# Realist evaluation comparison of dementia-friendly communities in England and Netherlands

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## Abstract

Introduction

Dementia-friendly communities coordinate activities and events which offer social inclusion and participation of people with dementia. Initiatives can include memory cafés, sports, tourist and heritage visits. This study explored how dementia-friendly initiatives are developed and sustained in England drawing comparisons with an equivalent case-study in the Netherlands.

Methods

We present a case study of dementia-friendly initiatives, of one city in England. Selection of this case study was on the basis of being a leading dementia-friendly community. We interviewed a variety of stakeholders, including people with dementia and their care partners, volunteers and staff. Semi-structured interviews were recorded, and transcripts were analysed using qualitative analysis software using a realist evaluation interpretation. Realist theories described within this English case study were compared with those described within the Dutch cases studies.

Findings

Five context mechanism outcome configurations were described. The dementia action alliance for the city was a coordinator of initiatives and provided funding and resources. The alliance facilitated advocates to partner with organisations with a shared commitment to plan activities. On the level of individual interactions, staff or volunteers were involved in communicating with local community members which may lead to improvement in awareness. Initiatives had various ways to listen and incorporate views of people with dementia. The five mechanisms identified within the English case study resonated with mechanisms identified within the larger Dutch case study, with differences in contexts due to local policies and practices.

Conclusion

Strategic coordination is an important factor for development and sustainability. The national policy in England has set the pattern for local structures, while the Dutch approach is 'bottom-up' with local leadership. Community advocates and public support were important factors in development of dementia-friendly initiatives in both countries.

## Introduction

There are many different conceptions of dementia-friendly communities which address different aspects of society and environment that are believed to be problematic for people with dementia (1). Across different approaches, the commonality is the social-model of disability which argues that many of the difficulties faced by people living with dementia result from societies that are shaped by stigmatisation, and environments that have been designed for people with able-bodies and minds (2). The social model of disability implies that the whole society has the responsibility  to reduce disabling factors within the environment and to reduce stigmatising aspects of society (2). A critique of the phrase dementia-friendly is that it connotes a superficial or patronising approach to individuals with dementia (3). However the underlying basis originates with the concept of age-friendly cities, developed by World Health Organisation (4), based on a human rights approach, which prioritises active, healthy ageing and good quality of life (5).

The terms dementia-friendly community and dementia-friendly initiative have been used interchangeably (6) but there are potentially different meanings. For example, the DEMCOM study (a national evaluation of dementia-friendly communities in England) uses the term initiative to refer to a dementia-friendly community, the authors also highlight an inconsistency, that sometimes community refers to a 'community of interest' rather than the more common meaning of a geographically defined population (7). A widely accepted concept of a dementia-friendly community (DFC) is where a city or town has created this as a policy; where implementation may include companies becoming dementia-friendly and built environments being designed with a dementia-friendly approach (6). In our study we define dementia-friendly initiatives as the activities that are organised by local communities which improve the inclusion of people with dementia (5).

The international policy context is that many countries (currently 37) have developed and adopted national dementia strategies (8). The UK dementia strategy included a framework in England for dementia-friendly communities called Dementia Action Alliance (a partnership of public sector and third sector organisations)(9). Registration of a community as a local alliance required documentation of pledges and actions. The charity, Alzheimer's Society, were commissioned to provide an accreditation process for organisations to demonstrate that they were working towards becoming dementia-friendly (10). The nature of the National Dementia Action Alliance (which is the national organising body) set the example of local alliances which were encouraged to be partnerships of local authorities (local government), healthcare services (including NHS) as well as charities and private sector organisations. Thus, one of the aims of this national policy is that communities, which undertake to develop dementia-friendly initiatives, can receive support and guidance from the local dementia action alliance (the city-wide organising group of the dementia-friendly community). In the Netherlands, dementia policy aims to develop community-based support for dementia in a more 'bottom-up' approach (11-13). Decentralisation of health and care services in the Netherlands means that municipalities themselves should find out how to provide dementia care and support (Social Support Act 2015) (12, 14, 15). Municipalities are supported by a national web platform (Together Dementia-friendly) that offers educational material such as training and workshops on dementia-friendliness (15). Dementia-friendly communities are within the remit of this policy and municipalities have supported an increase in local initiatives (15, 16).

The aim of this study was to develop insights from a comparison of a best practice dementia-friendly initiative in England with a case series of multiple dementia-friendly initiatives in Netherlands (17). We selected realist evaluation as this method is appropriate for analysing programmes which are shaped and influenced by many stakeholders in the process of implementation. Realist evaluation

was the method used in our comparison study in Netherlands (17), and therefore this would enable direct comparison of contexts and outcomes. The research questions were as follows:

- Which mechanisms are important for developing and sustaining dementia-friendly initiatives in England and what outcomes are generated from these mechanisms?
- Which contexts are present in local dementia-friendly initiatives in the case study examples of England and Netherlands?
- On the basis of commonalities in mechanisms within the Dutch and English case studies for developing and sustaining Dementia-friendly initiatives, we explored what accounts for differences in contexts and outcomes?

Whilst we acknowledge national policy as discussed above, the focus of this study was on the local implementation, and thus the scope includes the dementia-friendly initiatives, with local policies as important contexts; whereas national policy is an indirect context.

## Methods

Sheffield was chosen as a case study for England because it is well-established as a dementia-friendly community and is one of the larger English cities. Strategic development is shaped by people with dementia and care partners, as demonstrated by a consultation on support and care, in 2018 (18). In a purposive sampling process, we recruited participants who were involved in local, community-based initiatives involving social participation for people with dementia and their carers. We recruited staff, volunteers, and participants with mild dementia and care partners. We searched for online documents about initiatives and visited initiative activities. We provided project summary documents and participant information sheets prior to inviting people to participate and asking for their consent. Where couples attended an event together, they were both invited to join the interview, with the care partner giving consultee advice for the individual who lacked capacity to consent for themselves. Semi-structured interviews followed an interview schedule which had been translated from the Dutch case study (17) and adapted to the English context; for example, exploring how the local initiative related to the infrastructure of the local dementia action alliance (see Supplemental File 1). Interviews were held either in person, or via video or teleconference between September 2019 and March 2020. Digital recordings of interviews were transcribed verbatim by professional transcribers. Transcripts were imported into NVivo computer aided analysis software. Transcripts were coded and themes were extracted, which were developed through discussion with research team (all authors) and with reference to international literature reviewed within our realist review (19) with the aim of developing realist context mechanism outcome configurations (CMOc). CMO configurations described within this English case study were then compared with the CMO

configurations from the Dutch case series (17), by finding similarity between mechanisms and noting similarity or difference in contexts and outcomes. For each CMOc described within the English case study, we identified a comparator within the outline CMOcs of the Dutch case series (described within Thijssen et al 2023, supplementary file 3 (17)).

## Ethics

The study was approved by University of Nottingham Research Ethics Committee (327-1906) and Radboud university Ethical Committee (2018-4238) (17).

## Sampling

The researcher (NC) made contact with the coordinator of the Sheffield Dementia Action Alliance in order to recruit participants for this study. Through attending a meeting of the alliance, as well as researching online information, it emerged that the infrastructure of the alliance played an important role in development and sustainment of local dementia-friendly initiatives (see Supplemental file 2). Sheffield City Council, the local authority (municipality), had provided funding for third sector organisations (including charities) to support development of initiatives within each neighbourhood of the city. Within each neighbourhood the organisation appointed a development worker (who was interviewed within this study). Also community support workers (employed within a local authority programme called 'People Keeping Well') were given additional duties to support the local dementia-friendly initiatives (see documents listed in Supplemental file 2). Following observing the meeting of the alliance, the researcher selected one initiative, a dementia café (A) and carried out an observation visit and interviews. The dementia café (A) held weekly social sessions, within a community centre, with food and drink provided. Different activities, such as singing and dancing, were scheduled for each session and members could participate or watch or chat amongst themselves. A coordinator of another dementia café (B) was interviewed as part of the strategic group (dementia action alliance). Table 1 shows a description of the participants included in the case study.

| | English case study | |
|---|---|---|
| Role | Dementia Action Alliance | Dementia-friendly initiative (dementia café A) |
| Coordinators and leaders of initiatives | 5 | 2 |
| Volunteers | 1 | 1 |

| | | |
|---|---|---|
| People with dementia and care partners as co-developers | 1 | |
| People with dementia and care partners as beneficiaries | | 5 |
| Total | 15 | |

*Table 1 Participants of English case study – from the strategic group (Dementia Action Alliance) or one initiative dementia café A. Note, a coordinator of another dementia café (B) was within the strategic group sample.*

## Results

The following sections describe key themes which emerged from the interviews within this English site. Each section is summarised with a realist CMO configuration. The mechanism within these CMO configurations were then compared with the mechanism of the Dutch outline CMO configurations described within the case study series (17).

### CMO configuration 1: Developing a strategic network facilitates funding, coordination and training

In order to gain an understanding of the contexts of the dementia-friendly initiatives within the study site, the researcher (NC) attended Sheffield Dementia Action Alliance committee meeting. At the meeting, many ongoing activities and initiatives were discussed across the city region (see observations summarised in Supplemental file 2). The meeting included representatives from the city council (municipality), healthcare and third sector organisations. The strategic approach of Sheffield Dementia Action Alliance has built capacity within the voluntary sector to implement dementia-friendly initiatives (see documents reviewed in Supplemental file 2). Dementia cafés have been established in Sheffield for approximately 15 years, but recent activity has been supported by funding from Sheffield City Council and a Big Lottery grant (this is distinct from central Government funding). Resources have provided for community development within third sector.

> *"The last year or so, they've [council] decided to spend the money on dementia - giving the voluntary sector more resources to do more around dementia - particularly the social side of it, groups, that kind of thing. People keeping well is how the money comes through to the voluntary sector." Participant #14 (staff)*

Views of people with dementia, care partners as well as staff and volunteers, suggested that the way that services were linked within a city-wide network was important. Services were interconnected in terms of resources, training, and information about different sessions. This network appears to have

built up around the core programme of dementia friends training events (provided by Alzheimer's Society).

> *"The general idea is about skilling-up workers and volunteers. I've had people from NHS come on it. A lot of volunteers, people from care homes [staff]. Smaller voluntary organisations. Thinking a bit more about it and in a sense simplifying it. Helping people to make stuff dementia-friendly, thinking it through, taking back to the group" Participant #14 (staff)*

A third sector training provider supported the development of initiatives across the city and had developed a tailored training package aimed at informing volunteers and staff about the impact of dementia on communication and behaviour and how to support people with dementia. Training was funded by the Council. The community development worker (participant #14) could target training to volunteers in order to support new groups, and also target local members of the public who may be beneficiaries of the new group (or may wish to volunteer in future).

Dementia-friendly initiatives depend on interrelationships between different sectors and members of the local community. In Sheffield, a manager of a dementia café (A) described one aim of the dementia café is to model the concept of dementia-friendly and encourage ownership of dementia as an issue by local community. Thus, while the activity of the café is to provide support for individuals with dementia and care partners, the broader aim is to communicate values of welcoming and accommodating needs of people with dementia to members of the public and other stakeholders.

> *"... we've run one in Sheffield for 15 years.  I think we started with one, now there's something like 19 dementia cafés in Sheffield.  So that modelling of that café ... I think a lot of our work has actually modelled what dementia-friendly is and then it's gone out and people have started it out there."  Participant #06 (Staff)*

Coordination between agencies was demonstrated by development of 'hubs' with coordinator staff (People Keeping Well advisor).

> *"…dementia hub which will receive newly diagnosed referrals, who pass those to those hubs, those People Keeping Well [hubs] who are going to ring the people and tell them about what's happening in the area." Participant #06 (Staff)*

Within the funded network, the Council had specified that there should be activities that are open to a broader section of the community, but where leaders have had dementia training and the activity

can accommodate needs of people with dementia. The aim is to encourage more and more services across the city to be dementia-friendly, rather than a feeling of restricting people with dementia to a specific set of activities.

> *"If it gets to the point that every service is good with dementia stuff, maybe people won't need to go to dementia café, because they are going to other groups, other support." Participant #14 (staff)*

In summary, the city-wide infrastructure enabled collaborations between various organisations, individuals and community groups. We have described this with the following macro-level context mechanism outcome configuration (CMOc). Sheffield City Council commissioned neighbourhood development workers to facilitate dementia-friendly initiatives, implementing recommendations of Sheffield Dementia Action Alliance (context), which made available personnel and resources (mechanism-resource) coming together as a collaborative network to meet and discuss (mechanism-response) the formation of dementia-friendly initiatives (outcome).

This CMO configuration (Table 2) has resonance with the first outline CMO from the Dutch case series (described within supplementary file of Thijssen et al 2023 (17)) and also with the first midrange programme theory (MRPT 1) (17).

| CMOc | Context | Mechanism-resource | Mechanism-response | Outcomes |
|---|---|---|---|---|
| E1 | Commissioning neighbourhood coordinators to support development of Dementia Action Alliance | Availability of resources and personnel | Individuals and organisations support each other | Development of initiatives |
| NL1 | People with expertise as a professional or by experience, sharing knowledge of issues in the community, including (need for) dementia (friendly) | Create opportunities to have a say, complement each other, propagate vision | Engagement, feeling connected, enthusiasm | Propose a joint approach by professionals, volunteers and community members |

*Table 2 Comparison of English CMOc1 with Dutch Outline 1*

On the basis of similarities in realist mechanism-responses between countries, the contexts were compared and also the outcomes. The context in England includes resources and impetus of the

local dementia action alliances; in turn based on national policy (9). The Dutch context appears less structured by national policy, rather information and training is provided by 'Together dementia-friendly' (11). Thus, the Dutch strategy could be described as 'bottom-up', shaped by local expertise and local needs (12). However, at the city-level, the outcomes appear similar, with development of initiatives (English CMOc1), or concrete intentions and plans (Dutch Outline1).

## CMO configuration 2: Community advocates help to develop initiatives

Key individuals were identified as being important within the following actions: setting up services, providing training and linking various agencies together. These people potentially have two roles; firstly advocating for strategic support and funding, and secondly drawing other members of the community into the campaign. This second part was described as an 'opening up' of what used to be a 'specialists only' domain of dementia care:

> "…organisations started dementia-friendly [activities]... started opening up this world that used to be a specialist world when I joined. So now everybody can be a 'dementia friend', everybody can be a 'dementia champion'." Participant #06 (staff)

In this quote the participant is using 'specialist' to refer to services offered by a charity that is dementia-specific; the likely implication is that the charity had an inward-looking culture. On the other hand, the recent approach with a focus on delivering training for community members (dementia friends) implies an outward-looking approach where the priority is to enable communities to lead in supporting community members with dementia. This generates a sense of ownership of the issue by the community; to accommodate the needs of people with dementia. Indeed, the sense of community ownership may be the best definition of the concept of dementia-friendly.

Thus volunteers can start to plan dementia cafés or other activities. Through support from advocates and local organisations including faith groups, the volunteer-led service can be successful:

> "Also a group in Chapeltown, run by the church - a lot of inbuilt volunteers - that's volunteer-run." Participant #14 (staff)

Health and social care practitioners get involved in projects which is seen as additional to their normal work duties or responsibilities. For example, the leader of another dementia café (B) commented that he was a district nurse when he was first involved in the café. These individuals can bring important expertise and links to organisations and this may be important for sustaining the initiative.

> *I was getting paid as a district nurse … But essentially this was sort of over-and-*
> *above, this was extra-curriculum we all wanted to do it." Participant #10 (Staff)*

The context mechanism outcome configuration for this aspect was: the resources and coordinator staff of the dementia-friendly community network (context) brings together advocates with coordinator and training staff to work with local organisations (including faith groups) (mechanism-resource) to commit to investing time and effort (mechanism-response) to share learning about dementia and create events or activities (outcome). See table 3 for a comparison with CMOc3 of the Dutch case series.

| CMOc | Context | Mechanism-resource | Mechanism-response | Outcomes |
|------|---------|--------------------|--------------------|----------|
| E2 | Resources and coordinator of Dementia Action Alliance | Advocates and organisations meet | Shared commitment of organisations and community | Create opportunities to share dementia learning and other events |
| NL3 | Commitment and enthusiasm of volunteers and professionals. Availability of driven initiator | Become a partner, receive and give trust, be findable, take on one's own role | Connection, trust, enthusiasm and appreciation | Taking initiative for set-up |

*Table 3 Comparison of CMOc2 in England with CMOc3 in NL*

The similarity between these CMOs is the mechanism-response, described as shared commitment in England and connection, trust, enthusiasm and appreciation in NL. Despite slight differences in context and mechanism-resource, there are similarities between advocates and committed volunteers. The English CMOc has a stronger emphasis on learning about dementia; potentially influenced by the high profile of the national campaign of dementia-friends learning sessions (coordinated by Alzheimer's Society). From the Dutch study, the following quote indicates a similar partnership between volunteers and professionals:

> *"I do think that professional guidance is needed, next to volunteers, to offer*
> *guidance and put the initiative on the map." Quote from Dutch case study*

Consistent with the bottom-up approach mentioned in the previous section, the pragmatism of this approach was seen with advocates linking with other existing local issues or priorities, to form a larger collaboration. This reciprocity may broaden the dementia-friendly network and have an added benefit of raising awareness about dementia outside of activities designed specifically for people with dementia.

## CMO configuration 3: Community engagement

Participants noted that public support or community ownership was needed to progress the ideas of the dementia-friendly community. One participant, a member of staff of the Alzheimer's Society, suggested that dementia-friendly initiatives needed to involve the broader community, rather than being a service delivered by a dementia-specific organisation (eg Alzheimer's Society).

> *"…there's a recognition that dementia isn't necessarily an illness that only a service can provide something for. The whole society needs to own the issue." Participant #06 (staff)*

To demonstrate how opportunities were found to convey messages about dementia to the public, a member of staff of the dementia café (A) had appeared on local radio and TV, and took the opportunity to highlight the café:

> *"Raising profile for dementia … she went on Radio Sheffield twice, and… Sheffield Live, on TV, she did things for that, and every spare time, every time we mention memory cafés…" Participant #16 (staff)*

Personal contacts with people with dementia, their family members and also professionals and volunteers are important for effective communication of the purpose of dementia-friendly communities (broadly) and contribution of views about specific initiatives. Carers were involved as participants and volunteers in helping to develop a new initiative in Sheffield where one participant described how he attended the café to help to build momentum, even though it was not local:

> *"There was a new memory café started in Stannington about 18 months ago. I said, "Right, I'll come to it,"… it's about a 7-8 mile journey. I said I would come to it until it gets going." Participant #21 (carer)*

An observation in the Netherlands case study showed that when community members meet individuals with dementia, this could normalise perceptions of dementia.

> *During an information session for the neighbourhood about the future intergenerational garden a volunteer said 'A very handsome well-groomed man stood up and said, such an initiative is for me, I have dementia and would love to work with others in the garden'. The public was surprised, they realized you can look this good when you have dementia'. As such, people with dementia can actually be a very nice icebreaker. (Field notes from an observation at an initiative in the Dutch case study).*

The CMO configuration for this section would be that the resources and knowledge within the network of dementia-friendly community (context) including staff (coordinators and managers), advocates and members of initiatives (mechanism-resource) seek opportunities to communicate with individuals and local communities about the initiative (mechanism-response) which raises awareness and could improve public perceptions about dementia and support available (outcome) (see Table 4). This CMOc has similarities to Dutch CMOc 2.

| CMOc | Context | Mechanism-resource | Mechanism-response | Outcomes |
|------|---------|--------------------|--------------------|----------|
| E3 | Resources and knowledge within the network of initiatives | Staff, volunteers and members | Communicate with individuals and public about initiatives | Raise awareness of dementia and potentially improve public perceptions |
| NL2 | People who are familiar with dementia, by knowledge or experience | Presenting another image of people with dementia, acknowledgement of experiences and pleasure, inspiration of ideas | Aroused interest, curiosity, better insight, increased insight into dementia | Better informed about the impact of dementia and its consequences, decreasing anxiety |

*Table 4 Comparison of CMOc3 in England with CMOc2 in NL*

Here the mechanism-responses are about communicating with members of the public who, in turn, gain interest and insight in dementia. There are similarities in contexts in the two countries with a variety of people and initiatives being involved in communicating with the public. Communication may be via media (TV or radio) or through direct meeting.

## CMO configuration 4: Participation in decisions and a rights-based approach

The coordinator of a dementia café (B) indicated that they encouraged co-production by avoiding having a 'programme of activities' but rather keeping things flexible and responding to people's requests at the time:

> *"[she] found it awkward when visitors first arrive – there is a hush, a wondering whether anything will get going at all. But the strength of this model is that it allows for co-production" Participant #10 (staff)*

The leader of café A described how members of the café would make suggestions of future activities and this included arranging trips.

These points are about co-ownership and co-production of the activities within dementia-friendly initiatives and this was an important aspect of the dementia-friendly community in Sheffield. This approach was consistent with rights-based values within the dementia action alliance, as championed by one participant with dementia:

*"Rather than decisions being made for us. We should have the opportunity to make those decisions first while we still have capacity...Well to me it's just when the organisations don't understand the rights, the right to be involved in your community."* Participant #01 (person with dementia)

The Sheffield dementia action alliance network aimed to strengthen the voice of people with dementia in many different services across the city. They have formed a consultation group called Shindig (Sheffield Dementia Involvement Group) which meets regularly and people with dementia and carers attend. Local services attend Shindig meetings to present a new project or service and seek views from people with dementia on whether it could be improved. The work of this group could in-turn enable better access to services for people with dementia.

*"...the Shindig that I'm involved in, it's a service user engagement group based on the idea that people should have a voice on services and other matters that affect them"* Participant #01 (person with dementia)

In the context of a culture of promoting human rights for people with dementia across the network of dementia action alliance (context), initiatives within the network aim to provide opportunities (mechanism resource) to enable people with dementia to choose activities and have their say in development of initiatives and other services (mechanism response) leading to improvements in services to better suit the needs of people with dementia (outcome) (see Table 5).

| CMOc | Context | Mechanism-resource | Mechanism-response | Outcomes |
|------|---------|--------------------|--------------------|----------|
| E4 | Culture of promoting rights | Initiatives provide ways of listening to members | Members can have a say about current and future activities | Improvement in services to better suit people with dementia |
| NL4 | Information and facilities aimed at people with dementia. Ambition to become a dementia-friendly community | At an interpersonal level: Be informed & ask questions. At an organisational level: attune to perspectives of PWD | Being taken seriously, connecting to needs | Incorporating needs and wishes in dementia-friendly initiatives |

*Table 5 Comparison of CMOc4 in UK and NL case series*

The comparison shows that outcomes in the Dutch study are similar to the English case study; that is attuning to wishes and needs of people with dementia. However, the starting point, the mechanism-resource, is different; where the English example shows a way of working to incorporate the voices

of people with dementia, in Netherlands, information about dementia-friendly initiatives is sent to professionals and volunteers, thus people with dementia and carers can react to this information. In England people with dementia and carers are consulted in local initiatives as well as being involved in strategic planning.

## CMO configuration 5: Finding out about dementia-friendly initiatives

It may be expected that there may be some information about local dementia-friendly initiatives at the GP surgery. However it appears that this was not the case, as one participant explained that there was so much information within the waiting room at the GP surgery, that any information on dementia would not be noticed:

> *"My local doctors, it's just a minefield, there's too much information in the waiting room, you don't know where to look. So, I think information does get lost…"*
> *Participant #16 (staff)*

Two care partners of individuals with dementia said that it was difficult finding out about groups when first diagnosed with dementia. They said that once they had made contact with one group, there was then substantial information about other groups and activities in different locations, and they were able to visit different activities on different days. However, they said that there should be better publicity to enable new people to join. Participants indicated that 'word of mouth' was the main way that people could find out about local dementia-friendly initiatives.

In the context of busy GPs with competing information in GP waiting rooms, even with the requirement for a dementia care plan (mechanism resource) the GP often is not able to recommend community activities or resources (mechanism response) and therefore there is a lack of a standard referral route from post-diagnosis care to support in the community for individuals with dementia and care partners (outcome) (see Table 6).

| CMOc | Context | Mechanism-resource | Mechanism-response | Outcomes |
|------|---------|-------------------|-------------------|----------|
| E5 | Competing information in GP surgery and demands on GP time | Post-diagnosis consultation and care plan | Lack of recommendation or referral to community activities or resources | Lack of standard referral route from post-diagnosis [medical] to community support |

| NL7 | Contact with professionals for information | Curiosity, ask questions | Being informed | Link people with dementia and carers to DFI |

*Table 6 Comparison of CMOc5 in England and CMOc7 from NL case series*

In the Netherlands, there are health and social care resources provided by long-term care services which may support people to access dementia-friendly initiatives. One participant within the case series noted that the GP would advise patients at an appropriate time. However, in the same quote, the participant raises a concern that there is insufficient knowledge among GPs.

> *"…you only need it when you're ready, I know that too, but also it is very nice that an elderly advisor or a general practitioner or the practice nurse thinks 'gosh I am now with this lady but she is really just completely confused and I see the social worker … about this who picked this up very well and I can see that yes and I have to talk about that too'. But I do have the idea that it is still very unknown at, well yes, at the GPs" Quote from Dutch case study (HA17)*

## Discussion

The following summarises the CMOc theories which we described in the English study site and then compared with similar CMOc described within the Dutch case series (17). The larger Dutch case series identified five other outline CMOcs, which may suggest variation between countries, but may also be a limitation of our single UK study site. We described a strategic or macro level CMOc (1) where the mechanism was the mutual support within members of the coordinating network of the dementia action alliance. A similar mechanism within the Dutch case studies described experts coming together to develop a joint approach. The second UK CMOc described how advocates with shared commitment developed initiatives with local organisations, and this had similarities to Dutch CMOc 3 which was about connection, trust, enthusiasm and appreciation. The third CMOc indicated that members of the dementia-friendly initiative were keen to share positive public messages, whilst the fourth CMOc was about listening to members and promoting a human rights-based approach. The final CMOc showed that people found out about initiatives mainly by word of mouth rather than signposting by health professionals.  In comparison, the Dutch study indicated that GP may make suggestions about attending dementia-friendly initiatives, also nurses may have more information.

The similarities identified between the English mechanisms and those described within the Dutch case study series strengthens the validity of the findings. However we may expect differences in

contexts due to different local policies and practices as well as potential differences in socio-cultural attitudes to dementia. For example in England, participants indicated that GPs did not have a direct role in signposting individuals to dementia-friendly initiatives (English CMOc5), whereas in Netherlands health professionals in the community, for example GP or case managers, may make recommendations to local initiatives (Dutch CMOc7); although word of mouth was also an important way that people found out about initiatives in both countries.

From the case study presented, we cannot make claims about the long-term sustainability of the dementia-friendly initiatives. However, an insight was given from one participant, who described his involvement in a group called SHINDIG (Sheffield Dementia Involvement Group; also 'shindig' is colloquial for a party). While we did not carry out observations of these meetings, their website indicates that it is a consultation group for services in the city, led by people with dementia and producing several reports. The work of this group, which is a partner of the Dementia Action Alliance, indicates that these partnerships have strategic support across the city institutions, and this may suggest future sustainability of the partnership.

## Comparison to other studies

We have described and interpreted a detailed level of nuance and complexity within dementia-friendly initiatives (locally) and dementia-friendly communities (at town or city-level). We believe that we are first to report an international comparison of dementia-friendly initiatives, which can lead to recommendations in relation to national policy and international strategy (1, 8). Previous research has explored the concept of dementia-friendliness, from the perspectives of both professionals and people with dementia, however the study focused on interpersonal relationships rather than social participation (20, 21). The DEMCOM study was a national evaluation of English dementia-friendly communities. It took a survey approach followed-up by in-depth case study and development of logic model (22). There are similarities between the themes of the logic model and the mechanisms described within our English and Dutch comparative case studies, for example consultation with members of the local community and involvement of leaders or advocates (22).

Considering international perspectives, a research programme about senior friendly communities implemented several activities in neighbouring regions in three European countries; although not dementia-specific, the study included dementia (23). However it was not clear whether there was substantial community buy-in and whether the research activities would become embedded in communities (23). In contrast our observational approach aimed to understand the underlying mechanisms of community-based initiatives.

## Strengths and weaknesses

The strength of this study is that it is a first exploratory study of mechanisms underlying successful dementia-friendly initiatives and gives new insights in the process of developing and sustaining dementia-friendly communities in England and the Netherlands, which can be used for further research in both countries and may be appropriate for knowledge translation to other Western society countries. Moreover, for our research we not only collected interview data with a broad spectrum of stakeholders but also made use of observations of meetings and interviews with stakeholders associated with dementia-friendly initiatives. Additionally, although the study was conducted within an international collaboration between researchers in England and the Netherlands, due to the different policy and practice contexts in the two countries we decided to analyse the data separately and then conduct a cross-national comparison analysis. Realist evaluation is a theory-led approach; and the researcher team had in-depth understanding of various theories from the international literature, due to recently completing a realist review (19). Whilst the English analysis was conducted subsequent to the Dutch analysis, the researchers remained sensitive to data which may have been inconsistent with prior theories.

A weakness was that the English sub-study was limited by being only one city compared to four sites in Netherlands. Sites in the Netherlands and England were selected on the basis of being leaders or innovators in the concept of dementia-friendly communities. This was important to enable development of theory about the processes and outcomes within a dementia-friendly community, however it should be acknowledged that these may not be typical or common across all cities and towns which have started work towards being dementia-friendly.

## Implications and recommendations

Recommendations from this study are that cities and towns should continue to develop infrastructure and strategic planning to support dementia-friendly communities, as appropriate to local demographic and political contexts. This appears to be successful in both support for individuals and also wider awareness of dementia for the public. One issue that emerged within the English study site was a lack of continuity of information for individuals recently diagnosed with dementia (and their care partners) to access support activities. Connections appeared to mainly occur via word of mouth in the English study site. This also occurred in the Netherlands sites, however individuals may also be supported by GP, case managers or other healthcare professionals. Therefore this aspect could be strengthened in England. People living with dementia attended Dementia Action Alliance meetings in the English study site and this should be encouraged to ensure the voice of people experiencing dementia is heard within strategic development, demonstrating a human rights approach.

Future research should explore diverse communities to gain understanding how dementia-friendly coordinators or trainers engage with different groups including different ethnicities, socio-economic status, faith groups and others. The greater challenge is to examine the impact that dementia-friendly initiatives and communities have on local public perceptions of dementia and whether these initiatives encourage help-seeking behaviour of individuals who are recently diagnosed with dementia (and their care partners).

## Conclusion

This research programme (Mentality programme) is the first to describe realist mechanisms which are present in dementia-friendly initiatives and communities. The two-country comparative analysis we have presented adds further validity to the realist theories and highlights some aspects of policy and practice which may differ between the two countries. We draw implications about how initiatives may continue to develop or be sustained over the longer term.

## Acknowledgements

## Conflict of interest

All authors declare that they have no potential conflicts of interest, such as financial interests, affiliations, or personal interests or beliefs, that could be perceived to affect the objectivity or neutrality of the manuscript.

### Data availability

Qualitative interview data are available on request. Despite removing names, the in-depth interview data may be identifiable, therefore we will not make the dataset open access.

### Supplemental Files

Supplemental File 1. Interview guide for people with dementia/carers and interview guide for professionals/volunteers.

Supplemental File 2. Observations and document analysis

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