict
Raising Awareness
Evidence of Value
Impact of Policy
Networking
Synergy & Conflict
Links w/national advocacy groups
Outreach education & training of public & professionals
Challenging current systems & services
Lobbying govt
Public awareness & profile of dementia support
Clear communication of activity & its value
Professionals involved in activity
Startegic overview from national organisations
Engagement w/research
Demand
Champions within other organisations
Ringfenced incentives for LA support
Social Return on Investment
Written reports
Waiting list
Disjoin betwen national policy & local need
Trained in standard self-evaluations
Commitment from H&SC services/commissioners to support local groups
Lack of strong evidence-base
Fit w/national policy
Clarity on social prescribing
Shared use of mainstream venue/location
Better communication across sectors
Pathway developed around existing networks
Centrally-based in community
Other groups in community/ locality
Support for private sector involvement
Focus on local
Identifying key people
Flexibility of model
Benefit/resource to community
Offer of student placements
Pro-active & skilled people in community
Time & skill of staff/governors
Rurality
Designated person for collaborative liaison
Reciprocal work
Links with social-care related businesses
Small scale
Authority guidance on planning & networking
Minimal service/role overlap
Pooling knowledge & resources w/network of similar groups
Links with education/ training/research organisations
Others informed & involved from start
Use of same venue/resources
Clarity of place


Keeping Support of Other Organisations
Retaining staff knowledge & expertise
Maintaining interest & enthusiasm
Networking & maintaining relationships
Consolidating place in system
Smooth & productive collaboration
Community led/ownership
Recognition of need/ importance
Loss of key people & contacts
Demand
Burnout of energy & enthusiasm
Chronic waiting lists
Plan ahead to avoid burnout
Dedicated person for regular & cosistent communication
Continual contact with referrers
Champions within other organisations
Regular communciation & knowledge transfer with partners
Lack of ongoing commitment from others
Synergy w/other's goals
Fit w/national policy
Embedding in life of host organisation
Disjoin betwen national policy & local need
Staff experience in working collaboratively
Flexibility of staff
Negative competitive attitude
Sharing data, resources learning & practice
DIfference in culture of organisations
Independent advice on communication & culture differences
Focus on shared agenda & complimentarity
Formal collaboration protocol
Discusssions recorded & reviewed
Sub-groups for delegated tasks
Strong & enthusiastic inter-professional leadership
Outside organisations included in steering
Capacity of members/stakeholders to support
Collaboration at multiple levels (planning to practice)
Equality between parnter organisations
Maintaining Contact & Interest
Staff Attitude & Approach
Impact of Policy & Infrastructure
Managing Collaboration


Getting Funding
Recognition of need/ importance
Perception of viability
Perception of legitimacy
Value for money
Clear place in system
Capacity to seek, find & apply
Timescale issues
Fit with funder's goals
Clarity of communication /awareness of intervention
Ringfenced money for dementia
Funds must be diverted from other services
Acting as link/ gateway for others
Theoretical grounding
Trust of potential members
Demand
"Crowded market"/ Competition
Support of other organisations
Income from producing goods or services
Loss-making/ financial difficulties
Social capital
Ample volunteers
Student manpower
Low cost/free venue use secured
Low cost/cost effective
Partnerships
Rurality
Small scale
Lack of time & training
Low numbers for statitstics
Valuing of social/community interventions
Evidence of effectiveness
Financial incentives for referrers
Clear commitment from local/national authorities
Local/national infrastructure to support
"Falling between stools"
Misalign with local need
Fit with national agenda
Resources not in place to match rhetoric
Lobbying Government
Aims align with corporate sponsor
"Grey pound"
Sympathetic Trusts
Legacy donations
Formal plans & strategy ready
Knowledge sharing network
Help to develop planning/networking
Better evaluation reporting (w/practical focus)
Staff time
Staff expertise
Meeting Costs
Demonstrating Value & Need
Impact of Policy & Infrastructure
Planning, Strategy & Staff Capacity


Keeping Funding & Income
Efficient and flexible use of funds
Faith of funders in use of funds
Recognition of need/ importance
Growth/ proliferation
Clear place in system
Cuts in funding offer
Timescale issues
Maintaining multiple streams
Social capital
Offering of skills & expertise services
Cost & complexity setting up goods trading business
Loss-making/ financial difficulties
Steady community fundraising schemes
Ample volunteers
Self-generated income
Student manpower
Low cost/cost effective
Low cost/free venue use secure
Lack of communication & co-operation
Resources stretched by inefficiencies & competition
Core activity prioritised & protected
Long-term financial planning
Budget in moveable chunks
Partnerships
Value to current members & community
Continued communication /awareness raising
Support of other organisations
Demand
Rurality
Small scale
Lack of time & training
Low numbers for statitstics
Evidence of effectiveness
Valuing of social/community interventions
Clear commitment from authorities w/ringfenced money
Local/national infrastructure to support
"Few and new" vulnerability
Unstable funder's goals
Resources not in place to match rhetoric
Unstable national policy
Lobbying Government
Culture of short-term funding
Sympathetic Trusts
Legacy donations
Corporate sponsors
Diverse portfolio
Continual contact with potential funders
Long-term fundraising strategy
Continual searching /applying for potential funding
Capacity to seek, find & apply
Knowledge sharing network
Staff time & expertise
Help to develop planning/networking
Better evaluation reporting (w/ a practical focus)
Meeting Costs
Demonstrating Value & Need
Impact of Policy & Infrastructure
Planning, Strategy & Staff Capacity

Supplementary file 6: Full list of CMOCs

Getting Members

CMOC 1: If the social aspect of an intervention is emphasised (C), then a wider range of people are likely to be interested (O), as a desire for social connection and activity is more universal than interest in a niche and potentially intimidating activity (M). [40,48,50,57,58,62,64,75]

CMOC 2: If food is offered (C), then people are more likely to attend (O), because the enjoyment of good food is universal and communal eating is associated with comfort, relaxation and social connection (M). [40,59]

CMOC 3: If facilitators are knowledgeable and empathetic, with good interpersonal skills (C), an initiative will be perceived as more welcoming and inclusive (O), as they will be better at understanding needs, engaging and building trust with potential members and their families (M). [36,37,38,39,40,41]

CMOC 4: If an initiative has an informal, unrushed and warm welcome on first visit (C), then people are more likely to want to return (O), as they are more likely to find the experience relaxing and enjoyable, not uncomfortable and intimidating (M). [40,42,43,44,45]

CMOC 5: If potential members have had poor previous experiences with groups or activities (dementia related or not) (C), they may not want to try another group or activity (O), because they think the experience will be similar and will want to avoid it (M). [37,41,46,47]

CMOC 6: If time is taken for personal contact, home visits or taster sessions with potential members (C), then people are more likely to come (O), as they will feel more familiar with the initiative and more trusting of those running it (M). [36,38,47,48,49,50]

CMOC 7: If an initiative is familiar and trusted, or local and well integrated with other organisations in the community (C), then people are more likely to come (O), as its links to familiar things that they trust will make it less intimidating (M). [37,41,42,48,51,52,53,54,55,56]

CMOC 8: If an intervention is based in familiar surroundings in, and open to, the community (C), then people are more likely to come (O), because potential members will find the normalcy, lack of stigma and chance for social integration appealing (M). [38,41,48,52,57,58,59,60,61,62]

CMOC 9: If a venue is dementia-friendly, comfortable and accessible (C), people are more likely to come (O), as they will not have concerns about comfort or access (M). [48,55,63,64]

CMOC 10: If an intervention is recommended by trusted family members and health professionals (C) people are more likely to go (O), as they will trust their judgement that it will be of benefit to them (M). [54,65]

CMOC 11: If discussion/training is held with families, carers and health professionals about their attitudes and beliefs towards dementia (C), they may be more likely to successfully encourage the person they care for to try an intervention (O), because they will understand dementia and be better able to overcome stigma and emotional barriers (M). [36,54,56,65]

CMOC 12: If evidence of an intervention's therapeutic benefits is made clear to families and care partners (C), then people are more likely to attend (O) as families and care partners will have confidence in the intervention so be more likely to encourage them to go (M). [38,41,75,78]

CMOC 13: If there is support for family/care partners alongside the intervention (C) then people are more likely to attend (O), as family and care partners will feel more able and inclined to attend themselves and encourage those they care for (M). [42,48,56,58,76,77,79]

CMOC 14: If an initiative is in a close-knit community with where there is stigma about dementia (C), then people and their families may be put off coming (O), as they may be concerned about confidentially and word of their condition (or that of their family member) getting out (M). [47,56,62,73]

CMOC 15: If an initiative provides enjoyable, meaningful activities (C), then this is likely to attract members (O), as doing them will provide a reason and motive for many to attend initially, even if they stay on for other benefits (M). [41,44,45,50,64,67,70,71,72,83]

CMOC 16: If an initiative provides normalised, mainstream activities (C), then they are likely to attract members (O), as they will have resonance with people's previous interests, experience and history that would like to continue in some form (M). [46,48,57,58,65,67,71,81]

CMOC 17: If an initiative offers a range of different activities and services (C), then people are more likely to attend (O), as the initiative will appeal to a wider range of people with a range of needs (M). [47,48,62,84]

CMOC 18: If potential members' culture, ethnicity and language are acknowledged and catered for within the initiative (C), then they are more likely to come (O), as they will feel more comfortable and valued (M). [47,56,63,69,80]

CMOC 19: If there is a lack of diversity (of members and personnel) or pandering to stereotypes (C), then people may be put off coming (O), as they may have concerns about discrimination and stigma beyond dementia (M). [53,56,70,77]

CMOC 20: If the initiative is run by a religious organisation or in religious venue (C), then people may be put off coming (O), if they are not of that religion or cultural background (M). [56,82]

CMOC 21: If a group is too inclusive when not appropriate (C), this can alienate potential target members (O), as they will feel it will not be focussed on their specific needs (M). [37,60,62]

CMOC 22: If an initiative differentiates activities and roles for members by ability (C), then this can encourage potential members to attend (O), as they will feel there is an appropriate place for them rather than everyone being lumped in together (M). [48,79]

CMOC 23: If an intervention is risk averse or underestimates members' abilities and avoids challenge (C), then potential members will be put off (O), because they will see its activities as too easy, boring or not appropriate for them (M). [63,64,69,73]

CMOC 24: If an intervention is ability-focussed with tailored support and sensitive design of facilities (C), it is more likely to persuade potential members to attend (O) as they will be encouraged and supported to overcome physical impairments and negative attitudes (M). [43,58,62,64,69]

CMOC 25: When an intervention can offer practical advice, information and links to services that can help people (C), then it is more likely to attract members/service users (O), as they will be able to see that it has something to offer them that will meet their most immediate and pressing needs (M). [42,44,45,54,73,85]

CMOC 26: If safe, supported transfer from home to venue can be guaranteed (C), then people will be more likely to come (O), because they will be more likely to overcome any concerns about going out and getting to a group or activity session (M). [36,38,44,45,47,60,64,65,85,73]

CMOC 27: If the transport available isn't appropriate, reliable and respectful of people with dementia (C), then people will not come (O), as will not want to use that transport to get there (M). [37,47,49,64,76,77,82]

CMOC 28: If transport costs are significant and there is no financial support (C), then people will not come (O), as they will not be able to afford the transport costs (M). [36,38,56,59,64,76,78,82]

CMOC 29: If the venue is not in people's own neighbourhoods, is geographically distant or hard to reach (C) then people will not come (O), as they will find it difficult or intimidating to get there (M). [49,60,61,86]

CMOC 30: If an initiative forms links with community and public transport/taxi firms (C), then this will attract members (O), as they will find it less difficult or intimidating to travel to the venue (M). [48,76,77]

CMOC 31: If referrers are not made clearly aware of the added value, target population, ethos and activities of an intervention (C), then they will be less likely to refer appropriately (O), as they will not understand the value of it to their clients (M). [41,51,61,75,79]

CMOC 32: If there is constant contact and collaboration with potential referrers (C), then they are more likely to refer members (O), as they will build a relationship with the intervention that will mean they are better able to understand and remain alert to it (M). [46,51,54,55,74,75,79]

CMOC 33: If PR materials are not available in the right places or presented to people in the right circumstances (C), then they will not try an intervention (O), because they will not access those materials to find out about an intervention's potential value to them (M). [36,47,56,78,82]

CMOC 34: If PR materials are not in an understandable and appropriate format and tone (C), then people will not try an intervention (O), as they will find the materials too off-putting to engage with (M). [38,49,56,61,67,73,74,80]

CMOC 35: If PR materials do not make clear the specifics of an intervention, what to expect and how to attend (C), then people will be less likely to come (O), as they may be anxious due to uncertainties over what they will have to do and its value to them (M). [41,48,51,56,89]

CMOC 36: If an intervention has a stigma-free name that resonates with its target population (C), then people are more likely to come (O), as they will have confidence that they will be treated with respect and not suffer stigma when they go (M). [38,46,56,59,66,72]

CMOC 37: If the local community is fragmented with no local welfare organisation to distribute information (C), then people will be less likely to come (O), as it will be more difficult to get the word out to the right people in the community (M). [37,56,61]

CMOC 38: If in intervention forms links with existing groups, organisations and venues serving same demographic (C), then people will be more likely to come (O), as information and marketing materials will be more likely to reach them (M). [48,54,62,67,83]

CMOC 39: If all those involved in a person's care work together to collate and co-ordinate information (C), then people will be more likely to come (O) as information and marketing materials will reach them more efficiently (M). [36,61]

CMOC 40: If there is a dedicated linking, contact or health care adviser service (C) then people will be more likely to come (O) as information and marketing materials will reach them more efficiently (M). [36,38,44,45,47,56,75,80,88]

CMOC 41: If awareness of the needs of people dementia and of how an intervention can meet them is raised in the community in general (C), then people will be more likely to come (O), as stigma will be reduced and the value of the intervention communicated through word of mouth (M). [36,37,38,46,47,48,51,54,56,59,67,70,83,84,87]

CMOC 42: If GPs were given more incentive and guidance for social prescribing (C), then they would refer more people (O), because they would have a vested interest and confidence in doing so (M). [47,69]

CMOC 43: If there are significant bureaucratic problems with referring (such as chronic waiting lists, area border issues or the need for signed consent) (C), then professionals will be less likely to refer (O), as they will anticipate difficulties that will thwart their attempt to refer (M). [47,61,80,88]

CMOC 44: If GPs do not diagnose dementia until people are at later stages (C), then they will not refer people to community initiatives (O), as they will not see initiatives targeted towards those at earlier stages still able to live at home as appropriate for those they are diagnosing (M). [76,79]

CMOC 45: If an intervention waives the need for a diagnosis and accepts self-diagnosis (C), more people will come (O), as this will encourage a wider range of potential members and avoid excluding people who might benefit (M). [38,57,79,83]

CMOC 46: If an initiative's membership application process is not simple, clear, concise and easy (C), then people will not come (O), as the difficulty in applying will put them off joining (M). [38,44,45,74]

Keeping Members

CMOC 47: If there is group cohesion and mutual trust between members (C), then a group is more likely to sustain (O), because members will feel more solidarity and investment in the group (M). [65]

CMOC 48: If friendships between members are encouraged, recognised and supported by staff and activities (C), then people are likely to keep coming (O), as they will feel more supported, comfortable and engaged, and able to support each other (M). [43,54,66,67,68]

CMOC 49: If an intervention is too focussed on agendas, rules and expectations (C), then people may stop coming (O), because they feel pressured, restricted and unable to relax and enjoy the social and emotional benefits important to them (M). [44,45,63,67,69,70,71]

CMOC 50: If the pace of activity through the day/session is too fast and strict (C), then people may stop coming (O), because they will struggle to stay engaged and will not enjoy themselves (M). [43,48,57,61,72]

CMOC 51: If ample informal time is made for socialising, peer support and feedback (C), then members are more likely to keep coming (O), as they will be more likely to feel comfortable and supported (M). [40,43,48,50,58,62,65,67,69,70,71,72,73,74,75]

CMOC 52: If there is opportunity to have communal eating and relaxing in a "cozy" environment (C), then members are more likely to keep coming (O), as this will provide comfort and foster group cohesion. [40,65]

CMOC 53: If there is regular social integration with others outside of the group (C), then members are more likely to keep coming (O), as they will feel more connected and less stigmatised (M). [38,41,47,48,49,52,54,59,61,62,66]

CMOC 54: If activities are mainstream and involve others without dementia (e.g. family/carers or locals from the community) (C), then members are more likely to keep coming (O), as they will feel activities are more normalised, reducing stigma and increasing enjoyment (M). [37,46,47,48,54,57,61,76]

CMOC 55: If an intervention is treated as a "dementia free zone" where talk is not about a person's condition or medical issues (unless they want to raise them) (C), then people are more likely to keep coming (O), as they will find the environment more normalising and less stigmatising (M). [58,71]

CMOC 56: If an initiative contains projects which enable members to contribute to helping others in the community (C), then people are more likely to keep coming (O), because they will feel valued, useful and empowered (M). [47,67]

CMOC 57: If an initiative has links to existing mainstream public amenities (C), then people are more likely to keep coming (O), as they will recognise it gives them access to wider networks of support and friendship (M). [90]

CMOC 58: If members are involved in group decision-making and setting expectations (C), then people are more likely to keep coming (O), because they will feel ownership and investment in the group and confidence that the group is tailored towards their needs (M). [43,52,65,66,71,74,84]

CMOC 59: If regular feedback meetings are held to "tune" an intervention to the wants and needs of members (C), then people are more likely to keep coming (O), as activities will be kept appropriate and evolve to suit the membership (M). [41,44,45,48,55,67,91]

CMOC 60: If individuals are allowed to make their own decisions about what they do or don't do during a session (C), then they will be more likely to keep coming (O), as they will feel their independence and freedom is respected and their voice heard (M). [36,40,43,63,91]

CMOC 61: If staff treat people respectfully as equals and relate personally (C), then people are more likely to keep coming (O), because they will feel staff and the group as a whole understands them and their needs(M). [40,42,44,45,46,63,65]

CMOC 62: If strategies are planned to review individual progress and involvement (C), then people are more likely to keep coming (O), as they are more likely to remain engaged and feel part of the group as a whole (M). [43,59,74]

CMOC 63: If personnel listen to and act upon regular input from family and caregivers (C), then people are more likely to keep coming (O), as they will appreciate the increased personalisation and sensitivity to their needs (M). [41,59,61,63,91]

CMOC 64: If an initiative does not pay attention to the needs of family and care partners (C), then people are less likely to keep coming (O), because there may be unaddressed logistical difficulties for the family or carers such as fit with work or transport issues (M). [38,44,45,47,54,60,61,73,78]

CMOC 65: If an initiative can open for more hours and help arrange transport (C), then people are more likely to come (O), as this will take the pressure off family members and carers to be flexible and arrange things, and bypass logistical difficulties (M). [44,45,48,49,50,57,78]

CMOC 66: If members who are no longer the target for the intervention stay on because there is no exit strategy or onward service capacity (C), then this can discourage target members from continuing to attend (O), as they may feel the service is too stretched to meet their needs (M). [41,43,61]

CMOC 67: If an initiative does not cater equally both for new members and older members whose condition has progressed (C), then this can discourage one group or the other from continuing to attend (O), as they will feel the initiative is more focussed upon the other group hence not appropriate for them (M). [66,71,75]

CMOC 68: If a group or activity is not matched with members' interests and ability (C), then members may stop attending (O), as they will feel it is not appropriate for them or meeting their needs (M). [46,48,49,78]

CMOC 69: If activities involve a degree of challenge or learning (C), then members may be more likely to keep coming (O), as they will feel empowered and have a sense of achievement (M). [37,47,58,67,71,76]

CMOC 70: If an intervention pre-assesses members and plans strategies to meet their individual needs (C), then members are more likely to keep coming (O), because activities and support will be more likely to be appropriate for them (M). [43,44,45,57,59,60,74]

CMOC 71: If a venue is comfortable, familiar and stable, with adequate space and facilities (C), then people are more likely to keep coming (O), as they will feel relaxed, secure and at home there (M). [43,48,55,63]

CMOC 72: If a venue has multiple spaces within it (C), then people are more likely to feel comfortable there (O), as they will be able to move around and have a choice of activities, environments, social sub-groups or levels of involvement in activity (M). [63,89]

CMOC 73: If sessions are regular, routine and structured (C), then members will be more likely to keep coming (O), as they will feel comfortable and secure in the familiarity and reliability of proceedings (M). [38,40,43,47,48,65,72,73,75]

CMOC 74: If the venue and timings remain reliably the same (C) then members are more likely to keep coming (O), as it will become part of their routine (M). [43,48]

CMOC 75: If there is no continuity of staff or not enough staff to ensure reliable provision (C), then members may be less likely to keep coming (O), as they will find it difficult to have confidence and build trust in the intervention and its staff (M). [36,47,66]

CMOC 76: If an intervention works to a tried and tested model (C), then members are more likely to feel secure (O), as that model will provide a structure that works (M). [61]

CMOC 77: If there are not new ideas and some variety planned across the calendar (C), then members may stop coming (O), because they may feel the group/activities have become stale and boring (M). [37,43,67]

Getting Staff and Volunteers

CMOC78: If an initiative engages in community outreach such as talks and training with other groups and at events (C), then this will help attract volunteers (O), because the initiative's profile will be raised with wide range of stakeholders in the community (M). [46,59,83]

CMOC79: If awareness is raised in the community about the activities and benefits of a what an initiative does (C), then it will be more likely to attract appropriate personnel (O), as potential staff and volunteers will understand its value to service users and what they can do to help (M). [56,61,89,91]

CMOC80: If an initiative has links with like-minded groups (C), then they may get help finding and training staff volunteers (O), as they will be able to share ideas and practice on what is successful (M). [50,91]

CMOC81: If an initiative approaches established community organisations and authorities (third sector, faith or local authority) (C), they are more likely to get help with finding volunteers (O), as these organisations are likely to have access to an existing volunteer workforce or contacts that could help (M). [69,77]

CMOC82: If an initiative has links with professional, third sector or educational bodies (C), they may help with creating a more skilled workforce (O), because they may have the remit provide training for staff and volunteers (M). [80,84]

CMOC83: If an initiative is hosted by a public venue or local club (C), this may help with staffing (O), as the venue or club may have existing staff who can help with running things (M). [48,58,67,69]

CMOC84: If a community has an educational establishment running a health and social-care course (C), this could be a source of volunteers (O), as students/trainees will have the drive and interest to work with social-care-related activities to gain experience (M). [62,65,91,92,93]

CMOC85: If a formal partnership is agreed with an educational establishment (C), this will guarantee regular volunteers during term time (O), as work placements can be formalised as part of students' courses (M). [65,92,93]

CMOC86: If the initiative is in a rural area (C), then it can be more difficult to recruit volunteers (O), as there may be no educational establishment or body of students/trainees to recruit from (M). [53,83]

CMOC87: If the initiative is in a rural area (C), then it may take more time to recruit volunteers (O), as familiarity and personal contacts tend to be more important in small, close-knit communities (M). [83]

CMOC88: If the initiative is in a rural area (C), then it may be more difficult to recruit staff and volunteers (O), as they may not live geographically near members or the venue, presenting extra logistical challenges (M). [53,83]

CMOC89: If a community has a population of active retirees (C), this could be a source of volunteers (O), as they are likely to have time and experience conducive to volunteer work with older people (M). [56]

CMOC90: If there are friends and family of current or previous members/service users that are available (C), this could be a source of volunteers (O), as they will understand the value of the intervention and already be invested in it (M). [56,81]

CMOC91: If there are no specialist elements to the intervention or members with high care needs (C), then personnel do not need to have professional training or expertise (O), as they will still be able to understand and deliver the intervention for the benefit for service users (M). [58,72]

CMOC92: If in intervention has more than one skilled facilitator (C), then it can benefit more members (O), as the workload can be split and more one-on-one support for members offered (M). [71,73,75]

CMOC93: If an initiative's leaders/co-ordinators have good communication and interpersonal skills (C), then it is more likely to be successful (O), as they will engage and inspire other staff and volunteers (M). [38,51,61,79]

CMOC94: If volunteers' availability and interpersonal skills are inconsistent (C), an initiative is less likely to be successful (O), as it will not have a reliable workforce to run it (M). [73]

CMOC95: If funded support worker roles exist (C), then a reliable volunteer workforce is more likely (O), because they can help build a volunteer base (M). [50]

Keeping Staff and Volunteers

CMOC 96: If personnel are flexible and open to new ways of working (C), then they are more likely to work effectively (O), as they will be more likely to collaborate with others, sharing knowledge, experience, innovation, resources and effective working practices (M). [59,60,79,93]

CMOC 97: If personnel have advice or training to boost communication and collaboration skills (C), then they are more likely to work effectively (O), as they will be more able to share knowledge, experience, innovation, resources and effective working practices (both internally and externally) (M). [60,76]

CMOC 98: If personnel are driven and able to deal with stress (C), then they are more likely to continue (O), as they will be able to overcome the challenges and demands of running an intervention (M). [61]

CMOC 99: If facilitators are not able to take time for self-care (C), then they will burn out (O), as running an intervention can be challenging and emotionally demanding (M). [43,75]

CMOC 100: If time is taken to plan strategies for recruitment, training, support, retention and balance of personnel at the start (C), then personnel problems and burn out can be avoided (O), as planners will have thought through the challenges involved and put in place actions to tackle them (M). [70,74]

CMOC 101: If personnel have access to experienced tips and guidance (from materials or individuals) throughout an intervention's start-up period (C), they are more likely to continue (O), as they will be better informed to resolve problems and avoid common pitfalls (M). [37,56]

CMOC 102: If there is an ethos of inclusion, community, camaraderie and helping people (C), then personnel will be more likely to continue (O), as they will feel enjoyment and benefit from this ethos along with members/service users (M). [52,58,75]

CMOC 103: If there are a range of roles and levels of involvement for volunteers (C), they are more likely to be satisfied with volunteering (O), as they can do something that suits them and their abilities that they are comfortable with and interested in (M). [84]

CMOC 104: If volunteers are included in professional activities and training (C), they are more likely to be satisfied with volunteering (O), as they will feel their skills and development are valued by the initiative (M). [38]

CMOC 105: If there is limited and inconsistent funding (C), then an intervention is less likely to be able to retain paid staff (O), because their jobs and the long-term future of the intervention will not be secure (M). [73,79,84]

CMOC 106: If personnel roles are not secure (C), then an initiative is less likely to sustain (O), because turnover will be high and key individuals with key experience and contacts will be lost (M). [67,79,84]

CMOC 107: If volunteers are seen by authorities and commissioners as "coming for free" (C), then they are less likely to continue (O), as they will feel un-valued with their time and expertise taken for granted (M). [87]

CMOC 108: If unpaid volunteers are treated as a replacement for professional staff (C), then staff are less likely to continue (O), as they will feel their roles are undermined and un-valued (M). [51]

CMOC 109: If financial assistance is made available for volunteer groups (C), then they are more likely to continue (O), as they will have the resources and support to run more activities (M). [50]

Getting Support of Other Organisations

CMOC 110: If there is a higher public awareness and profile for people living with dementia (C), then dementia-targeted interventions are more likely to get support from other organisations, services and amenities (O), because there will be more recognition of their importance for society in general (M). [39,84,90]

CMOC 111: If the added value of an intervention is made clear to other organisations (C), then it is more likely to get support and find a place in the local care offer (O), because other organisations will understand it's value to their members/service users (M). [41,42,50,54,55,61,75,79,86]

CMOC 112: If an intervention engages with research and evaluation to gather evidence of benefits (C), then it is more likely to get support (O), because the resulting reports will lend it legitimacy in the eyes of other organisations (M). [37,70,80]

CMOC 113: If it is made clear that an intervention is based upon a strong evidence-based model (C), then it is more likely to get support (O), because that model will lend it legitimacy in the eyes of other organisations (M). [41,79,86]

CMOC 114: If an intervention involves the local community in its steering (C), then it likely to attract further community support (O), as key people and organisations in the community with wider links will feel a sense of ownership and investment (M). [84]

CMOC 115: When there are a range of organisations (e.g. local authority, third sector, faith, business and education) active in the community (C), they may be willing to offer support if asked (O), as they may have a remit to share resources such as venue space and facilities, equipment, training, staff, volunteers or contacts (M). [48,52,58,62,65,67,69,77,80,92,93]

CMOC 116: If an intervention model is flexible (C), then it has a better chance of finding support (O), as it can accommodate being run at a range of venue types in, a range of ways, by a range of host organisations (M). [69,71,72,75]

CMOC 117: If an existing social care business is approached (C), they may support, host or partner an intervention (O), as it may help them attract clients/customers (M). [75]

CMOC 118: If training and guidance is available from a public or third sector authority (C), this may help gain further support (O), as it will help an intervention develop its skills and expertise in marketing, networking and outreach (M). [46]

CMOC 119: If an intervention is based in a civic centre or public venue (C), then it is more likely to get support from other local organisations (O), because it will be visible to others sharing that space (M). [59,79]

CMOC 120: If an intervention focuses on building links with local organisations and services (C), it is more likely to get support (O), as it is easier to bring together a network of those who are already invested in the same community and some links will already exist (M). [41,42,62]

CMOC 121: If an intervention is run at a public venue or local club (C), then links with others in the community are easier to forge (O), as there will be an existing network of venue/club users and contacts that the intervention can access (M). [41,48,58,62]

CMOC 122: If a group or activity is small scale (C), then it can be hard to get support (O), as it is more difficult for them to network with larger organisations, authorities, movers and shakers (M). [77]

CMOC 123: If struggling groups in the same area merge (C), they can support each other (O), because they can pool resources, personnel, knowledge and ideas (M). [67]

CMOC 124: If links are forged with a national network of similar interventions (C) then they can support each other (O), because they can pool resources, knowledge, contacts and strategy (M). [42]

CMOC 125: If a locality has other organisations working with the same target population (C), then in intervention may struggle to get support (O), as those other organisations and their supporters may perceive the intervention as competition (M). [41,79]

CMOC 126: If an intervention has a clear place in the local offer without service/role overlap (C), then it is more likely to get the support of others (O), because they will see it as complimenting their service not competing with it (M). [42,51]

CMOC 127: If other organisations are informed, invited to meetings and asked for help and advice early on (C), then an intervention is more likely to get the support (O), because they will feel respected and invested in the success of the new intervention (M). [51,61,79,84]

CMOC 128: If groups involve professionals already working with individual members (e.g. case workers, carers) in activities (C) then they are more likely to increase support from professional services (O), because professionals will understand the value of the intervention to their service-users and feel invested in its success (M). [79]

CMOC 129: If an intervention acts as a hub for/gate/link to other services and is tuned to dovetail with them (C), then it is more likely to get the support of those services (O), because they will see the intervention as being of help to them (M). [42,60,61,72,86,88]

CMOC 130: If an intervention offers a benefit or resource to the wider community (C), then it is more likely to get the support of other community organisations (O), as they will see it as benefiting their members/service users (M). [41,46,67,70]

CMOC 131: If an intervention offers to do reciprocal work, sharing knowledge and resources with other organisations (C), then it is more likely to get their support (O), as they will see the benefit to working together (M). [41,46,67,70]

CMOC 132: If there is a disjoin between national policy and local need (C), then initiatives can struggle to get and keep support (O), because by adhering to one they will neglect the other, alienating would-be supporters (M). [51]

CMOC 133: If there were ring-fenced funding to support dementia-targeted community initiatives as part of national policy (C), then small, local initiatives would get support (O), as there would be incentives for health services and LAs to help them (M). [39,59,69]

CMOC 134: If health and social care authorities commissioned services to work with community initiatives (C), then small, local initiatives would get support (O), because it would ensure the collaboration of services and organisations at different levels (M). [47,50,77]

CMOC 135: If health pathways were developed around existing social networks (C), then small, local initiatives would get support (O), as it would encourage more community collaboration and co-production with health services (M). [47]

CMOC 136: When national and official organisations take the lead in working with small, local initiatives (C), this helps more consistent provision of local services across regions (O), because there is more joined-up strategic direction of what is on offer and available (M). [39,50]

CMOC 137: When national and official organisations show support for the involvement of private sector partners (C), then small, local initiatives are more likely to get support (O), as it provides private sector organisations with the incentive, tools and guidance to work in partnership (M). [39]

Keeping Support of Other Organisations

CMOC 138: If communication is not maintained (C), then support of others can drop away (O), as interest and enthusiasm may dwindle in tandem with an intervention's contact and visibility to its collaborators (M). [41,55]

CMOC 139: If information sharing and knowledge transfer is not maintained (C), then support of others can drop away (O), as communication and administration problems may arise between collaborating parties (M). [44,45,77]

CMOC 140: If there is a designated person with responsibility for regular and consistent communication with other organisations (C), then continued support is more likely (O), as they will have the time to pay attention to maintaining collaborative working, and build experience and relationships with key people in doing so (M). [41,50]

CMOC 141: If relationships with key people in other organisations are maintained (C), then support of those organisations is more likely to continue (O), as an intervention will create "champions" within those organisations (M). [39,51]

CMOC 142: If staff turnover (internal and external) is high (C), then support can be lost (O), because communication and relationships with contacts and "champions" can suffer due to the loss of key personnel (M). [67,79,84]

CMOC 143: If there is a difference in culture between collaborating organisations (C), then effective support can be hindered (O), as personnel from each organisation will not be working with the same focus and goals (M). [41,51,79]

CMOC 144: If groups or sectors have a negative or competitive attitude towards each other (C), then effective support can be hindered (O), as it creates problems sharing data, learning and resources (M). [41,76,77]

CMOC 145: If an intervention makes effort to learn about and embed in the life of a supporting organisations (C), then it is more likely to maintain support (O), as it will understand that host organisation better and share the same goals (M). [70]

CMOC 146: If staff (internal and external) are experienced in working collaboratively (C), then an intervention is more likely to maintain support (O), as staff will be more skilled, flexible and understanding when working with those from another organisation (M). [79]

CMOC 147: If independent advice on communication (internal and external) and collaboration is available (C), then an intervention is more likely to maintain support (O), as leaders, staff and volunteers will become more skilled at networking and working together while overcoming differences in culture (M). [60,79]

CMOC 148: If there are multiple forms of strong inter-professional leadership (C), then collaboration is likely to be more successful (O), because there will be mutual learning with leaders setting an example for others to follow (M). [51,59,79,86]

CMOC 149: If time is taken to plan well early on (C), then support from others is more likely to be maintained (O), as personnel will have thought through the challenges involved in maintaining energy and enthusiasm and put in place actions to tackle them (M). [70]

CMOC 150: If there is a steering group including outside organisations (C), then support is more likely to be maintained (O), as steering will include a focus on shared agenda and complementarity with outside organisations (M). [51]

CMOC 151: If a partnership is not equal and collaborating at all stages, from planning to practice (C), then this could hinder support (O), as one party may feel the other is not contributing what it should while the other feels dictated to, creating friction (M). [44,45]

CMOC 152: If a collaboration protocol with supporting organisations is drafted and discussions logged and reviewed (C), then support is more likely to be maintained (O), because all parties will have the chance air and resolve issues and have clarity over expectations and mutual goals (M). [41,44,45,61,70]

Getting Funding and Income

CMOC 153: If potential funders are not clear on what a service/intervention is and does (C), then they will be less likely to fund it (O), because they do not understand its purpose or value (M). [89]

CMOC 154: If potential funders are made aware of the added value and benefit of an intervention (C), then they will be more likely to fund it (O), because they will recognise it has something uniquely valuable to offer service users (M). [61,70]

CMOC 155: If communication and publicity is regularly disseminated to potential funders (C), then they are more likely to fund in the future (O), as they will be familiar with and alert to the work of an intervention (M). [94]

CMOC 156: If recognised and standardised materials (e.g. Alzheimer's Society materials, PQASSO or Social Return on Investment evaluation) are used to gather and communicate evidence of worth (C) then funders are more likely to fund (O) as they will see that evidence as more legitimate than anecdotal accounts (M). [80]

CMOC 157: If potential funders are made aware of links with and support from other organisations (C), then they're more likely to fund (O) because they are likely to view the support of others as adding legitimacy to a community initiative (M). [70]

CMOC 158: If corporate organisations are made aware of how an intervention aligns with its aims (C), then they will be more likely to sponsor or donate (O), as they will feel supporting that intervention helps progress their goals (M). [94]

CMOC 159: If an intervention develops its skill in networking and communicating with other organisations (C), then it is more likely to find funding (O), as it will learn of funding opportunities through a wider network of support and contacts (M). [46]

CMOC 160: If awareness of the wants and needs of people with dementia is raised in society in general (C), then funders are more likely to support a dementia-targeted initiative (O), as they are more likely to recognise that it meets the needs of service-users (M). [39,46]

CMOC 161: If there is demand for an intervention from service users and referrers (C), then funders are more likely to fund (O), as they will recognise that it is meeting people's needs (M). [46]

CMOC 162: If potential members/service users are not clear on what a service/intervention is and does (C), then they will be less likely to try it (O), because they do not understand it's purpose or value to them (M). [41,51,56,89]

CMOC 163: If potential referrers are not clear on what a service/intervention is and does (C), then they will not refer people to it (O), because they do not understand its purpose or value to their service users (M). [41,51,61,75,79]

CMOC 164: If an intervention is perceived as more expensive than alternatives on offer without offering significant added value (C), funders will be less likely to fund (O), as they will not see it as value for money (M). [79,80,87,95]

CMOC 165: If an initiative is perceived as having financial difficulties (C), potential funders are less likely to fund (O), as they will see it as a high risk funding decision (M). [56,61]

CMOC 166: If an initiative has co-operative working arrangements with other community organisations (C), then this can help keep costs low (O), as they can agree to share resources (venue, personnel, equipment, training etc.) (M). [70,75,76,78,80,93]

CMOC 167: If an initiative can generate some income through offering services to others(C), then funders are more likely to have confidence in it (O), as they will perceive it be to more viable (M). [94]

CMOC 168: If funders are made aware of the support from other organisations for a new initiative (C), they are more likely to fund (O), as they will perceive the initiative as being more viable due to that support (M). [70]

CMOC 169: If initiative can act as a gate/link for other services and community organisations (C), then it is more likely to get funding (O), as it will be seen as of value to enhancing existing services and organisations (M). [60,61]

CMOC 170: If intervention personnel have good, up-to-date knowledge of funding processes and policy (C), they are more likely to get funding (O), because they will understand how to plan and implement an effective strategy to seek and find it (M). [55,61,86]

CMOC 171: If like-minded groups share successful ideas (C), they are more likely to find funding solutions (O), because they will be able to learn from each other about what works or doesn't work (M). [80,91]

CMOC 172: If interventions include more practical detail on resources, costs and funding as part of standard reporting/evaluation (C), then others in the future will be more likely to find funding solutions (O), as they can learn from the experience of others about what works or doesn't work (M). [37]

CMOC 173: If authoritative help is available to develop personnel's expertise regarding business planning and networking (C), then an intervention is more likely to find funding solutions (O), because personnel will be better at developing and implementing a strategy to do so (M). [46]

CMOC 174: Ifan intervention has a realistic strategy to attract donations and grants (C), then it is more likely to find funding solutions (O), as personnel will have thought through the challenges involved and put in place actions to tackle them (M). [94]

CMOC 175: If an intervention has a business case ready (C), then it is more likely to secure funding (O), as it will be able to respond quickly when a window of opportunity opens with a potential funder (M). [60]

CMOC 176: When an initiative is in a more rural area (C), it is likely to be small scale with fewer members/service users (O), because the population is geographically diffuse without the infrastructure to gather together easily (M). [84]

CMOC 177: If an initiative is small-scale (C), it will not be able to robustly demonstrate demand, effectiveness and H&SC savings (O), because it's number or members/service users will not be enough to capture robust evidential statistics (M). [84]

CMOC 178: If funders demand robust statistical evidence before funding (C), then small and rural groups and activities will be disadvantaged (O), because they will not have the numbers and resources to produce this (M). [50,84,91]

CMOC 179: If an initiative is small-scale (C), it will be disadvantaged in securing funding (O), as it will have fewer personnel with more limited time and resources to continually apply (M). [84]

CMOC 180: If an intervention is aligned with national agenda (C), then it is more likely to get funding (O), because the policy and infrastructure will be in place to support it (M). [42,55,59,84]

CMOC 181: If national policy is not consistent with local need (C), then local groups serving those needs will struggle to attract funding (O), as funders will not see their cause as a priority (M). [41,51,84]

CMOC182: If the national (and by extension funders') agenda focuses on medical needs and costs over social and emotional needs (C), then community-focussed groups and activities will struggle to get funding (O), as funders will not understand their benefits or see their cause as a priority (M). [77,80,86,91,95]

CMOC 183: If intervention providers, service users and families speak out about their needs (C), providers may be more likely to get funding for local community-focussed services (O), as authorities will feel pressure to change the national agenda to meet people's needs (M). [96]

CMOC 184: If resources are not allotted and ring-fenced to match changes in national or local policy (C), there will be no benefit to community interventions (O), as funders will not have the resources to invest in making a difference in practice (M). [39,50,76,87]

Keeping Funding and Income

CMOC 185: If communication and publicity is regularly disseminated to funders (C), then they are more likely to fund again in the future (O), as they will be kept informed and alert to the continuing work and benefits of an intervention (M). [94]

CMOC 186: If publicity and networking is pared back to cut costs (C), this could negatively impact changes of finding continued funding (O), as an intervention will drop off funders' "radar" and risk being forgotten or overlooked (M). [94]

CMOC 187: If funders are made aware of a growth in demand for an intervention from service users and referrers (C), then they are more likely to continue to fund (O), as they will recognise that it is meeting people's needs (M). [46,55]

CMOC 188: If funders are made aware of accruing evidence of the added value and benefit of an intervention (C), then they will be more likely to fund it (O), because they will recognise it has something uniquely valuable to offer service users (M). [61,70]

CMOC 189: If groups and organisations do not communicate and work together (C), then existing funds will not go as far (O), as available financial resources will be split and lost on inefficiencies and duplication of services (M). [76]

CMOC 190: If an initiative has co-operative working arrangements with other community organisations (C), then this can help keep costs low (O), as they can agree to share resources (venue, personnel, equipment, training etc.) (M). [70,75,76,78,80,93]

CMOC 191: If an initiative has multiple and diverse income streams (C), then it is more likely to maintain a proportion funding (O), because if one stream stops, others will still be available. [70,80,84]

CMOC 192: If an initiative's budget is broken down into identified parts (C), then it is more likely to be able to weather changes in funding (O), as what can be used to pay for what is more flexible, and core activity can be prioritised (M). [70,84,94]

CMOC 193: If financial planning is done with a focus on the long-term (C), then an initiative is more likely to weather changes in funding (O), as it will be able to spread existing funds more effectively by allotting spending carefully (M). [44,45,70]

CMOC194: If an intervention has a realistic strategy to continually attract donations and grants (C), then it is more likely to find funding solutions (O), as personnel will have thought through the challenges involved and put in place actions to tackle them (M). [94]

CMOC 195: If there is no long-term funding available (C), this will place significant demands on the time and resources of personnel (O), because they will need to continually seek and apply for fresh funding (M). [84]

CMOC 196: If an initiative is small-scale (C), it will be disadvantaged in continuing to secure funding (O), as it will have fewer personnel with more limited time and resources to continually seek and apply (M). [84]

CMOC 197: If an initiative continually and systematically seeks new income streams (C), then it is more likely to maintain a proportion funding (O), because if one stream stops, it will be more likely to have multiple other streams available (M). [70,80,84]

CMOC 198: If funders objectives are always short-term and keep changing (C), then deep learning on what works for services users and communities will be lost (O), as "quick win" projects will be encouraged over support for existing and experienced initiatives (M). [51,79]

CMOC 199: If funders only support short-term or new projects (C), then initiatives will struggle to become established long-term (O), as they will be unable to plan ahead with confidence or have time to learn how activity can be supported sustainably (M). [77,86,87]

CMOC 200: If resources are not allotted and ring-fenced to match changes in national or local policy (C), there will be no benefit to community interventions (O), as funders will not have the resources to invest in making a difference in practice (M). [39,50,76,87]

CMOC 201: If intervention providers, service users and families speak out about their needs (C), providers may be more likely to get funding for local community-focussed services (O), as authorities will feel pressure to change the national agenda to meet people's needs (M). [96]

RAMESES publication standards (realist synthesis) checklist

(After BMC Medicine 2013, 11:21 http://www.biomedcentral.com/1741-7015/11/21)

Items required when reporting a realist synthesis			Reported on page(s)
1		In the title, identify the document as a realist synthesis or review	1,2
ABSTRACT			
2		While acknowledging publication requirements and house style, abstracts should ideally contain brief details of: the study's background, review question or objectives; search strategy; methods of selection, appraisal, analysis and synthesis of sources; main results; and implications for practice.	2
INTRODUCTION			
3	Rationale for review	Explain why the review is needed and what it is likely to contribute to existing understanding of the topic area.	4
4	Objectives and focus of review	State the objective(s) of the review and/or the review question(s). Define and provide a rationale for the focus of the review.	5
METHODS			
5	Changes in the review process	Any changes made to the review process that was initially planned should be briefly described and justified.	N/A
6	Rationale for using realist synthesis	Explain why realist synthesis was considered the most appropriate method to use.	6
7	Scoping the literature	Describe and justify the initial process of exploratory scoping of the literature.	6-7
8	Searching processes	While considering specific requirements of the journal or other publication outlet, state and provide a rationale for how the iterative searching was done. Provide details on all the sources accessed for information in the review. Where searching in electronic databases has taken place, the details should include, for example, name of database, search terms, dates of coverage and date last searched. If individuals familiar with the relevant literature and/or topic area were contacted, indicate how they were identified and selected.	7-8
9	Selection and appraisal of documents	Explain how judgements were made about including and excluding data from documents, and justify these.	8-9
10	Data extraction	Describe and explain which data or information were extracted from the included documents and justify this selection.	8-9
11	Analysis and synthesis processes	Describe the analysis and synthesis processes in detail. This section should include information on the constructs analyzed and describe the analytic process.	9
RESULTS			
12	Document flow diagram	Provide details on the number of documents assessed for eligibility and included in the review with reasons for exclusion at each stage as well as an indication of their source of origin (for example, from searching databases, reference lists and so on). You may consider using the example templates (which are likely to need modification	8

Items required when reporting a realist synthesis			Reported on page(s)
		to suit the data) that are provided.	
13	Document characteristics	Provide information on the characteristics of the documents included in the review.	10
14	Main findings	Present the key findings with a specific focus on theory building and testing.	10-14
DISCUSSION			
15	Summary of findings	Summarize the main findings, taking into account the review's objective(s), research question(s), focus and intended audience(s).	14-15
16	Strengths, limitations and future research directions	Discuss both the strengths of the review and its limitations. These should include (but need not be restricted to) (a) consideration of all the steps in the review process and (b) comment on the overall strength of evidence supporting the explanatory insights which emerged. The limitations identified may point to areas where further work is needed.	15-16, 17-18
17	Comparison with existing literature	Where applicable, compare and contrast the review's findings with the existing literature (for example, other reviews) on the same topic.	16-17
18	Conclusion and recommendations	List the main implications of the findings and place these in the context of other relevant literature. If appropriate, offer recommendations for policy and practice.	16-18
19	Funding	Provide details of funding source (if any) for the review, the role played by the funder (if any) and any conflicts of interests of the reviewers.	19-20