



**University
of Worcester**

**Association for
Dementia Studies**

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Sustaining Meeting Centres and similar community-led dementia support

Suggestions for health and care professionals

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Introduction

Meeting Centres are places for people to socialise, get involved in activities and access information to help to meet their needs. They are a form of community-led support for people living with dementia and those that support them.

It can be challenging for Meeting Centres to keep going long term, so we carried out a 2-year research project called Get Real with Meeting Centres, funded by The National Institute for Health and Care Research (NIHR). This project looked at how Meeting Centres can run both sustainably and successfully, and the issues they face in doing this.

We have spoken to a wide range of people involved with Meeting Centres in England and Wales. They have helped us find out how things work and what the challenges are.

In this booklet we talk about what we have learnt, in five broad topics:

- Referrals to Meeting Centres, and the dementia care pathway
- Reaching people and Meeting Centre membership
- Venue and location
- Meeting Centre practices
- Finances and funding

Referrals and the Dementia Care Pathway



Making links and raising awareness in the health and social care system

“Most of our referrals are coming through NHS professionals who are supporters of, and are aware of, the Meeting Centre and how it operates - it's not a recognised local NHS pathway, as such.” – Meeting Centre trustee

“Some social workers will speak to you, and they'll say I discovered the Meeting Centre, and I think, well, that's been going a long time, why have you just discovered it now?” – Health care professional

“The dementia care pathway for this county, it's a mythical beast... you go around and it's just like hunting the Loch Ness monster at times.” – Meeting Centre staff member

Meeting Centres typically do not insist on members having a formal diagnosis of dementia. Nevertheless, members may be accessing health and social care services – whether seeing their GP, visiting a memory clinic, speaking to a dementia advisor or getting support at home.

Such services can refer people to Meeting Centres and can also work with them beyond simply referring, so ensuring there is strong collaboration with professionals in the health and social care pathway is key to sustaining high quality Meeting Centres.

However, clarity and good communication are needed to ensure people working within the various organisations and services that make up the health and social care system remain aware of Meeting Centres, who is responsible for referring, and how and when to refer.

Health and social care professionals need to know what Meetings Centres aim to do and for whom, to understand the potential benefit to their own patients or service users.

Third sector organisations such as regional or national charities can also have a role to play, whether acting as referrers themselves or helping forge links between health and social care services and community support such as Meeting Centres.

Suggestions for health and social care professionals:

Ensure information on community support like Meeting Centres is kept up to date, and make use of third sector partners that can connect patients or service users to that support.

Ensure the dementia care pathway is well understood and clearly communicated between colleagues, external partners and patients or service users.

Share information provided by Meeting Centres widely with people living with dementia in the community, and those that support them, and ensure the Meeting Centre offer and how it differs from other forms of dementia support is clearly understood and articulated to people.

Diagnosis issues

“*To get somebody to the GP practice in the first place is really, really important because if it doesn't do anything else, you open support networks.*” – Meeting Centre trustee

“*The diagnosis stats are dreadful all over the country, and the more rural you are, generally the worse it is... it seems ridiculous to be reliant on a formal diagnosis from a system that is failing, when you've got people there who want to be members, and need the support.*” – Meeting Centre trustee

Dementia is underdiagnosed by clinicians and underreported by people and families, especially in the earlier stages.

People may not want to seek a diagnosis or find it difficult getting diagnosed. This may be due to stigma, denial or worries about practical repercussions, or difficulties accessing health services.

Whatever the reason, if people don't seek a diagnosis, they are much less likely to hear about, or want to attend, a Meeting Centre.

Suggestions for health and social care professionals:

Continue to work to overcome barriers to diagnosis, including raising awareness of dementia, the benefits of an early diagnosis and support available.

Continue to work to reach people who are more isolated.

Alternative support beyond Meeting Centres

“*We've been dire, actually, at letting go of people when they've passed through mild to moderate and reached advanced stages. We haven't let go of people because we know that there's nowhere else for them to get that support.*” – Lead of Meeting Centre-running organisation.

“*That's the problem, that means all these people are holding onto their places, there's no room for new people to come who have got the recent diagnosis.*” – Health care professional

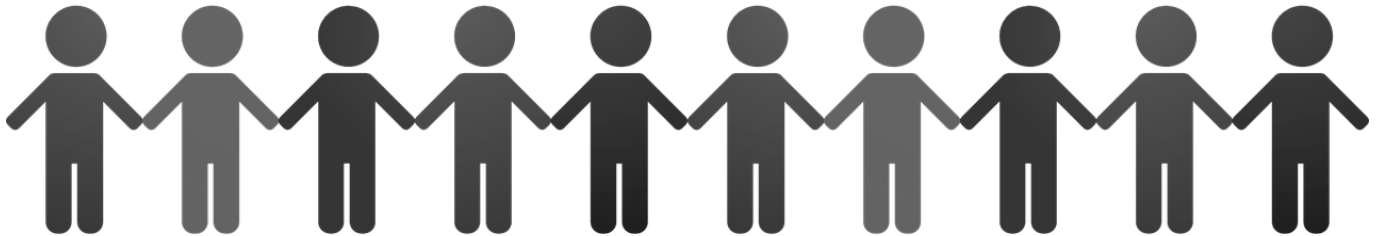
Meeting Centres are for people with mild to moderate dementia. As a person's dementia progresses a Meeting Centre may not be able to meet their needs any longer, so they will need support from another part of the care pathway.

If more appropriate forms of support are not available, accessible or do not appeal, people might feel reluctant to stop attending the Meeting Centre. Staff might feel like they are unable to suggest the Meeting Centre is no longer appropriate for them if they do not have any alternative form of support, meaning more people with more advanced dementia will end up staying on at the Meeting Centre.

Suggestions for health and social care professionals:

Ensure there is adequate support available for those whose needs can no longer be met by a Meeting Centre – and that everyone knows about it and how to access it.

Reaching People and Membership



Appropriateness and access

“ I think there’s lots of stigma to it...like ‘I’m not going sitting in a room doing painting and throwing a ball to someone or listening to this music, that’s not what I need’, because he...doesn’t associate himself...with someone who’s late 70s, 80s.”
– Family carer

“ If they want to come along to try a session, that’s the best bet really. Come and see for yourself and if it’s something that you particularly like, stay and become a member.” – Meeting Centre staff member

“ Some people came and they shouldn’t have really been there according to the model, because it was a long time after their diagnosis, and it was more of a place for them to come and occupy during the day rather than get out of the Meeting Centre what exactly it was meant for.” – Health care professional

Whether someone attends a Meeting Centre or not will depend upon whether they feel it is appropriate for them. Understanding what Meeting Centres are and do is key to their appeal. If staff and volunteers do not adhere to the Essential Features and ethos, that could be a problem when recruiting members.

Taking the step to go to a Meeting Centre can be daunting, especially if you’re not used to attending social groups or are still coming to terms with a diagnosis. People may need time and support.

Insisting on a formal diagnosis will restrict numbers and turn away many who could benefit.

There may also be barriers to access, such as cost or practical problems. It is important that the Meeting Centre is available at a time and frequency to suit members, and it needs to be affordable. Helping people to source support to attend can be crucial.

Balancing what appeals to different generations, or is appropriate for people at different places in their dementia journey, can be difficult. For example, if activities are mainly tailored towards older people or those at more advanced stages, this may put off younger people or those with milder symptoms.

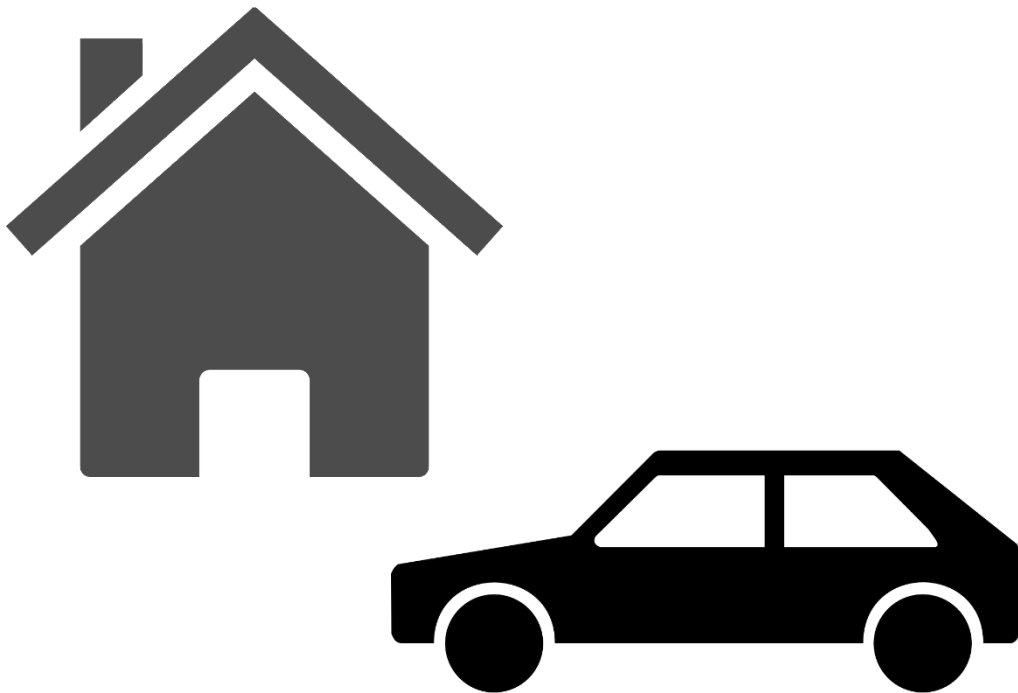
There is a danger Meeting Centres may put off people from diverse backgrounds without realising, for example if members are all of one cultural group or socio-economic background – so extra care and effort may be needed to ensure it is welcoming and inclusive for all.

Suggestions for health and social care professionals:

Provide information and practical support for potential Meeting Centre members to access financial support, homecare, personal support and community transport in order to attend.

Liaise with local ethnic minority groups and mild cognitive impairment services to increase awareness and understanding. Raise awareness of the importance and benefits of diagnosis and community support such as Meeting Centres - and feed back to Meeting Centres how they can meet the needs of these groups.

Venue and Location



Transport and rurality issues

“ *Getting here is probably the main thing, but that’s my problem. But I think it is probably a general problem.*” – Meeting Centre member

“ *I’d say just transport would probably be their biggest issue.*” – Meeting Centre volunteer

The location of a Meeting Centre can present some challenges, including how easily people can get there.

In rural areas people are more likely to have further to go between places – and public transport is likely to be less available. People living with dementia, and those that care for them, might be unable to drive, on a tight budget or have health or mobility issues, which can make things even more challenging. Some people may not have anyone who can support them to get out to somewhere like a Meeting Centre.

If people have to cross borders into different areas or communities, that can also act as a barrier for some.

Suggestions for health and social care professionals:

Provide information and practical support for potential Meeting Centre members to access financial support with transport, or community transport, in order to attend.

If there are different services, trusts or bodies covering different places in your area, ensure there is good communication between them about what is available where, and to whom.

Venue issues

“ *I think if we’d got a building that we could be in continuously, you wouldn’t be moving equipment all the time, you wouldn’t have to set it up every session – probably we could maybe offer more than we can at the moment.*” – Meeting Centre staff member

“ *A place you can call your own, is important. Because the members themselves feel at home, and they take ownership of the place, and they feel comfortable at it because it’s consistent... you are where you are, and you are known and can go out into the community, and be a part of the community from a fixed spot.*” – Meeting Centre trustee

“ My first impression when I came a long time ago were those blue chairs... I couldn't believe those lovely blue chairs, but then when I knew I was coming again I thought oh I do hope the chairs are there.” – Meeting Centre member

The venue a Meeting Centre is held in can be crucial to its success and sustainability. It is rare for a Meeting Centre to have use of a perfect venue that ticks all boxes. However, it is important to provide a space that is as accessible and welcoming as possible, and suitable for carrying out a good range of activities.

But that's not the only thing to consider – issues raised by sharing the space with others are also important. When a Meeting Centre is in a fixed venue, and has exclusive use of that space, it opens up a range of possibilities. Staff can adapt the environment and give members ownership of it; you can make the most of having a presence in the community; and you can create a supportive community with others in the same building or area.

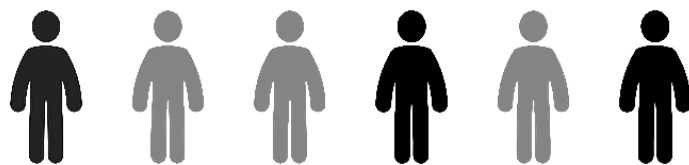
If the Meeting Centre is not open multiple days a week, exclusive use is unlikely, which can create difficulties. If the space is shared, staff and volunteers may have to bring equipment, set up and pack away each session. If the venue keeps changing then the Meeting Centre may struggle to establish a presence in its community and members may lose confidence in its future.

A venue owner that is invested in and supportive of the Meeting Centre really helps to ensure it is sustainable.

Suggestions for health and social care professionals:

Consider Meeting Centres as a possible user of any shared community spaces for joint health and social care services.

Meeting Centre Practices



Mission drift

“ I have a slight concern that some Meeting Centres are being pushed into a role which is not actually what the Meeting Centres were intended to be set up as.” – Meeting Centre trustee

“ I would hate it to become a [respite] day care centre. And you could easily go down that road unfortunately.” – Meeting Centre trustee

“ I think the last six months we've been pretty at the beck and call of funding streams and it's quite easy to get sucked down the route of well, this is what government want, so what can we do to tick that box to get their money?... Sometimes you feel it's the tail that's wagging the dog with funding, don't you?” – Meeting Centre staff member

Meeting Centres have a clear ethos, purpose and place in the dementia support pathway. That is to help people living with mild to moderate dementia and their families to adjust to change together. This is achieved via a social model of support that can connect people with their communities, while delivering stimulating and meaningful activities in a person-centred way. However, there are various pressures that may drive Meeting Centres to veer away from one or more of these elements.

Some areas of the health and social care system around Meeting Centres have different priorities and therefore might encourage something different to what Meeting Centres are designed to offer – for example, day care-style respite provision for people with more advanced dementia. This can lead to unwanted or unintentional “mission drift”. Mission drift can also result from a lack of training and different agendas in staff and volunteers.

Suggestions for health and social care professionals:

Ensure that the Meeting Centre offer is clearly understood so that referrals, and the expectations your patients and service users, are appropriate.

Suggestions for potential commissioners or funders of Meeting Centres:

Ensure the Meeting Centre offer, and how it differs from other forms of dementia support, is clearly understood. You can then decide if this fits with your funding aims and objectives without having to change the Meeting Centre model.

Finances and Funding



External funding

“Because we try and keep our membership fee pretty reasonable, then the challenge is to make sure we keep enough money to keep the Meeting Centre actually running with staff and rent and all that sort of stuff. So again, looking for funding is one of the big challenges. That’s what everybody is looking for, aren’t they?” – Meeting Centre staff member

“If you’re spending half your life trying to fundraise to keep the show on the road, then that’s going to be really, really difficult.” – Meeting Centre trustee

“There are so few funders out there that want to fund something that’s already working.” – Lead of Meeting Centre-running organisation

“I think they should fund the places, more than anything. I think it’s a very good idea – I’m enjoying it – and that means quite a lot.” – Meeting Centre member

“You know, so many people are grateful for it being here, I think it’s well worth somebody putting some cash into it, really.” – Meeting Centre member

Many Meeting Centres run on a combination of different income and funding streams. Finding available external funding is a key part of supporting a Meeting Centre to keep going.

It is unlikely Meeting Centres will be able to offer a range of high quality provision purely on income from members fees, unless those fees are high. Therefore some external income is likely to be necessary in order for Meeting Centres to be inclusive and accessible to many.

Stable, ongoing community support for dementia, such as Meeting Centres, requires stable, ongoing funding. This is difficult to find in a funding landscape that prioritises new projects and only offers short term competitive grants. Accessing funding in such a landscape is difficult and time consuming and requires expertise.

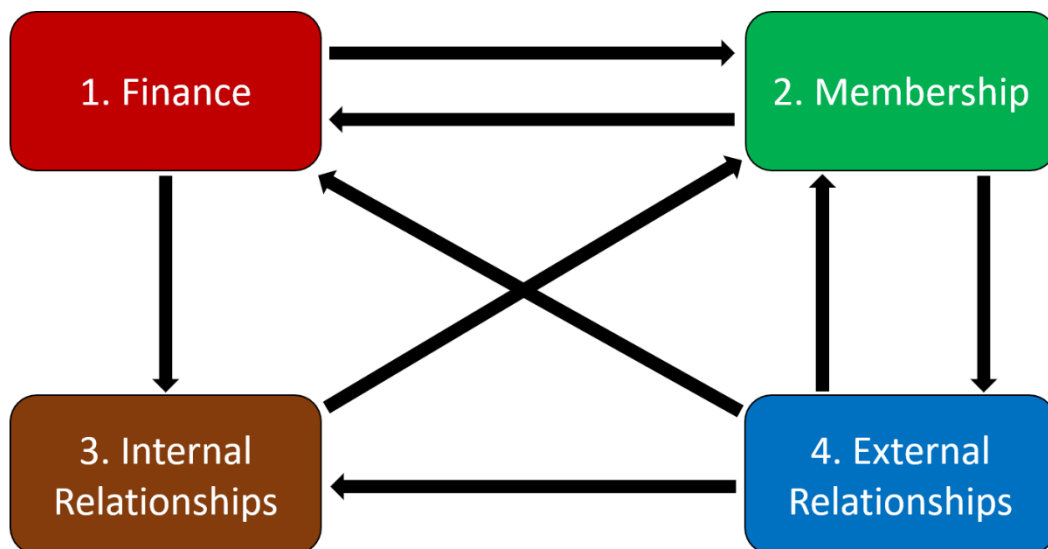
Health services and local authorities may recognise the importance of tackling social isolation, but they have a primary responsibility to meet the most acute medical and social care needs. This means funding may be limited for a social model of support that seeks to help delay acute problems or people reaching crisis point; or funding to support people who attend Meeting Centres, but whose needs are not yet acute.

Suggestions for potential commissioners or funders of Meeting Centres:

Consider longer-term funding to support third sector initiatives that can demonstrate they are filling a gap or fulfilling a need in the care pathway. This way, skilled and experienced practice is not lost.

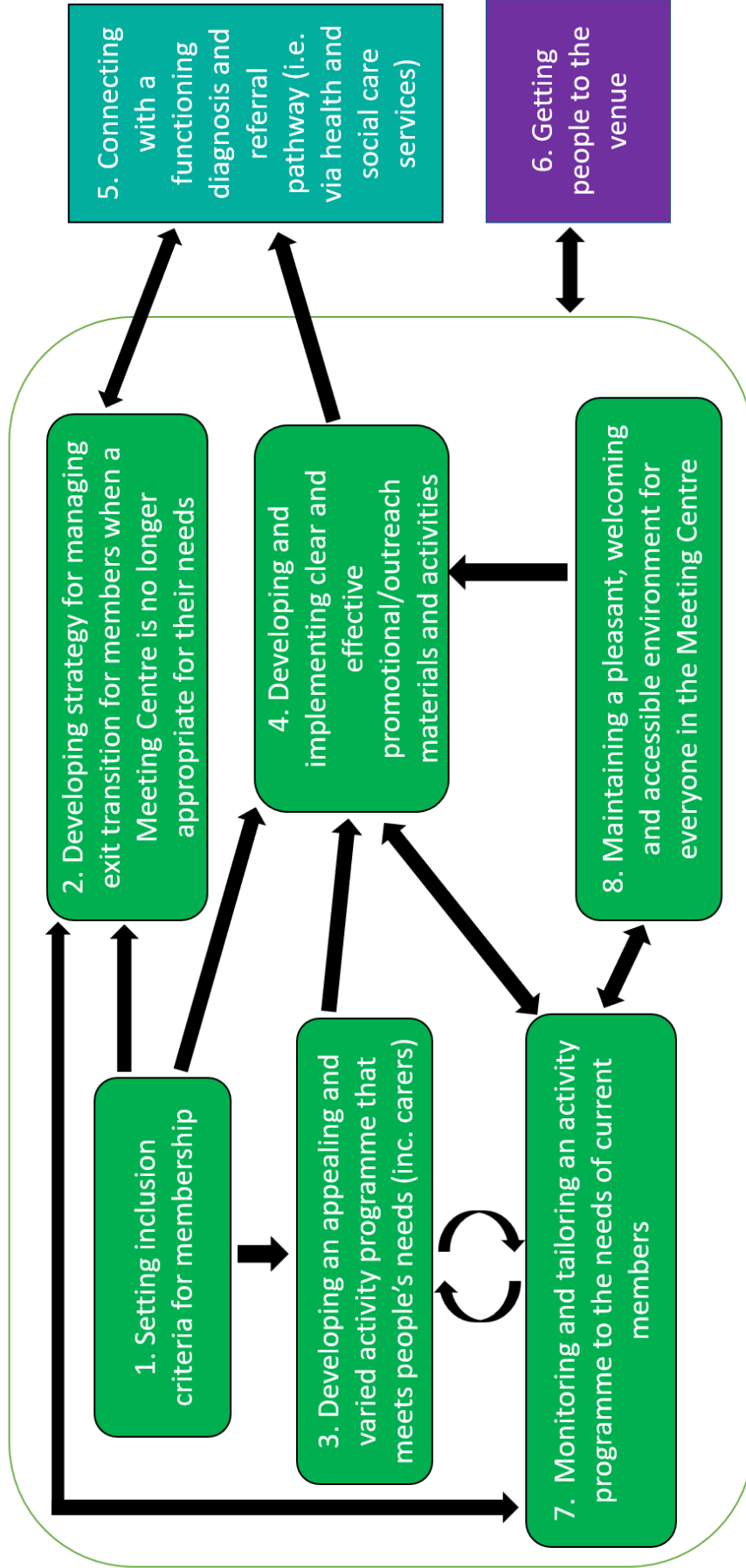
Try to ensure applications for funding are not too demanding, difficult and time consuming. This is important for making funding more accessible to grass-roots organisations with limited resources.

‘Systems’ of Activity Involved in the Sustainability of Meeting Centres



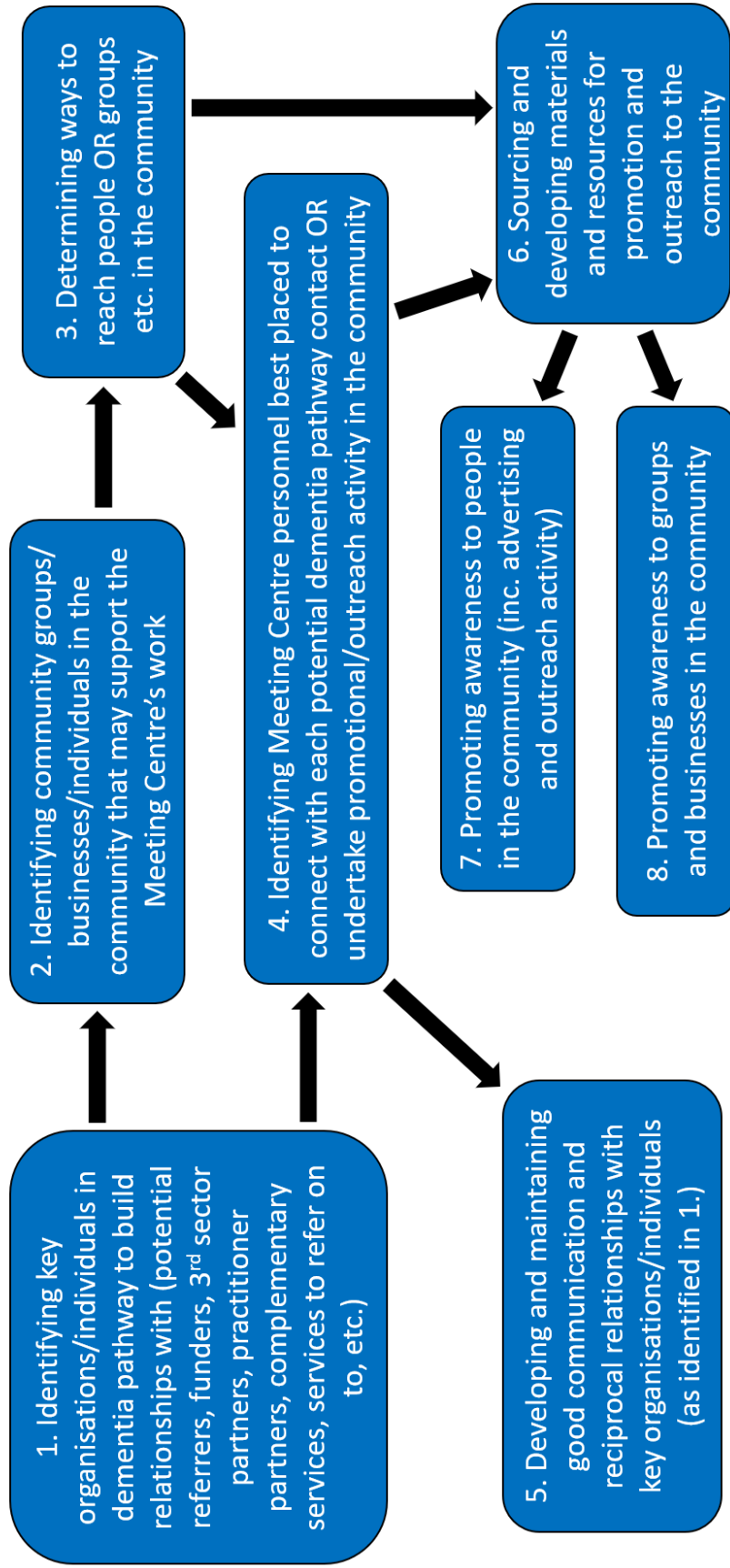
Membership

A system to get and keep appropriate members through effective referral pathways, provision of attractive activities and support that meets people's needs, in order to maintain a functioning Meeting Centre on an ongoing basis.



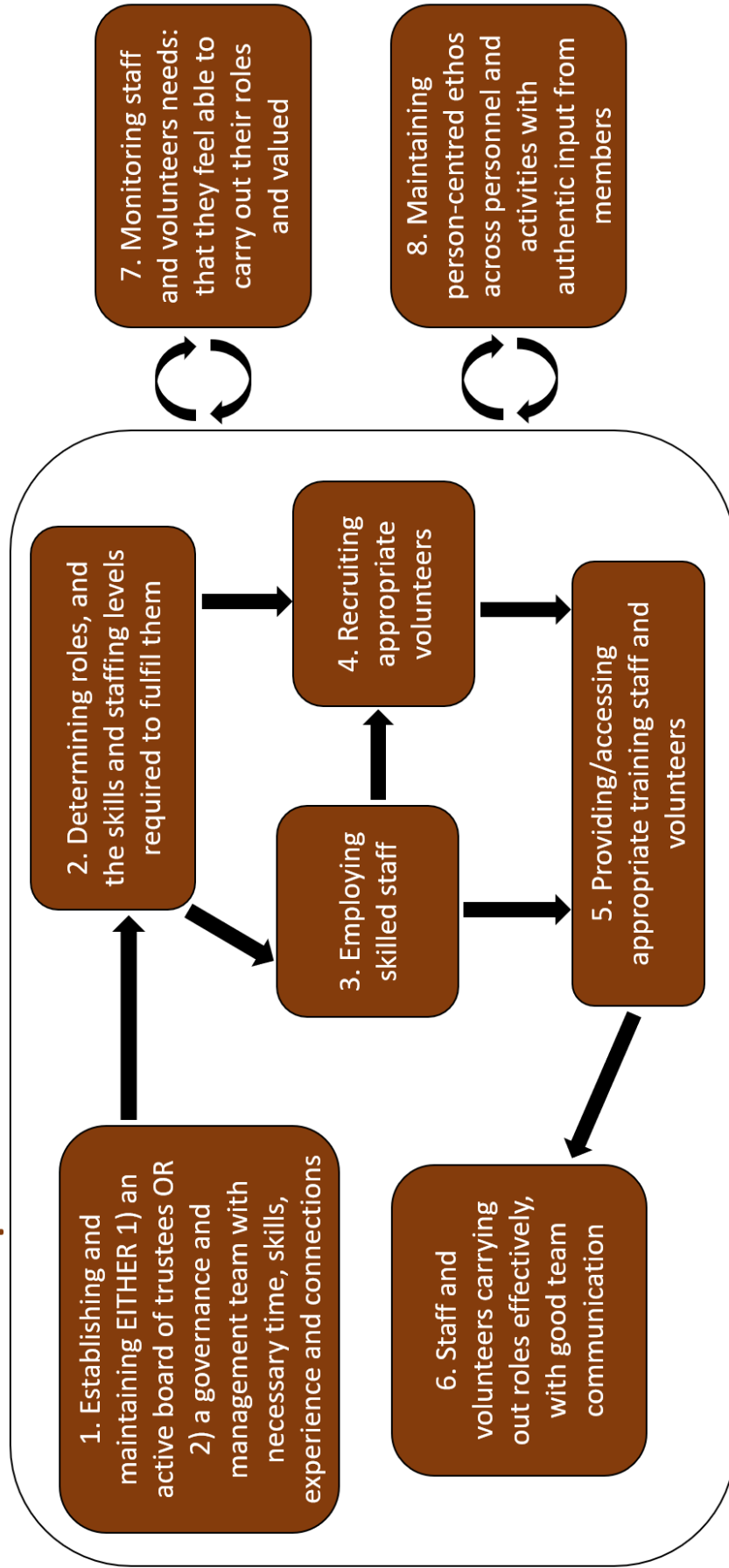
External Relationships

A system to embed the Meeting Centre in the community and establish a clear and distinct position in the local health and social care system in order to maximise the Meeting Centre's reach and impact for all potential beneficiaries.



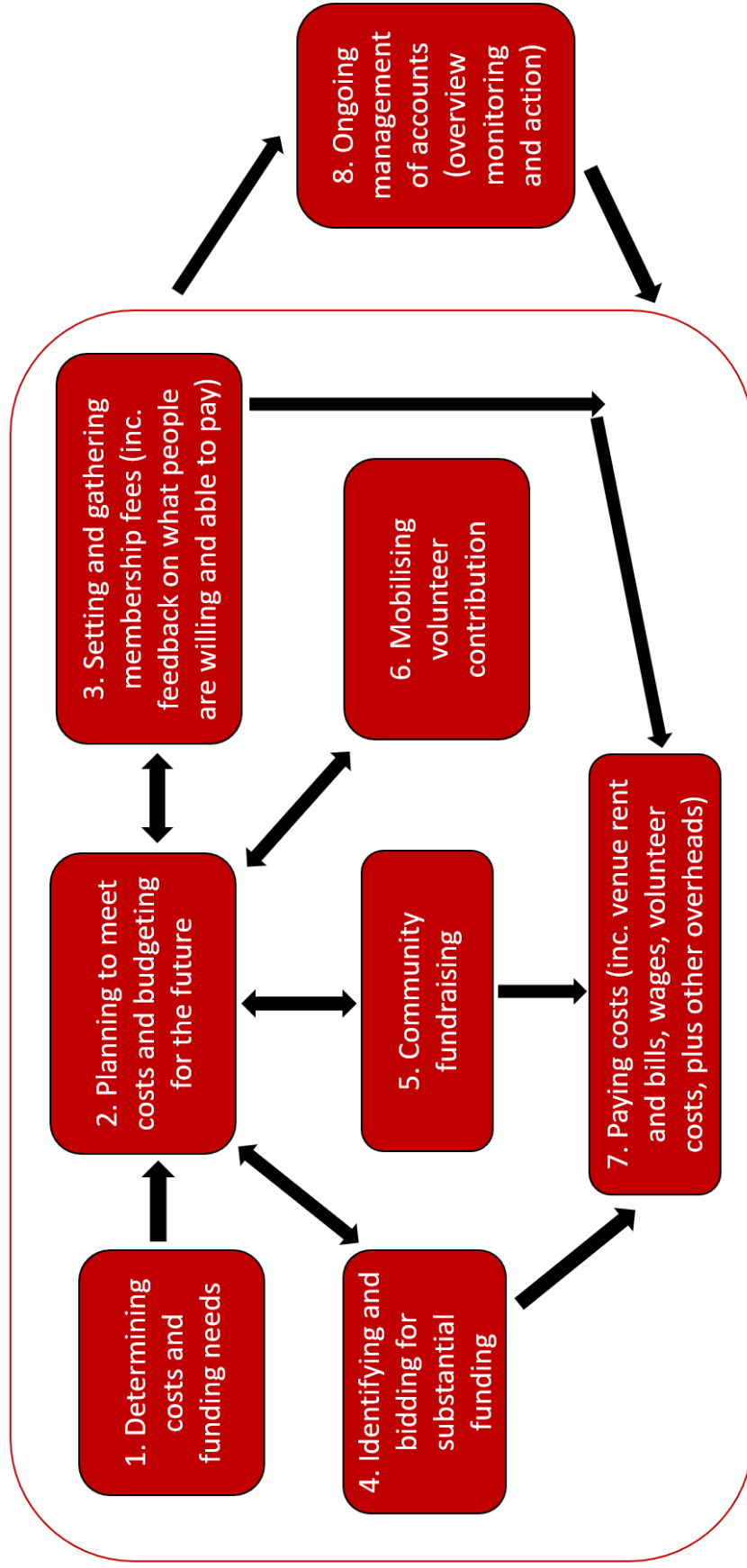
Internal Relationships

A system that encourages good internal relationships - sharing skills, experience, ethos and goals, and understand each other's roles, preferences and needs – so that a Meeting Centre can run effectively and consistently on an ongoing basis to maximise benefit for all stakeholders.



Finance

A system that provides financial stability for on-going payment of staff and volunteers costs, costs of premises and other running costs so that all Meeting Centre stakeholders feel safe and confident that there will be continuity of provision.



About the Get Real with Meeting Centres project

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For more information on Get Real:

The Get Real and SCI-Dem Projects online blog: scidemreview.wordpress.com

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The Association for Dementia Studies – Changing Hearts and Minds in Dementia Care

The Association for Dementia Studies (ADS) is a multi-professional university research and education centre. We make a cutting-edge contribution to developing evidence-based practical ways of working with people living with dementia, their families, friends and carers that enable them to live well.

If you think that we can help please contact us.

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