

# **Physical Activity Inclusion in Dementia-Friendly Communities:** A Mixed Methods Study

Rebecca Hadley, <sup>1</sup> Elspeth Mathie, <sup>2,3</sup> Elizabeth Pike, <sup>4</sup> and Claire Goodman<sup>2,3</sup>

<sup>1</sup>Centre for Applied Clinical, Health and Care Research (CACHE), University of Hertfordshire, Hatfield, United Kingdom; <sup>2</sup>Centre for Research in Public Health and Community Care (CRIPACC), University of Hertfordshire, Hatfield, United Kingdom; <sup>3</sup>NIHR Applied Research Collaboration (ARC) East of England (EoE), Cambridge, United Kingdom; <sup>4</sup>Institute of Sport, University of Hertfordshire, Hatfield, United Kingdom

Dementia-friendly communities (DFCs) are a policy-endorsed approach to community engagement in England that promotes social inclusion to enable people affected by dementia to live well. Research suggests that physical activity is beneficial in encouraging social connection and improving health. A mixed method sequential study design in England involving a national survey (n = 31) and semistructured interviews (n = 65) in three DFCs was carried out. The aim was to understand how DFCs enable people affected by dementia to participate in physical activities. An evaluation framework for DFCs was used to organize and interpret the data, and analysis was informed by the inclusive (social) citizen lens. Findings showed that DFCs offered a range of adapted dementia-inclusive and dementia-specific activities; however, people were not routinely offered information at time of diagnosis. Local authorities (councils) were key to enable access to information and infrastructure change to support sustainable inclusion within their local community.

Keywords: disability, participation, qualitative research, survey

# **Kev Points**

- Local authorities are key in funding, coordinating, signposting, and facilitating physical activity in dementia-friendly communities.
- Interactions with health and social work professionals are an opportunity to link people living with dementia to local dementia-specific and inclusive physical activities.
- Inclusion of people living with dementia in the strategic planning of physical activities enhances access and is an indicator of awareness and inclusivity of local populations and local governments.

The World Health Organization has declared dementia as a global challenge and a public health priority (World Health Organization, 2021). International initiatives, such as dementiainclusive societies, aim to enable people living with dementia to remain engaged in usual daily life (Alzheimer's Disease International, 2017; Hung et al., 2021; World Dementia Council, 2020). Dementia-inclusive societies or DFCs are one expression of this goal to "support individuals, communities and countries in empowering people with dementia to remain in, and be a significant part of their community" (World Health Organization, 2021, p. vi).

© 2024 The Authors. Published by Human Kinetics, Inc. This is an Open Access article distributed under the terms of the Creative Commons Attribution 4.0 International License, CC BY 4.0, which permits unrestricted noncommercial and commercial use, distribution, and reproduction in any medium, provided the original work is properly cited, the new use includes a link to the license, and any changes are indicated. See http://creativecommons.org/licenses/by/4.0. This license does not cover any third-party material that may appear with permission in the article.

Hadley https://orcid.org/0000-0003-1799-8965 Pike https://orcid.org/0000-0003-3721-6449 

Mathie (e.j.mathie@herts.ac.uk) is corresponding author, https://orcid.org/0000-0002-5871-436X

energy expenditure" (World Health Organization, 2020). Family carers and people living with dementia benefit from engaging together in physical activity (Lowery et al., 2014; Quinn & Toms, 2019; Sampaio et al., 2021). This, with the recognized benefits of physical activity in reducing the risk of developing dementia and slowing or potentially preventing physical/cognitive decline, demonstrates its potential as a shared intergenerational interest (Gronek et al., 2019; Livingston et al., 2020; Nuzum et al., 2020; Pringle et al., 2021; Wang et al., 2021;

English policy supports DFCs as an approach to community engagement that raises awareness of what it is like to live with dementia, creating and lobbying for opportunities for individuals to

This paper addresses how "DFCs" promote participation in physical activity. Engaging in physical activity has a wide range of physical, psychological, and social health benefits for adults living with dementia and the people who support them (Bangsbo et al., 2019; Pike, 2019). Specifically, physical activity can reduce social isolation and mediate the relationship between loneliness, self-rated health, and well-being (Chen et al., 2018; Pike, 2019; Schrempft et al., 2019). This is significant given the stigma associated with dementia and people reporting not feeling connected with their communities (Alzheimer's Disease International, 2016; Jopling, 2017). In this paper, physical activity is defined as "any bodily movement produced by skeletal muscle that required

Yoon et al., 2021).

be active citizens accessing the services and support they need (British Standards Institution, 2015; Heward et al., 2017). As part of promoting inclusion and participation, there is a case for making access to physical activities integral to the work of DFCs. Recent guidance advocates involving people affected by dementia in planning, adapting, and promoting existing provision and dementia training for activity providers (Bould et al., 2019). This study takes an "inclusive social citizen" stance (Bartlett, 2022; Bartlett & O'Connor, 2007; Lister, 2007; O'Connor et al., 2022).

Social citizenship is evident when a person with dementia's right to be included is recognized and actively supported, enabling them to participate fully as a valued member of society.

A national evaluation of DFCs (The DEMCOM study; National Institute for Health and Care Research, Policy Research Programme Project; Buckner et al., 2019, 2022; Darlington et al., 2021; Goodman et al., 2020; Woodward et al., 2019) differentiated between dementia-specific activities (just for those affected by dementia) and dementia-inclusive activities, enabling people living with dementia to join activities that are open to everyone in the community. Both types of provision were valued by people living with dementia. Dementia-inclusive provision, however, challenges negative stereotypes of what people with dementia can achieve.

The aim of our research was to explore the range, opportunities, and challenges of physical activity provision for people living with dementia in DFCs. We aimed to gain an understanding of the experience of people living with dementia and family carers participating in physical activity. The specific research questions were (a) What are the current level and types of physical activity on offer for people living with dementia? (b) Does provision of physical activity enable community inclusion? and (c) How equitable and inclusive is physical activity provision?

## Methods

This study (DEMCOMactive study 2020–21) was a mixed method sequential study design. It included a national online survey supplemented with semistructured interviews and three focus groups in three geographically distinctive DFC case study sites in England.

# Sampling

#### Survey

A purposeful sampling approach via an Alzheimer's Society webinar and their register of DFCs recruited DFC leads for an online survey. The survey link was also promoted on social media (Facebook and Twitter). The survey (Qualtrics; Provo, Utah) of DFCs aimed to map the range of dementia-friendly physical activities delivered or facilitated by DFCs across England. There were no exclusion criteria apart from that the DFC had to be in England. One participant was excluded because their DFC was in Wales.

#### Interviews and Focus Groups

The three DFC sites were recruited to maximize learning about what supports people living with dementia and their family supporters' involvement in physical activities. The sites included an established DFC located in a city with a history of physical activity provision for people affected by dementia (Site Brook), one with a history of using sport (football) to connect with people living with dementia (Site Hazel), and one that had no prior history of

promoting physical activity as part of its dementia-friendly work and was working toward becoming a DFC (Site Glen). Participants were recruited to include commissioners and providers of physical activity services, people employed to support people with dementia postdiagnosis, and DFC volunteers. Potential physical activity provider participants were identified through online searches of local organizations and leisure services and snowball sampling. Eligible participants were approached via email (identified, n = 99; expressed an interest, n = 84, participated, n = 50).

The study was advertised to people affected by dementia in the three sites, and they were invited to participate via leaflets, or personal invitation, via local dementia services, physical activity providers, and online by the Dementia Engagement and Empowerment Project. Join Dementia Research platform (Department of Health and Care, 2022) also issued a site-specific invitation to people on their register. Inclusion criteria were people living with dementia or their family supporters within the three sites aged over 18 years old. All 15 people that expressed an interest in the study participated. Two potential participants from the Join Dementia Research platform declined.

# **Data Collection**

Data collection ran from March 2021 to September 2021. The survey and interview and focus group topic guides drew on an evaluation framework (Figure 1) developed and piloted in the National DEMCOM study (Buckner et al., 2022; Goodman et al., 2020). The survey consisted of 63 closed questions with space for free-text replies (see Supplementary Material S1 [available online]). Questions focused on the physical activities available within their communities, how they were set up, who was involved, and funding sources. Specific attention was paid to whether people affected with dementia were involved in planning or the evaluation of services provided.

The semistructured interviews and focus groups were conducted online (by Hadley, female postdoctoral researcher with qualitative interviewing experience). One interview was completed with a couple who requested face to face in their own home (carried out by E. Mathie, experienced qualitative senior research fellow). Both interviews and focus groups explored the experience of providing (Supplementary Material S2 [available online]) or participating in organized physical activity (Supplementary Material S3 [available online]). All interview and focus groups were audio recorded and transcribed. Interviews lasted from 30 to 90 min, and some were conducted across two sessions on the same day when participants requested a break.

Focus group sizes ranged from three to seven participants (Table 1). The same topic guides were used as for individual interviews (Supplementary Materials 2 and 3 [available online]). In Site Brook, dementia link workers from different districts added the focus group to a regular online meeting. In Sites Hazel and Glen, there was one joint focus group held with health walk officers, and a focus group wherein people living with dementia and their family carers who attended a music group chose to participate in the study together (with the group facilitator present). Each focus group lasted approximately 60 min. The researcher had no previous connection with any of the focus group participants, but there was informal time at the start.

Field notes were made during and after each interview or focus group. After completing a total of 50 interviews and three focus groups, no new issues or ideas were identified, consistent with data saturation.



Figure 1 — The evaluation framework for DFCs (Buckner et al., 2022; Goodman et al., 2020). DFC = dementia-friendly community.

Table 1 Participants

Data collection method	Participants	Number of responses
Online survey	DFC leads	31
Interviews	Service providers**	42
	People living with dementia	2
	Family carer***	6
Focus groups	People living with dementia	3
	Family carers***	4
	Dementia link workers	5
	Service providers (health walk officers)	3
Total responses		96
Total participants		95*

*Note.* DFC = dementia-friendly community.

# **Data Analysis**

The quantitative survey data were analyzed using SPSS (version 27.0, IBM). The open questions from the survey and the interview and focus group transcripts were imported into NVIVO12 (QSR International Pty Ltd, 2020), and the nine domains from the DEMCOM evaluation framework were used to structure the coding (Buckner et al., 2022). The evaluation framework "domains" covered nine main areas (basis for DFCs, leadership and governance, resources, activities and environments, monitoring and evaluation, involvement of people living with dementia and cross-cutting areas of evolution/sustainability, equalities, and inclusion and outcomes). The interpretation of these findings is informed by the interpretive (social) citizen lens (Bartlett, 2022).

The qualitative data were analyzed deductively using the six steps of thematic analysis (Braun & Clarke, 2021). The coders (Hadley/Mathie) first familiarized themselves with the data by repeatedly reading the survey responses and individual transcripts and made annotations regarding extracts that pertained to the

evaluation domains. Coding was line by line to capture all extracts relating to the "domains" of the evaluation framework and the research questions. The two coauthors then separately recoded a sample of each other's and discussed extracts that were relevant to the DEMCOM framework but fitted across two domains. Data were first mapped and analyzed within each study site, and then, findings were compared. Multiple sources and methods were used to test the interpretation and credibility of the findings.

Involving members of the public and those with lived experience in research is a given in health and care research (National Institute for Health and Care Research, 2015). "Public involvement" is defined as research "carried out 'with' or 'by' members of the public rather than 'to,' 'about,' or 'for' them" (National Institute for Health and Care Research, 2021). Fifteen individuals living with dementia and 11 family carers (relatives of a person living with dementia [current or previous]) from three different public involvement groups (a university-based public involvement group [University of Hertfordshire, 2023; n=3], a dementia support group [n=7], and VOICE [n=5]; National Innovation Centre for Ageing]) were involved throughout the study. Their input led to changes to how questions were framed, data collection, and definitions of physical activity. Three members reviewed two anonymized interview transcripts and provided their interpretation on themes. Preliminary findings were presented to the dementia support group to see whether they resonated with the groups' experiences.

# **Ethics**

The study was approved by the Health, Science, Engineering and Technology Ethics Committee for the University of Hertfordshire (aLMS/SF/UH/04411(4)). All participants provided written informed consent.

# **Findings**

A total of 95 participants from 31 DFCs took part (Table 1). Eight out of 728 DFC leads (or those connected with DFCs) were recruited via an Alzheimer's Society webinar, 116 DFCs' leads listed on the Alzheimer's Society register of recognized DFCs were directly approached, and 23 completed the survey (response rate of 20%).

<sup>\*</sup>One DFC lead was interviewed in addition to completing the online survey.

\*\*Service providers included physical activity providers (39), dementia link
workers (4), dementia involvement coordinators (2), provider and funder (3),
and DFC leads (2). \*\*\*Family carers included spouses (8), a partner (1), and a
daughter (1) of a person living with dementia.

In three selected DFC sites, 45 physical activity providers, five dementia link workers, and 15 people affected by dementia took part in interviews and focus groups (Table 1). The 15 people affected by dementia consisted of 10 family carers (seven women and three men) and five people living with dementia (one woman and four men). The average age of the people living with dementia was 74 years, and the average age was 70.5 years for family carers. There was a mix of diagnoses, including Alzheimer's, vascular dementia, mixed dementia (vascular and Alzheimer's), and dementia with Lewy bodies and atypical Alzheimer's.

The survey findings are presented first followed by the sitespecific information from the three DFC sites.

The 31 DFC leads held a variety of roles. Six worked with the local authority, eight for charity organizations, and six for the local Dementia Action Alliance (the remainder either did not specify or gave vague details). Nearly half (13) were volunteers, 12 did not specify, and six were salaried. Twenty-four participants were directly involved in providing physical activities, and seven participants provided information about what was available. The motivation or "basis" for providing physical activities was identified as a response to "identified local need" (74%), two thirds had a concern or personal link with people living with dementia (61%), and for a third of participants, physical activity was part of their DFC strategy.

Table 2 Dementia-Specific/Dementia-Inclusive **Activities Provided by DFCs (Most Popular First)** 

Types of PA* available		DS or DI or both		
to people affected by dementia $(n = 24)$	n	DS	DI	Both
Seated exercise	18	4	5	9
Dancing/movement to music	16	3	4	9
Walking/hiking	14	0	10	4
PA in care homes	12	3	3	6
Gym sessions	10	1	8	1
Yoga/pilates	10	0	9	1
Tai-Chi/qigong	8	0	7	1
Fall prevention	7	0	5	2
Bowling/bowls/skittles	7	1	3	3
Swimming/aqua aerobics	7	2	3	2
Table tennis	6	2	4	0
Gardening related	5	1	2	2
PA at home	6	2	4	0
Football	4	1	2	1
Cycling	3	0	3	0
Tennis/squash/badminton	3	0	3	0
Golf	1	0	1	0
Darts	1	0	1	0
Other (dementia cafe [with regular walks incorporated], cricket, music group, singing group, and coffee morning for older adults)	5	3	1	1

Note. PA = physical activity; DFC = dementia-friendly community; DI = dementia inclusive: DS = dementia specific.

The 24 DFCs provided a wide range of up to 18 different dementia-friendly physical activities (Table 2). DFC leads identified more dementia-inclusive activities (open to members of the public, including people affected by dementia) than dementia specific (only for those affected by dementia). Activities could be categorized as those that were sport related and played with others (i.e., football), organized group activities to promote social connection (walking groups and dance), and those that supported individual interests (cycling and gym session). Many of the activities were offered with adaptations to reflect the target group, such as seated exercise. The activities were provided in private homes (including sheltered accommodation), in the community (in halls and outside), and in leisure centers. Table 2 shows 78 dementia-inclusive and 23 dementia-specific activities.

Twenty-four DFC leads reported providing physical activities that were dementia friendly (the range was 1–22). Table 3 provides the number of activities per DFC (or counted under the DFC remit). Many of the DFCs with more activities reported close links with local authorities. The DFC with 22 activities, of which 14 were categorized as dementia inclusive, was led by the local authority.

Working with the local authority supported leisure and sport providers to offer free or low-cost activities in some DFCs. Thirteen DFC leads did not charge people affected by dementia

Table 3 Number of Dementia-Specific/Dementia-**Inclusive Activities by DFCs** 

		DS o	DS or DI		
DFC $(n = 24)$	n	DS	DI		
DFC 1	7	3	4		
DFC 2	7	5	2		
DFC 3	4	0	4		
DFC 4	4	0	4		
DFC 5	1	0	1		
DFC 6	3	3	0		
DFC 7	14	4	10		
DFC 8	4	1	3		
DFC 9	1	1	0		
DFC 10	5	2	3		
DFC 11	17	4	13		
DFC 12	15	4	11		
DFC 13	4	4	0		
DFC 14	5	1	4		
DFC 15	3	2	1		
DFC 16	8	4	4		
DFC 17	5	2	3		
DFC 18	13	5	8		
DFC 19	7	3	4		
DFC 20	22	8	14		
DFC 21	2	1	1		
DFC 22	12	5	7		
DFC 23	12	0	12		
DFC 24	7	3	4		

Note. DFC = dementia-friendly community; DI = dementia inclusive; DS = dementia specific. Range in total number of activities offered (specific and inclusive) = 21 (min = 1, max = 22). Range in number of DS activities offered = 8 (min = 0, max = 8). Range in number of DI activities offered = 14 (min = 0, max = 14).

<sup>\*</sup>Adapted from Alzheimer's Society Guidance ("Dementia-Friendly Sport and Physical Activity Guide," by E. Bould, S. McFadyen, and C. Thomas, 2019, Alzheimer's Society [https://www.alzheimers.org.uk/get-involved/dementiafriendly-communities/organisations/sports-physical-activity]).

to take part in physical activities based in public venues (village, church, and sports halls) or residential care home/sheltered accommodation lounges, whereas six did, and three did so when working with private organizations to deliver the activity. Lack of funding and staff was an obstacle to provision; when it was available for physical activities or targeted services accessible for people living with dementia, this came from national, local, and sport-specific initiatives (Sport England) or charities (Alzheimer's Society and Age UK). A few providers referenced accessing generic funding (such as arts council or education). Local organizations that offered funding or resources in kind (e.g., staff time and free venues) included National Health Service (NHS), clinical commissioning groups, local authority, private businesses, and leisure centers. The majority of physical activities within DFCs were monitored by an attendance register. This information was not collated, and there were limited details of age, background characteristics, or health conditions. Eight DFC leads reported delivering an activity that had not been successful (dementia-friendly swimming, line dancing, and seated exercise). Reasons for stopping were mixed and included lack of resource (funding, venue, and trained staff), low attendance, activity too expensive, not enjoyed by attendees, and poor delivery by an external partner.

# **DFCs: Views From Physical Activity Providers** and Users of Services

The case studies of the three DFCs built on the survey findings and also used the domains of the DEMCOM evaluation framework (Buckner et al., 2022; see Figure 1) to structure the interviews and focus group.

# 1. Basis and Motivation for Physical Activity Within DFCs

Across the three sites, the motivation for physical activity providers was given as helping people to live a healthy lifestyle and be active. The focus on creating opportunities for social connection for people with dementia was less explicit. One provider (P2: Site Glen and Hazel) reported waiting lists as evidence of demand for their dementia-specific services. However, physical activity providers (covering Sites Glen and Hazel) also mentioned goals that emphasized "protecting your brain" and delaying dementia progress. Participants also recognized the respite and support benefits for carers. In contrast, people affected by dementia reported the many specific advantages of physical activity, listing mental stimulation, alleviating boredom, health benefits, aiding sleep, social interest, building confidence, and the longer term benefits of maintaining independence and slowing decline:

But I think it's very important just because somebody has a diagnosis of dementia not to give up on activities. Life does go on ... keep your body moving ... kept the dementia at bay for a little longer. (C6: Site Hazel, family supporter)

#### 2. Leadership and Governance and Collaborations

At the strategic level, in all three DFCs, the local authority dementia strategy prioritized physical activity and provision of services. However, none of the DFCs had a designated person to coordinate this aspect of the DFC work. This quote captures the need for a key person to coordinate dementia-appropriate services:

But part of me goes, can I not just see somebody up here that has maybe responsibility across all of this, so I don't have to keep replicating applications and wasting everybody's time and that's kind of where I'd like to get to with this for the dementia stuff. (P5: Site Glen, physical activity provider; talking about local authority)

This absence of leadership meant that information sharing was poor, limiting services' ability to link with DFC goals. Some people affected by dementia were unaware that they were living within a DFC and what was on offer locally:

I just wish these places could give you a lot more information about what's available to you, rather than saying, 'We're very sorry. This is the diagnosis. We can't do any more for you, and goodbye'. So, really, this information should be gathered at the memory clinics, at the general practitioners surgeries. It's not that difficult. Even just to give somebody a pamphlet with names, phone numbers, organisations, websites would be so helpful, other than to leave people on their own ... that's where the system falls flat. (C6: Site Hazel, family supporter)

Several physical activity providers were willing to expand service delivery but needed more support from local organizations to raise awareness and promote and fund their services. As well as the lack of coordinated information, geographical jurisdictions affected how activity providers were able to work across borough and county boundaries.

There were a few examples of collaborations working well (particularly in the more established city DFC [Site Brook]). The local council had a community partnership initiative wherein dementia link workers within different districts cross-referred people living with dementia to activities that they might benefit from and held regular meetings to support each other in their roles. This included working directly with local leisure and sports providers, offering their dementia expertise and training. There were established relationships and agreed referral pathways that meant people living with dementia could be enabled to join activities offered by local trained leisure providers.

#### 3. Resources

National imperatives to widen access to sport and physical activities, and known local need, were not sufficient to benefit indirectly or release resources for people affected by dementia. Short-term funding and having to continually apply for funding (which is not specific to dementia activities) characterized the sport and leisure providers' initiatives for targeted groups, such as older adults and those living with dementia.

Activities that were not run at public purpose-built venues relied on volunteers, family carers, and paid staff in care homes to support the delivery of activities. Delivery within community spaces such as church halls and community centers required resources to cover the venue fee, staffing costs, refreshments, and a minimum number of paying attendees per session. Some activity providers prioritized settings such as care homes where people with dementia were guaranteed to be. They did not have the resources or support to generate and sustain interest from a scattered and undocumented local population:

We can achieve much more, much quicker by working directly with care settings. If we try and do it in the community settings, there's all logistical issues, the issues with local councils, disjointed NHS provision. It's incredibly difficult to get set up. It's time-consuming. It's expensive, and we can't guarantee that we're going to get help. (P4: Site Glen and Hazel, physical activity provider)

Access, transport, and costs (not specific to people living with dementia) all affected uptake and could be seen as lack of social inclusion and "access to the outside world" (Bartlett, 2022). Some providers addressed access issues by delivering their sessions (e.g., music sessions and seated cricket) where people lived, such as care homes and sheltered accommodation, and one provider took people out for a cycle on a trishaw around the local community. Ironically, despite DFCs being about creating enabled environments, the links were not evident between accessible transport and creating opportunities to participate in physical activity.

When DFCs and their partner providers integrated activities in community buildings or cafes, this was a conscious attempt to use local resources to make links with mainstream activities. Examples of where this was seen as effective were when it provided both a focus for physical activity and a place to promote and find information about physical activity (e.g., libraries supplying activity packs with exercise compact disks).

#### 4. Activities and Environments

Table 2 provides the range of physical activities provided by DFC leads. People affected by dementia expanded the definition to include functional physical activities, such as housework, cooking (peeling vegetables), playing board games, playing games with grandchildren (badminton), walking to the shops, and gardening at home. This was an interesting and important distinction between choosing a leisure-time activity or carrying out a physical activity that is part of maintaining daily lifestyle activities and being a member of a household.

In all three sites, service providers (e.g., cycling organizations and walking groups) that were willing to engage with, and include, people living with dementia in physical activities could only do this if issues of access and adapting their activities had been addressed. Those responsible for mainstream sports and physical activities wanted to build on the existing skills and knowledge of individuals living with dementia and enable them to continue to participate even when aspects of the activity were no longer achievable:

So often people drop off from doing it once they get dementia, not because they can't do it anymore but they can't do the competitive stuff, the scoring and it was to me one of the things I feel that each sport needs to look at, how it can make itself accessible and kind of create a place where everybody who likes bowling in [Site Brook] could go and do bowling. (P16: Site Brook, dementia group coordinator)

Some activities did not need to be specifically adapted for dementia (e.g., walking groups), and other activities (e.g., cricket and cycling) were suitable for tailoring more closely to individual needs and interests.

(i) Dementia-Specific Physical Activities. Dementia-specific activities have the advantage of meeting people in a similar situation, reducing stigma, and offering a safe space and peer support. For example, one provider developed a service to support people from early through to late-stage dementia, delivering community groups and one-to-one sessions in resident care home rooms (if needed at later stages):

We wanted to create this three-tier service where we have oneto-one work funded, and then a small therapy-based group, and then a bigger social singing café style group, and the idea is that people come in at any point and move through the stages as they need to. (P14: Site Glen and Hazel, provider musicbased group)

An additional benefit for family supporters was the opportunity during these activities to step back and have a rest,

because it's a hard gig being a carer for somebody with dementia. It's very demanding on time, stress, energy levels, all the rest of it, and patience, as I've said before. So, when you can get that relief because somebody's taking over for you, it matters big time. (C6: Site Hazel, family supporter)

For those family supporters and paid carers who took part, they had a "shared" experience:

So if it's a family member, quite often it's a son or daughter who will often—around my age, or older—and I think what works ... it gives them something to talk about with their parents. (P1: Site Brook, cycling activity provider)

(ii) Dementia-Inclusive Physical Activities. Mainstream activities such as walking and cycling could be adapted to be more dementia friendly and were thought not to require a particular expertise from a leader (Table 2). It was also a pragmatic response to having limited resources. The adaptations brought together people with different kinds of disabilities as one group with shared interests, and learning about how to make it work was an organic process:

Basically the way we run our project is that everyone is welcome ... we approach it in terms of whoever comes to us on the day and what their needs are on that day. (P4: Site Brook, cycling activity provider)

Although there are different sort of needs and nuances, in the end a walk is such a simple thing we can adjust for that and everybody is in the same boat. (P4: Site Glen, physical activity provider)

Walking was a popular activity, with service providers altering the pace, time, and length to reflect participants' abilities. Dementia-inclusive walks included walks around historical buildings, in local parks, and around football stadiums. These were organized to ensure that people who were physically fitter could have a longer walk to "have a good blow out" (*P4: Site Glen (physical activity provider)*.

Activities were modified by offering a range of choices (time and venues), the type of activity (standing and seated), modified equipment, and a range of individualized support. Sport activities such as cricket were adapted to be played seated, indoors, and in community halls with soft bats and balls. Playing darts meant that the location and size of a dart board and darts (using magnets) could be altered. Gardening activities could be made portable for hospital ward-based delivery. Two DFCs offered cycling with a range of machines (i.e., solo trikes, side-by-side tandems, or being cycled by the service provider in an adapted trishaw). Adaptations to environments such as community buildings, leisure centers, changing rooms, or personalized support were also important for accessibility.

One person living with dementia described how she used the treadmill (following a hospital referral) at the gym in the sports center. She wore a special zero-gravity harness and had one-to-one support from sport center staff, and this enabled her husband to use

the gym at the same time. People described how dementia affected balance, memory, recognition of team members, eye sight, muscle strength, hand—eye coordination, and orientation, raising questions around some providers' views that little training or adaptation was required.

(iii) Dementia Progression, Inclusive Physical Activities— Learning From Disability Sport. Dementia is a progressive disease. The findings emphasized the importance of providing a range of modified physical activity opportunities (some familiar and some unfamiliar) that the person could manage and recognizing that this will change over time. In this quote, the family supporter is emphasizing the opportunity to do things together that are fun and stretch the person not just physically but cognitively too:

Yes, absolutely. Anything to do with nature, anything at all. Once we got the diagnosis, I threw myself into giving her as much time outdoors as I could, because I knew it was going to come to an end at some point ..., anything that was enjoyable, exciting, stimulatory, physically demanding to some extent. We just had a terrific time doing that. (C6: Site Hazel, family supporter)

A disability cycling organization in Site Brook emphasized the need to provide options:

So, depending on their level of advancement of their dementia they would either have somebody riding on the side-by-side tandem, or if it wasn't too advanced potentially they might be on a solo trike with a support worker on a trike alongside, you know, cycling with them on another trike. (P4: Site Brook, physical activity provider)

We support clients from the beginning of their journey throughout. So we do see that progression over time, and we do see that certain activities that they're able to engage in a year ago, we have to adapt to make sure that they can still take part in them. (P3: Site Glen and Hazel, provider dementia support group)

One novel finding was that in undertaking physical activity, people living with dementia revealed physical skills that may have previously been "hidden." This particular service provider applied their learning from disability sport (Clock Cricket) to provision for people living with dementia:

And then suddenly they'll do a proper cricket stroke, it's really strange. And I say, "oh, you've obviously played cricket." And way back, they would then start telling me about a cricket club, they suddenly remembered this cricket club ... we have a couple who just will not do 'beach cricket' and obviously in their background somewhere is cricket proper ... it obviously does stimulate a memory of something. (P12: Site Glen and Hazel, physical activity provider)

She talked about cycling when she was younger. Her whole face lit up. Five minutes later I went in to fill in a feedback form with her and she couldn't remember me or the ride at all. When I showed her the pictures she asked "did I really do that?" It showed me the value of providing experiences for people whose dementia means they live in the moment. She may not have remembered it but for that short ride she seemed to come alive and open up. (P13: Site Brook, physical activity provider)

# 5. Monitoring and Evaluation

Physical activity service providers were convinced that participation improved the well-being of those people living with dementia. Two providers referenced using formal evaluation, specifically picture scales, to measure change in well-being; however, most did not comment on whether these perceived benefits were validated in any way. This quote illustrates how the coordinator was looking for changes in behavior and communication as signs of positive engagement:

But just something that was key was vocalisations, so when people, when the doors were open and people had the freedom to get out, move, dig, touch, whatever, there was a definite increase in what was said, and also the clarity of communication improved. (P14: Site Brook, dementia group coordinator—hospital)

Funding requirements could require evidence of participation; however, it was unclear how the information was used or if it had any impact on service provision.

# 6. Involvement of People Living With Dementia

Feedback from people living with dementia could be used to shape the activity at a local level, including adapting equipment further so that people could participate more easily.

So, for example with the trike loan scheme, quite early feedback was, and I was kicking myself that I hadn't thought of it, but that people found it difficult to turn around and look over their shoulder, so, you know that was an early thing to go back and buy some mirrors for them, for example. (P4: Site Brook, physical activity provider)

One provider spoke about how an informal comment from a family supporter led them to change how they demonstrated bowling techniques. Despite the survey findings reporting that people living with dementia were involved, there was minimal evidence of how this had been achieved at a strategic level. The exception was a group of people with young-onset dementia who were involved in planning activities, but there were no examples of how they had influenced decisions.

# 7. Equalities and Inclusion

The three sites had diverse populations (with those identifying ethnic groups Black, Asian, and other categories) ranging from 17% to 39% of the population (Office for National Statistics, 2021). Several providers commented that they had limited success engaging with men and underrepresented groups. Reasons included digital exclusion, lack of interest, perceived cultural stigma, and proximity of the offered activity to where members of community groups lived. One exception was a physical activity provider who emphasized an ongoing relationship that built on a long history of offering wider health education sessions for older groups.

So we've got [an] Asian Elders Society in [our local county], and that is predominantly women of Pakistani and Indian heritage, some Hindus, some Muslim, and we've supported that group for probably over ten years with a regular two, twice-weekly exercise session. (P4: Site Glen and Hazel, physical activity provider)

Interviews with providers revealed a range of approaches, offering activities and times for sessions to attract different groups, maximize uptake, and address their physical abilities.

Some participants believed that their approach meant they were already inclusive to all. However, without data about the people attending their activity and who they were, this was not verifiable. There was limited information under the two domains "evolution/sustainability" of DFCs and "outcomes," so they are not included in the findings.

# **Discussion**

The interpretation of these findings is informed by the interpretive (social) citizen lens, which is increasingly being used to understand and respond to the experience of living with dementia (Bartlett, 2022). Key tenets of this approach include consideration of the narratives of living with dementia, access, policy issues, discrimination, and social inclusion. Hung et al. (2021) acknowledged a limited theoretical basis for informing (DFC) strategy development and suggested application of implementation science theories. Our findings have provided multiple narratives demonstrating DFCs and their promotion of physical activities. This study demonstrated what is possible, though not consistently and systematically achieved. There is clear potential for a range of physical activities to be incorporated within existing leisure and sporting activities as well as developing those that are dementia specific.

Physical activity was offered not only as a separate space for people living with dementia and family supporters but also as something that was available to all. The findings demonstrated that people affected by dementia often found it hard to access information about physical activities within their locality and needed adapted activities on offer from time of diagnosis and also as dementia progressed.

Our study found that there was no clear method of coordinating information, sharing good practice between physical activity organizations, resourcing these initiatives, or monitoring them within the DFCs. Older adults living with dementia find it particularly challenging to engage in many organized physical activities (Bould et al., 2019). The World Health Organization global plan on physical activity (2018–2030) calls for "a paradigm shift in both supporting and valuing all people being regularly active, according to ability and across the life course" (World Health Organization, 2020, p. 6). The National Institute for Health and Care Excellence (2015) report on "Dementia, disability and frailty in later life" encourages local governments to improve environments where people live to promote physical activity. Policy recommendation for increasing physical activity for the general public is that it should be made as inclusive as possible. It is recommended that increasing physical activity on a societal level is important as it is a protective factor for all-cause dementia and Alzheimer's disease (Iso-Markku et al., 2022). Given the progressive nature of dementia, access to dementia-inclusive physical activities needs to be made available before and after diagnosis and through to end of life. The coordination of information between the National Health Service, social care, and community is vital in connecting people who are recently diagnosed to available activities (Müllers et al., 2019).

Some providers held ambitious rationales (such as dementia risk reduction) for providing physical activities, and it is important to include the priorities and narratives of people living with dementia to achieve meaningful engagement. Pringle et al. (2021) found that physical activity "may be of greatest benefit if incorporated into ongoing lifestyle and combined with social interaction." Our study found that physical activity provides a common focus for people living with dementia and their family

supporters and could retain skills, encourage memories, and stimulate movement. In terms of service providers, there was little information about how people were trained or prepared to provide services for people living with dementia. So many activities for people with dementia rely on volunteers, but little is known about how to support them and develop dementia-specific skills (Mayrhofer et al., 2021).

The findings illustrate how it is possible to locate activities where people live to minimize the challenge of access and transport (local community buildings, parks, sheltered accommodation, care homes, or hospitals), although sustaining this work was more precarious. That people living with dementia were largely absent from decision making and strategic overview in physical activity provision is a persistent and troubling issue (Mathie et al., 2022).

Physical activity also reinforces the asset-based approach of what people living with dementia can do (Rahman & Swaffer, 2018). Participants with dementia were, however, aware of how it affected their ability and confidence to take part in physical activity. Adapting physical activity to/for individuals is not new and is part of disability rights. What the findings suggest is that there is very little provider awareness or assessment of what people with different types of dementia might need to mitigate its impact. Recent debate has highlighted dementia as a "potential disability" while also recognizing the associated stigma (dementia as a disability; All Party Parliamentary Group, 2019; Alzheimer Europe, 2017; Swaffer et al., 2019). Strategies that have been successful for others living with disabilities and health conditions, or as people grow older (Kiuppis, 2018; Pike et al., 2022), may be helpful in how local authorities and others understand the range and scope of their dementia provision: access to services and, crucially, awareness of what is appropriate to provide. The inclusive (social) citizenship lens focuses on the "multifarious ways in which social rights and responsibilities are exercised in everyday life" (Bartlett, 2022, p. 1129). This study showed how people living with dementia can be enabled to take part in everyday physical activity.

The findings demonstrate that organizations within DFCs that act as place-based organizations (such as local authorities and the National Health Service) can be key in funding, coordinating, signposting, and acting as facilitators to physical activity opportunities. They help to "anchor" the work of the DFC and, in the case of physical activity, promote it through services it commissions, such as leisure centers (Health Foundation, 2021).

The evidence from our study provides the basis of recommendations for such organizations, that service providers will need access to dementia training and support to adapt activities (Bechard et al., 2020). Furthermore, any interactions (diagnosis, general practitioner annual reviews, and hospital admissions) with health and social care professionals could be an opportunity to promote access to local physical activities, including tailoring physical activities to individuals with local support within their neighborhood (van der Wardt et al., 2020).

# **Strengths and Limitations**

The strengths of this study are that it provides a national overview and focuses on one aspect of DFC work and the collaboration of partner organizations. The use of an evaluation framework supported a systematic approach to data collection and analysis; it also highlighted an absence of evidence. The lack of data to populate the domains of sustainability of DFCs and outcomes may suggest that services were not yet addressing issues of continuity or impact. Physical activity provides an opportunity to provide services to

people living with dementia, who are often a marginalized and isolated group of people. The sample of people living with dementia included a variety of diagnoses; however, due to small numbers, it was not possible to explore their specific impact and relevance. The timing of the research during COVID-19 had a significant impact on recruitment, particularly including people living with dementia. The limitations are the low survey response rate and the three case study sites that were all purposively sampled as DFCs. It is acknowledged as there is progress toward a more inclusive approach; places/areas that are not specifically "Dementia Friendly" may also be contributing significantly to physical activity inclusion.

# **Conclusions**

DFCs as a community engagement initiative could be an important partner supporting interagency, collaborative working between health and social care to enable people living with dementia to access physical activities within their locality. Including people living with dementia in the strategic planning of physical activities within dementia-friendly or dementia-inclusive communities is vital. Their success or otherwise in this aspect of community living is a useful indicator of how aware and inclusive a local population and its local government are to the needs of people living with and affected by dementia.

# **Acknowledgments**

**Funding and Support Statement:** This work was supported by the ESRC-UKRI Industrial Strategy Challenge Fund: Healthy Ageing Catalyst Awards 2020 (grant number ES/V009699/1) and by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridgeshire and Peterborough NHS Foundation Trust. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care. **Data Source Statement:** Anonymized interview transcripts and survey data from participants who consented to data sharing, plus other supporting information, are available from the U.K. Data Service at https://doi.org/10.5255/UKDA-SN-855475.

# References

- All Party Parliamentary Group. (2019). *Hidden no more: Dementia and Disability*. https://www.alzheimers.org.uk/sites/default/files/2019-06/APPG\_on\_Dementia\_2019\_report\_Hidden\_no\_more\_dementia\_ and\_disability\_media.pdf
- Alzheimer Europe. (2017). Dementia as a disability? Implications for ethics, policy and practice. A Discussion Paper (European Union's Health Programme (2014–2020). https://www.alzheimer-europe.org/sites/default/files/alzheimer\_europe\_ethics\_report\_2017.pdf
- Alzheimer's Disease International. (2016). *Dementia friendly communities key principles*. https://www.alz.co.uk/adi/pdf/dfc-principles.pdf
- Alzheimer's Disease International. (2017). *Dementia friendly communities. Global developments* (2nd ed.).
- Bangsbo, J., Blackwell, J., Boraxbekk, C.J., Caserotti, P., Dela, F., Evans, A.B., Jespersen, A.P., Gliemann, L., Kramer, A.F., Lundbye-Jensen, J., Mortensen, E.L., Lassen, A.J., Gow, A.J., Harridge, S.D.R., Hellsten, Y., Kjaer, M., Kujala, U.M., Rhodes, R.E., Pike, E.C.J., Skinner, T., Skovgaard, T., Troelsen, J., Tulle, E., Tully, M.A., van Uffelen, J.G.Z., & Viña, J. (2019). Copenhagen Consensus statement 2019: Physical activity and ageing. *British Journal of Sports Medicine*, 53(14), 856–858. https://doi.org/10.1136/bjsports-2018-100451

- Bartlett, R. (2022). Inclusive (social) citizenship and persons with dementia. *Disability & Society*, *37*(7), 1129–1145. https://doi.org/10.1080/09687599.2021.1877115
- Bartlett, R., & O'Connor, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies*, 21(2), 107–118. https://doi.org/10.1016/j.jaging.2006. 09.002
- Bechard, L.E., McDougall, A., Mitchell, C., Regan, K., Bergelt, M., Dupuis, S., Giangregorio, L., Freeman, S., & Middleton, L.E. (2020). Dementia- and mild cognitive impairment-inclusive exercise: Perceptions, experiences, and needs of community exercise providers. *PLoS One*, 15(9), e0238187. https://doi.org/10.1371/journal.pone.0238187
- Bould, E., McFadyen, S., & Thomas, C. (2019). *Dementia-friendly sport and physical activity guide*. Alzheimer's Society. https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/organisations/sports-physical-activity
- Braun, V., & Clarke, V. (2021). Thematic analysis. Sage.
- British Standards Institution. (2015). PAS 1365: 2015 Code of practice for the recognition of dementia friendly communities in England. BSI Standards Limited. https://www.bsigroup.com/en-GB/about-bsi/media-centre/press-releases/2015/july/New-dementia-care-guidance-is-published/
- Buckner, S., Darlington, N., Woodward, M., Buswell, M., Mathie, E., Arthur, A., Lafortune, L., Killett, A., Mayrhofer, A., Thurman, J., & Goodman, C. (2019). Dementia Friendly Communities in England: A scoping study. *International Journal of Geriatric Psychiatry*, 34(8), 1235–1243. https://doi.org/10.1002/gps.5123
- Buckner, S., Lafortune, L., Darlington, N., Dickinson, A., Killett, A., Mathie, E., Mayrhofer, A., Woodward, M., & Goodman, C. (2022). A suite of evaluation resources for Dementia Friendly Communities: Development and guidance for use. *Dementia*, 21(8), 2381–2401. https://doi.org/10.1177/14713012221106634
- Chen, Y., Holahan, C., & Li, X. (2018). Loneliness, physical activity, and self-rated health in middle-aged and older adults. *Innovation in Aging*, 2(Suppl. 1), 967. https://doi.org/10.1093/geroni/igy031.3582
- Darlington, N., Arthur, A., Woodward, M., Buckner, S., Killett, A., Lafortune, L., Mathie, E., Mayrhofer, A., Thurman, J., & Goodman, C. (2021). A survey of the experience of living with dementia in a dementia-friendly community. *Dementia*, 20(5), 1711–1722. https://doi.org/10.1177/1471301220965552
- Department of Health and Care. (2022). Join Dementia Research. Department of Health and Social Care, delivered by National Institute of Health and Care Research (NIHR) in partnership Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society. https://www.joindementiaresearch.nihr.ac.uk/
- Goodman, C., Arthur, A., Buckner, S., Buswell, M., Darlington, N., Dickinson, A., Killett, A., Lafortune, L., Mathie, E., Mayrhofer, A., Reilly, P., Skedgel, C., Thurman, J., & Woodward, M. (2020). National Institute of Health Research Policy Research Programme Project Dementia Friendly Communities: The DEMCOM evaluation (PR-R15-0116-21003). University of Hertfordshire. https://uhra.herts.ac.uk/handle/2299/23477
- Gronek, P., Balko, S., Gronek, J., Zajac, A., Maszczyk, A., Celka, R., Doberska, A., Czarny, W., Podstawski, R., Clark, C.C.T., & Yu, F. (2019). Physical activity and Alzheimer's disease: A narrative review. *Aging and Disease*, 10(6), 1282–1292. https://doi.org/10.14336/ad. 2019.0226
- Health Foundation. (2021). *The NHS as an anchor institution*. https://www.health.org.uk/news-and-comment/charts-and-infographics/the-nhs-as-an-anchor-institution
- Heward, M., Innes, A., Cutler, C., & Hambidge, S. (2017). Dementiafriendly communities: Challenges and strategies for achieving

- stakeholder involvement. *Health & Social Care in the Community*, 25(3), 858–867. https://doi.org/10.1111/hsc.12371
- Hung, L., Hudson, A., Gregorio, M., Jackson, L., Mann, J., Horne, N., Berndt, A., Wallsworth, C., Wong, L., & Phinney, A. (2021). Creating dementia-friendly communities for social inclusion: A scoping review. *Gerontology & Geriatric Medicine*, 7. https://doi. org/10.1177/23337214211013596
- Iso-Markku, P., Kujala, U.M., Knittle, K., Polet, J., Vuoksimaa, E., & Waller, K. (2022). Physical activity as a protective factor for dementia and Alzheimer's disease: Systematic review, meta-analysis and quality assessment of cohort and case–control studies. *British Journal of Sports Medicine*, 56(12), 701–709. https://doi.org/10.1136/bjsports-2021-104981
- Jopling. (2017). Promising approaches to living well with dementia. AgeUK. https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/health--wellbeing/rb\_feb2018\_promising\_approaches\_to\_living\_well\_with\_dementia\_report.pdf
- Kiuppis, F. (2018). Inclusion in sport: Disability and participation. *Sport in Society*, 21(1), 4–21. https://doi.org/10.1080/17430437.2016.1225882
- Lister, R. (2007). Inclusive citizenship: Realizing the potential. *Citizenship Studies*, 11(1), 49–61. https://doi.org/10.1080/13621020601099856
- Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C., Costafreda, S.G., Dias, A., Fox, N., Gitlin, L.N., Howard, R., Kales, H.C., Kivimäki, M., Larson, E.B., Ogunniyi, A., Orgeta, V., Ritchie, K., Rockwood, K., Sampson, E.L., Samus, Q., Schneider, L.S., Selbæk, G., Teri, L., & Mukadam, N. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*, 396(10248), 413–446. https://doi.org/10.1016/S0140-6736(20)30367-6
- Lowery, D., Cerga-Pashoja, A., Iliffe, S., Thuné-Boyle, I., Griffin, M., Lee, J., Bailey, A., Bhattacharya, R., & Warner, J. (2014). The effect of exercise on behavioural and psychological symptoms of dementia: The EVIDEM-E randomised controlled clinical trial [Journal Article; Randomized Controlled Trial; Research Support, Non-U.S. Gov't]. *International Journal of Geriatric Psychiatry*, 29(8), 819–827. https://doi.org/10.1002/gps.4062
- Mathie, E., Antony, A., Killett, A., Darlington, N., Buckner, S., Lafortune, L., Mayrhofer, A., Dickinson, A., Woodward, M., & Goodman, C. (2022). Dementia-friendly communities: The involvement of people living with dementia. *Dementia*, 21(4), 1250–1269. https://doi.org/10.1177/14713012211073200
- Mayrhofer, A.M., Goodman, C., Lafortune, L., Smeeton, N., Littlechild, B., Shora, S., & Bunn, F. (2021). Third sector provision of dementia support in the community: Results from a scoping exercise of charity involvement in the UK. *Voluntary Sector Review*, 14(2), 368–378. https://doi.org/10.1332/204080521x16333394034496
- Müllers, P., Taubert, M., & Müller, N.G. (2019). Physical exercise as personalized medicine for dementia prevention? *Frontiers in Physiology*, *10*, 672–672. https://doi.org/10.3389/fphys.2019.00672
- National Institute for Health and Care Excellenc. (2015). Dementia, disability and frailty in later life—Mid-life approaches to delay or prevent onset. https://www.nice.org.uk/guidance/ng16/resources/dementia-disability-and-frailty-in-later-life-midlife-approaches-to-delay-or-prevent-onset-pdf-1837274790085
- National Institute for Health and Care Research. (2015). Going the extra mile: Improving the nation's health and wellbeing through public involvement in research. Retrieved May 19, 2021, from https://www.nihr.ac.uk/patients-and-public/documents/Going-the-Extra-Mile.pdf
- National Institute for Health and Care Research. (2021). Briefing notes for researchers—Public involvement in NHS, health and social

- *care research.* https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371
- Nuzum, H., Stickel, A., Corona, M., Zeller, M., Melrose, R.J., & Wilkins, S.S. (2020). Potential Benefits of Physical Activity in MCI and Dementia. *Behavioural Neurology*, 2020, Article 7807856. https://doi.org/10.1155/2020/7807856
- O'Connor, D., Sakamoto, M., Seetharaman, K., Chaudhury, H., & Phinney, A. (2022). Conceptualizing citizenship in dementia: A scoping review of the literature. *Dementia*, 21(7), 2310–2350. https://doi.org/10.1177/14713012221111014
- Office for National Statistics. (2021). Ethnic Group, England and Wales: Census 2021. https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/bulletins/ethnicgroupenglandandwales/census 2021
- Pike, E. (2019). Aging, sports and society. In J. Maguire, M. Falcous, & K. Liston (Eds.), *The business and culture of sports* (pp. 15–27). MacMillan. https://go.gale.com/ps/i.do?p=GVRL&sw=w&u=&v=2. 1&it=etoc&id=GALE%7C8ODA&sid=GVRL
- Pike, E., Mathie, E., & Buckley, D. (2022). Sport, aging and adaptation. In L. Wenner (Ed.), *The Oxford Handbook of Sport and Society*. Oxford University Press.
- Pringle, J., Jepson, R., Dawson, A., McCabe, L., & Bowes, A. (2021). How does physical activity benefit people living with dementia? A systematic review to identify the potential mechanisms of action. Quality in Ageing and Older Adults, 22(1), 3–25. https://doi.org/10. 1108/QAOA-09-2020-0046
- QSR International Pty Ltd. (2020). NVIVO (released in March 2020). https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home
- Quinn, C., & Toms, G. (2019). Influence of positive aspects of dementia caregiving on caregivers' well-being: A systematic review. *The Gerontologist*, 59(5), e584–e596. https://doi.org/10.1093/geront/gny168
- Rahman, S., & Swaffer, K. (2018). Assets-based approaches and dementia-friendly communities. *Dementia*, 17(2), 131–137. https://doi.org/10. 1177/1471301217751533
- Sampaio, A., Marques-Aleixo, I., Seabra, A., Mota, J., & Carvalho, J. (2021). Physical exercise for individuals with dementia: Potential benefits perceived by formal caregivers. *BMC Geriatrics*, 21(1), 6. https://doi.org/10.1186/s12877-020-01938-5
- Schrempft, S., Jackowska, M., Hamer, M., & Steptoe, A. (2019). Associations between social isolation, loneliness, and objective physical activity in older men and women. *BMC Public Health*, *19*(1), 74. https://doi.org/10.1186/s12889-019-6424-y
- Swaffer, K., LeBlanc, B., & Mittler, P. (2019). Dementia as a disability. In M. Berghs, T. Chataika, Y. El-Lahib, & D. Kudakwashe (Eds.), *The Routledge handbook of disabilty activism* (pp. 171–181). Routledge.
- University of Hertfordshire. (2023). *Patient and Public involvement groups*. https://www.herts.ac.uk/research/centres/cripacc/public-involvement-in-research-group-pirg
- van der Wardt, V., Hancox, J., Pollock, K., Logan, P., Vedhara, K., & Harwood, R.H. (2020). Physical activity engagement strategies in people with mild cognitive impairment or dementia—A focus group study. *Aging and Mental Health*, 24(8), 1326–1333. https://doi.org/10.1080/13607863.2019.1590308
- Wang, S., Liu, H.-Y., Cheng, Y.-C., & Su, C.-H. (2021). Exercise dosage in reducing the risk of dementia development: Mode, duration, and intensity—A narrative review. *International Journal of Environmental Research and Public Health*, 18(24), 13331. https://www.mdpi. com/1660-4601/18/24/13331

- World Health Organization. (2020). *Physical activity*. Retrieved August 31, 2022, from https://www.who.int/news-room/fact-sheets/detail/physical-activity
- World Health Organization. (2021). *Towards a dementia-inclusive society:* WHO toolkit for dementia-friendly iniatives (DFIs). https://www.who.int/publications/i/item/9789240031531
- Woodward, M., Arthur, A., Darlington, N., Buckner, S., Killett, A., Thurman, J., Buswell, M., Lafortune, L., Mathie, E., Mayrhofer, A., & Goodman, C. (2019). The place for dementia-friendly communities in England and its relationship with epidemiological need.
- International Journal of Geriatric Psychiatry, 34(1), 67–71. https://doi.org/10.1002/gps.4987
- World Dementia Council. (2020). Defining Dementia Friendly Initiatives. Presenting a global evidence base for dementia friendly initiatives.
- Yoon, M., Yang, P.-S., Jin, M.-N., Yu, H.T., Kim, T.-H., Jang, E., Uhm, J.-S., Pak, H.-N., Lee, M.-H., & Joung, B. (2021). Association of Physical Activity Level With Risk of Dementia in a Nationwide Cohort in Korea. *JAMA Network Open*, 4(12), e2138526. https://doi.org/10.1001/jamanetworkopen.2021.38526