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THE CHARACTERISTICS AND CORE COMPONENTS NEEDED TO IMPLEMENT EXERCISE CLASSES FOR PEOPLE WITH DEMENTIA IN THE COMMUNITY

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Abstract

Background

Dementia is a significant cause of disability and dependency in adults, and its growing prevalence has produced both individual and societal challenges. Exercise has been identified as an intervention with the potential to provide physical, mental and well-being benefits for those experiencing symptoms of dementia. This thesis explores the proposition that exercising within a group setting may provide benefits beyond the exercise's physiological mechanisms, offering social and support elements that would be absent when exercising alone.

Aim

By adopting a pragmatic mixed methods approach, the thesis aimed to identify the key characteristics and core components that are necessary to successfully implement an exercise class for older people living with dementia in the community. An ecological perspective underpins an exploration of whether older people living with dementia want to access exercise classes and, if they do, whether classes are available and the factors that may facilitate or prevent prolonged engagement.

Methods

A mixed methods literature review initiated the search to identify the key characteristics of group exercise interventions designed for older people living with dementia and the barriers and facilitators to attendance. Subsequently, a mixed methods study explored the benefits of an existing class for the client group that was operating before the outbreak of COVID-19. A mapping and spatial analysis established where and how many exercise classes were taking place. An

ethnographic study explored the context-specific characteristics of classes and how these may have changed during the pandemic. Finally, the main chapters were synthesised to provide recommendations to encourage older people living with dementia to attend and continue participating in exercise classes.

Results

The mixed methods review, and subsequent mixed methods study, established four main findings for this client group. Firstly, multicomponent interventions that included aerobic, strength and balance activities improved physical function. Secondly, people living with dementia experience a wide range of benefits (physical, psychological, and social) from exercise interventions. Thirdly barriers to participation can be overcome with positive attitudes, and suitable environments and interventions that included a social dimension in their design were more likely to yield positive outcomes. Finally, people living with dementia want to take part in community exercise classes, and their participation produces a positive impact for both the person living with dementia and the carer, which increases the likelihood of continued participation and maintenance of those benefits.

In relation to the availability of appropriate classes, the main findings were that although exercise classes for older adults are widely distributed, many are held in locations where there is a low percentage of the population over 65, and there are very few dementia-specific classes available. The final key finding was that older adults, especially those living with dementia, appreciate knowledgeable, trained, and motivated staff. However, there is a lack of specific training available for exercise instructors, which limits their ability to offer inclusive classes.

Conclusions

Recommendations based on the main findings are provided on how community exercise classes could be adapted to encourage participation over the longer term. Multicomponent classes that include opportunities for social interaction and are delivered face-to-face are ideal for people living with dementia. Exercise instructors who are appropriately trained and have positive attitudes will enhance motivation and enable the provision of fully inclusive classes. This will allow people living with dementia to participate in classes that can suitably address their needs and expectations.

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Publications and Dissemination

Publications

- Long AL, Di Lorito C, Logan P, Booth V, Howe L, Hood-Moore V, et al. The impact of a dementia-friendly exercise class on people living with dementia: A mixed methods study. *Int J Environ Res Public Health.* 2020. Jun 24; 17(12):4562. **https://doi.org/10.3390/ijerph17124562**
- Long A, Timmons S, Di Lorito C, Booth V, Logan P. "We Just Don't Know Where They Are": The Geographical Distribution of Exercise Classes for Older People, Including Those Living with Dementia in the East Midlands. *Int J Environ Res Public Health*. 2023 Jan 24; 20(3):2142. **https://doi.org/10.3390/ijerph20032142**

Poster Presentations

- Long A, Timmons S, Di Lorito C, Booth V, Logan P. *Spatial Analysis of Exercise Classes for Older People in the East Midlands.* The Academy of Medical Sciences Midlands Research Festival. March 2022
- Long A, Timmons S, Di Lorito C, Booth V, Logan P. *Spatial Analysis of Exercise Classes for Older People in the East Midlands.* Co(l)laboratory Launch Event. October 2022

Oral Presentations

- Long A. *Implementing Exercise Classes for People with Dementia in the Community*. Post Graduate Impact Forum, University of Nottingham. September 2020 (Online)

- Long A. *Interview with Kate Lee, CEO Alzheimer's Society.* Alzheimer's Society Briefing. May 2021 (Online)
- Long A. *Exercise and Dementia: What does the evidence tell us?* Dementia Researcher Lunchtime Webinar. May 2021 (Online)
- Long A. *Exercise and Dementia: What does the evidence tell us?* PrAISED Therapist Teleconference. July 2021 (Online)
- Long A. *Promoting Physical Activity in Care Homes.* PROTECT-CH Care Home Drop-in Session. August 2021 (Online)
- Long A. *Annabelle's Arc.* Centre for Rehabilitation and Ageing Research PGR Research Seminar. February 2022 (Online)
- Long A. *Come for the Exercise, Stay for the Cake.* Applied Research Collaboration 3MT (Three Minute Thesis) Competition. March 2022 (Online)
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Abbreviations

ADL	Activities of Daily Living
BBS	Berg Balance Scale
CBA	Controlled Before and After
CDR	Clinical Dementia Rating
COPD	Chronic Obstructive Pulmonary Disease
CSP	County Sports Partnership
CST	Chair Stand Test
DAPA	Dementia and Physical Activity
DemQoL	Dementia Quality of Life Scale
DRVS	David Ross Sports Village
EF	Enhance Fitness
EQ5D3L	EuroQol 5 Dimension 3 Levels
FA	Football Association
GDS15	15-Item Geriatric Depression Scale
GIS	Geographical Information System
GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
HVLT	Hopkins Verbal Learning Test
JBI	Joanna Briggs Institute
Km	Kilometre
LAPAQ	LASA Physical Activity Questionnaire
LASA	Longitudinal Ageing Study Amsterdam
m	Metre
M-ACE	Mini Addenbrooke's Cognitive Examination
MADRS	Montgomery-Asberg Depression Rating Scale
MET	Metabolic Equivalent
MMSE	Mini-Mental State Examination

n	Number
NEADL	Nottingham Extended ADL Scale
NHS	National Health Service
Non-SMI	Non-Serious Mental Illness
Obs.	Observation
OP	Older People
PA	Physical Activity
Phys	Physical
PlwD	People living with Dementia
PPIE	Patient and Public Involvement and Engagement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
Psych	Psychological
PWD	People With Dementia
QL	Qualitative Studies
QN	Quantitative Studies
QoL	Quality of Life
QOL-AD	Quality of Life in Alzheimer's Disease
QUALID	Quality of Life in Late-Stage Dementia
RCT	Randomised Controlled Trial
SMI	Serious Mental Illness
SUMARI	System for the Unified Management, Assessment and Review of Information
TUG	Timed Up and Go
UCLA	University of California, Los Angeles
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

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Chapter One

1. Introduction

1.1 Summary

This thesis has been structured in a 'mini-thesis within a thesis' style with an introduction chapter (Chapter One) followed by a methodology chapter (Chapter Two). There are then four research study chapters structured as standalone publications (Chapters Three – Six), followed by a concluding chapter (Chapter Seven) which synthesises the findings from Chapters Three, Four and Six. Recommendations for further research are offered alongside concluding remarks to summarise the thesis.

This introductory chapter will discuss the individual and societal challenges arising from the growing prevalence of dementia worldwide. Evidence is outlined of both global and local recognition of the need for improvement in the quality of life of people living with dementia. Exercise has been identified as an intervention that could provide physical, mental and well-being benefits for this group.

Exercise can be performed individually or in a group. This thesis proposes that group exercise may provide benefits beyond the physiological mechanisms by supporting engagement and adherence and reducing social isolation and loneliness.

An ecological perspective has been outlined in which individual and societal influences on behaviour are acknowledged in developing an understanding of how participation in exercise can be sustained. This systems-based model emphasises the

importance of the relationships and interactions between the different system elements in a structured intervention.

1.2 Background literature on dementia and exercise

1.2.1 Dementia

Dementia is an umbrella term used to describe a range of cognitive and behavioural symptoms, including memory loss, judgement and personality changes that can lead to a substantial decline in cognitive function and difficulties with activities of daily living (1–3). The World Health Organisation (WHO) action plan for dementia recognises that the condition is a significant cause of disability and dependency in older adults. Worldwide, 47 million people were estimated as living with dementia in 2015, and if the current trend is maintained, it will increase to 75 million by 2030 (3). In the UK alone, in 2019, there were estimated to be 885,000 people living with dementia; on current trends, this figure is set to rise to 1.6 million by 2040 (4).

Dementia leads to increased costs for individuals and society. The cost of dementia to the UK before the COVID-19 pandemic was £34.7 billion, projected to increase to £94.1 billion by 2040 (5). Social care accounts for £15.7 billion of the total cost of care for people living with dementia in the UK, with £13.9 billion attributable to unpaid care (5). At the 2013 G7 summit, leaders called for a global response to facilitate improvements in the quality of life for people living with dementia (6). The difference between social care costs and unpaid care costs outlined above, emphasises the wide gap between the provision of services for treatment and care of people living with dementia and what is required. Moreover, a lack of understanding of dementia means this group do not always receive appropriate care

and support (3). People can still live well with dementia, and keeping as active as possible is one of the approaches that can help both with the symptoms and sustaining independence (7–9), potentially reducing the cost burden to the National Health Service (NHS) and social care.

1.2.2 Exercise and physical activity

The Physical Activity Guidelines Advisory Committee Scientific Report defines physical activity as *"a bodily movement produced by skeletal muscles that result in an energy expenditure"* (10 pg. 36). This movement need not be of any particular type or quality and includes all levels of intensity. It also defines exercise as *"physical activity that is planned, structured, repetitive and designed to improve or maintain physical fitness, physical performance or health"* (10 pg. 36). Therefore, physical activity is an umbrella term that encompasses all activities from incidental activity, which is integrated into daily life such as housework or gardening, through to planned, structured exercise (11). This thesis focuses on using structured group exercise sessions for older people living with dementia. This choice was made to ensure that the studies were feasible within the time and resources available.

Several systematic literature reviews have identified that exercise has the potential to improve the mobility, physical function, activity levels and mood of people living with dementia (7–9,12). Forbes et al. (8) reviewed 17 trials which included 1067 participants, of which six trials, including 289 participants, showed a benefit in activities of daily living from exercise. However, these were of low quality, so the results should be treated cautiously. They found no evidence that exercise improved symptoms of depression in five trials, including 341 participants. Fox et al. (7) also

reviewed 17 trials but reported that only three were of good quality. These trials showed that exercise had promising benefits for improving activities of daily living, mobility, strength, balance, and physical activity levels. The remaining trials were all low quality and provided mixed or inconclusive evidence of the benefit of exercise. Many of the trials were heterogeneous in terms of the severity of dementia, the type of exercise, the duration and the frequency of exercise, which makes comparisons between trials difficult.

Pitkala et al. (9) reviewed 20 trials, including 1378 participants, of which three were of high quality and six were of moderate quality. Of these nine studies, eight showed positive effects on mobility, functional limitations, or physical function. They concluded that the most effective high-quality trials consisted of multi-component interventions that involved more than one type of exercise (such as aerobic, strength or balance training) that took place at least twice a week for at least a 12-week duration. However, there was still a high degree of heterogeneity in terms of type, duration, and frequency of exercise alongside the severity of dementia, and it cannot be assumed that people in different stages of dementia will benefit from the same type of exercise.

Other empirical studies (13–19) alongside a meta-analysis (20) have provided evidence that older people with dementia benefit from exercise, with participants gaining improvements in strength, physical function, mood, and activities of daily living. Pereira et al. (15) conducted a multi-component group intervention twice a week for ten weeks and found a significant increase in strength for the intervention group, whilst Borges-Machado et al. (16), who also conducted a multi-component

group intervention twice a week for 24 weeks, found a positive but non-significant increase in strength in their intervention group. A systematic review conducted by Heyn et al. (20) also found a significant improvement in strength. Pereira et al. (15) found a significant improvement in aerobic endurance, and Teri et al. (17) conducted a multi-component home intervention which tapered in intensity from twice a week for three weeks to once a week for four weeks and then once a fortnight for four weeks found a non-significant improvement in levels of physical activity.

Two studies explored the benefits of exercise for mood; Teri et al. (17) found a significant improvement in the Cornell Depression scores for the intervention group, whilst Litchke et al. (18) also found significant improvements in depression from their trial of chair yoga twice a week for ten weeks. Steinberg et al. (14) investigated a daily home-based multi-component exercise intervention and found that these improved activities of daily living.

Exercise needs to be sustained to continue these benefits, and Borges-Machado et al. (16) commented on the high level of adherence in their study. They suggested that this may be due to the ability of carers to attend the exercise classes and participate alongside the participants. Khoo et al. (13) undertook a qualitative study with people who attended a light-intensity group exercise intervention. Some of the key themes reported from their interviews were the enjoyment that the participants gained from the exercises and that they liked to keep active. Many participants reported that they would like to continue with the class after the intervention had finished. These trials suggest that people living with dementia are gaining benefits, enjoy taking part in exercise and would like to continue classes.

To enable people living with dementia to take part in exercise classes, there is a need to increase their understanding of factors that may enhance or limit their participation. Many exercise interventions provided by community services are neither designed nor tailored for people living with dementia (21), and barriers such as availability, accessibility, perceptions of ability to engage, and lack of understanding may limit involvement (22,23). A greater understanding of the challenges faced by people living with dementia in accessing exercise and other physical activity pursuits may help to promote innovative ways to facilitate a higher level of participation and thereby maintain the benefits gained from taking part in exercise (24).

1.2.3 Groups and group exercise

Group exercise offers another option to one-to-one engagement for many health improvement initiatives (25–29). The benefits of exercising in a group may arise not only from the physiological mechanisms of the exercise itself (such as improved cardiac and respiratory function, increased blood flow to the brain and increased muscle size) but the psychological, social, and support elements that would be absent when exercising alone (30). Physical performance can improve when taking part in group exercise, and a trial by Tsekoura et al. (31), which examined the effects of group and home-based exercise programmes in older people with sarcopenia, found that, after 12 weeks, the group-based group had significant improvements in 15 (88%) of the 17 variables measured whilst the home-based group had significant improvements in 7 (41%). After 24 weeks (3 months post-intervention), the group-

based group still had significant improvements in 11 (65%) of the variables, whilst the home-based group had just 3 (18%).

In terms of psychosocial elements, a group format can enhance motivation and enjoyment (30,31), support engagement and adherence to exercise (32,33) and reduce social isolation and loneliness (34). A systematic review by Dickens et al. (34) explored the differences between interventions that targeted social isolation in older people, including group and individual interventions. Interventions offered in a group format had significant outcomes in 28 (54%) of the 52 outcomes measured, whereas those offered in an individual format had significant outcomes in 9 (17%) of the 32 outcomes measured. A qualitative study by Komatsu et al. (35) found that group exercises contributed to physical, mental, and social well-being. Participants reported that regular activities helped to improve their functional health, and they enjoyed the opportunity to socialise. They also commented that this level of enjoyment would not have been gained from doing exercises at home. Participants also reported increased social connectedness, and as time went on, they began to plan social activities with peers beyond the class (35).

Groups can be described in a variety of ways. In his book Group Processes, Rupert Brown, a social psychologist, proposes the following definition of a group.

> *"A group exists when two or more people define themselves as members of it and when its existence is recognised by at least one other person or group of people who do not so define themselves"* (36 pg. 3).

More usefully, in the context of this PhD, group activities have been further defined as:

> *"A planned exercise or activity session that is delivered by one or more persons, who are accepted as the facilitators, to three or more people who interact with each other and recognise that they are members of that group"* (37 pg. 230).

Several studies have found that social interaction can be an effective tool for people with dementia in improving engagement in interventions (38–40) and suggest that group activities may provide added benefits for this cohort as they combine a social stimulus with an additional stimulus, e.g., exercise (41). Several systematic reviews have examined the benefits of exercise for people living with dementia (9,42–45) but have not considered the impact of the social element of group exercise. Therefore, it can be speculatively proposed that group exercise may prove effective in addressing the physical health, mental health and well-being of people living with dementia alongside their need for greater social interaction (41).

Before March 2020, group exercise classes were usually delivered face-to-face in a gym environment or a village hall, and the delivery of exercise classes online to older people was relatively uncommon in the UK. Between March 2020 and February 2022, the COVID-19 pandemic significantly changed the delivery of classes to older people as this face-to-face delivery stopped completely (46).

1.2.4 Online exercise delivery

As society transitioned to online working, many gyms and private exercise instructors followed suit, offering online classes both live and on demand. However,

there was limited evidence that this online provision extended to older people or people living with dementia. Online group exercise classes are another format that needs to be considered, particularly as this PhD was conducted between October 2019 and March 2023. Online delivery is a form of telehealth which was defined by Lederman et al. as *"the use of telecommunication services to provide telemedicine, medical education and health education remotely"* (46 pg. 21). Before the COVID-19 pandemic, telehealth was often used by practitioners to deliver education and interventions to people living in rural or remote areas who were unable to access services (46).

Several systematic reviews were completed before the pandemic on the delivery of telehealth in several environments, including cardiac rehabilitation (47,48), pulmonary rehabilitation (49), chronic pain (50), musculoskeletal conditions (51) and knee arthritis (52). In these reviews, telehealth was defined as delivering health interventions, often exercise interventions, using a combination of telephones, smartphones, videoconferencing, mobile apps, computer-based programmes, and/or internet programmes to either patients' homes or local health centres. These reviews found that telehealth delivery of exercise interventions were feasible, acceptable, and at least as effective as standard clinic-based delivered interventions.

Not all the reviews reported the ages of participants in the trials, but for those that did, the average age was under 65 (47,48,50–52) and there has been little research into online delivery of exercise for older people. A study conducted in Texas (USA) during the COVID-19 pandemic found that the likelihood of conversion to telehealth decreased for older participants with serious and non-serious mental illnesses (53).

Although smartphones and internet access are considered a necessity for younger people, it is a possibility that interventions delivered in this way will be much less appealing to older people, who may not be as comfortable with technology or do not have easy access to a computer or the internet (54).

A randomised controlled trial undertaken in the UK, which delivered an exercise intervention to people living with dementia in their own homes, switched to remote delivery using telephone and video calls during the COVID-19 pandemic. They found that telephone contact was ineffective in supporting participants to continue their exercises, with patients reporting lower levels of motivation. However, for those who could confidently use the software needed for video calls, the visual input provided by the therapists provided extra motivation to carry on (55). Telerehabilitation's success depended on the digital ability of the participant or the carer and confirmed that bridging the digital divide would be a key component of successful online exercise delivery (56).

Lederman et al. (46) synthesised telehealth guidelines from the Australian College of Physicians (57) and the Australian Agency for Clinical Innovation (58), where telehealth was more commonly used before the pandemic, and outlined several key themes that were important to enhance access to online support for people living with mental health conditions. These included considering the needs of the recipients, particularly their ability to communicate using telehealth, their level of cognition and the availability of equipment such as internet access and a computer with a webcam and microphone (46). More specifically, for those living with cognitive impairments, they highlighted the need to recruit support from family and

carers and to provide supplementary instructions or support materials in written or video format to provide a consistent reminder. To help with adherence, it was also suggested that tools used in face-to-face services, such as automated reminders and online exercise tracking, should continue.

Mui et al. (53) considered whether participants with serious mental illness (SMI) would transition, utilise, or initiate therapy differently from people with non-serious mental illness (non-SMI) during the COVID-19 pandemic. They used data from 816 participants who were engaged in therapy before 16th March 2020 (SMI n = 124, non-SMI n = 692) and a further 136 participants who sought therapy during COVID-19 via telehealth (SMI n = 20, non-SMI n = 116). They found no significant differences between the groups for transitioning to telehealth. However, there was a significant difference in the total number of telehealth visits, with SMI participants having a higher number of visits than non-SMI participants. Before COVID-19, the groups had no significant difference in the number of in-person appointments. There was also no significant difference between initiating telehealth therapy between the groups. It was expected that people with SMI would be more difficult to engage as more barriers were put in place due to the COVID-19 pandemic. However, this research has suggested that telehealth interventions are feasible and acceptable to people living with severe mental health problems.

Although some research undertaken during the COVID-19 pandemic has suggested that the online delivery of services has been relatively successful, there has been little literature on the online delivery of exercise classes for older people and those

living with dementia. The studies that have been done have indicated that this success may not be replicated with these groups.

1.3 Background literature to the theoretical concepts

1.3.1 Ecological perspectives and social ecological model

Group exercise classes for older people, both with and without dementia, could fall under the remit of public health. They are organised by a variety of providers ranging from large national organisations to individual instructors. They offer a wide range of exercise interventions located in settings such as leisure centres and village halls.

The focus on public health has its origins in the mid-nineteenth century when rapid urbanisation persuaded far-sighted members of the medical profession to look beyond individual causes of ill health and began to investigate other factors that may influence an individual's health (59). The gradual acceptance of this perspective over the past 150 years has been strengthened by a growing body of evidence which suggests a causal relationship between health, social structures, and the environment (60). Organisational, institutional, environmental, and economic factors can influence an individual's health behaviour choices (60,61).

Alongside their focus on health protection with vaccination programmes and disease control, public health also has a role in health improvement and the promotion of healthier lifestyles. Interest in health promotion increased throughout the 1970s and 1980s but tended to encompass strategies that aimed to change an individual's behaviour and focused on issues such as lifestyle and individual responsibility. However, this approach often failed to consider the social and organisational

contexts in which the individual had to make those changes (62). Health promotion and public health policies that tended to focus on individual behaviour were not always successful as they were not accompanied by appropriate levels of support and wider opportunities (60,63–66). A systematic review by Twyman et al. (67) explored the perceived barriers to smoking cessation and found individual and interpersonal factors, including low motivation, behavioural habits, combatting loneliness, socialisation, and a positive smoker image. These factors could be amenable to short-term strategies such as a behaviour change intervention. However, there were also cultural and environmental factors, including access to resources to quit, living and working circumstances and cultural norms that would need a more long-term strategy such as a policy change (67).

In the UK, the proportion of smokers remained relatively stable between 1992 and 2003, with figures ranging from 28.4% to 26% over that period (68). On 1st July 2007, a law came into effect banning smoking in pubs, restaurants, and most workplaces. In 2007 the proportion of smokers dropped to 21% and has steadily decreased since, with figures in 2019 at 13.9% (69). A study by Dai et al. (70) also showed a drop in smoking in the UK for men and women by at least ten percentage points over the last ten years. Despite the dominance of individual-level smoking cessation interventions over that period, prevalence fell more rapidly following the policy change that led to the current legislation.

Within dementia research, there has often been more focus on prevention by seeking to persuade individuals to make better lifestyle choices in terms of diet and

exercise to reduce personal risk rather than considering the social and physical environments that may maintain or reinforce potentially unhealthy behaviours (62).

Well-established behavioural interventions to promote physical activity or exercise, such as feedback, goal setting, behaviour contracts and prompts, along with clinical exercise interventions, often employ an individual approach to behaviour change. These interventions have successfully increased short-term participation by up to 25% (71) but do not always consider prevailing social and environmental conditions. As these factors often remain unchanged, it is less clear how successful they are in promoting long-term maintenance (71). Often these types of interventions require the participants to seek out activities that meet their needs and preferences and attract those who are already reasonably fit and active (72). With no thought given to modifying their environmental and social circumstances, less active participants often return to their previous sedentary behaviour once an intervention has finished (73,74). A systematic review exploring exercise referral schemes in the UK (75) found that although uptake of exercise referral was high (85%) for those who were allocated to the intervention, those who took part were only 12% more likely to achieve the target of 150 minutes of moderate exercise a week than those allocated to usual care. The referral schemes increased physical activity levels for people with coronary heart disease but not for people with mental health conditions. The number of participants completing the course varied from 21% to 86%, but the review did not look at how many participants continued to take part in exercise sessions after the referral period was over.

Research has also focused on behaviour change theories (14,76–78) a recent systematic review by Nyman et al. found that the use of behavioural change techniques did not lead to sustained participation in physical activity beyond the intervention period in people living with dementia (79). A further systematic review conducted by Carraca et al. found mixed results when behaviour change techniques were used to increase physical activity in overweight adults. Evidence suggested that goal setting and behavioural practice may obtain more favourable outcomes in the short term. However, there was no evidence that the use of any behaviour change technique led to increasing activity levels long-term (80).

If systems are not in place to encourage long-term participation beyond the research trial, it may be worthwhile to employ an ecological approach, which acknowledges both the social contexts that shape an individual's behaviour alongside societal and cultural influences, to understand how we can sustain participation (62,81). An ecological approach to an intervention to increase physical activity or exercise goes beyond the individual behaviour change to include social networks, organisational norms, and policies alongside the physical environment, to increase the chances of long-term maintenance of activity levels (72).

Urie Bronfenbrenner was the first to propose a model of behaviour that is both affected by and influences multiple levels. He divided the environmental influences on behaviour into four nested levels, as shown in Figure 1 below (82,83).

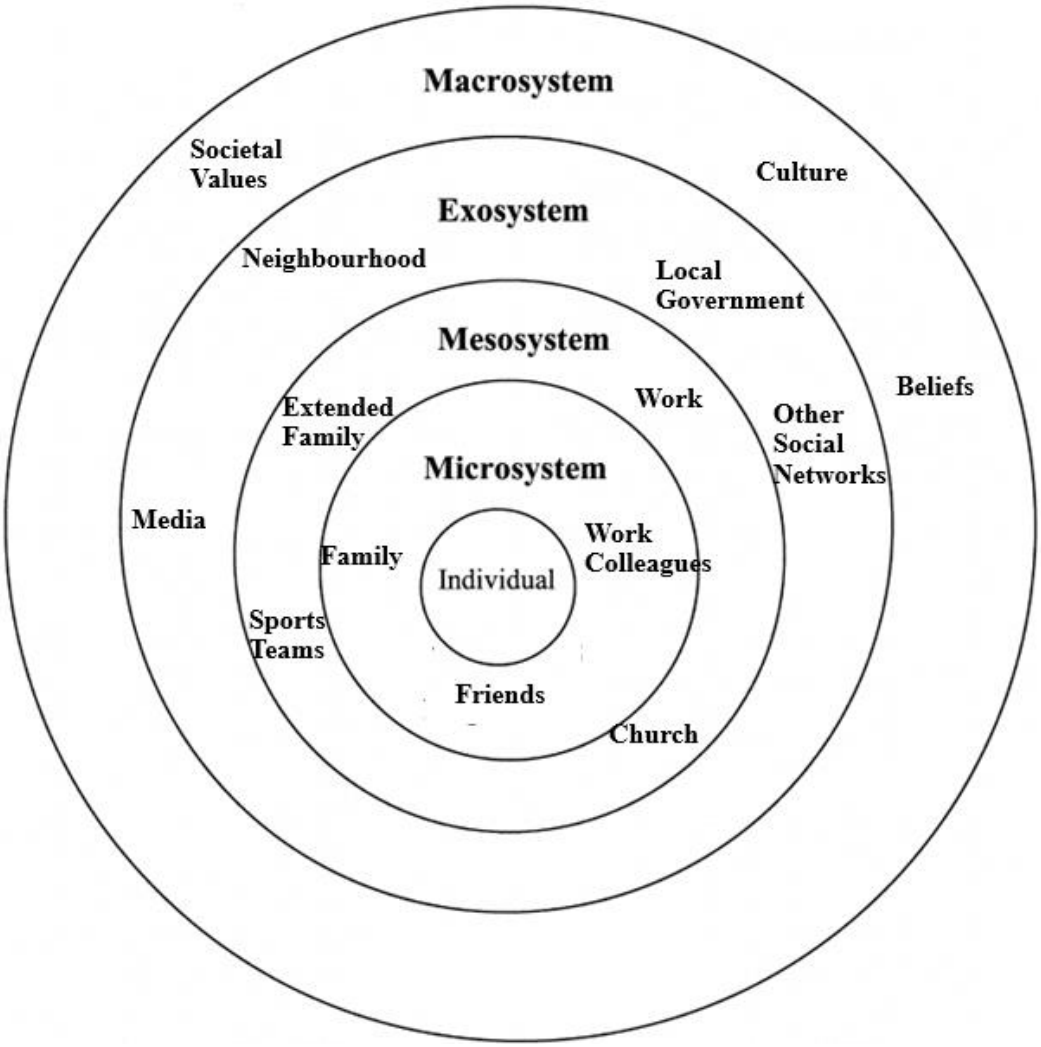


Figure 1 Bronfenbrenner's ecological systems theory (1979) Adapted from Swanson et al. 2003

The microsystem is concerned with the face-to-face influences on an individual's behaviour, such as spouses, friends, and work colleagues. The mesosystem comprises the interrelations between settings in which the individual is involved, such as work, church, sports teams, and extended family groups. The mesosystem is therefore a system of microsystems. The exosystem is an extension of the mesosystem. It incorporates broader social structures that can influence an individual's behaviour, such as the wider neighbourhood, local government, media, and other informal social networks. The macrosystem incorporates society's cultural

beliefs and values, which will exercise influence within the micro, meso and exo systems of the individual (83).

Ecological models suggest that health behaviour is influenced at multiple levels and that these influences interact across the levels. Single-level interventions which impact an individual's behaviour at the individual or microsystem may not be sustained long-term if there is no wider environmental support for the targeted behaviour change in the meso, exo or macro systems (74). Suppose an individual participates in an exercise trial which changes their attitude and behaviours during the trial, but there are no community exercise classes for them to continue after the study has finished. In that case, only short-term benefits may be experienced. The importance of an ecological model is that it provides a perspective which incorporates environmental interventions that may act to support behaviour change (62). This model was first described in 1977 and was used to encourage a broader perspective when looking at the behaviour of children. Although the levels are nested within each other, there was no recognition of the interdependence of those levels. Since then, several researchers have argued the case to apply ecological models specifically to physical activity (74,84,85). They have built on the original work of Bronfenbrenner (83) to develop models that share the common features of interdependent levels that can directly impact others (85).

1.3.2 Ecological approach to physical activity

Most physical activity interventions across a wide range of participant groups have focused on the micro and meso systems, targeting the intrapersonal and interpersonal variables such as the individual and their family or work colleagues

(64,75,80,86). Despite the potential insights offered by an exploration of the wider exo and macro systems, they have been studied less. However, these may be important variables if a complete understanding of how best to promote physical activity is to be achieved (81,84). Community factors such as the availability of appropriate exercise classes in an area, accessible transport options and/or sufficient parking, alongside environmental factors such as a bright and airy exercise hall, may be invaluable in bringing about long-term sustainable changes to an individual's activity levels (73,87).

One of the few examples of the use of a social ecological model in physical activity research was from Cochrane and Davey (60), who designed a physical activity intervention to work with a neighbourhood rather than individuals; this assumed that the environment exerted an influence on an individual's behaviour. Results at the end of the intervention period showed an increase in the number of participants taking part in physical activities, alongside an increase in the number of activities available in the intervention area compared to the control. They also showed that this increase in physical activity was associated with health benefits following the intervention period (60). Environmental interventions such as providing safe walking areas, bike paths and local community exercise classes may have the potential to provide a longer-term impact on a whole population rather than individual interventions, which may only provide a short-term impact for the individuals involved (84).

Bronfenbrenner's model incorporates cultural and societal norms in the macrosystem (83). To understand the choices made by individuals regarding physical

activity, the changing culture and environment that underpins current lifestyles need to be considered (85). People living in industrialised nations are expending approximately 76% less energy than those living 40 millennia ago despite the relationship between energy intake, energy expenditure and activity requirement remaining constant (85). This level of physical inactivity has created a serious public health issue in many Western countries. Many members of the generation currently over 65 had jobs that were more physically active than those of today. 'Exercise' such as going to a gym, taking a class, or going for a run after work was not commonplace, as those who were physically active at work had no further need for formal exercise to maintain the relationship between energy intake and expenditure. Previous generations also had shorter retirement periods; they did not live for as many years with 'ill health' and did not consider exercise as a potential activity during retirement. In this situation, there is an expectation that individuals will change their behaviour to something that, although quite normal to someone in their thirties, is unfamiliar to them. Without considering this change in both culture and environment when designing an intervention, it is easy to see why it may fail to produce long-term change.

Wachs outlined a model to enhance understanding of the role of the environment in children's development (88), and this was adapted by Spence and Lee to describe the role of the environment in physical activity (85) (Figure 2).

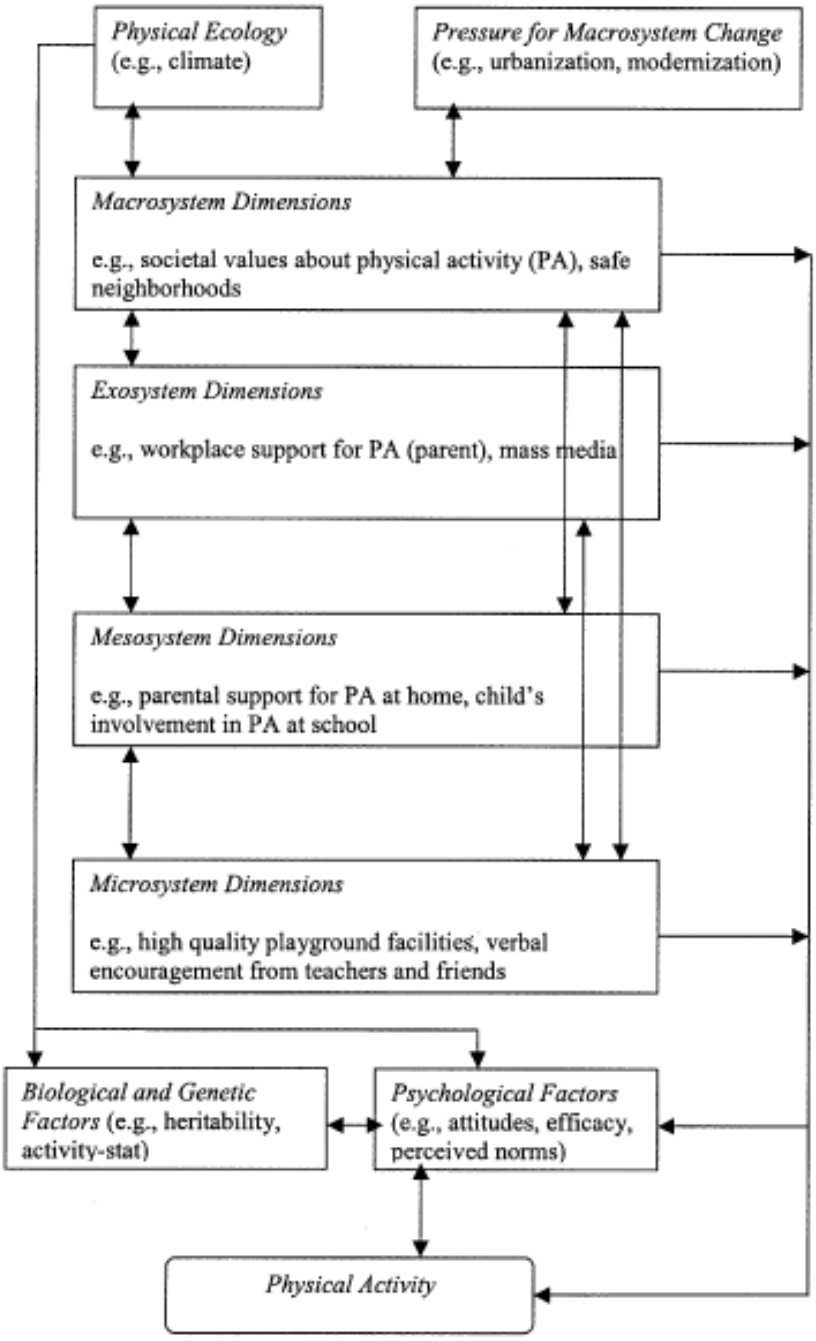


Figure 2 The Ecological Model of Physical Activity (EMPA) (Spence and Lee 2003)

The ecological perspective views the population health challenge as a consequence of actions within multiple levels of influence (81). There is evidence to suggest that individual health problems are associated with social structures and environmental conditions (73). The ecological approach serves to reduce the 'victim blaming' that is

often associated with traditional individual-level approaches and highlights the need to work at multiple levels to achieve a wider population change (73,81). Whilst recognising the importance of psychosocial factors, including knowledge, beliefs, self-efficacy and attitudes on individual behaviour change, the ecological perspective also incorporates organisational, environmental and policy-level influences (89). The model by Spence and Lee incorporated the interdependence of levels but assumed that the factors that affected the physical activity levels of children would be the same across the life course.

Further building on this work, Boulton et al. (89) developed a social ecological model that was employed in a study of community-dwelling older adults aged 50 to 87. They found, similarly to Spence and Lee (85), that individual and interpersonal (microsystem dimension) along with perceived environment (mesosystem dimension), community or organisational factors (exosystem dimension) and policy (macrosystem dimension) all influenced the levels of engagement in physical activity for older adults. However, the factors in each dimension were different for the two groups. Whereas the mesosystem in the model by Spence and Lee incorporated parental and school support for physical activity (85), the model by Boulton incorporated accessibility, flexibility, and adaptability as factors for increasing physical activity engagement for older people (89). Sociability cut across the micro and meso levels for older people and was often crucial to sustained engagement but was not a factor in the engagement of children.

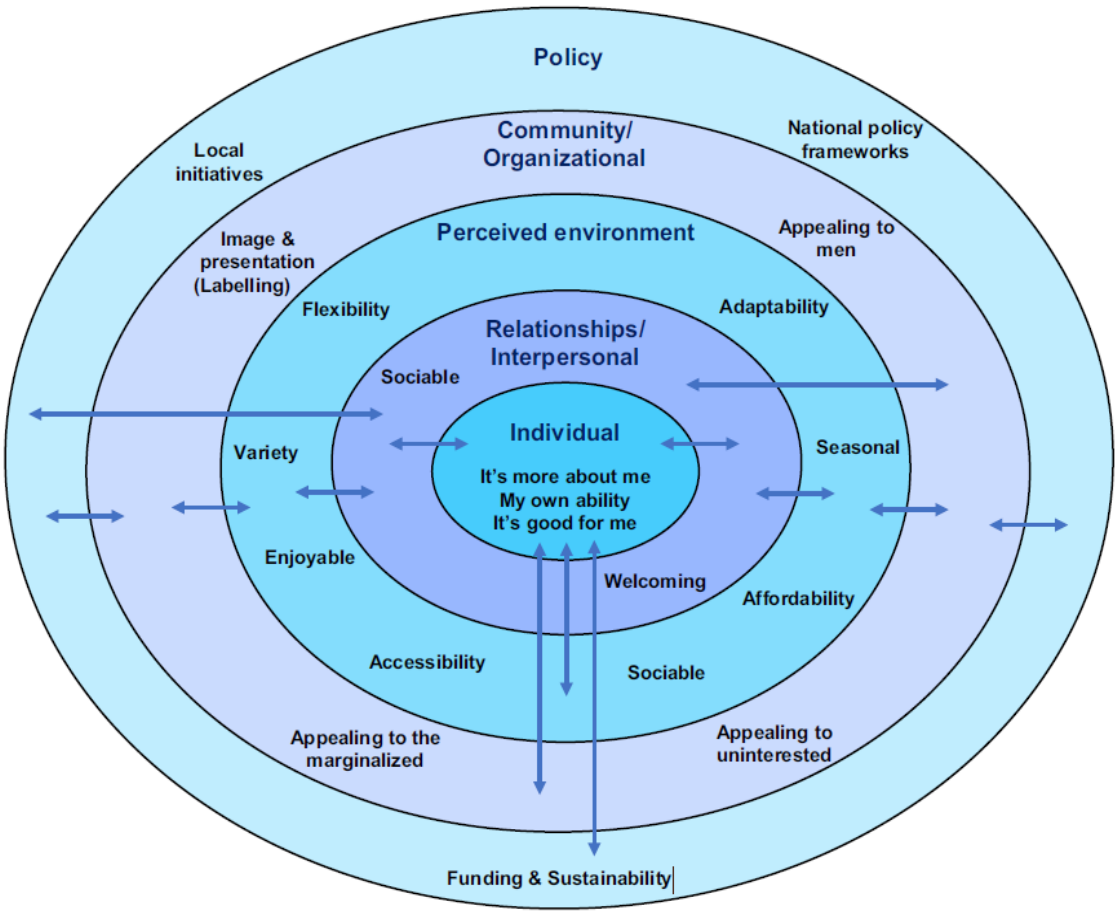


Figure 3 A social ecological model for promoting physical activity amongst older adults (Boulton et al. 2017)

To this author's knowledge, a social ecological model has not been applied to the promotion of physical activity for older people living with dementia, although Di Lorito et al (90) created a behaviour change model for physical activity in people living with dementia.

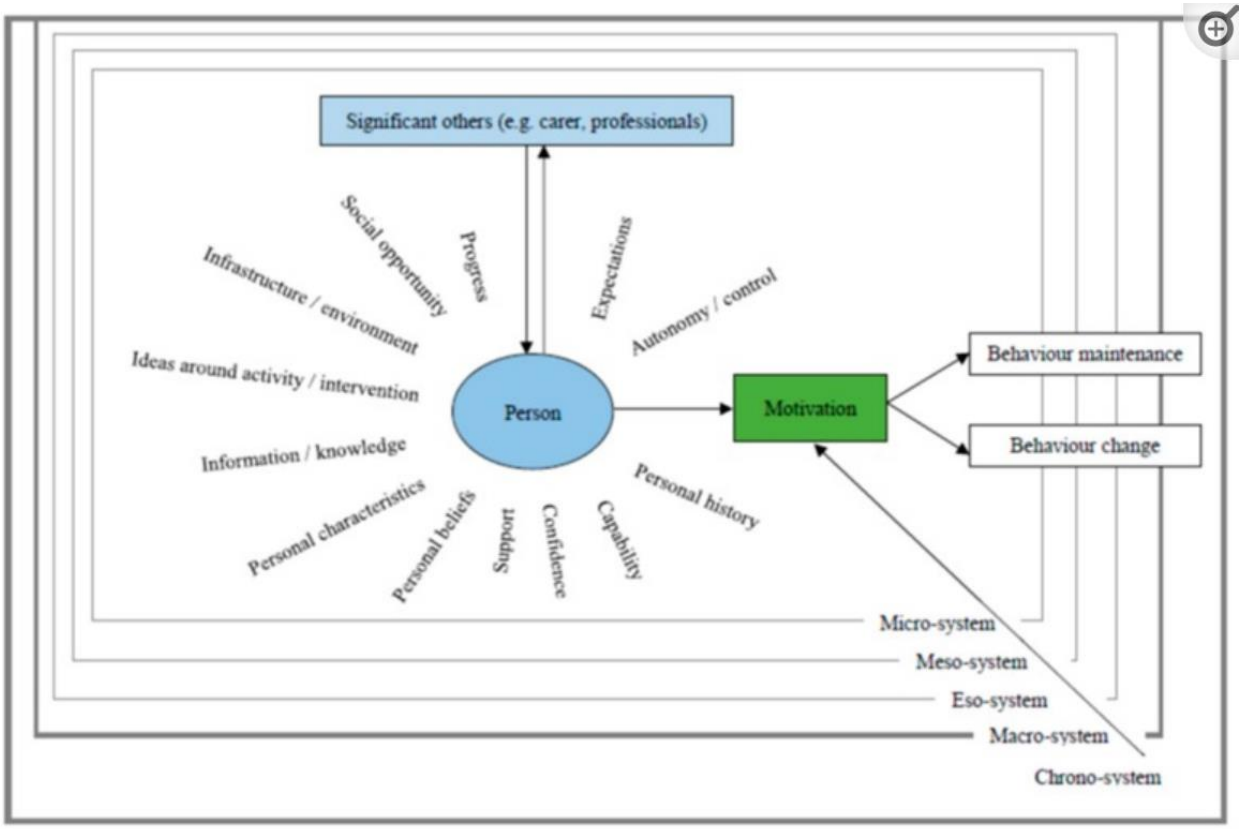


Figure 4 PHYT in Dementia Model (Di Lorito et al. 2020)

The PHYT in Dementia Model, explains the individual and micro dimensions of Bronfenbrenner's original model but does not explore the meso, exo and macrosystem components as in previous studies (74,85,89). Hence, a specific social ecological model that can be applied to the promotion of exercise for people living with dementia would be a useful addition to the current literature.

This thesis will use the social ecological model for promoting physical activity, presented by Boulton (89), as a useful starting point to consider what influences older people living with dementia to engage with exercise over a prolonged period at

multiple levels. This will, in turn, aid the development of recommendations to encourage people living with dementia over the longer term.

The social ecological model of health promotion draws on concepts from systems theory. By viewing behaviour as something that can be both affected by and have an influence on the environment, a systems approach can facilitate an understanding of the interrelationships between people and their environments (91). This ecological perspective presents a view where community settings are recognised as an ecological system. As a system, it follows the principles of system dynamics, which emphasise the importance of the relationships and interactions between the different system parts (92).

1.3.3 Systems thinking and systems approach.

Systems thinking emerged in the twentieth century as a critique of reductionism which had been the dominant approach in science. Reductionism posits that observations about the world are best understood by breaking them down into their constituent parts and studying these parts in terms of cause and effect. By contrast, systems thinking presumes that the world is a system in which all parts are interrelated; therefore, a greater understanding will come from building up a picture of the system as a whole (93). Ecological theories, as opposed to individual theories about behaviour, are based on the relationship of these parts to one another and stress the need to acknowledge the role of the system in the intervention (85,92).

An exercise intervention designed using a behaviour change theory might fail to consider the supporting systems that need to be in place for this behaviour to be

sustained (e.g., easily accessible and appropriate community classes) and may not provide the desired continued change in behaviour. A systems-based approach integrates personal, social, organisational, and societal perspectives, which can support a more collaborative approach to physical activity and exercise promotion and, potentially, be more effective than narrowly targeted individual-based approaches (91). It is also important to have positive engagement from all contributors to the intervention and understand the intervention settings. This is where using a systems approach could also be beneficial in providing context for specific behaviour, as individuals often behave differently in different settings (73,84).

The systemic approach also helps to define this dimension of the ecological perspective. Intervention settings operate in different levels of the system, which could be organisational (e.g., exercise provider companies, leisure centres), communities (restricted geographical areas, e.g., Willington, West Bridgford or county areas, e.g., Derbyshire), societal including individual nations such as the United Kingdom and supranational systems such as the European Union. These are all social systems, and the setting of any intervention would be defined as the social system in which the participants are located. Hence, it is important to define within which social system the intervention will be set (73).

Midgley defines an intervention as *"a purposeful action to create change"* (59 pg. 467) and a systems intervention as *"a purposeful action by an agent to create change in relation to reflection upon boundaries"* (59 pg. 467). Defining the boundaries is a critical step for any systems intervention. The boundaries must make

clear the focus of the intervention, what is important and valued, and the potential impact of the intervention. This helps not only in designing the intervention but in increasing its transferability across settings (94).

How should systems boundaries be defined and set? Churchman believed that decisions on boundaries are directly influenced by an individual's value judgements. What is valued will determine the boundaries which dictate who or what is included within an intervention. Ideally, this would lead to the boundaries being set as far as possible to include a wide range of stakeholders (95). However, in practice, this becomes difficult to operationalise. In his work on boundary critique, Ulrich recognised that external factors such as time or resources make extending boundaries beyond rationally chosen limits challenging. Therefore, boundary critique should justify the choices made (96). In this thesis, the system boundaries chosen included the selection of the East Midlands as a restricted geographical area and limiting the scope of the work to structured exercise classes. These rational boundary choices ensured that the work was feasible for the available time and resources.

Systemic intervention, as defined by Midgley, supports 'methodological pluralism.' He recommends drawing from differing methodologies and mixing methods from those methodologies to address the complex issues that are found within systems. In his work to design new services for young people living on the street, he used a variety of methods, including interviews, focus groups, stakeholder workshops and questionnaires. He argued that no one methodology could provide the range of knowledge needed to answer complex research questions. Hence, employing various

methods from different paradigmatic sources offers the flexibility needed to provide comprehensive solutions to complex problems (59).

Midgely also advocates an innovative stance which he terms ‘process philosophy.’ It posits that any organism is dependent on its interaction with its environment, and knowledge is gained through interactions with and actions within that environment. By adopting this premise, he acknowledges that individuals function within the wider ecological system and need to be viewed as part of that system and not apart from it (97).

1.4 Conclusion

This chapter has discussed the need for improvements in the quality of life for people living with dementia as its prevalence increases both globally and nationally. It has outlined the benefits of exercise as an intervention for older people generally, alongside its potential to provide physical health, mental health, and well-being benefits for those living with dementia. Group interventions have been shown to provide an alternative to one-to-one engagement for many health improvement initiatives. Group exercise interventions may provide an innovative way of addressing the physical and mental well-being of people living with dementia. They may also offer greater levels of social interaction and peer support than would be found with traditional one-to-one interventions.

In exploring the current delivery and existing evidence for exercise interventions for people living with dementia, it is evident that individual approaches, underpinned by behaviour change theories, have been favoured. However, these have not always

proved effective in sustaining long-term participation. An ecological approach which acknowledges both the individual and societal causes of behaviour may be needed to understand how participation can be sustained beyond the life of an intervention. In acknowledging that individuals are situated within a wider social environment, an ecological perspective presents a view where community settings are recognised as an ecological system. Introducing an intervention through a systems approach requires a re-examination of how interventions are characterised and implemented in a wider context.

1.5 Thesis aim

This PhD aimed to identify the key characteristics and core components needed to implement an exercise class for older people living with dementia in the community. Beyond this, to understand if older people living with dementia wanted to access exercise classes and, if they did, whether they were available and what factors were facilitating or preventing prolonged engagement. Evidence-based recommendations could then be provided on how community exercise classes can be best adapted to encourage older people living with dementia to participate in exercise over the longer term.

1.6 Thesis objectives

The objectives of the thesis were therefore to:

- Establish the need for exercise classes for older people living with dementia through a geographical mapping of the exercise classes currently available, a survey of exercise instructors and an exploration of the benefit of exercise classes for older people living with dementia who are attending classes

- Establish the characteristics of exercise classes for older people living with dementia through a mixed methods systematic literature review and an ethnographic study
- Establish the core components needed to set up or adapt an exercise class for older people living with dementia through a synthesis of information gathered in the previous objectives

1.7 Layout of the thesis

The thesis progresses as follows:

Chapter Two: The philosophical position of the research is summarised with an overview of the primary schools of thought in the philosophy of science, followed by a justification of pragmatism as the philosophical stance for this PhD considering its alignment with mixed methods. The methodology of mixed methods research has been outlined alongside the specific research methods used in this PhD.

Chapter Three: A mixed methods systematic literature review was conducted to identify the following:

- the characteristics of effective group exercise interventions for older people living with dementia
- the barriers and facilitators to attendance at exercise classes

Chapter Four: A mixed methods study, consisting of participant observations, a prospective repeated measures cohort study and focus groups, was conducted with an existing face-to-face dementia-friendly exercise class to investigate:

- the benefit of these classes on older people living with dementia before the COVID-19 pandemic
- the perception of benefits from the perspective of the person living with dementia and their carers
- to map the quantitative and qualitative data against the matrix developed in Chapter Three to synthesise the results against that found in the literature review

Chapter Five: A quantitative study consisting of a geographical mapping exercise and spatial analysis alongside a survey of exercise class instructors to establish:

- where and how many exercise classes were taking place in the East Midlands
- analyse these locations with regard to population age, socioeconomic and rurality data
- who was participating in exercise classes and the type of exercise that was being delivered

Chapter Six: An ethnographic study consisting of observations, focus groups and interviews of online and face-to-face exercise classes for older people living with and without dementia to explore:

- the context-specific characteristics of classes alongside the barriers and facilitating factors
- if these characteristics could be consistently provided through different modes of delivery and maintain the benefits that participants reported before the pandemic

Chapter Seven: A synthesis of the data gathered in Chapters Three, Four and Six was conducted to explore :

- the essential elements needed for an effective evidence-based exercise class and whether these were consistently provided through online and/or face-to-face delivery
- a proposed social ecological model specifically for older people living with dementia
- recommendations intended to provide fresh approaches to encourage older people living with dementia to attend and continue to take part in exercise classes in their communities
- the implications of these findings for both exercise providers and participants
- recommendations for further research

Chapter Two

2 Philosophical Foundations and Methodology

2.1 Summary

Traditionally, there have been two main research paradigms: quantitative research, which uses numerical data and is grounded in a positivist philosophical paradigm, and qualitative research, which uses narrative data and is grounded in an interpretivist philosophical paradigm (98,99).

However, people are complex and do not fit into the neat boxes of quantitative or qualitative numbers or text. When a patient has a problem, clinicians do not look at them in terms of the range of movement a joint may have, or the numbers shown in a blood test. Clinicians are taught to take a history from the patient and look at the problem and presenting symptoms before providing a diagnosis and a treatment plan (100). As patients cannot be put into neat boxes, neither should the research questions we ask (100,101).

Mixed methods research has been described as the third research paradigm (101) and, by Creswell (102), as an approach where quantitative and qualitative data are gathered and integrated by the researcher, who draws interpretations based on their combined strengths to understand research problems. A mixed methods approach is suited to health research which often addresses complex issues that arise from lived experience. However, it has often been regarded as philosophically problematic within the positivist/interpretivist debate (103–105).

2.2 Philosophical foundations

2.2.1 Positivism and Interpretivism

The primary schools of thought in the philosophy of science can be categorised as positivism and interpretivism (106).

Positivism proposes that knowledge is based on information derived from sensory experience and empirical evidence, surmised to create general laws. It holds that all knowledge is discovered *a posteriori* and, as science is 'outside society', we can have no *a priori* knowledge of the world. Positivism is also grounded on the basis that the social world, like the physical world, operates according to general laws (99,107).

Alternatively, interpretivism proposes that the social world cannot be studied using positivist approaches and offers a different methodology. It was adopted by those who rejected positivist and post-positivist theories as being inadequate to capture the variability of social interaction. They contended that conducting wholly objective research is unattainable, as the researchers' values and beliefs can never be fully detached from the research process. Interpretive researchers look to draw meaning from the subjects they are studying through interviews and observations and build a theory from these interactions (99,107,108).

Hence, positivism does not recognise the social dimension and cannot sustain a reality independent of the objects of scientific knowledge, while interpretivism, although recognising the social dimension, does not provide a coherent account of the independent reality of the objects of scientific knowledge (106). The difficulty lies in how the different paradigms view knowledge. The positivist paradigm asserts

that it is possible to gain objective knowledge about the world that is independent of the 'knowers'. However, interpretivism claims that all knowledge contains a subjective element that is provided by the 'knower' (109).

2.2.2 Pragmatism

Johnson and Onwuegbuzie argue that mixed methods research requires an entirely separate paradigm and advocate the classical pragmatism of Charles Peirce (110), William James (111) and John Dewey (112) which challenges this epistemology debate. It highlights the importance of the research question and uses the most appropriate methods to answer this question to provide practical solutions that can be used in the real world (101,109). Similar to the process philosophy advocated by Midgely (97), classical pragmatism cuts through the subjective/objective dualism of traditional philosophy by suggesting subjects and objects should be defined through the same process, that is the creation of knowledge, not the knowledge that is created (97). Hence, pragmatism aligns itself well with the ecological approach outlined in Chapter One.

Dewey's theory offers a view of knowledge based on interactions or experiences. He asserts that, as living organisms, we are part of the environment and not separate from it. He challenges the idea that it is only through gaining knowledge that we can understand reality. He claims that all types of experiences are equally 'real' as they are all interactions between us as living organisms and our environment (109). Dewey's approach cuts across the traditional objective/subjective view. There is no gap between people and the environment as we are all *"participants in an ever-evolving universe"* (109 pg. 109), and the world appears as a function of what we do

(109). This approach supports the ecological perspective outlined in Chapter One, which acknowledges that individuals are situated within a wider social environment (92).

Dewey further asserts that knowledge is about relationships between actions and consequences, not about a world that is 'out there'. This view is rooted in the assertion that the only way to acquire knowledge is through a combination of action and reflection. The framework for this theory lies in Dewey's view of action, which proposes that action is a process of experiential learning where the learning is not an acquisition of information but a process whereby learners acquire a set of predispositions for action (109). Healthcare research often focuses on the need to answer a question or solve a problem that has been identified in clinical services. Dewey takes the question posed or the problem that needs to be solved as the starting point of the research design and allows for the use of different methods to acquire the relevant knowledge (113).

No one knowledge can offer us a better account of the world. Different 'knowledges' are simply the result of engaging with the world in different ways (109). Combining qualitative and quantitative methods through a pragmatist paradigm can provide a more comprehensive approach to the types of complex questions posed in healthcare research, as different approaches will provide different outcomes (109,114). Dewey's philosophical stance of pragmatism asserts that knowledge is both constructed and based on the reality of the world we experience. This brings together a realist view of the physical world and an interpretivist view of the social

world, providing theoretical legitimacy to the integration of quantitative and qualitative research methods (104,115).

In other respects, pragmatism as a philosophy is closely aligned to health care research and practice, which seeks to address the practicalities of health care and endorses theory that informs effective practice. It also stresses the importance of context, which is essential when implementing research findings in different settings (104,114).

2.3 Methodology

2.3.1 Mixed methodology

In their seminal paper '*Towards a Definition of Mixed Methods Research'*, Johnson, Onwuegbuzie and Turner established their definition as *"the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration"* (101 pg. 123).

The key components of mixed methods research outlined by Creswell and Plano-Clark (100) include organising quantitative and qualitative methods into a logical research design that outlines procedures for conducting the study by, collecting and analysing both sets of data to answer appropriate research questions, combining the subsequent data and the results whilst also framing the study design within an appropriate theory and philosophy.

Not all research problems are suitable for mixed-methods research. Some questions can be more appropriately answered using either quantitative or qualitative methods, such as epidemiological questions in which participants' views are not an essential part of the research, nor would they provide any greater understanding (116). However, many research questions are suited to mixed methods. Examples include studies where there is a need to obtain more complete results or where one data source does not provide all the relevant information (100). A mixed methods study by Lindsay-Smith et al. explored the impact of membership of a community group on the social well-being of older adults. The quantitative data showed that loneliness had reduced significantly over time, but there was only a small improvement in social support. The focus group added supplementary data, which showed that increased social resources were available through membership, improving social well-being over time. This information had not been gathered through the survey data (117).

Mixed methods can also be useful where there is a need to build a further understanding of initial quantitative results (100), such as the study by Hägglund et al., which considered the impact of Tai Chi on patients with chronic heart failure. The quantitative data did not show any significant differences in the level of fatigue, quality of life or physical performance in the Tai Chi group compared to the control group. However, qualitative data reported benefits in participants' balance that were unclear from the quantitative data. The interview participants did not mention that Tai Chi had increased their fatigue or caused them to reduce their activity levels,

suggesting that some of the selected outcome measures may not have been appropriate for the study (118).

Studies where participant involvement is crucial also benefit from a mixed methods approach (100). A study by Salisbury et al. to develop a conceptual model for the design and evaluation of a telehealth intervention, was able to elicit the barriers and motivators for patients using this form of intervention for chronic conditions from their qualitative interviews. They were able to establish that the engagement of both patients and healthcare professionals was vital to the success of the intervention (119).

There are many advantages to using mixed methods to answer complex research questions in health care. Both qualitative and quantitative research have strengths and weaknesses, and using mixed methods enables researchers to utilise the strengths of one method to balance weaknesses found in the other. It is also highly practical: individuals do not think purely in terms of numbers or words and tend to solve problems using a combination of the two. Morgan suggested that individuals predominantly operate through abductive thinking, moving back and forth between induction (quantitative) and deduction (qualitative). Therefore, he reasoned that employing a similar approach through mixed methods research was natural to understand and solve research questions (100,105). Although it is highly useful and practical, mixed methods research is not without its challenges. It is both time, and resource heavy as two different sets of data need to be collected and analysed (100). Mixed methods can work to bridge the divide between quantitative and qualitative research supporting greater collaboration as the researcher is encouraged to

consider multiple worldviews. It may also encourage the adoption of other paradigms that embrace both quantitative and qualitative research, such as critical realism and pragmatism (100).

2.3.2 Designs

As a methodology that employs multiple methods, they can be utilised flexibly, and this has led to an evolution in the design of mixed methods studies. There are several purposes for combining methods, including complementary, expansion, development, and confirmation (103), and the methods can be used sequentially or concurrently (103,113). As outlined below, the study that forms a central part of this thesis applied an explanatory sequential design (Figure 5).

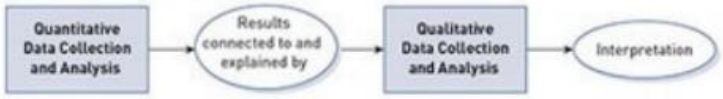


Figure 5 Explanatory Sequential Design (Creswell and Plano Clark 2018)

2.3.3 Explanatory Sequential Design

This design develops through two phases: collecting and analysing quantitative data, followed by collecting and analysing qualitative data to explain or expand on the initial quantitative data (100). Morgan (113) also describes the use of quantitative data to guide further qualitative research as an explanatory sequential design, in which preliminary quantitative input forms the basis for collecting the qualitative data and guiding purposive sampling.

This PhD started by using an online survey to gather information about exercise classes in the East Midlands before the COVID-19 pandemic. The location data

captured by the survey was also employed to show the distribution of classes with reference to the percentage of the population over 65 years of age, socioeconomic status, and level of urbanisation. This quantitative research included data on the provision of exercise classes for both older people and those living with dementia.

However, it did not capture the voice of participants to gauge their views on the strengths and weaknesses of the classes and what facilitated or prevented their attendance. The survey data was further used to purposively sample classes to participate in the ethnographic study, including observations, interviews, and focus groups. This enabled a more comprehensive set of results to be produced, which included where classes were located, what was being provided and participants' views on the value of the classes. Hence, the participants' voice could be reflected in the recommendations.

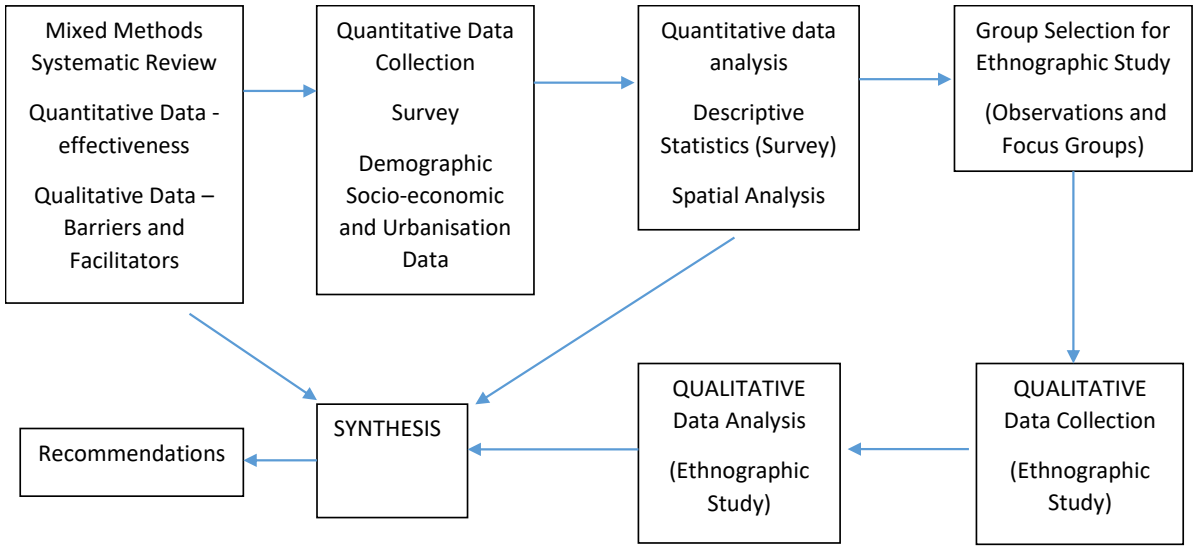


Figure 6 Explanatory sequential design for this PhD

As the design for this study is an explanatory sequential design, this will now be explained in greater depth.

The primary purpose of an explanatory sequential design is to use qualitative data to explain quantitative results. This type of design can be useful where a study produces outliers or unexpected results, such as the study described earlier in the chapter from Hägglund, where the quantitative results were non-significant, but the qualitative results showed positive benefits of Tai Chi for the participants (100,118).

It is also a useful method when the researcher wants a purposeful sample in the qualitative phase (100). This approach was used by Pavlovskaya (120), who studied the impact of privatisation on the everyday life of Russians in Moscow following the transition from the Soviet system to a market economy. Initially, Pavlovskaya mapped underprivileged areas enabling the qualitative sample to be stratified by income level (120). Morgan describes this method as using sources of aggregate data to locate participants who provide a best fit for the researcher's purpose, as an example of using quantitative data to purposively sample for qualitative data collection (121). Before changes brought about by the COVID-19 pandemic, the online survey was also intended to be used to purposively sample classes to take part in the ethnographic study, ensuring that a broad range of settings were covered: local authority, private and charity-run classes, rural and urban areas, areas of relative affluence and socioeconomic deprivation.

The main strength of the explanatory sequential design is its simplicity. Its basic linear structure makes it easy for a single researcher to manage as each data set is

collected separately, which is helpful for a PhD. This also lends itself to a clear final report as each section can be written separately, making it straightforward to write and easy to read (100). Despite its simplicity, the explanatory sequential design is not without its challenges. Its linear approach also means it can take a long time to complete. This extended period means that study participants may need to be accessible over a longer time than in a concurrent study (100).

2.4 Methods

The explanatory sequential design used in this PhD thesis (shown above in Figure 6) outlines the different methods used in both the quantitative and qualitative phases of the research. The following section will explore those different methods further.

2.4.1 Quantitative methods

2.4.1.1 Surveys

A survey is a set of pre-defined questions designed to collect information from participants. It can be used for many purposes and completed in various ways: face-to-face; a telephone interview; a questionnaire through a paper-based survey; or, as is more common today, using an electronic medium such as email or the internet (122,123). For a survey to capture the data that is needed, the researcher needs to use the most appropriate sample and design (123). Surveys can be conducted to meet policy or programme needs and are an efficient way to generate data from large numbers of people (123,124). The survey in this study was designed to gather information that would provide an overall picture of exercise class provision in the East Midlands.

The design of a survey needs to be appropriate to the information the surveyor is looking to gather and clarify: how often the survey is to take place, the method of collection, how the participants for the survey are to be selected, and how many groups of participants are needed (123). This survey was designed to establish what type of exercise classes were available for older people, including those living with dementia in the East Midlands, and to purposively sample exercise classes for a future ethnographic study.

2.4.1.2 Spatial Analysis

Geographers are concerned with the where, how, and why of the physical environment as well as the societal environment in which humans exist and operate. Consequently, geography embraces both the objective and subjective views of science, lending itself to the philosophy of pragmatism.

Spatial analysis is a method geographers use to understand the world. It involves mapping where things are and how they relate. It is an important area of public health as it can be used to combine spatial data to show social issues (125). There are six main categories of spatial analysis: understanding where; measuring size, shape, and distribution; determining how places are related; finding best locations and paths; detecting and quantifying patterns and making predictions (126). This study has used spatial analysis to understand where things are and to detect patterns. Therefore, these will be described in further detail.

Board has described a map as a representation or abstraction of a geographical reality (127). To understand where things are, spatial data needs to be located on a

map. Point data identifies an object, such as a house, a shop, or a hospital, reducing it to a specific set of coordinates (128). This is discrete quantitative data, and postcodes are often used to locate the point data on the map, a technique called geocoding (126). This study used the postcode of all the exercise classes to locate them on a map of the East Midlands.

However, locating an object on a map cannot provide any further information. To detect any patterns, a second set of data is required. Choropleth maps use areal data, typically population-based census area units (128). This is also discrete quantitative data and uses information provided in the census to populate a thematic map (127). This study used census data from 2011 for the percentage of the population over 65, the 2015 UK Index of Multiple Deprivation for socioeconomic status and the 2016 World Population Density Estimate for the level of urbanisation to provide choropleth maps of the East Midlands.

The simplest form of spatial modelling is an overlay analysis whereby maps are laid on top of one another to allow an analysis of the patterns. This is commonly used in health care planning and involves matching point-referenced postcode data, such as patient locations, with areal locations, such as GP catchment areas. In this study, the point location maps of the exercise classes were overlaid onto small area population census choropleth maps to see if there was any correlation between where classes were located and the percentage of the population over 65 years of age, socioeconomic status, and level of urbanisation (128).

2.4.2 Qualitative methods

2.4.2.1 Ethnography

Ethnography is a research process which is generally utilised 'in the field'. It is a 'live' method where the researcher spends an extended period engaging with people in one or more social environments (129,130). It incorporates multiple research techniques, primarily qualitative, and always includes participant observations (129).

One established form of ethnographical research is when the researcher spends an extended period, at least a year, within a setting, taking part in the everyday activities of the people in that environment (131). However, there are other ethnographical techniques, including multi-sited ethnography, where a researcher follows a story, person, or object through different locations (132) and mini-ethnographies, where a researcher spends a shorter period with participants in one particular social situation (133). Ethnographic research can take place in various settings, from city neighbourhoods, hospital wards, care homes, and community centres and, with the use of technology, even on internet forums and chat groups (131,133–135).

This study aimed to explore the experiences of people who attended exercise classes in community settings. As a physiotherapist by background, I was aware that I would be placing myself in an environment where people might want to make a 'good impression' and tell me what they thought I wanted to hear. As American anthropologist, Margaret Mead noted that *"what people say, what people do and what people say they do are entirely different things"* (136 pg. 170). By participating in the exercise classes and immersing myself with the participants during both the

exercises and the refreshments, I hoped to reduce this bias to allow more open answers and opinions during the focus groups and interviews.

Several techniques can be utilised within an ethnographic study. This study used participant observation, focus groups and interviews, which will be discussed in further depth.

2.4.2.1.1 Participant observation

Participant observation is the principal technique used in ethnography: the researcher places themselves within a social environment to observe and experience that situation (131). There is a spectrum of participant observation with variable levels of both observation and participation from a complete observer, where the researcher will sit outside the environment and watch events unfold, to a complete participant, where a researcher immerses themselves fully in the environment (129,137). This study used a participant-as-observer approach which lies between these extremes. Time was spent with the participants in the exercise classes and other activities, leaving as they did after each session. Following each session, notes were written on what was observed, which provided some topic areas for further exploration with the focus groups (129,137).

2.4.2.1.2 Focus groups

A focus group provides a method of collecting qualitative data. It is well suited to exploratory qualitative research as group discussions can give participants the confidence to express views that may contradict other group members and can often generate rich data (33,138,139). The researcher acts as a facilitator who guides

the group and keeps them on topic but does not direct the conversation. This allows group members to explore the topic under discussion from several different angles (140,141). This interaction between members is a key characteristic of a focus group and distinguishes them from interviews which rely solely on the interaction between the interviewer and interviewee (140).

Focus groups can be used for generating information or ideas and for exploring participants' experiences and beliefs (141). They enable a large quantity of data to be collected using less time and financial resources. It is also possible to conduct focus groups online using software such as Zoom and Microsoft Teams (140).

The initial plan for this study was to conduct face-to-face focus groups in each exercise setting and a face-to-face focus group with instructors. However, the COVID-19 pandemic made it necessary to remain agile and offer what was appropriate and within the regulations at the time of each mini-ethnography. After the observations were complete with the initial exercise group, regulations were in place preventing groups from gathering; hence an online focus group was offered. Following the completion of the subsequent class observations, regulations were in place that allowed groups of six to meet, so two focus groups were completed of up to five people to ensure that the activity was compliant and continued to protect the participants. After the final observations were completed, the regulations had eased, so one large focus group could take place for carers.

2.4.2.1.3 Semi-structured interviews

Semi-structured interviews usually consist of predetermined questions set by the interviewer. However, these are designed to guide the structure of the interview and allow the scope to pursue ideas or answers in greater depth (140,141). Semi-structured interviews are often used in healthcare research as they offer structure to guide the conversation while also providing flexibility to elaborate on topics that are of importance to the participants (141). As with focus groups, interviews can be conducted online using appropriate software (140).

Interviews were not an integral part of the study's original design but were offered as an option if participants were uncomfortable in a focus group. However, due to the COVID-19 pandemic, interviews became a crucial data collection method. Due to the restrictions, an online interview was completed with a participant following the online exercise class, and all instructors were interviewed separately. The timescales and changing regulations between each observation period meant that conducting one focus group with all the instructors was not a feasible option. Separate interviews were also conducted with members of the dementia-specific exercise class due to the differing needs of the participants.

Focus groups and individual interviews can be complementary techniques across a research project. Using both in the study enabled data collection to continue and be flexible with the ever-changing regulations due to the pandemic (142).

2.5 Conclusion

The two classical schools of thought in the philosophy of science offer two options: objective knowledge and subjective knowledge. However, an ecological approach where it is acknowledged that individuals are situated within a wider system requires an alternative philosophical position. The traditional subjective/objective dualism does not provide a useful theoretical foundation for a study of this kind. Hence, the thesis is underpinned by the philosophy of classical pragmatism of John Dewey, which provides a perspective that not only supports a systems approach to physical activity promotion but offers a theoretical foundation that is well aligned with mixed methods research.

Chapter Three

3 Mixed methods systematic literature review

3.1 Introduction

This chapter presents a mixed methods systematic review of the wider published literature. It investigates the extent to which group exercise classes are effective for people living with dementia in the community and the barriers and facilitators to attendance for this cohort.

There have been no published systematic reviews which consider the effectiveness of group exercise for people living with dementia, and many primary studies exclude this group (87,143–146). In addition, those which include people living with dementia can fail to identify them as a distinct cohort within a mixed population, making it unwise to draw firm conclusions from the results (147–150).

As it is unclear which components of exercise classes provide maximum benefit and encourage people living with dementia to attend and continue to attend them, the objective of this mixed methods literature review was to enhance this understanding.

3.2 Review questions

1. What is the effectiveness of group exercise interventions over usual care for adults over 65 years of age living with dementia in community settings?
2. What are the barriers and facilitators to attending or delivering group exercise classes for people over 65 years of age living with dementia in the community?

3. To what extent do the barriers and facilitators influence the effectiveness of the intervention?

3.3 Methods

A preliminary search of PROSPERO, MEDLINE, the Cochrane Database of Systematic Reviews and the JBI Database of Systematic Reviews and Implementation Reports was conducted before undertaking the review, and no current or underway systematic reviews on the topic were identified (21.04.20).

A mixed methods systematic review was identified as most appropriate to support this study as it synthesises and integrates qualitative, quantitative, and mixed methods primary studies to increase the breadth and depth of understanding of a particular issue (151). This approach enabled the investigation of different but related review questions regarding group exercise for people with dementia (152) to be investigated and synthesised to answer the research questions.

The review was conducted in accordance with the Joanna Briggs Institute (JBI) methodology for segregated mixed methods systematic reviews (153) and the protocol was registered on PROSPERO (https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020178966).

3.3.1 Inclusion criteria

3.3.1.1 Population

The review included studies of adults over the age of 65 years, of any gender, diagnosed with any type of dementia living in community settings. Community settings were defined as all settings other than hospitals, including, but not limited

to, day centres, community groups and care homes (42). Studies with mixed-age populations were included if the mean age was over 65 (154). Studies were included if more than 75% of the sample had been categorised as living with dementia (155,156). Studies where the population was ambiguous were excluded.

The review also included the views of people directly involved in or attending the classes, including people living with dementia, carers of participants and exercise instructors.

3.3.1.2 Intervention

Studies that involved interventions described by their authors as providing any form of group physical activity or exercise, in its broadest sense, were included.

Physical activity was defined as *"a bodily movement produced by skeletal muscles that results in an energy expenditure*" (10 pg. 36). Exercise was defined as *"a physical activity that is planned, structured, repetitive and designed to improve or maintain physical fitness, physical performance or health"* (10 pg. 36). A group was defined as one or more persons, who were accepted as the facilitators, delivering an activity to three or more people who interact with each other and recognise that they are members of that group (37). Studies where an intervention reported increased physical activity or exercise benefits but where the aim of the intervention was not defined as group physical activity or exercise were not included. No restrictions were applied regarding the frequency, intensity, or length of time of the intervention. Studies were included where the intervention had not been specifically developed for people living with dementia.

3.3.1.3 Comparator

The comparator was usual care control; no treatment control or socialisation control used to exclude the Hawthorne effect. The socialisation control varied but usually consisted of activities such as reading, playing cards, and listening to music. These activities took place for the same length of time as the intervention and were led by a member of staff or a member of the research team. Usual care was variable between studies but usually described as the routine treatment available in the country where the study occurred. Studies that compared the intervention to talking therapy, reminiscence therapy or another form of psychological therapy were excluded as these were not considered usual care in all countries.

3.3.1.4 Outcome measures

Studies that included standardised, validated or published outcome measures related to physical health, psychological health and quality of life were included, e.g., timed up and go (157), 30-second stand (158), 6-metre walk (159) and grip strength (160), Montgomery-Asberg Depression Rating Scale (161), Cornell Scale for Depression in Dementia (162), Dementia Quality of Life Scale (163) and the Quality of Life in Alzheimer's Disease (164).

The outcome measures were grouped according to umbrella categories (e.g., physical health, psychological health, quality of life etc.) (42).

3.3.1.5 Phenomena of interest

The review included studies that identified and explored the barriers and facilitators to people living with dementia, their families and carers accessing and attending

community group-based exercise classes alongside barriers and facilitators to staff delivering the classes.

3.3.1.6 Context

Studies exploring interventions delivered in community groups (per previous definitions) and those with a mix of group and home-based individual intervention sessions were included if the article stipulated that at least 50% of the intervention occurred in a group setting. Groups which took place within an acute setting, such as a hospital ward, were excluded.

3.3.1.7 Types of studies

The review considered quantitative, qualitative, and mixed methods studies. Quantitative studies included randomised and quasi-randomised controlled trials, including cluster-randomised trials, which evaluated the benefits of group exercise or physical activity. Qualitative studies included those that focused on qualitative data and included designs such as grounded theory and ethnography. Mixed methods studies were only included if data from the quantitative or qualitative components could be clearly extracted. Only studies published in English were included.

3.3.2 Search methods for identification of studies

3.3.2.1 Search strategy

With the assistance of a professional research librarian at the University of Nottingham, an initial search of MEDLINE was undertaken (20/11/19) to refine a search strategy by reviewing words used in the titles, abstracts, and index terms of

relevant articles. The final search strategy was adapted for each information source; the search terms are provided in Appendix A. The reference lists of all included studies were screened for additional material. Studies published from each database from inception to present were included.

3.3.2.2 Information sources

Six electronic databases (MEDLINE; Embase; CINAHL; AMED; PsycINFO; and PEDRO) were searched for primary studies on 21/04/20 (quantitative) and 28/04/20 (qualitative).

3.3.2.3 Study selection

All records identified through the searches were imported into Mendeley Version 1.19.4, and duplicates removed. Titles and abstracts of all studies were screened by one reviewer (AL) to determine whether they met the inclusion criteria. Full-text articles for all potentially relevant studies were retrieved, and their citation details imported into the Joanna Briggs Institute System for the Unified Management, Assessment and Review of Information (JBI SUMARI) (Joanna Briggs Institute, Adelaide, Australia) (165). Two reviewers (AL and LH) assessed the full-text articles to determine whether they met the inclusion criteria.

Any disagreements arising between the reviewers at each stage of the study selection process were resolved through discussion.

3.3.3 Assessment of methodological quality

Eligible studies were critically appraised by two independent reviewers (AL and LH) for methodological quality using JBI standardised critical appraisal instruments for

Randomised Controlled Trials (RCTs) (166), quasi-experimental studies (166) and qualitative studies (167). These forms are available through JBI SUMARI and are provided in Appendix B. The quantitative and qualitative components of mixed methods studies were appraised separately using the appropriate JBI critical appraisal instruments.

Any disagreements arising between the reviewers were resolved through discussion. Due to the limited number of relevant studies of any specific design, all were included in the review regardless of methodological quality.

3.3.4 Data extraction

Quantitative and qualitative data were extracted from the included studies by one reviewer (AL) using the standardised Joanna Briggs Institute data extraction tools in JBI SUMARI (165). For quantitative studies, data extracted included details of interventions, population, study methods, and final post-intervention means and standard deviations from relevant physical health, psychological health, and quality of life questionnaires.

For qualitative studies, data extracted included details about the population, study methods, barriers and facilitators, and information regarding setting and geographical location. Findings and their illustrations were extracted and assigned a level of credibility (unequivocal, credible, or not supported) (167,168).

Unequivocal (U) or evidence that was beyond reasonable doubt included findings that were matters of fact, directly reported, or observed and were not open to challenge. Credible (C) included findings that could be logically inferred from the

data. However, because they were interpretive in nature, they were open to challenge. Not supported (NS) were findings that were unsupported by the data (169).

Following the quantitative and qualitative syntheses, the intervention studies were revisited. Data were extracted from each study by the same reviewer (AL) to identify if the barriers and facilitators identified in the qualitative synthesis had been included in the design of the intervention.

As the number of studies for inclusion was over 20, a second reviewer (LH) independently extracted data from 20% of the studies to reduce error and minimise bias. Both reviewers were full-time PhD students and had limited time and resources to complete data extraction. Single data extraction with verification does not necessarily affect the results and conclusions of an analysis but does take significantly less time (170). Both reviewers piloted the extraction tools to ensure consistency and extracted data independently before conferring. Any disagreements arising between the reviewers were resolved through discussion.

3.3.5 Data synthesis and integration

The review followed a convergent segregated approach to synthesis and integration according to the JBI methodology for mixed methods systematic review using JBI SUMARI (153,165). This approach is usually selected when literature from quantitative and qualitative studies complement each other. The quantitative and qualitative evidence are synthesised separately, followed by the integration of the resultant evidence (171).

3.3.5.1 Quantitative data synthesis

A meta-analysis of data from the quantitative studies was not possible because the experimental studies that were included used a range of interventions assessed by a series of different outcome measures and using a variety of intervention dosages. Therefore, quantitative findings from the RCT and quasi-experimental studies have been presented as a narrative synthesis (42).

To provide a clearer representation of the results, an effect direction plot was produced which used the four broad intervention categories to reflect the types of exercise interventions. Studies were initially grouped by intervention category and then ordered by study design (prioritising randomised controlled trials [RCT] ahead of controlled before and after studies [CBA]), study quality (using the results from the critical appraisal) and date of publication. Visual representations (arrows) indicated the reported effect direction (improvement ↑, deterioration ↓ or no change/mixed findings ←→). An indication of study size and statistical significance was incorporated within each arrow using size and colour (172,173).

3.3.5.2 Qualitative data synthesis

Qualitative research findings were pooled using JBI SUMARI with the meta-aggregation approach (167). This involved a synthesis of the findings from the primary studies. Comparable findings were grouped into categories which reflected their similarity. These categories were combined further and used to generate statements representing this aggregation.

3.3.5.3 Integration of quantitative evidence and qualitative evidence

To further integrate the findings of the quantitative and qualitative synthesis, a matrix was constructed using a Microsoft Excel spreadsheet (pg.93) to juxtapose the barriers and facilitators for people living with dementia in attending exercise classes with the outcomes measured in the intervention studies (174). Since the outcome of the qualitative synthesis was not known in advance, the intervention studies were revisited to identify whether the barriers and facilitators were considered in each intervention (175). Data were extracted from each study by one reviewer (AL) to ascertain if the barriers and facilitators identified in the qualitative synthesis had been considered in the design of the interventions. This data was then used in the matrix which was structured to show whether there was an impact on the effectiveness of the interventions if the barriers and facilitators outlined in the qualitative synthesis were considered part of the intervention's design.

3.4 Results

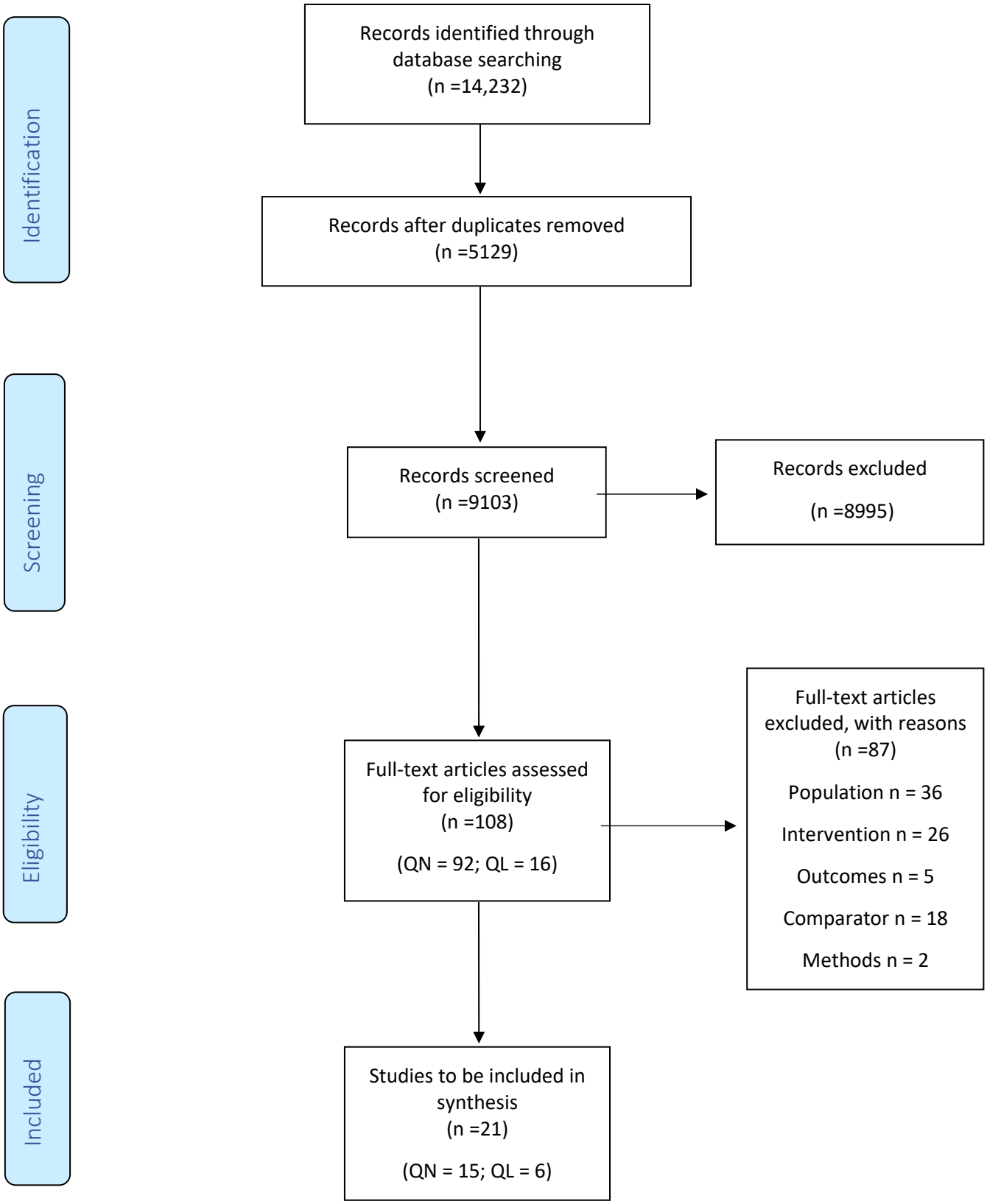
3.4.1 Study inclusion

There were 14,232 studies identified as being potentially relevant to the review. After 5129 duplicates were removed, 9103 records were screened at the title and abstract level for inclusion; full-text articles were assessed for eligibility and a further 87 were excluded. Reasons for exclusion of full-text studies were recorded and presented in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram below (176).

Data were extracted independently by one reviewer (AL) for the remaining 21 articles, with a second reviewer (LH) extracting data from 20% (n=4) to minimise bias

and reduce error. Twelve studies from fifteen articles were included in the quantitative review, and six studies from six articles in the qualitative review.

Figure 7 Flow diagram of search and study selection process (176)



n = number; QN = Quantitative Studies; QL = Qualitative Studies

3.4.2 Quality appraisal

The critical appraisal scores of the eleven included RCTs ranged from nine to eleven from a possible score of thirteen. The four quasi-experimental studies scored eight or nine out of nine, and the six qualitative studies ranged from three to eight out of ten. Tables 1 – 3 provide a summary of the quality appraisal, including a ranking to indicate the comparative quality of each study.

3.4.3 Critical appraisal results

Table 1 Randomised controlled trials

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Score	Rank
Lamb S.E, Mistry D, Alleyne S, et al. 2018.	Y	Y	Y	N	N	Y	Y	Y	Y	Y	Y	Y	Y	11/13	= 1
Telenius EW, Engedal K, Bergland A 2015.	Y	Y	Y	N	N	Y	Y	Y	Y	Y	Y	Y	Y	11/13	= 1
Toots A, Littbrand H Lindelof N, et al. 2016.	Y	Y	Y	N	N	Y	Y	Y	Y	Y	Y	Y	Y	11/13	= 1
Telenius EW, Engedal K, Bergland A 2015.	Y	Y	Y	N	N	Y	Y	Y	Y	Y	Y	Y	Y	11/13	= 1
Toots A, Littbrand H, Holmberg H, et al. 2017.	Y	Y	Y	N	N	Y	Y	Y	Y	Y	Y	Y	Y	11/13	= 1
Bostrom G, Conradsson M, Hornsten C, et al. 2015	Y	Y	N	N	N	Y	Y	Y	Y	Y	Y	Y	Y	10/13	= 6
Nyman SR, Ingram W, Sanders J, et al. 2019.	Y	Y	Y	N	N	U	Y	Y	Y	Y	Y	Y	Y	10/13	= 6
Huang N, Li W, Rong X, et al. 2019	Y	Y	Y	N	N	U	Y	Y	Y	Y	Y	Y	Y	10/13	=6
Venturelli M, Lanza M, Muti	U	U	Y	N	N	Y	Y	Y	Y	Y	Y	Y	Y	9/13	= 9

E, Schena F. 2010.															
Kemoun G, Thibaud M, Roumagne N, et al. 2010	Y	U	Y	N	N	U	Y	Y	Y	Y	Y	Y	Y	9/13	=9
Miu DKY, Szeto SL, Mak YF 2008.	U	U	Y	N	N	Y	Y	U	Y	Y	Y	Y	Y	8/13	11

Y = Yes; N = No; U = Unclear; JBI critical appraisal checklist for randomised controlled trials

Q1 = Was true randomisation used for assignment of participants to treatment groups?
Q2 = Was allocation to treatment groups concealed?
Q3 = Were treatment groups similar at baseline?
Q4 = Were participants blind to treatment assignment?
Q5 = Were those delivering treatment blind to treatment assignment?
Q6 = Were outcome assessors blind to treatment assignment?
Q7 = Were treatment groups treated identically other than the intervention of interest?
Q8 = Was follow-up complete, and if not, were strategies to address incomplete follow-up utilised?
Q9 = Were participants analysed in the groups to which they were randomised?
Q10 = Were outcomes measured in the same way for treatment groups?
Q11 = Were outcomes measured in a reliable way?
Q12 = Was appropriate statistical analysis used?
Q13 = Was the trial design appropriate, and any deviations from the standard RCT design (individual randomisation, parallel groups) accounted for in the conduct and analysis of the trial?

Of the eleven randomised controlled trials, nine used true group randomisation (Q1), and allocation to treatment was blinded in eight (Q2). Treatment groups were similar in all trials apart from one (177), where anti-depressant use was higher in the intervention group (Q3). Blinding of participants and personnel delivering the intervention was not possible due to the nature of exercise intervention trials (Q4, Q5). Outcome assessors were blinded in eight trials (Q6). Follow-up was either complete, or strategies to address incomplete follow-up were utilised in ten trials (Q8). All studies met criteria seven and nine to thirteen.

Table 2 Quasi-experimental studies

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Scores	Rank
Thurm F, Scharpf A, Liebermann N, et al. 2011.	Y	Y	Y	Y	Y	Y	Y	Y	Y	9/9	=1
Tsugawa A, Shimizu S, Hirose D, et al. 2020.	Y	Y	Y	Y	Y	Y	Y	Y	Y	9/9	= 1
Sampaio A, Marques EA, Mota J, Carvalho J. 2019.	Y	Y	U	Y	Y	Y	Y	Y	Y	8/9	= 3

Henwood T, Neville C, Baguley C, Beattie E. 2017.	Y	N	Y	Y	Y	Y	Y	Y	Y	8/9	= 3

Y = Yes; N = No; U = Unclear; N/A = not applicable; JBI critical appraisal checklist for quasi-experimental studies

Q1 = Is it clear in the study what is the cause' and what is the 'effect' (i.e., there is no confusion about which variable comes first)?
Q2 = Were the participants included in any comparisons similar?
Q3 = Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?
Q4 = Was there a control group?
Q5 = Were there multiple measurements of the outcome, both pre and post the intervention/exposure?
Q6 = Was follow up complete, and if not, were differences between groups in terms of their follow up adequately described and analysed?
Q7 = Were the outcomes of participants included in any comparisons measured in the same way?
Q8 = Were outcomes measured in a reliable way?
Q9 = Was appropriate statistical analysis used?

In the four quasi-experimental trials, the participants included in comparisons were similar in all but one trial (Q2) (178). In one trial (179), it was unclear whether the comparison group was receiving similar care other than the intervention of interest (Q3). All four trials met criteria one and four to nine.

Table 3 Qualitative studies

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Scores	Rank
Brett L, Traynor V, Stapley P, Meedya S. 2018.	Y	Y	Y	Y	Y	U	N	Y	Y	Y	8/10	= 1
Wright A. 2018.	Y	Y	Y	Y	Y	N	N	Y	Y	Y	8/10	= 1
Guzmán-García A, Mukaetova-Ladinska E, James I. 2012	Y	U	Y	Y	Y	N	U	Y	Y	Y	7/10	= 3
Barrado-Martín Y, Heward M, Polman R, Nyman SR. 2019.	U	Y	Y	Y	Y	N	N	Y	Y	Y	7/10	= 3
Lamb S.E, Mistry D, Alleyne S, et al. 2018.	U	Y	Y	Y	Y	U	N	Y	Y	Y	7/10	= 3
Post D, Corlis M, Penington A, Parfitt G. 2018.	N	U	Y	U	U	N	N	U	Y	Y	3/10	6

Y =yes; N = no; U = unclear; JBI critical appraisal checklist for qualitative research.

Q1 = Is there congruity between the stated philosophical perspective and the research methodology?
Q2 = Is there congruity between the research methodology and the research question or objectives?
Q3 = Is there congruity between the research methodology and the methods used to collect data?
Q4 = Is there congruity between the research methodology and the representation and analysis of data?
Q5 = Is there congruity between the research methodology and the interpretation of results?
Q6 = Is there a statement locating the researcher culturally or theoretically?
Q7 = Is the influence of the researcher on the research, and vice versa, addressed?
Q8 = Are participants and their voices adequately represented?
Q9 = Is the research ethical according to current criteria, or for recent studies, is there evidence of ethical approval by an appropriate body?
Q10 = Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

Of the six qualitative studies, three reported congruity between philosophical perspectives and the research methodology (Q1) and four reported congruity

between the research methodology and the research question or objectives (Q2). Five studies reported congruity between the research methodology and the representation and analysis of data (Q4) alongside the interpretation of results (Q5). None of the studies located the researcher culturally or theoretically (Q6) or addressed the influence of the researcher on the research and vice versa (Q7). Participant voices were adequately represented in all but one study (Q8). In all studies, there was congruity between the research methodology and the methods used to collect data (Q3), evidence of ethical approval (Q9), and conclusions that flowed from the analysis or interpretation of the data (Q10).

3.4.4 Characteristics of included studies

Detailed information on all the included studies is provided in Appendix C.

3.4.4.1 Quantitative studies

Twelve studies conducted between 2008 and 2020 were included from the fifteen articles. In the following sections, the main features of these studies are summarised.

3.4.4.1.1 Study settings

Eight studies were undertaken in Europe with one study each in Germany (180), Portugal (179), France (181), Italy (182), Norway (183), and Sweden (177). Two studies were undertaken in the United Kingdom (184,185), and the remaining four in Japan (186), Australia (178), China (187), and Hong Kong (188). Two articles described the same study in Norway (76,183), and three articles discussed one study in Sweden (177,189,190).

The interventions described were undertaken in residential care homes in eight studies (177–181,183,186,187), one in an assisted living facility (182), two in community settings (184,185) and one in an outpatient memory clinic (188).

3.4.4.1.2 Participants

A total of 1,313 participants were included, ranging from 15 to 494 per study. Approximately 56% (n = 729) of participants were female, with one study including only female participants (182).

The inclusion criteria for the studies varied. Age was used as a criterion in nine studies with three not specifying age. Two studies used over 18 (184,185), one over 55 (183), two over 60 (187,188) and three over 65 (177,179,182). One study included 'older adults' with no specific age range (180). All studies reported mean age ranging from 75 to 87 years, whereas the age range was only reported in three studies and was 59 to 97 years.

Ten studies had a diagnosis of dementia as a specific inclusion criterion (177–181,183–185,187,188).

One study did not specify a diagnosis of dementia (182), and another required a diagnosis of cognitive impairment (186). There was variation in both the measures used to establish the criteria for judging the stage of dementia and in the cut-off points used in the studies. Six used the Mini Mental State Examination (MMSE) (177,180–182,184,188), three used the Clinical Dementia Rating (CDR) (179,183,187), one used the Mini Addenbrooke's Cognitive Examination (M-ACE) (185) and two used no measurement (178,186). The cut-off points for the MMSE

varied greatly. Two studies used more than 10 as the cut-off point (177,184), with 10 – 26 (188), 15 – 25 (182), lower than 24 (180) and lower than 23 (181) being used in one study each. CDR range was variable too, with one study using lower than 2 (187), one study 1 – 2 (183), and one study not stating a cut-off point (179). The M-ACE was used in one study with a cut-off of 10 (185).

Three studies had community-dwelling as an inclusion criterion (184,185,188); the remaining nine studies all took place in residential care facilities. Eight studies had a physical ability inclusion criterion. One of these required participants to be ambulatory (188), and another that they could participate in the measures and outcomes (180). Two studies required the ability to walk ten metres without aid (178,181), one to walk ten metres without human assistance and the ability to independently stand from a seated position (184). One study required the ability to stand from sitting with the assistance of one person (177), whilst another specified this alongside being able to walk six metres (183). One study required participants to have the ability to stand to perform tai chi movements (185), and another included only participants with serious mobility issues (182).

3.4.4.1.3 Interventions/comparators

The interventions were varied, with durations ranging from ten weeks (180) to twelve months (186), with the majority being 12 to 16 weeks. The frequency of intervention varied from once a week (185) to twice a week (178–180,183,184,186,188) and three times a week (177,181,182,187). One study evaluated sessions of 20 minutes (187), whilst all others had sessions between 45 minutes and one hour. Five studies were categorised as multi-component

interventions featuring a combination of at least two components, including aerobic, strength, balance, and flexibility exercises (177,179,180,183,184). Four studies consisted of aerobic exercises only (178,181,186,188), two were based on tai chi (185,187) and one upper limb exercises (182). All studies stated that they were comparing the exercise intervention to usual care or conventional treatment. This was variable between studies but usually described as the routine treatment available in the country where the study was undertaken. Two studies devised a programme for the control group (177,183) described as activities usually provided in nursing homes, such as playing games, singing, and listening to music; this was proposed to ameliorate the Hawthorne effect.

3.4.4.1.4 Outcome measures

A range of outcome measures were used in the included studies. Physical outcome measures have been grouped and included: a 6-minute walk (188) and a 2-minute step test (179) for endurance; grip strength (178,186), 30-second chair stand (179,183), arm curl (179,182) and sit-to-stand (178,180) for strength. Balance measures included Berg Balance Scale (183,185,188,190), timed up and go (178–180,185), functional reach tests (178,180,188) and a standing balance test (178). Gait and gait speed were variously measured using a 6-metre walking test (183), a 10-metre walking test (181), a 2.4-metre walk (178) and a 4-metre walk (179). Psychological outcomes were measured using the Cornell Scale for Depression in Dementia (183,188), the Montgomery-Asberg Depression Rating Scale (177) and the Geriatric Depression Scale 15 (177,186,187). Quality of life was assessed using the

EuroQol 5D 3L (EQ5D3L) (184), the Quality of Life in Alzheimer's Disease (QoL-AD) (184) and the Quality of Life in Late-Stage Dementia Scale (QUALID) (183).

3.4.4.2 Qualitative studies

Six qualitative studies conducted between 2013 and 2019 were included: four were undertaken in the United Kingdom (184,191–193) and two in Australia (171,194). Four studies did not describe the specific methodology they employed: one used grounded theory (193) and another ethnography (192). Data collection methods included observations (184,191,192), interviews (171,184,192–194) and focus groups (191). All studies analysed data thematically; one aimed to develop a theoretical model (193). Participants were people living with dementia, care staff and informal carers/family members. One study also interviewed the physiotherapists who delivered the intervention (184). The total number of participants drawn from the included studies was 122, comprising: 43 people living with dementia, 33 carers/family members, 34 care staff and 12 people delivering the intervention.

3.4.5 Review findings

3.4.5.1 Quantitative evidence

Fourteen physical, three psychological and three quality-of-life outcome measures were used in the included studies. To synthesise the results, the interventions evaluated in the twelve quantitative studies were grouped into four broad intervention categories: multi-component, aerobic, strength, and tai chi. The reported effect directions for each individual outcome are presented as arrows in the tables below.

3.4.5.1.1 Multi-component interventions

Five studies were reported as evaluating a multi-component intervention (177,179,180,183,184) which included at least two of aerobic, strength, balance, and flexibility exercises.

Table 4 Multicomponent interventions outcome measures results

Study	Physical outcome measure	Results	Psychological outcome measure	Results	Quality of life outcome measure	Results
Lamb 2018					EQ5D3L	◁ ▷
					QoL -AD	◁ ▷
Telenius 2015	BBS	▲	Cornell Scale for Depression in Dementia	△	QUALID	◁ ▷
	30 Sec CST	△				
	6m walk (m/s)	◁ ▷				
UMDEX 2015	BBS	▲	MADRS	◁ ▷		
	4m walk (m/s)	◁ ▷	GDS15	◁ ▷		
Sampaio 2019	30 Sec CST	▲				
	Arm Curl (kg)	▲				
	2 min step test	▲				
	TUG (m/s)	▲				
Thurm 2011			GDS-15	◁ ▷		

Sample size: large arrow ▲ > 300; medium arrow ▲ 50 – 300; small arrow ▲ <50. Effect Direction: upward arrow △ positive findings, downward arrow ▽ negative findings, sideways arrow ◁ ▷ no change/mixed findings. Statistical significance: black arrow ▲ p <0.05; grey arrow △ p >0.05; empty arrow △ no statistics reported.

3.4.5.1.1.1 Physical outcomes

In these trials, physical outcomes were the most frequently measured (177,179,183). The physical outcome measures used were variable, so these have been further grouped (balance, endurance, and strength) to allow for analysis.

Balance was measured in three trials using a Berg Balance score in two (177,183) and timed up and go in one (179); significant improvement was found in all three trials ($p = 0.02$; $p < 0.001$; $p = 0.029$ respectively). Endurance was measured in three trials using the 6-metre walk test (183), the 4-metre walk test (177) and the 2-minute step test (179). Two trials (177,183) found no significant change ($p = 0.86$ and $p= .034$, respectively), whilst one trial (179) reported a significant improvement ($p< 0.001$). Strength was measured in two trials using the 30-second chair stand test (179,183) with one (183) reporting a non-significant improvement of 1 repetition ($p = 0.11$) and the other (179) a significant increase of 3.8 repetitions ($p < 0.05$).

3.4.5.1.1.2 Psychological outcomes

Three studies explored the effect of exercise on mood (177,180,183). One (183) used the Cornell Scale for Depression in Dementia and found a non-significant positive change in mood ($p = 0.39$); the other (177) used the Montgomery-Asberg Depression Rating Scale (MADRS) and found no change in mood ($p = 0.94$). Two studies (177,180) used the Geriatric Depression Scale (GDS15) and found no change in mood ($p = 0.91$ and no statistics reported, respectively).

3.4.5.1.1.3 Quality of life outcomes

Two studies measured the effect of exercise on quality of life (183,184). One (183) used the Quality of Life in Late-Stage Dementia Scale (QUALID) and found a small non-significant change in quality of life (p = 0.97). The other (184) used both the EQ5D3L and the Quality of Life in Alzheimer's Disease (QoL-AD) scales and found no significant difference in quality of life (p = 0.240 and p =0.879, respectively).

3.4.5.1.2 Aerobic interventions

Four studies were reported as evaluating aerobic interventions (178,181,186,188) and included swimming, static biking, treadmill, and walking.

Table 5 Aerobic interventions outcome measures results

Study	Physical outcome measure	Results	Psychological outcome measure	Results	Quality of life outcome measure	Results
Kemoun 2010	10 m walk (m/s)	▲				
Miu 2008	6-min walk (m)	▲	Cornell Scale for Depression in Dementia	▼		
	Functional Reach (cm)	▲				
	BBS	▲				
Tsugawa 2020	Grip (kg)	▲	GDS-15	△		
Henwood 2017	Grip (kg)	▲				
	TUG(m/s)	△				
	Functional reach (cm)	◀ ▶				
	Standing Balance (sec)	◀ ▶				
	2.4 m walk (m/s)	◀ ▶				
	CST (secs)	◀ ▶				

Sample size: large arrow ▲ > 300; medium arrow ▲ 50 – 300; small arrow ▲ <50. Effect Direction: upward arrow ▲ positive findings, downward arrow ▼ negative findings, sideways arrow ◁ ▷ no change/mixed findings. Statistical significance: black arrow ▲ p <0.05; grey arrow ▲ p >0.05; empty arrow △ no statistics reported.

3.4.5.1.2.1 Physical outcomes

Physical outcomes were most commonly measured in trials using aerobic interventions, with all four trials using at least one outcome measure of physical function. Due to the variability of the outcome measures, they have been grouped for analysis as previously.

Balance was measured in one study using a Berg Balance Score and a functional reach test (188) and in another using a timed up-and-go (178). There was a significant improvement in one trial (188) ($p < 0.001$ and $p = 0.007$, respectively) but not in the other (178) ($p = 0.396$). Endurance was measured in three studies using a 10-metre walk (181), a 6-minute walk (188), and a 2.4-metre walk (178). There were significant improvements in two studies (181,188) ($p <0.01$, $p <0.001$), but not in the third (178) ($p = 0.255$). Strength was measured in two studies using a grip test (178,186) and found significant improvements over time ($p = 0.017$, $p = 0.007$, respectively).

3.4.5.1.2.2 Psychological outcomes

Two trials considered the effect of exercise on mood (186,188) with differing results. Tsugawa (186) found a non-significant change ($p = 0.242$) using the GDS15. Miu (188) used the Cornell Scale for Depression in Dementia and reported that post-intervention, the control group were less depressed than the exercise group ($p = 0.004$).

3.4.5.1.2.3 Quality of life outcomes

No aerobic intervention used quality of life as an outcome measure.

3.4.5.1.3 Strength interventions

One study was categorised as a strength intervention (182) and used an upper limb strength training circuit. The study found a significant improvement in upper limb strength using an arm curl test ($p<0.05$).

Table 6 Strength interventions outcome measures results

	Physical outcome measure	Results	Psychological outcome measure	Results	Quality of life outcome measure	Results
Venturelli 2010	Arm Curl (kg)	▲				

Sample size: large arrow ▲ > 300; medium arrow ▲ 50 – 300; small arrow ▲ <50. Effect Direction: upward arrow ▲ positive findings, downward arrow ▼ negative findings, sideways arrow ◁ ▷ no change/mixed findings. Statistical significance: black arrow ▲ p <0.05; grey arrow ▲ p >0.05; empty arrow △ no statistics reported.

3.4.5.1.4 Tai chi

Two studies were categorised as tai chi interventions (185,187) which had been modified for older people living with dementia. One study measured balance as a physical outcome (185) using a Berg Balance Score and timed up and go and found no significant difference ($p = 0.99$, $p = 0.59$, respectively). Another study examined the effect of tai chi on mood (187) using the GDS 15 and found a significant improvement in mood ($p< 0.05$). Neither tai chi intervention used quality of life as an outcome measure.

Table 7 Tai chi interventions outcome measures results

Study	Physical outcome measure	Results	Psychological outcome measure	Results	Quality of life outcome measure	Results
Nyman 2019	TUG (m/s)	◁ ▷				
	BBS	◁ ▷				
Huang 2019			GDS - 15	▲		

Sample size: large arrow ▲ > 300; medium arrow ▲ 50 – 300; small arrow ▲ <50. Effect Direction: upward arrow ▲ positive findings, downward arrow ▼ negative findings, sideways arrow ◁ ▷ no change/mixed findings. Statistical significance: black arrow ▲ p <0.05; grey arrow ▲ p >0.05; empty arrow △ no statistics reported.

3.4.5.2 Summary of quantitative evidence

The effect direction plot below (Table 8) displays the 12 studies with the intervention under investigation in the first column and the intervention type in the fourth. The primary outcome measures for each study are then highlighted in the rows.

Table 8 Summary of effect directions from included studies.

Intervention	Author, Year	Study Design	Intervention Type	Balance	Endurance	Strength	Psychological Health	Quality of Life
Multicomponent Intervention								
	Lamb 2018	RCT	Cycling; Resistance work with weights					◁ ▷
	UMDEX 2015	RCT	High-Intensity Functional Exercise	▲	◁ ▷		◁ ▷	
	Telenius 2015	RCT	High-Intensity Functional Exercise	▲	◁ ▷	▲	▲	◁ ▷
	Sampaio 2019	CBA	Aerobic exercises; strength and balance training	▲	▲	▲		
	Thurm 2011	CBA	Seated strength, balance, and stamina training				◁ ▷	
Aerobic Intervention								

	Kemoun 2010	RCT	Walking; ergo cycle and dancing		▲			
	Miu 2008	RCT	Treadmill, cycling and arm ergometry	▲	▲		▼	
	Tsugawa 2020	CBA	Sitting aerobic exercises			▲	△	
	Henwood 2017	CBA	Aerobic exercises in water	◁ ▷	◁ ▷	▲		
Strength Intervention								
	Venturelli 2010	RCT	Upper limb resistance work using weights and therabands			▲		
Tai Chi								
	Nyman 2019	RCT	Tai chi classes and home practice	◁ ▷				
	Huang 2019	RCT	Tai Chi classes				▲	

Sample size: large arrow ▲ > 300; medium arrow ▲ 50 – 300; small arrow ▲ <50. Effect Direction: upward arrow △ positive findings, downward arrow ▽ negative findings, sideways arrow ◁ ▷ no change/mixed findings. Statistical significance: black arrow ▲ p <0.05; grey arrow △ p >0.05; empty arrow △ no statistics reported.

Three medium-sized trials of high or good quality (183,188,190) and one small trial of high quality (179) provided evidence that exercise interventions were effective in improving balance. However, two medium-sized trials of high quality (178,185) showed no clear benefit, providing mixed evidence of the benefit of exercise for balance.

Two small trials of high or good quality (179,181) and one medium-sized trial of good quality (188) provided evidence that exercise interventions were effective in improving endurance. Three medium-sized high-quality trials (178,183,189) showed

no clear benefit, thus providing mixed evidence of the benefit of exercise for endurance.

One medium-sized high-quality trial (178) alongside three small good or high-quality trials (179,182,186) provided evidence that exercise interventions are effective over time for improving strength. One medium-sized high-quality trial (183) showed a positive trend towards improvement. This provides evidence that exercise can improve strength in people with dementia.

Four medium-sized trials of high or good quality (177,183,187,188) provided mixed evidence of the benefits of exercise for mood with one showing the intervention as effective, one showing a positive trend towards improvement, one showing no clear benefit and one showing that the intervention had a worsening effect. Two smaller high-quality trials (180,186) showed a positive trend towards improvement. Hence, no clear benefit of exercise for mood was found in this review.

One large and one medium-sized high-quality trial (183,184) showed no clear benefit of exercise for quality of life.

3.4.5.3 Qualitative evidence – barriers and facilitators to attendance

Findings from six studies (171,184,191–194) were extracted and aggregated to form eight categories which explored the barriers and facilitators people living with dementia experienced when attending group exercise classes. The findings were graded as unequivocal (U) or credible (C) (167). The illustrations for each of these findings are provided in Appendix D.

The eight categories were further synthesised, which yielded the following two synthesised findings: i) barriers to physical activity can be overcome with positive attitudes and the right environmental attributes; ii) people with dementia and their carers experience a wide range of benefits from taking part in physical activity. These are outlined in Tables nine and ten below. The meta-aggregative flow charts illustrating each synthesised finding are provided in Appendix E.

3.4.5.3.1 Synthesised Finding 1: Barriers to physical activity can be overcome with positive attitudes and the right environmental attributes.

Table 9 Synthesised Finding 1

Category 1: Barriers for Care Staff
1. Barriers to physical activities for people with dementia (U) (194)
2. Barriers to implementation (C) (171)
3. Barriers/Difficulties (care staff) (C) (193)
4. The therapeutic alliance between participant and physiotherapist (C) (184)
5. Dementia symptoms and delivering the interventions (U) (184)
6. Navigating the stigma of dementia (C) (184)
Category 2: Environmental Barriers to Participation
7. Wanting to but not quite getting there (C) (192)
8. It's just not happening (C) (192)
9. The intervention as a burden for participant and carer (C) (184)
Category 3: Environmental Attributes
10. Social and physical environment – degree of support available enhanced participation (C) (192)
11. Engaging in Activity (U) (192)
12. Expressing Identities (U) (192)
13. Doing it anyway (C) (192)
14. Participants getting to the classes (C) (184)

Category 4: Positive Attitudes and Beliefs
15. Attitudes and Beliefs – motivated to take part in physical activity (U) (192)
16. It's all coming together (C) (192)
17. Perceptions (C) (171)
18. Acceptability (C) (171)
19. Instructional methods – facilitators (U) (191)
20. Positive Activity (family members) (C) (193)
21. Carer's perspectives on the experiences of participants of the intervention (C) (184)

3.4.5.3.1.1 Category 1: Barriers for care staff (Findings from four studies (171,184,193,194)*)*

There were difficulties sourcing people to organise and supervise the exercise sessions, which made participation more difficult (finding 1). Some care home staff found it challenging to find the time to implement exercise sessions (finding 2), and others needed encouragement to undertake these tasks (finding 3). Other group leaders found it difficult to deliver the intervention (finding 5) and were concerned about navigating the stigma of dementia with the participants (finding 6). Participants reported that the people delivering the intervention were overly concerned about their health and safety (finding 4).

3.4.5.3.1.2 Category 2: Environmental barriers to participation (Findings from two studies (184,192)*)*

In some settings, lack of flexibility and social support made engagement difficult (finding 7); in others, the chaotic environment presented a barrier (finding 8). Some participants found the intervention a burden, making participation challenging (finding 9). In some situations, despite minimal support and chaotic environments,

engagement in activities was maintained, and participants reported positively on benefits to their well-being (finding 16).

3.4.5.3.1.3 Category 3: Environmental attributes (Findings from two studies (184,192)*)*

Both the social and physical environment could enhance participation (finding 10) and often led to successful engagement in activity (finding 11 and 13). Carers appreciated being able to express their own personal identity rather than being identified solely in their role as a carer (finding 12). Participation was also facilitated by the ease of access to the class (finding 14).

3.4.5.3.1.4 Category 4: Positive attitudes and beliefs (Findings from five studies (171,184,191–193)*)*

The positive attitudes of participants (finding 15), care staff (finding 16) and family members (findings 19 and 20) towards exercise for people living with dementia facilitated and supported their involvement in the exercise interventions. This was enhanced when care staff accepted the exercise session as part of their day rather than additional work (finding 17) and when instructors showed flexibility in adapting classes to participants' needs (finding 18).

3.4.5.3.2 Synthesised Finding 2: People living with dementia and their carers experience a wide range of benefits from taking part in physical activity.

Table 10 Synthesised Finding 2

Category 5: Psychological Benefits
22. Feeling good (U) (192)
23. Psychological improvements and benefits (U) (194)
24. Benefits to mood (PWD) (C) (193)
25. Benefits to behaviour (PWD) (C) (193)
26. Reminiscence (PWD, spectators) (C) (193)
27. Mental stimulation (PWD) (C) (193)
28. Affective states (PWD, spectators) (C) (193)
29. Participants gain pleasure from exercising (C) (184)
30. Little or no change in cognitive function (C) (184)
Category 6: Social Benefits
31. Social improvements and benefits (U) (194)
32. Interactions with others (C) (191)
33. Socialising (PWD) (C) (193)
34. Participants enjoy being with other people (U) (184)
Category 7: Physical Benefits
35. The lived body (C) (192)
36. Type of physical activities (U) (192)
37. Physical improvements and benefits (U) (194)
38. Benefits (Physical) (U) (171)
39. Mobility (PWD) (C)(193)
40. Physical Health (PWD) (C) (193)
41. Improving physical health and functioning (C) (184)
Category 8: Benefits for Carers
42. Person-centred approach (C) (171)
43. Professional satisfaction (care staff) (C) (193)

44. Caring strategies (care staff) (C) (193)
45. Expectations (care staff) (C) (193)
46. Carer's own experience of the intervention (C) (184)

3.4.5.3.2.1 Category 5: Psychological benefits. (Findings from four studies (184,192–194)*)*

Psychological benefits to mood (findings 22, 23 and 27), behaviour (finding 24) and mental stimulation (finding 26) were experienced by participants. Others who could not participate also enjoyed reminiscing whilst watching sessions (finding 25); this appeared to benefit their mood (finding 27). People with dementia enjoyed taking part in the exercise sessions (finding 21 and 28).

3.4.5.3.2.2 Category 6: Social benefits. (Findings from four studies (184,191,193,194)*)*

Participants in the exercise session enjoyed being with other people (finding 34). They appreciated the opportunity to interact and socialise with people they might not regularly see (finding 32 and 33) which promoted improvements in participants' social confidence (finding 31).

3.4.5.3.2.3 Category 7: Physical benefits. (Findings from five studies (171,184,192–194)*)*

Carers, family members and participants all commented on improvements to the physical health and functioning of people living with dementia (findings 37, 38, 40 and 41), including improvements in their overall mobility (findings 37, 39 and 41), a reduction in their need for assistance during transfers (finding 38) and medication (finding 40). The types of physical activities that were used during sessions also

facilitated engagement in people living with advanced stages of dementia, as they were able to spontaneously interact using embodied skills and abilities (finding 35 and 36).

3.4.5.3.2.4 Category 8: Benefits for staff and carers. (Findings from four studies (171,184,192,193)*)*

Care staff expressed professional satisfaction from taking part in the interventions (finding 43) and being able to interact with participants using different caring strategies (finding 44). They also found that their expectations of participants' abilities changed (finding 45). Family carers appreciated the ability to talk to other people with shared lived experiences (finding 46).

3.4.5.4 Integration of quantitative and qualitative evidence

To establish if the barriers and facilitators identified in the qualitative synthesis above had been considered in the design of the quantitative trials, these were revisited. This data is presented in Table 11 below.

Table 11 Consideration of barriers and facilitators within the intervention study design

Study	Physical Barriers	Carer/Staff Barriers	Environmental Barriers	Environmental Attributes	Positive Attitudes	Psychological Benefits	Social Benefits	Physical Benefits	Carer Benefits
Lamb et al, 2018	✓	✓	✓	✓	✓	X	✓	X	✓
UMDEX Study (2015 – 2017)	✓	N/I	✓	✓	N/I	X	N/I	✓	X
Telenius et al 2015	✓	✓	✓	✓	N/I	✓	N/I	✓	X
Sampaio et al 2019	✓	✓	✓	✓	N/I	X	N/I	✓	X
Thurm et al 2011	✓	N/I	✓	✓	N/I	✓	✓	X	X
Kemoun et al 2010	N/I	N/I	N/I	N/I	N/I	X	✓	✓	X
Miu et al 2008	N/I	X	N/I	N/I	N/I	✓	N/I	✓	✓
Tsugawa et al 2020	✓	N/I	N/I	✓	✓	✓	✓	✓	X
Henwood et al 2017	✓	✓	✓	✓	✓	✓	N/I	✓	X
Venturelli et al 2010	✓	N/I	✓	N/I	N/I	X	N/I	✓	X
Huang et al 2019	✓	N/I	N/I	N/I	N/I	✓	N/I	X	X
Nyman et al 2019	N/I	N/I	✓	✓	N/I	X	✓	✓	✓

✓ = Barrier considered/Benefit measured; x = barrier not considered/benefit not measured; N/I = no information within article regarding barrier/benefit

To establish if recognition of the barriers and facilitators made a difference in the effectiveness of the intervention, a matrix was constructed, presented below in Table 12.

Table 12 Mixed methods synthesis matrix

Interventions	Lamb et al 2018	UMDEX Study (2015 – 17)		Telenius et al 2015			Sampaio et al 2019	Thurm et al 2011	Kemoun et al 2010	Miu et al 2008		Tsugawa et al 2020		Henwood et al 2017	Venturelli et al 2010	Huang et al 2019	Nyman et al 2019
Barriers/ Facilitators																	
Physical Barriers (1)	+	+		+			+	+				+		-	±		
Carer/Staff Barriers (2)	-			+			+							-			
Environmental Barriers (3)	-			+			+							-	±		±
Environmental Attributes (4)	+	+		+			+	+				+		±			±
Positive Attitudes (5)	-											+		+			
Benefits																	
Psychological Benefits (6)		-		+				-		-		+		±		+	
Social Benefits (7)	+							±	-			+					±
Physical Benefits (8)		±		+			+		+	+		+		±	+		-
Carer Benefits (9)	±									-							-
Outcomes Measured	QoL	Phy	Psy	Phy	Psy	QoL	Phys	Psych	Phys	Phy	Psy	Phy	Psy	Phys	Phys	Psych	Phys

Matrix Key

+ Barrier taken into consideration and improved delivery of intervention/benefit measured and shown

- Barrier considered but did not improve delivery of intervention/benefit measured and no effect shown

± Barrier considered but unknown if affected delivery/benefit measured and mixed results/benefit considered but not measured

□ No information in the study relating to barrier/benefit

Significant	Statistically significant outcomes
Positive	Positive trend in outcomes
Mixed	No clear trend in outcomes
Negative	Negative outcomes
No Change	No change in outcomes

The table above has been structured to show whether: a) the barriers and facilitators have been considered in the design of the intervention and b) if the interventions were considered effective. This table can be used to explore if there is any correlation between consideration of the barriers and facilitators that people living with dementia judge to be important and the effectiveness of the intervention.

Many interventions included in this review measured the physical benefits of exercise, and, in general, there were positive outcomes. Interventions which focused on specific physical outcomes such as balance had fewer clear-cut outcomes (178,185,190).

There was no clear evidence of the effectiveness of exercise in psychological outcomes within the studies included in this review, with three studies showing a positive benefit and three studies showing no effect. People living with dementia appreciated the psychological benefits they gained from participating in exercise groups, but there appeared to be a dissonance between measured outcomes and what the participants reported. Two studies (177,188) that did not show improvements in psychological outcomes had a trial design and exercises which concentrated explicitly on physical benefits. Although these interventions were provided in group sessions, participants tended to exercise individually as all had one-to-one supervision. One study (180) utilised the social character of group intervention as part of the trial design to enhance the sessions and reported no change in the mood of participants. However, this study did not report the post-intervention results for psychological outcomes.

People living with dementia reported positively on the social interaction and peer support that they gained from attending the sessions. Despite this review focusing specifically on group exercise interventions, very few assessed the importance of social interaction. Those that did so, did not measure this social benefit as a specific outcome. One study (184) which did use quality of life as an outcome measure reported no changes. Two studies (181,186), which specifically included sessions designed to take advantage of social benefits, were effective in improving physical and mental health.

Carers also appreciated the peer support networks they developed alongside the opportunities that were gained to share time with the person with dementia outside of caring tasks. Nine studies took place in care homes; eight did not consider carer or staff benefits directly. One study (178) did discuss staff burden in their findings, where members of staff were particularly supportive of the study. This site identified positive trends in reducing staff burden, and staff members expressed the view that the class was beneficial for themselves and the participants. This led to the staff self-funding the ongoing delivery of the programme after the trial had been completed. Three trials (184,185,188) that took place in community settings outside of residential care assessed the effect on carer burden and showed no differences between the groups. Interestingly, one of these studies (184) also assessed carer benefit using a five-point Likert scale, and most carers (71%) in the exercise group felt that they had gained moderate or substantial benefit from taking part in the study when compared to carers in the usual care group (46%) who judged that they had derived no benefit.

In the three studies in which the matter was discussed, people living with dementia reported that positive attitudes towards exercise and dementia from the instructors and other class members increased their motivation to participate. One study (184) reported that, at times, instructors found it challenging to lead participants, whilst the participants reported that instructors were not always positive in acknowledging their diagnosis, or the level of exercise they could manage. This study found no changes in participants' quality of life. Other studies (178,186) where instructors and staff had positive attitudes and prioritised enjoyable and familiar exercises had results that lacked a clear-cut trend.

People living with dementia commented on environmental attributes that contributed towards positive engagement as well as environmental barriers that hindered engagement. Having suitable open, accessible environments with familiar and enjoyable activities were all noted as facilitators to participation. Ten studies considered environmental barriers by having a suitable space and high instructor: participant ratios. Many of the studies reported on interventions which were tailored to the participant's abilities, or the programme was designed specifically for people living with dementia. Other studies included exercises that were easy to understand and enjoyable. However, the results of the studies showed no clear-cut trends, and there were examples where engagement was active despite chaotic environments, poor support, and a lack of flexibility (192).

Ten studies considered potential physical barriers for people living with dementia attending classes, including ensuring an appropriate number of supervisory staff (178,180,182–184,186,187,190), tailoring the exercises to participants' abilities

(178,183,190) and providing transport to promote access (178,184). However, the reported mixed outcomes would suggest that these provisions made no difference to the overall effectiveness of the trials. Physical barriers were only reported as a finding in one of the qualitative studies (194).

Three studies investigated carer/staff barriers; six that took place in care homes disregarded these as part of their trial. Two studies sought to overcome these barriers by including local physiotherapists who knew participants before the trial (183) and using the same trainer for all settings (179); both studies showed positive results for physical and mental health outcomes. In another study which did not consider the barriers to staff (184), the physiotherapists delivering the intervention reported difficulties with communication and adapting to participants' differing needs and abilities. This study reported no changes in quality of life.

A further study (178) reported that 25% of the invited care homes were unable to take part due to staff and resource issues, judging that they would have been unable to support their residents; consequently, the study control groups consisted of care homes that were unable to take part because of staff barriers to involvement. However, centres with available and supportive staff recorded increased attendance rates. This study had mixed results but with some positive physical and mental health outcomes. Staff interviewed in three of the qualitative studies (171,184,193) reported barriers to implementing exercise programmes which may have precluded them from continuing with exercise classes in the future.

3.5 Discussion

3.5.1 Summary of findings

The evidence presented in this literature review suggested that the impact of group exercise classes on people living with dementia was mixed. Aerobic activity showed physical and psychological health improvements, with all trials providing evidence of significant improvements in at least one physical outcome measure. Multi-component interventions improved physical and psychological outcomes with significant improvements to outcomes in some studies and a trend to positive outcomes in others. However, if no aerobic element was included as part of the intervention, the results were mixed.

Qualitative studies reported that exercise improved participants' mood and that they found it a pleasurable experience, whilst staff often reported benefits to participant behaviour and agitation. Studies that considered the enjoyment element and psychological benefits in their design tended to improve psychological outcomes. Very few studies examined the benefits of the social elements of group exercise; where this was included, the benefit to social activity was not measured directly. The main facilitators to group exercise attendance were positive attitudes from staff towards exercise and dementia, open and accessible environments, and familiar and enjoyable activities. Barriers included unsuitable environments and activities and lack of support from and for staff delivering the intervention.

The review identified some areas of cognisance but also gaps in the evidence with little attention being given to what people living with dementia are looking for from an exercise intervention and what is being provided. Studies highlighted that people

with dementia were concerned about their overall physical function and less concerned about specific outcomes such as improving their balance. There were other gaps in evidence on whether incorporating the barriers and facilitators to attendance into the trial design increased effectiveness. Several quantitative studies either did not consider the barriers and facilitators as part of their design or had not reported if these had been considered. Equally, whilst some of these studies had addressed these issues and provided evidence that this did increase the effectiveness of the intervention, others had not used outcome measures that reflected the benefits that were seen as important for people living with dementia.

3.5.2 Comparison with Other Studies

Earlier studies have investigated the use of exercise to help improve cognition or memory and other systematic reviews have assessed the value of exercise as an intervention for people with dementia. The latter have shown mixed results.

Seven reviews focused on exercise and physical function in people living with dementia. Lam et al. (195) included 43 trials and 3988 participants and found strong evidence of benefit for physical function in people living with dementia. Brett et al. (196) included 12 trials and 901 participants and concluded that multi-component interventions which combined strength, balance, flexibility, and endurance consistently resulted in a significant improvement in physical function. Five further reviews (7,9,42–44) found similar results to those identified in this review, that exercise shows promising benefits for physical function in people living with dementia.

Six reviews examined the relationship between exercise and depression. De Souto Baretto et al. (197) conducted a review of seven trials with 467 participants and concluded that exercise significantly reduced depression in people living with dementia. However, five further reviews (7,8,42,43,196) found no clear evidence of the benefit of exercise for depression, which confirmed the findings of this review.

Three reviews investigated the relationship between exercise and quality of life and found weak (43,198) or no evidence of benefit (195). Ojagbami et al. (198) also completed sub-analyses within their review and concluded that aerobic interventions might potentially impact the quality of life more than non-aerobic interventions. Moreover, it was concluded that the quality of life of carers might improve more significantly after an exercise intervention than that of the person living with dementia.

The studies that explored aerobic interventions in this review did not use quality of life as an outcome measure. However, this review did conclude that aerobic interventions generally improved physical and mental health and that multi-component interventions that did not include an aerobic element were less effective. Moreover, this review did not examine the benefits to carers in the quantitative evidence, but carers in the qualitative review did report their appreciation of two matters: firstly, having time with the person with dementia outside of the caring environment and, secondly, the peer support gained from contact with other carers.

Unlike others, this review adopted a wider perspective by including qualitative studies that have discussed the barriers and facilitators to exercise for people with dementia alongside the effectiveness review.

Social interaction and peer support for both the person living with dementia and carers was a key finding and was supported by results in four other qualitative reviews. Vseteckova et al (199) found that social interaction and support was a facilitator of adherence in group exercise sessions. Finnegan (200) also concluded that social interaction was important to participants who reported a preference for attending group sessions rather than exercising at home. A review by Di Lorito et al (201) found that adherence was higher when the intervention was delivered in group sessions in community settings. Van der Wardt (202) also concluded that the group format was influential in increasing adherence to exercise in people with dementia. Vseteckova et al. (199) noted that positive attitudes of both staff and group members were important in maintaining adherence to exercise classes. In addition, staff members being knowledgeable about exercise and dementia was a significant factor. This confirmed the results found in this review.

The review highlighted those environmental facilitators and barriers which encouraged or hindered attendance (e.g., suitable spaces, high instructor: participant ratios), which paralleled the findings in the review by Vseteckova (199). Similarly, spacious environments, flexible schedules and high staff-to-participant ratios were confirmed as facilitators to adherence whilst low staff numbers and larger group numbers acted as barriers to adherence. A review by Di Lorito et al (201) found that providing transport to the venue and offering refreshments also

facilitated adherence. Whilst tailoring of exercises to participants' needs was a further important finding in this study, mirrored in that of Vseteckova (199) and van der Wardt (202).

By juxtaposing barriers and facilitators alongside the effectiveness studies, this review could examine the extent to which the interventions had addressed the needs of people living with dementia; a small number of the barriers and facilitators have been considered in the interventions. Most studies have assessed the physical benefits of exercise by incorporating relevant outcome measures and including an evaluation of the physical and environmental facilitators to attendance at classes for those living with dementia.

This review's findings that people living with dementia wanted to improve their mood, confirmed those of studies in which psychological benefits were assessed as providing positive outcomes. Similarly, the conclusion that there were benefits to be derived from social interaction and peer support by attending a group exercise session was reinforced. Conversely, whilst this review included a focus on group exercise interventions, very few studies have considered the social dimension within their design.

Many of the studies in this review were undertaken in care homes, and the benefits to carers were not considered or discussed. It is relevant to consider benefits for both family carers and care home staff alongside the barriers that may be in place, as both groups have been highlighted in the review as significant contributors to the successful progress of participants in exercise programmes. When barriers for care

staff and family members are reduced or overcome, staff members, in particular, have more positive attitudes towards the benefits that exercise can provide for themselves and people living with dementia.

3.5.3 Strengths and limitations

The review was completed using a comprehensive, systematic approach with a robust search strategy and two independent reviewers for full-text review and data extraction. The review followed a pre-planned protocol which was registered on PROSPERO (pg. 58) before the initial search protocol.

One strength was the inclusion of different types of evidence sources which enabled an exploration of the effectiveness of exercise for people living with dementia in the context of the barriers and facilitators that exist to their attendance. It also enabled gaps in the evidence base and directions for further research to be identified.

The use of a matrix for the mixed methods synthesis allowed an exploration of why some interventions appeared more effective than others, and whether incorporating the views of participants living with dementia in the exercise session made a difference in terms of its effectiveness. Providing an effect direction plot was a novel way of presenting heterogeneous data, which precluded a meta-analysis. It offered a method of synthesis and visualisation of data in addition to the narrative synthesis.

The studies were limited to those written in English. This prevented consideration of sources in other languages unless they had an English abstract, which was a requirement for consideration of inclusion in the review. Some abstracts could be

assessed for suitability through computer-aided translation, but this was not possible for all studies.

There was significant variation in the quantitative studies. Most had small sample sizes and there were differences in quality although none were of low quality. The type of intervention delivered, alongside both the outcomes measured, and the specific outcome measures used, were extremely variable. Although some outcomes could have been used in a meta-analysis, there was significant heterogeneity. A meta-analysis of a small number of outcomes may not have accurately represented the available evidence. Hence, effect direction plots were used in this review.

Not every study provided specific results for all outcome measures, and some only stated that an outcome was not significant. This may have altered the effect direction plots to some extent as 'not significant with no underlying result' would be plotted as no change. However, the result may have shown a trend towards a positive outcome which, in turn, could have led to a difference in the overall effect direction.

Although seemingly straightforward, the choice of the comparator in effectiveness trials can be a challenge. It is common when testing an intervention for effectiveness to compare with usual care (203) and this was the comparator in all the quantitative studies. However, usual care is often not standardised within a country, and, in different countries, usual care practice may vary widely (204). This may limit the review, but usual care as a comparator is a standard choice when completing a systematic review of effectiveness.

A further limitation arose from the small number of qualitative studies from which to extract data. There were six qualitative studies of variable quality, two of which only included the views of family carers and staff. With limited data, one-third of the studies did not include the views of people living with dementia, conclusions were not solidly based.

Another limitation arose from the methodology: a mixed method systematic review is a relatively new technique, and there are no standardised methods for its conduct. A segregated approach was adopted whereby the quantitative and qualitative evidence was synthesised separately before 'mixing' was applied; this approach was selected as the literature from the quantitative and qualitative studies complemented each other (205). An integrated approach would be more appropriate where evidence from the quantitative and qualitative literature is likely to confirm, extend or refute findings from the other source (205).

3.5.4 Implications

This review has provided evidence that multi-component interventions, including aerobic, strength and balance activities, are more likely to improve overall physical function. There is mixed evidence on specific outcomes such as strength, balance, and endurance. However, a weight of evidence indicates that these specific features are less important to people living with dementia whose priority is to improve their overall physical health. This group also wants to improve their mood and participate in enjoyable activities. When designing an exercise intervention, it is vital that their priorities are acknowledged, and activities are included to promote mental health and well-being. In the qualitative studies in this review, none of the participants or

carers mentioned the importance of cognition or memory. However, they placed greater emphasis on social interaction and peer support, improvements to their mobility, general physical function, and mood.

This review also highlighted that people with dementia particularly enjoyed the social element of a class. Hence, in the design of an intervention, it is important to include opportunities for social interaction and peer support to optimise the psychological improvements of exercise that are reported by people with dementia.

In the qualitative studies in this review, people with dementia have not raised quality of life as a benefit in the same way that researchers have in the intervention studies. Tools used to measure quality of life focus on matters such as pain, mood, ability to carry out daily tasks, memory, using money etc. and include very few, if any, questions that relate to social interaction. In this review, people with dementia did refer to the physical and psychological benefits that are assessed within the standard quality of life measures. However, the benefits they reported from social interaction and peer support are not picked up using these standard measures. Different measures that include a social impact element may have generated more positive outcomes.

There was a significant difference in how carers in the qualitative studies described benefits and how researchers measured them in the quantitative studies. Carers reported benefits in the positive aspects of peer support and the time spent with the person with dementia in a different setting, whereas researchers measured benefit by the reduction in carer burden. Carers are gaining benefits from the interventions,

but these are not being recognised if carer burden is specified as the only significant outcome.

Positive attitudes towards exercise for people with dementia, considering carer and staff barriers and overcoming environmental barriers are reported by those living with dementia, their carers and staff in the qualitative studies as important to facilitate their attendance and participation in exercise classes. However, these issues were rarely reflected in the quantitative studies. Where they were discussed, the evidence indicated that if members of staff were not always positive and barriers were not reduced, trials were less effective than when staff held more positive and supportive views and strategies were in place to reduce or overcome barriers. Where this did happen, it produced a more positive experience for both staff and participants. Hence, these matters need to be considered when designing a group exercise intervention.

Future studies should also consider the importance of reporting the barriers and facilitators they have considered in their trial design. Gaps in the evidence may be due to a lack of reporting as opposed to these factors not being considered. It is important that in the future, researchers report whether they have considered the barriers and facilitators that are important to those living with dementia, and to what extent they have been able to incorporate these into their trial design. Only then will we be able to judge the extent to which the barriers and facilitators influence effectiveness. In the qualitative studies in this review, people living with dementia held clear views on what they wanted to gain from an exercise class, and these did not always coincide with what researchers thought they would want.

Hence, if the value of exercise classes for participants is to be enhanced, qualitative studies need to include opportunities for the views of people with dementia to be heard alongside those of professional and family carers.

It is important to provide opportunities for these views to be heard as early in the research process as possible. Patient and public involvement and engagement (PPIE) is vital if we are to ensure that we are doing all research with participants and not on or for them. As stated previously, what people living with dementia wanted from an exercise class was not always what the researchers assumed it would be. Therefore, including the views and perspectives of those living with dementia alongside professional and family carers is essential. There is a wide spectrum of PPIE from consultation on research ideas to co-production of a project from beginning to end with those for whom the research is the most relevant. The co-production or co-design of an exercise class with those who are likely to benefit would ensure that these views are considered early in the development of the research.

The importance of social interaction and peer support highlighted in this review would indicate that more research is required into the social benefits of group exercise. Identifying outcomes that can be used to measure these benefits with greater precision is essential since they cannot be assessed with standard quality-of-life outcome measures.

Moreover, further research is needed to develop and evaluate interventions which aim to overcome or reduce barriers not only for people living with dementia but those experienced by professional and family carers.

3.6 Conclusions

This review aimed to synthesise and integrate evidence to enhance the understanding of how and why group exercise generates benefits for people living with dementia as well as explore barriers and facilitators which enhance or hinder effectiveness.

There was evidence that multi-component interventions which included aerobic, strength and balance activities improved physical function. However, no clear evidence of the benefit of exercise for mood or quality of life was identified in this review.

People living with dementia and their carers experience a wide range of benefits (physical, psychological, and social) from participation in exercise classes. There are barriers to physical activities for people with dementia as well as professional and family carers, but these can be overcome with positive attitudes and suitable environments.

Interventions that included physical and psychological benefits in their design and incorporated a social dimension were more likely to yield positive outcomes. Most studies considered environmental and physical barriers for people living with dementia, but positive outcomes were more likely when barriers for both professional and family carers were considered alongside those impacting upon participants.

Further work is needed to ensure that exercise classes are developed to maximise the benefits that are perceived as important by people living with dementia. Equally

importantly, the creation of more specific outcome measures that can adequately quantify improvement should lead to an enhancement of the quality of provision.

Chapter Four

4 Exploring the need for dementia-friendly exercise classes

4.1 Introduction

The previous chapter found that people living with dementia experience a wide range of physical, psychological, and social benefits from taking part in exercise. It also highlighted the importance of social interaction and peer support for both people living with dementia and their carers. However, there is little evidence of significant community provision to support this population to gain the wide-ranging benefits that exercise can provide. In 2017, the University of Nottingham established a group exercise class in its sports centre for people with dementia and their families as a direct consequence of an ongoing programme of research into interventions to support physical activity, the Promoting Activity, Independence and Stability in Early Dementia Study (PrAISED) (206).

This chapter presents a mixed methods study which aimed to assess the benefits of an established dementia-friendly class for participants and their carers. The content of the chapter from the cohort study and focus groups has been published (87) and has been reproduced here with some adaptations as the observations were not part of the published work.

Three objectives were identified.

- to evaluate the benefits of an exercise class on the physical and mental health and quality of life for people living with dementia and their carers

- to investigate the perception of the benefits of an exercise class from the perspective of people living with dementia and their carers
- to map the quantitative and qualitative data against the matrix developed in Chapter Three to synthesise the results against that found in the literature review

4.2 Methods

4.2.1 Design

A mixed methods design was used, including observations, a prospective repeated measures cohort study, and focus groups. Exercise classes are a complex intervention and quantitative outcome measures alone may not provide a comprehensive assessment of the benefits they provide (100).

Outcome measures (listed below in the procedures section) were collected across two time points (March 2019 and June 2019) in a cohort of people with dementia and their carers who attended the dementia-friendly exercise class at the University of Nottingham. Participants of the cohort study were then invited to join the subsequent focus group.

Ethical approval was obtained from the Faculty of Medicine and Health Science Research Ethics Committee of the University of Nottingham (Ref No. 203-1902) (Appendix F).

4.2.2 Participants

Participants were people living with dementia and their carers who attended a dementia-friendly exercise class. Attendees were not required to produce evidence

of a dementia diagnosis and could participate regardless of dementia symptoms (e.g., mild to more severe) and with or without a carer.

The inclusion criteria for the study were: to be a current participant in the exercise class; and the ability to give informed consent. All those attending the class (people living with dementia and carers) who met the criteria were considered eligible and invited to take part in the study.

4.2.3 Procedures

The research team (AL, LH, VB) were introduced during the weekly class by the lead physiotherapist, who outlined the purpose of the research. Any attendees who were interested in participating in the study spoke to the researchers afterwards and were provided with further information and participant information sheets (Appendix G).

4.2.3.1 Observations

As part of the research team introduction, the lead researcher (AL) took part in and helped as a volunteer at some of the classes before the repeated measures cohort study and between the two data collection points. This enabled the class to be observed to understand how it was organised and how attendees interacted with each other before, during and after the class.

Over the five months that data was collected, five classes were observed. Observations lasted approximately two hours, including setting up by the volunteers, the class itself (during which the lead researcher (AL) helped three of the participants), and time spent with participants in the café (after the class). A qualitative semi-structured checklist for observations (191) was adapted and served

as a prompt to guide initial observations of the class. Where appropriate, brief notes were written before the start of the sessions, with more detailed field notes being written up directly after a class, including anything significant that participants may have commented on during the class. Participant identifications used in the observations corresponded with those assigned during the focus groups. Observations helped to identify areas to explore in more depth in the focus groups; these included the interactions and support when having coffee and how useful classes like this would be to other people living with dementia. The topic guide was then refined to incorporate more detailed questions.

4.2.3.2 Repeated measures cohort

Participants provided informed consent (Appendix H), and baseline measures (Appendices I – P) were collected during a three-week data collection phase in March 2019.

Outcome measures included:

a) Mobility: Berg Balance Scale (207) (I) and the Timed up and Go (157) (J)
b) Strength: handheld dynamometer (160)
c) Cognition: Hopkins Verbal Learning Test (HVLT) (208) (K)
d) Physical activity levels: LASA Physical Activity Questionnaire (LAPAQ) (209) (L)
e) Independence: Nottingham Extended ADL Scale (NEADL) (210) (M)
f) Loneliness: UCLA Loneliness Scale (211) (N)
g) Mood: Hospital Anxiety and Depression Scale (HADS) (212) (O)
h) Quality of Life: Dementia Quality of Life Scale (DemQoL) (213) (P)

All members of the research team (AL, LH, VB) completed the mobility (a), strength (b), cognition (c) and quality of life (h) assessments with the participants before, during or after the exercise class (depending on their preference). Participants were then given the other questionnaires (d-g) to be completed at home and returned at the next session. Participants were encouraged to complete them with their carer, where indicated. All measures were repeated three months later (June 2019) following the same procedure as the baseline.

4.2.3.3 Focus groups

All participants were invited to join one of two focus groups facilitated by the lead researcher (AL). A focus group topic guide (Appendix Q) was used to steer the discussion of their experiences of the class, as well as their perceptions of the benefits to their overall well-being. The topic guide was used as a template, but a flexible approach was adopted to facilitate discussion of any relevant new issue that emerged during the sessions.

Two focus group sessions (morning or afternoon) were offered to account for differing needs and capabilities during the day. The sessions took place at a location within the University of Nottingham with free accessible parking. Each focus group had two researchers present: one (AL) to facilitate the session and another (LH) to take field notes to inform and assist with transcription. Both groups were recorded on a digital audio recorder.

4.3 Data analysis

4.3.1 Observations

Field notes were uploaded onto NVivo 12 (214). The data was then extracted and coded using the code book developed during the focus group coding process (see below) and analysed alongside focus group transcripts.

4.3.2 Repeated measures cohort

All data were entered into SPSS 24.0 (215). Descriptive statistics were used to describe the sample. Mean differences were used to illustrate changes across outcomes over the two time points.

4.3.3 Focus groups

Focus group data were transcribed verbatim, checked, and fully anonymised using the audio field notes for accuracy. Audio files and transcription files were uploaded onto NVivo 12 (214). Each transcription was coded using a thematic, inductive, yet flexible coding process (216). If novel themes were identified from the transcripts during the coding process, new codes were generated. All codes were mapped and subject to expansion, restriction, or modification using concept maps within NVivo 12 (214) until a final list of codes was completed. A codebook (Appendix R) was then developed, and the data extracted and coded.

4.3.4 Synthesis

The matrix developed for the literature review (Chapter Three) outlining the benefits, barriers and facilitators found in that review was used to map the

quantitative and qualitative data from this study to enable findings from all the data sets to be synthesised.

4.4 Results

4.4.1 Observations

Due to the nature of ethnographic research, all observations within this thesis have been written in the first person. The class took place weekly in a studio of the David Ross Sports Village (DRSV) at the University of Nottingham. The DRSV is purpose-built to support a range of sports and exercise for university students, staff, and members of the public. The studio was easily accessible, located on the ground floor with level access and close to disabled toilets, had free parking for two hours and an onsite café.

A registered physiotherapist led the class with trained volunteer helpers. It was grounded in the framework of positive support developed by Clare (217) for the rehabilitation of people with dementia. This framework emphasises the importance of creating rehabilitation opportunities that provide positive experiences and include the support of family carers. Volunteers generally arrived at least 15 minutes before the start of the class. The room was laid out the same way each week, and volunteers typically helped the lead physiotherapist with the layout. A row of chairs was usually set out at the front of the studio, which enabled attendees to sit down if necessary and leave any coats and bags whilst they took part in the class.

Class attendees started to arrive at the studio approximately 10 minutes before the start of the class and were registered. Regular attendees were observed to have

developed informal friendship groups, usually gravitating towards the same people each week. Being familiar with each other from different support group sessions, these small groups socialised freely. The lead physiotherapist assigned a volunteer to assist each group as required, keeping the informal friendship groups together. Some attendees gathered themselves together with people at a similar stage in their dementia journey.

Each class followed a consistent structure, starting with a five-minute instructor-led warm-up comprising cardiovascular work (e.g., marching and running on the spot) and movement of major muscle groups. The class then became a small group (two to six participants) six-station circuit, completed in one minute and repeated twice. Each station featured the same exercise each week and could be completed at different levels, depending on individual physical capability. Exercises at the stations included sit-to-stand, step-ups, bicep curls with weights, push-ups, boxing, and shuttle runs. Each station was completed for one minute before moving to the next until an entire circuit was completed. After the first circuit, there was a short, timed break during which everyone was encouraged to have a drink; water was provided, but many attendees brought their own refreshments. After the break, the circuit was repeated. The class finished with 10 minutes of instructor-led balance exercises, including static and dynamic postures (e.g., tandem walking backwards walking and single-leg stands).

A group of four or five men attended alone, appeared reasonably fit and active and seemed to be relatively early in their journey. I observed that the same volunteer, an older lady who also appeared quite fit and active, was usually placed with these

participants. This group completed many of the activities at a higher level than the other attendees, particularly the sit-to-stand station, which was set up with benches of variable heights for people to practice a sit-to-stand movement. More frail attendees used a high bench to make the activity more manageable, with a bar to assist them if necessary. More physically able participants used a lower bench to ensure that they made more use of their quadricep muscles to push into a standing position. These more physically able male participants used this activity station to perform independent squats whilst holding a medicine ball, creating a more challenging activity. This station, alongside the push-up station and the shuttle run/walk, were excellent examples of how the equipment and exercises could be adapted to enable people at any stage of their dementia journey to gain benefits.

Reflecting later with this volunteer, she confirmed that she was a retired physiotherapist, which explained why she was usually the volunteer supporting this particular group. Her professional skills enabled her to confidently adapt the exercise stations to provide a challenging workout for these fitter attendees, leaving other volunteers to help participants that needed more intensive support.

During the circuits, group members were very supportive of each other. Some carers commented on how well participants were coping with the class, while others commented that they struggled to manage some of the tasks themselves. After one class, a carer observed:

"I always find the one leg stand hard, and the physiotherapist will look at me and crack up as I am so terrible at it, but I am getting better, and I can sometimes do it for 10 (seconds)." (P9)

During one session, I offered to individually assist one attendee, who was living with more severe symptoms of dementia, to give his wife a break enabling her to do some exercise herself. She mentioned that he liked to run, and she had not been able to run when she took part. He was still very physically able, so we ran instead of walking during the shuttle runs.

After the session, she commented:

"He used to be very athletic, and normally he has to walk as I can't manage to run with him - he would have really appreciated that." (P5)

Within each group, there was usually a lot of encouragement at the stations, participants commenting *"just a few more"* or *"just a couple more,"* especially during the last few seconds.

The facilities of the DRSV were available to participants following the class (e.g., changing rooms, toilets and café), providing additional opportunities for social interaction. Following each session, many of the attendees migrated to the coffee shop and often sat and chatted in their regular informal friendship groups. However, due to the layout of the shop and other members of the public using the facilities, participants were obliged to sit where they could, which generated new social interactions. Following one session, two couples sat together discussing an exercise

class they attended during the week when a third couple, sitting at the same table but not part of this informal friendship group, overheard this conversation, and the lady enquired further. One of the carers told them about an exercise class run by the Alzheimer's Society as part of a support group they attended in their local area. After exchanging times and locations, the third couple thought they might give this a try, and I later discovered they had done so.

I also observed that volunteers developed friendships with attendees, meaning that the lead physiotherapist did not always need to 'assign' volunteers, as they were already informally linked, as with the retired physiotherapist and the more active male members. These bonds between the volunteers and attendees appeared to strengthen the cohesion of the groups and the class. I further observed that trust between carers, group members with dementia and their usual volunteer began to emerge. On one occasion, an attendee's wife could not stay for the session as she had a clashing appointment. On another occasion, an attendee's wife was unwell and had to sit on the side rather than participate. On both occasions, the carers left their spouse with one of the volunteers. The presence of a known volunteer meant they could leave their partner with that volunteer knowing they would be safe and respond positively.

The environment and atmosphere observed in this exercise class was positive for both partners, leading to increased attendance and continued participation. Participants, carers, staff, and volunteers all offered continuing encouragement creating a mutually supportive and enjoyable experience.

4.4.2 Repeated measures cohort

Sixteen participants (n=8 living with dementia, n=8 carers) consented to take part in the physiological and cognitive outcome assessments. All participants were recruited in dyads. There was no attrition of participants; all completed baseline and follow-up assessments (n=16, 100%). Four of the eight outcomes included within the repeated assessments were not completed at baseline (n= 4/160, 3%) and three at follow-up (n= 3/160, 2%).

The participants' demographic information is reported in Table 13. In the complete sample, nine participants were female (56%). Of the participants living with dementia, six (75%) were male, and five (62.5%) had a diagnosis of Alzheimer's disease.

Table 13 Participants Demographics

		Number	**Percentage (%)**
Gender	Male	7	44
	Female	9	56
Carer relationship	Spouse	6	75
	Child	2	25
Diagnosis	Alzheimer's Disease	5	62
	Vascular Dementia	1	12
	Parkinson's Dementia	1	12
	Lewy Body Dementia	1	12
Ethnicity	White-British	16	100

There were increases in physical activity levels, loneliness, cognition, anxiety, and depression for all participants following a three-month attendance at a dementia-friendly exercise class. Strength and activities of daily living remained essentially unchanged, whilst mobility, balance, and quality of life slightly decreased (Table 14).

Table 14 Outcome Measure Statistics at Baseline and Follow Up

Outcome Measure	Baseline (n=16) (mean±SD)	Follow Up (n=16) (mean±SD)	Mean Difference [95% CI]
Cognition			
HVLT Recall (/36)[a]	15.63 ±10.85	16.75 ±11.48	1.13 [-2.74, 0.22]
HVLT Recognition (/12)[a]	7.88 ±4.94	7.94 ±3.80	0.06 [-1.80, 1.67]
Quality of Life			
DemQoL (/116)[a]	93.00 ±10.33	92.00 ±11.60	-1.00 [-4.62, 6.62]
Mobility			
TUG (secs)[b]	9.72 ±3.67	11.02 ±8.44	-1.29 [-5.28, 2.69]
Berg Balance (/56)[a]	50.38 ±6.29	49.13 ±6.90	-1.25 [-0.43, 2.93]
Strength			
Grip Strength R (kg)[a]	24.44 ±6.76	24.15 ±6.19	-0.29 [-1.53, 2.11]
Grip Strength L (kg)[a]	22.81 ±5.48	23.69 ±7.28	0.89 [-2.98, 1.21]
Independence			
NEADL (/22)[a]	14.31 ±7.51	13.56 ±8.30	-0.75 [-.06 – 1.56]
Mood			
HADS (/42)[b]	13.00 ±6.69	11.67 ±7.90	1.33 [-1.44, 4.11]
Physical Activity			
LAPAQ (/MET hrs/wk.)[a]	45.42 ±28.53	49.86 ±41.03	4.44 [-23.03, 14.14]
Loneliness			
UCLA Loneliness Scale (/80)[b]	44.17 ±10.45	42.42 ±10.79	1.75 [-1.24, 4.74]

a: higher scores better, b: lower scores better

Over the three months, physical activity scores changed by 4.44 MET hours per week (45.42 – 49.86). The participant's ability to recall changed slightly by a score of 1.13 (15.63 – 16.75), but recognition remained relatively static. Both loneliness (1.75 points, 44.17 – 42.42) and mood (1.33 points, 13.00 – 11.67) scores decreased.

Activities of daily living showed minimal changes of >1 point, with independence scores decreasing by 0.75 (14.31 - 13.56). Grip strength in the right hand decreased by 0.29kg (24.44 – 24.15) and increased in the left by 0.89kg (22.81 – 23.69).

The participants' quality of life scores decreased by 1 point (93.00 – 92.00). Balance also changed slightly over the three months, with a reduction of 1.25 points (50.38 – 49.13).

However, as the confidence intervals for these measurements are wide, we can only state that there were no statistically significant changes.

4.4.3 Focus groups

Ten participants were included in the two focus groups (n=5 people living with dementia, n=5 carers). All participants attended as dyads. The remaining six participants from the repeated measures cohort did not want to attend this study phase due to other commitments. The first group (FG1) consisted of four participants (n=2 people living with dementia, n=2 carers) and the second (FG2) of six participants (n=3 people living with dementia, n=3 carers).

Table 15 Participants Demographics

Pseudonym	Carer/PWD	Diagnosis	Gender
FG1 P1	Carer	n/a	Female
FG1 P2	PWD	Vascular Dementia	Female
FG1 P3	Carer	n/a	Female
FG1 P4	PWD	Alzheimer's	Male
FG2 P5	Carer	n/a	Female
FG2 P6	PWD	Alzheimer's	Male
FG2 P7	Carer	n/a	Female
FG2 P8	PWD	Alzheimer's	Male
FG2 P9	Carer	n/a	Male
FG2 P10	PWD	Alzheimer's	Female

4.4.3.1 Themes

Data analysis identified four key themes: benefits to the person living with dementia, benefits to the carer, environmental characteristics, and exercise class characteristics.

4.4.3.1.1 Benefits to the person with dementia

All participants reported their perception that the classes had helped them maintain their current abilities and prevented deterioration.

> *"Well, I think it's kept my mum continue to be mobile…she can still go upstairs. So I don't have to do anything for her. She gets dressed and undressed. So, she's still got muscle strength. So perhaps that would have deteriorated if she hadn't been coming to the classes." (FG1 P1)*

Most participants also felt that attending the class increased their activity levels by encouraging them to engage in other activities or enabling them to continue with or return to previous activities.

> *"It's almost like building up a bank of things...You pick your activity just like you or I would do it. You wake up one day, you feel like doing something, or you don't. And it's just to have the option of different things, I think." (FG2 P7)*

Some participants commented that the classes increased their confidence and helped them be more willing to participate in other activities, even if they were not advertised as dementia-friendly.

> *"We try everything…I say...we're going to go here, if you don't like it, we won't go again, simple as that. That's all you can do, but you've just got to give it a go, because what suits one doesn't suit another does it?" (FG2 P7)*

4.4.3.1.2 Benefits to carers

Although carers did report positively on the impact of their participation, they added that a more significant benefit was the supportive community the class had provided and the sharing of useful knowledge between carers.

> *"The things I've picked up have been so good. And the people we've got to know, you get really friendly with people in a short time because you're in a mess together, and you pick brains. And one of the guys told us about, he just said, are you aware that you can get money back if you've altered powers of attorney?" (FG2 P9)*

This informal peer support network also extended beyond the class, with valuable tips being exchanged informally over refreshments.

> *"I overheard the conversation you were having with the gentleman…that's all about the exercise class today." (FG2 P7)*

Many carers also commented on the changes that occurred in their support networks following the dementia diagnosis.

> *"You lose people, I'm amazed at some people that we were very friendly with. We never see them, gone." (FG2 P9)*

> *"Look here, we've met these lovely people I never want to be without." (FG2 P5)*

They also commented on how burdensome it is to be a carer, dealing with lack of sleep, fatigue and dealing with the diagnosis itself. However, they commented that the group provided support as everyone was on a similar dementia journey.

> *"Well, the support, the people's experience, and their knowledge...the little bits of information that we got, I felt quite desperate to start with, what are we going to do? I'm always picking up on what people say." (FG2 P9)*

Other carers valued just getting out of the house to enjoy social interaction.

> *"Well, getting out the house for a start. Sort of, I don't know, the older you get, you can't be bothered to go out." (FG1 P1)*

"Well, it's mixing with other people basically…and we have a lot of fun." (FG2 P10)

4.4.3.1.3 Environmental characteristics

Both carers and people living with dementia reported that the environment provided by the class impacted their views and encouraged their continuing attendance.

In this respect, the availability and accessibility of parking and toilet facilities as well as the opportunity to socialise with refreshments after the class, were seen as key elements.

"I was a bit worried for quite a while about the parking because I couldn't make out where we would park. Anyway…there is parking…" (FG1 P3)

"There's loads of toilets. And there's disabled toilets. So, I don't think they're lacking in anything, are they really?" (FG1 P1)

"So, to be able to extend it and know that Geoff will have a lovely chat with his friends as well, that just makes the whole experience last longer in my view." (FG2 P7)

It was acknowledged that, although some participants liked to attend on their own, giving their carer 'free' time, others preferred to attend with a partner, friend, carer, or family member. Having volunteers who were knowledgeable about dementia was a key factor in promoting confidence to attend.

"They've just got so much confidence. They seem to know what they're doing. And he enjoys it far more when he's with somebody else than me." (FG2 P7)

"I wouldn't think of taking my mum to any exercise class unless it said it was specifically for dementia…you'd know that the people doing it would know about dementia and all what happens to people when they've got dementia and the different kinds and…they'd know what to do." (FG1 P1)

The volunteers were all given Dementia Friends training which gave them the knowledge and confidence to work with the attendees, but this, in turn, gave the attendees confidence in them (Obs.)

4.4.3.1.4 Exercise class characteristics

The class was advertised as specifically designed for people with dementia. This was important to most participants, who reported that they would not have been comfortable attending an exercise class designed for older people in general.

"Well, it said it was dementia friendly so I just assumed it would be…I hadn't really wanted to go to things that people said oh it might have been with dementia and their partners, it just didn't seem to appeal to me much. So, I wasn't very motivated to go to any of that, but I thought, well, an exercise class, anyone can do that. I'll enjoy doing that as well." (FG1 P3)

"I wouldn't think of taking my mum to any exercise class unless it said it was specifically for dementia." (FG1 P1)

Observation of the class suggested that people with dementia managed the exercise class quite well and were encouraged to push themselves to work harder. However, this did not always carry over into activities outside the class.

> *"When I watch him doing walking fast and a bit of running…he did walk really fast for her. But if I say, can you walk any faster, he says yes, but he doesn't do it. And if I walk on ahead, he's…so I don't think he will walk faster for me." (Obs. P3)*

An element of camaraderie developed between attendees, with participants commenting that having others doing the same exercise meant they worked harder.

> *"You get swept away in it. Oh, they're doing it, I'm going to carry on." (Obs. P5)*

> *"You get like a team thing really in a way." (Obs. P9)*

Some carers commented that their spouses had been quite competitive in the past, which re-emerged during the class.

> *"We borrow our friend's dog sometimes and take it round for a walk...it's a very slow walk, that's all he wants to do with me but look at him here racing with his mate and wanting to get the strongest lifts!" (Obs. P7)*

Participants also felt that holding the class once a week was very beneficial as they attended other activities that took place once a fortnight or monthly and considered that these were not frequent enough.

"Forget me Notts does…walking football, so we can do that once a month. But once a month, it's not enough." (FG2 P7)

"And it's nice the once a week as well, because a lot of things are only once every three weeks or four weeks. To have this nearly every week, and it's just awesome." (FG2 P7)

Another relevant intervention characteristic that participants appreciated was the flexibility to accommodate the needs of those at different levels of capability.

"It's just the whole package. You can do as much or as little as you like. You can see that it's got so much mileage in the class, because even if either you deteriorate or you're not feeling great, you can just do whatever you want to do. It's adaptable. And you know what, even if you do very little, it's still a social thing." (FG2 P5)

4.4.4 Synthesis

In Table 16 (below), the quantitative and qualitative data have been mapped onto the matrix developed in the literature review.

Most attendees were aiming to maintain their current physical abilities and prevent deterioration, although a minority also wanted to increase their overall activity levels. This confirmed the findings shown in the literature review (Chapter Three), which highlighted that what people living with dementia wanted from an exercise class was to improve their overall physical health and general mobility. There were trends towards positive results in physical activity and mobility but mixed or negative

results in the specific outcome measures for balance and strength. This is similar to the findings of the literature review (Chapter Three).

Attendees reported that they considered the class increased their confidence to participate in other activities. The camaraderie between attendees, both those with dementia and their carers, was regarded as a benefit alongside the informal support network that carers formed. This corresponded to the findings of the literature review (Chapter Three) that participants want to derive psychological benefits from attending an exercise class. The results of this study also showed a more positive trend in mood than those from the literature review (Chapter Three), which were mixed for this outcome. However, where the enjoyment of exercise was considered as part of the intervention, there were more positive results.

Social benefits reported in the literature review (Chapter Three) were confirmed in this study; both participants and carers commented on the value of social interaction during and after the class. Measuring social benefit is difficult: the literature review provides no evidence of change in the quality of life for either the people living with dementia or their carers. However, this study included loneliness as an outcome, and a positive trend was evident. Lonely people often lack social interaction, and previous research has shown a modest association between social interaction and loneliness (218,219), suggesting that loneliness could serve as a proxy for lack of social interaction.

Carers reported that they had found a supportive community by attending the classes and benefitted from sharing useful knowledge; this corresponded with the

literature review findings. Although carer burden was not used as an outcome in this study as it was in the literature review, mood and loneliness for carers, as well as for people with dementia, were measured. Both showed a trend towards positive results, so it is a reasonable supposition that these outcomes improved for both groups.

Many of the barriers reported in the literature review (Chapter Three) were known before this class was set up. There was accessible parking, toilet facilities, and the organisation of the class was flexible. The latter characteristic included allowing attendees to do as much or little as they could manage, carers being able to choose to stay or leave the participant with a volunteer or joining the class and benefitting from the activities. The on-site café facilitated social interaction and support networks after the sessions. Staff and volunteers were knowledgeable and had participated in Dementia Friends training, and there was a good ratio of staff/volunteers to attendees. The barriers and facilitators experienced by participants attending this class were similar to those found in the literature review. These features have brought about increased and more consistent attendance. Although there were mixed results in the quantitative analysis, the reported positive outcomes were those that were perceived to be important to people living with dementia and their carers in the literature review.

Table 16 Matrix Synthesis

Interventions	Outcomes	Psychological Benefits	Social Benefits	Physical Benefits	Carer Benefits	Positive Attitudes	Environmental Attributes	Physical Barriers	Carer/Staff Barriers	Environmental Barriers
Multicomponent	Cognition	Improved confidence for participants, Support network for carers Camaraderie between attendees	Participants and carers valued the social interaction	Maintain current abilities and prevent deterioration. Increasing levels of activity	Supportive community sharing of useful knowledge	Knowledgeable staff and volunteers. Dementia Friends training	Availability and accessibility of parking and toilet facilities, the opportunity to sit and chat over coffee after	These were not specifically mentioned but had been considered before the class started. Flexibility of class	Carers were able to attend with participants or able to leave with a volunteer. Could do their own exercise as well.	Not specifically mentioned and also considered before class started.
	QoL									
	Mobility									
	Balance									
	Strength									
	Independence									
	Mood									
	Physical Activity									
	Loneliness									

Significant	Positive	Mixed	Negative	No Change

4.5 Discussion

4.5.1 Summary of Findings

This study provided clear evidence that exercise classes specifically designed for people with dementia can be delivered in a novel environment such as a university sports centre. In addition, some cognitive and physiological abilities improved as a result of the attendance at the class over three months. Importantly, most measures did not decline over time, which in people with dementia is considered a positive outcome (77,220). This study also confirmed that people with dementia and their carers enjoyed attending an exercise class and wished to maintain their current physical abilities, prevent deterioration and increase overall activity levels. Several themes were identified that contributed to the benefits that participants gained from the class and highlighted characteristics that may explain their continued participation.

The characteristics which influenced joining a class and achieving a positive benefit included the knowledge that the class had been developed for people with dementia and their family carers and that it was facilitated by professionals and volunteers with knowledge of and previous experience with dementia. Participants felt motivated and comfortable about joining the group if they knew that others would have a shared experience with dementia. Other crucial practical aspects to promote attendance were easy access (parking close by) and the opportunity to socialise in a café. Taking place before the COVID-19 pandemic, this study was able to examine the benefit of social interaction to those living with dementia and their carers in 'ordinary' circumstances. This reflects the results of a study exploring barriers to

leisure participation in people with dementia, which found good transport opportunities to be a central feature for engagement in activities (24). The café offered a chance to talk to people on a shared journey, opportunities for carers' respite and access to readily available peer support. These features have been identified in other studies as acting as motivators for people with dementia and their family carers (24,221).

Given the multiple benefits of exercise (8,77,222), it is vital to enable people with dementia to participate in exercise activities. Group exercise will not appeal to everyone (202) and some people with dementia might prefer groups designed for the general population. However, the steadily increasing numbers of these exercise classes (223) show that there is an interest in a physiotherapist-led exercise group if appropriate contextual conditions are met.

4.5.2 Comparison with other studies

This study confirmed some of the findings reported in the existing literature and contrasted with others. Despite using different outcome measures, Barnes et al. (224) also found a small, non-significant improvement in physical and cognitive ability following an 18-week group exercise programme. However, unlike Barnes (224), this study identified deterioration in mobility and quality of life measures. Other group exercise studies in dementia populations have also reported negative effects on some outcomes (184). These contrasting findings could be due to the progressive nature of dementia. Indeed, similar group exercise studies have reported maintenance of ability as positive results (77). Moreover, there is some doubt that the population was representative of a dementia population. Telenius (225) reported

a mean BBS of 38±13.7 in their sample of residents with mild-to-moderate dementia, a cohort which is significantly lower and, therefore, less physically able than this sample.

This study has also provided evidence of the multi-level influences that promote the participation in exercise of older people living with dementia, which overlap with Boulton's social ecological model for promoting participation in older people (89). At an individual level, participants in this study reported benefits, including improved mood and confidence, alongside better health and fitness, which acted as motivators for continued attendance. Boulton also identified both physical and psychological health benefits as drivers for continued participation. On an interpersonal level, people in the study highlighted social interaction as a key factor in their continued attendance which was also identified in Boulton's model. However, people living with dementia and their carers also highlighted the peer support offered and the sharing of knowledge as significant features towards their sustained attendance.

The flexibility, adaptability and accessibility of the classes were highlighted by people living with dementia and their carers. The opportunity for carers to participate in the class overlaps between the interpersonal and environmental sectors of the social ecological model. These features again overlapped with the model proposed by Boulton (89), but for people living with dementia, environmental factors also included having an appropriate staff/participant ratio alongside trained and knowledgeable staff.

Marketing and labelling of classes were important organisational factors within the Boulton model: appealing to men, appealing to all ages, and appealing to the uninterested were identified as key target groups in promoting physical activity for older people (89). Within this study, marketing also appeared to be as important a factor as the labelling of classes. A dichotomy of opinion emerged during focus group discussions on inclusivity and exclusivity in class membership: one participant said that they would not have brought their mother to a class unless it had been labelled as dementia-specific, whereas another did not want to attend dementia-specific classes as she considered such classes were 'not for them'.

4.5.3 Strengths and limitations

This study has both strengths and limitations. It would have been preferable to recruit new members to the class rather than people who had attended for some time. This might have produced a more significant impact on the outcome measures, particularly as the length of time the participants had been attending the class was not documented. However, most of the outcomes improved, which in people with dementia is deemed to be a substantial benefit as they are usually experiencing a decline over time (77). Another limitation was that only people who had already chosen to participate in the class were included. Consequently, the views of others who had not joined or had only attended once are unknown.

A small sample size is also a limitation of the study as outliers in a small group can lead to skewed results. The design of the study (non-randomised cohort with no control group) is a further limitation that could influence the generalisability of findings.

Despite these limitations, this study has strengths, particularly its use of a mixed methods design to fully investigate the phenomenon of interest (226). This is specifically relevant when exploring complex interventions in heterogeneous populations (227). The convenience sample of people already involved in an exercise class has limitations (228), but it ensured that participants were committed to the activity.

A further strength of the study is that it identified significant characteristics that can be replicated: being able to attend with or without a family member, carer, or friend; being able to undertake different exercises at an individual pace, supervised by a trained person who is knowledgeable in dementia care and exercise. Others have recommended this type of person-centred exercise (229,230), and whilst it was not delivered by a multidisciplinary rehabilitation team as suggested by Ravn (230), the results of this study indicated that the participants created their own multidisciplinary programme by combining the exercise class with other activities.

4.6 Conclusion

Well-resourced environments such as university sports centres are well suited to deliver exercise to under-served populations such as people with dementia. If similar conditions could be replicated in other venues, the evidence gathered indicates that participation in exercise classes is likely to produce a positive impact both for the person with dementia (e.g., maintaining current abilities and preventing deterioration, increasing confidence and chances to participate in other activities) and the carer (e.g., supportive community, sharing of useful knowledge). This positive impact could increase the likelihood of continued participation in the class

which, in turn, will contribute to the maintenance of the class (i.e., carers will attend), which supports them and others.

Having established that people with dementia want to participate in exercise classes in community settings, further investigation was required to clarify whether classes are available in the wider East Midlands area. The next chapter explores, through a spatial analysis, the location and availability of exercise classes in the designated area before the COVID-19 pandemic.

Chapter Five

5 Exercise classes: distribution and participation

5.1 Introduction

This chapter describes the methods and results of a survey and a geographical mapping study which provides data on where, what, and who provides exercise classes for people living with dementia. The content of the chapter from the geographical mapping study has been published (231) and has been reproduced here with some adaptations as the survey was not part of the published work.

The literature review (Chapter Three) indicated that there was a range of different types of exercise delivered in a group format available for people living with dementia. The evidence set out in Chapter Four suggested that people living with dementia are willing and able to attend exercise classes under the right conditions. However, the published literature is scant, and there is limited information to inform potential attendees of the current provision of classes. A detailed survey was planned to understand the variety of classes taking place, who was running them and who was taking part.

The first step to enable the survey to be distributed across all the exercise classes was to geographically map existing classes to investigate current service provision for people living with dementia. The location of classes could then be measured against population characteristics such as age. As well as using the maps to locate exercise classes, they can reveal other patterns and provide answers to more complex questions on relationships that may exist between sets of data, for

example, the location of exercise classes for older people compared to the concentration of older people in a particular area (127,232). Mapping can be a useful tool in health care planning, as data on the current accessibility and utilisation of health services can be used to inform planning for the location of new services to maximise the benefit for the representative population (128). Hence, this type of mapping has been widely used in healthcare planning, from measuring accessibility to specialist services, describing the geographic patterns of fall injuries among elderly people, mapping the pattern of disease, and exploring the risk factors of a particular disease (233–236).

Very little literature has studied the distribution of exercise facilities, including for people living with dementia. Where this has been undertaken, the focus has been on the relationship between socioeconomic status and the provision of exercise classes. Pascual et al. (237) studied the number of sports facilities available per 1000 people in Spain and established a positive relationship between facility provision and levels of affluence. However, Giles Corti and Donovan (238) concluded that people living in areas of low socioeconomic status in Perth (Australia) had equal or better access to sporting and recreational facilities than those living in areas of higher socioeconomic status. Billaudeau et al. (239) studied the distribution of sports facilities in four areas of the Paris Ile-de-France district and found that their availability was not related to socioeconomic status in general but depended on the nature of the facilities. Tennis courts and gym facilities were found more often in affluent areas, whilst football and rugby pitches alongside athletic facilities and free outdoor gym facilities were more prevalent in deprived areas.

There is very little available data from the UK. Therefore, this study aimed to investigate where exercise classes are located in the East Midlands and how they are distributed with regard to population age, socioeconomic status, and population density. The selection of the East Midlands for this study represents a rational boundary-setting choice (96). It is a reasonably large representative region in terms of socioeconomic structure, a balance of rural and urban communities and a diverse, multicultural population.

This study is designed to provide further context for exercise class provision in the East Midlands with the following objectives:

- to gather and geocode the location data of exercise classes for older people in the East Midlands and populate point location maps for each county
- to establish how many and what type of exercise classes are available for older people in the designated area and to correlate the findings with population age, socioeconomic and rurality data to analyse the geographic patterns of distribution
- to explore the use of these classes for people living with dementia in the designated area, including the availability and appropriateness of the classes provided
- to inform the purposive sampling framework for the next phase of the research

5.2 Methods

5.2.1 Study Area

The East Midlands is a region of England comprising five counties: Derbyshire, Leicestershire and Rutland, Lincolnshire, Northamptonshire, and Nottinghamshire. It covers an area of 15,627 km^2, with an approximate population in 2018 of almost five million (240). The area is diverse in terms of socioeconomic status, with a wide range of deprivation categories (241) and around 30% of the population living in rural areas (242). Data from the Office of National Statistics estimated that there were just over 800,000 people over 65 living in this region in 2019 (243). In 2015, the region was split into 19 clinical commissioning groups (CCGs), and data from Alzheimer's Research UK indicated that just over 68,000 people were living with dementia across the region (244). UK government data confirms that dementia prevalence in the East Midlands is 0.9% which is higher than the national average of 0.8% and ranges from 0.8% in Northamptonshire and Leicestershire to 1.0% in Lincolnshire (245).

5.2.2 Study data

The study collected the following data across the designated area:

- demographic data: Percentages of the population over 65 years were gathered from the 2011 census, which was available through the ArcGIS software (246)
- socioeconomic data: UK Index of Multiple Deprivation 2015 was gathered through the ArcGIS software (247)
- population density data: World Population Density Estimate 2016 was gathered through the ArcGIS software (248)

- location data: postcode data for exercise classes were gathered through an internet search using Google (see Appendix S)

5.2.3 Study population

All instructors who delivered exercise classes to older people in the East Midlands were deemed eligible to participate in the survey. Participants were invited to provide details of other classes of which they were aware. This snowballing recruitment method was designed to enable classes without internet presence to be included in the study.

5.2.4 Sample size

In a review of email survey response rates over a nine-year period, the average response rate was 37% (249). With a similar response rate, this survey would expect 198 responses, so a total of 100 – 200 completed responses was deemed appropriate to get generalisable results.

5.2.5 Survey design

Since no existing survey was suitable for this study, one was developed with the content being based on the information needs of the research (123). The survey (Appendix T) was designed to collect factual information and used closed survey questions to ensure an efficient and reliable way of gathering the data (123). The survey used a cross-sectional design, with each participant only needing to complete the questionnaire once, to enable data to be collected from a sample of organisers of exercise classes for older people. It was designed to take approximately five minutes to complete online for one class. Each additional class for which the

respondent was willing to provide information would take a further two minutes to complete. It was piloted by an experienced physiotherapist who ran exercise classes for people with neurological impairments.

Ethical approval was obtained from the Faculty of Medicine and Health Sciences Research Ethics Committee (Ref No: 31-0420) (Appendix U). It was hosted on the Jisc Online Survey platform at: https://nottingham.onlinesurveys.ac.uk/group-exercise-classes-and-dementia.

5.2.6 Data collection

5.2.6.1 Geographical mapping study

A geographic information system (GIS), a software system that allows data input, storage, mapping, and spatial analysis, was used to collect, map, and analyse data. GIS provides a different understanding of relationships and can support decision-making, so it was chosen to highlight where gaps in services may exist (238). It also provides a visual representation of patterns that is more complex than can be derived from a database as it integrates various data sources. This data can then be linked by spatially matching datasets in overlays which can be analysed to generate further information (250). In addition, GIS can provide information about the geographical distribution of exercise classes for older people analysed in relation to population distribution, socioeconomic status, and population density. In turn, this can generate more detailed information about accessibility to classes for the population they are intended to support (251).

5.2.6.2 Geocoding

To enable geocoding for data entry into the ArcGIS Pro database, an internet search, using Google, was undertaken (February 2020). Location data were gathered for exercise classes for older people in each county within the region. The search terms "exercise" AND "older people" were added to a county location, e.g., AND "Derbyshire".

A scaled map was created using Google Maps for each county in the East Midlands region. These maps were then merged to form a visual boundary map of the region (see Appendix V), which was used to establish a centre point for each county. This centre point enabled an appropriate postcode and radius to be calculated, which was used to search and gather details of all the classes in each county. A centre point of the East Midlands region was also established alongside an appropriate postcode and radius to ensure that classes were not missed. This was then used to check the entire region in a 'second sweep', ensuring that no class falling within the boundary had been missed.

Spreadsheets were created to gather basic information about each company, group or individual identified through this search. Details recorded included the organisation running the class; type of class (including if they stated that the class was appropriate or specifically for people living with dementia); age range (if stated); location, postcode, and contact details of the instructor.

The information gathered from this internet search was geocoded, using the postcodes for each individual class location. This enabled the locations to be mapped

and a point location map created. A geodatabase for each county was created in ArcGIS Pro (252). These geocoded point locations were then used in conjunction with an Ordnance Survey background map to show the distribution of exercise classes across the region (252).

Further data were gathered through the ArcGIS software regarding the percentages of people over 65, levels of socioeconomic status and levels of urbanisation. The data within the ArcGIS software is provided by default within the application. These data were gathered from the 2011 UK Census (population data) (246), the 2015 UK Index of Multiple Deprivation (socioeconomic status) (247) and the 2016 World Population Density Estimate (levels of urbanisation) (248).

Data were gathered from the Office of National Statistics website and Alzheimer's Research UK website to calculate population to available class ratios (253,254).

5.2.6.3 Survey study

Contact details collected from the geographical mapping study were used to send emails to organisations that promoted exercise classes for older people. The email introduced the researcher and the study and explained the purpose of the survey (Appendix W). It requested that the link to the survey be shared with instructors who ran exercise classes for older people in the East Midlands. Potential participants were then invited to click on the link if they were interested in participating. Emails were sent on the 8th June 2020.

A social media account (@DemfitThe) was set up for the study. It was used to advertise the survey to exercise professionals in the designated area through

exercise or physical activity specific Twitter accounts (Appendix X). Emailed organisations were also tagged to further promote the study among their members. The survey was retweeted every fortnight. The survey was opened on 8th June 2020 and remained live until 8th December 2020. All organisations were sent reminder emails on the 1st September 2020.

5.2.7 Data analysis

5.2.7.1 Spatial analysis

Spatial analysis tools within the ArcGIS software were used to calculate the number and percentage of classes within each county with respect to population age, socioeconomic status, and population density. Demographic data was displayed for the percentage of the population over 65 years of age within each geographical location (area data) (246); these were represented by polygons on a background location map. The socioeconomic data for each geographical location were also represented by polygons on a background map (247).

Population density data (248) was only available in a raster data format which could not be used for further analysis in conjunction with class location data. This data required conversion to polygon data to make further analysis possible which was completed with the Raster to Polygon conversion tool within ArcGIS Pro. Once data was converted to polygon data, it could be displayed on a background map.

Using the analysis tool available within the ArcGIS software, the location of classes (point data) was overlaid on each set of the available polygon (areal) data (age of population, deprivation index and population density) using the spatial join tool. This

enabled the number of points present within each polygon to be calculated. These datasets were then used to calculate the percentage of classes present in areas split by population age, level of deprivation and level of urbanisation. Appendices Y1, Y2 and Y3 show the raw data tables for each dataset.

5.2.7.2 Survey analysis

Data was downloaded from the JISC Online Survey Platform and imported into a Microsoft Excel document. SPSS v28.0 (255) was used to store the data and complete descriptive statistics, including type and qualification of instructors, locations of classes, number of people attending classes and number of attendees with dementia.

5.3 Results

5.3.1 Geographical mapping study

The internet search found 520 exercise classes advertised as appropriate for older people in the region, but these were not evenly spread by county or population per class. Figure 8 below shows the point location map of all exercise classes for older people in the region. Classes specifically advertised as dementia-friendly were located using a red pin, whilst other classes for older adults were located using a blue pin.

Figure 8 Point location map of classes in the East Midlands

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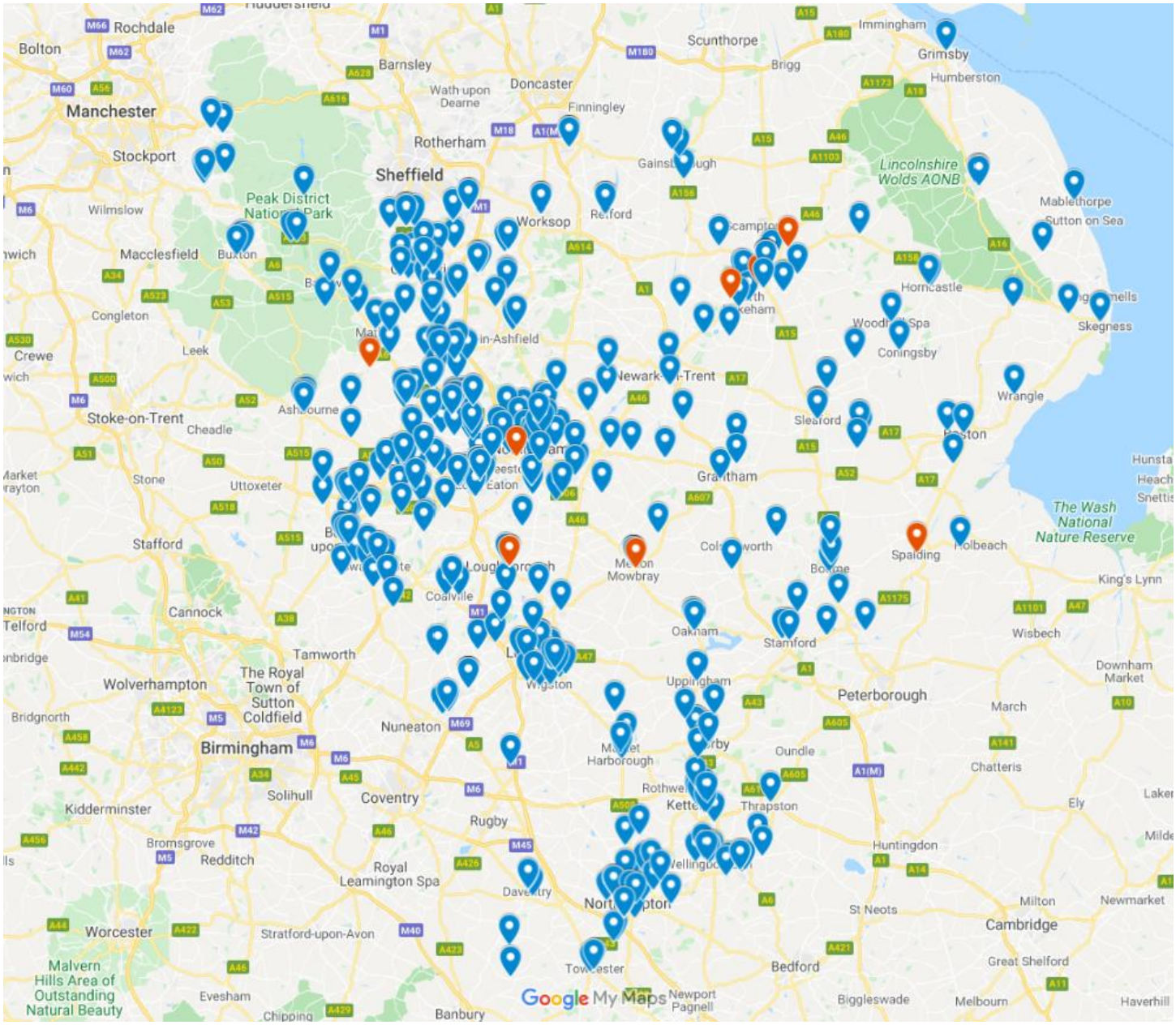


Table 17 below shows the number of exercise classes separated by county, alongside the number of people over 65 living in each county (243).

Table 17 Number of classes and population over 65.

County	Number of Classes	Population Over 65	Ratio (population/class)
Derbyshire	201	174,956	870
Leicestershire	82	144,892	1,767
Lincolnshire	91	179,805	1,976
Northamptonshire	79	136,682	1,730
Nottinghamshire	67	173,311	2,586

Of the 520 classes located, only 13 (2%) were explicitly advertised as suitable for people living with dementia. Table 18 shows the number of classes for people living with dementia alongside the population figures for each county from 2015 (244).

Table 18 Number of classes and people living with dementia.

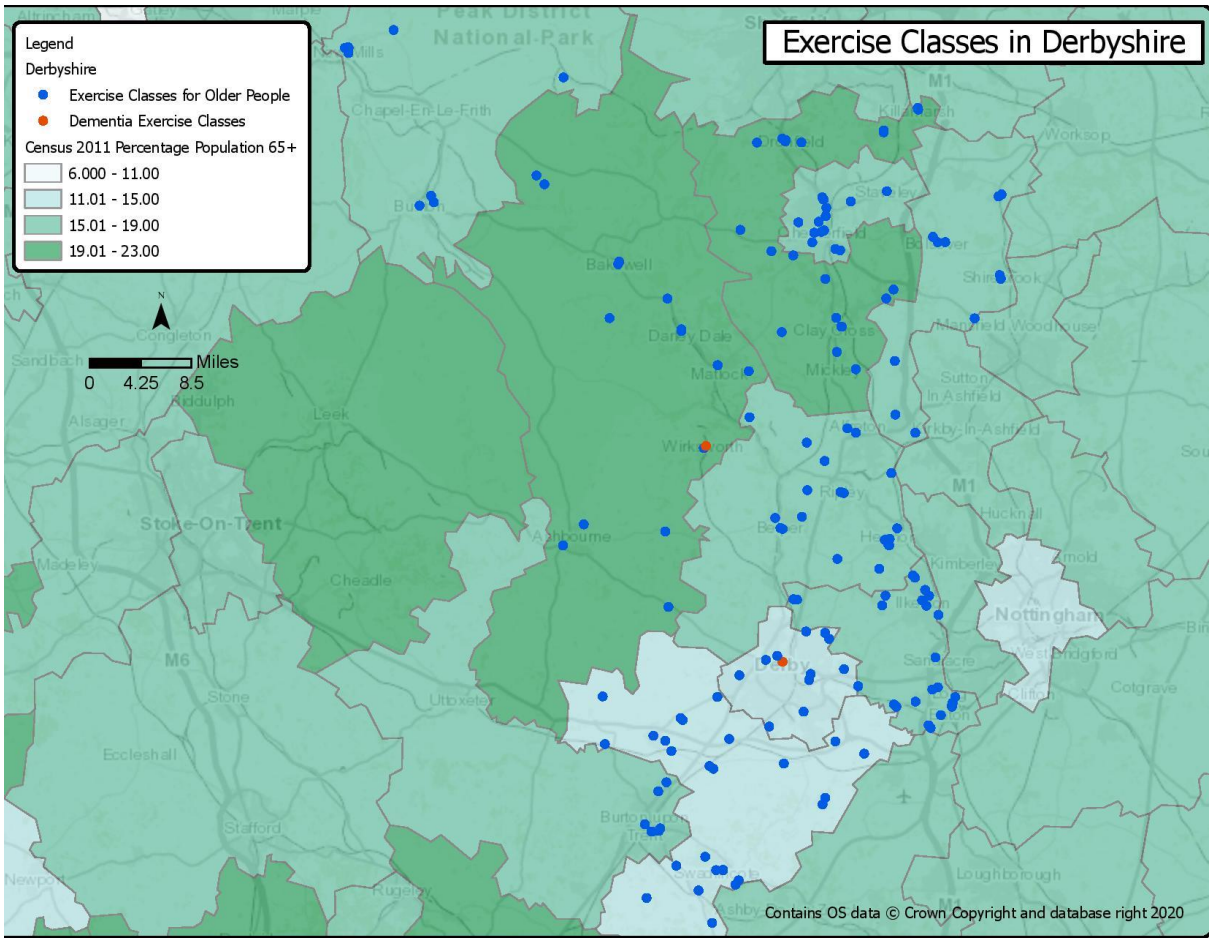
County	Number of Classes	Population Living with Dementia	Ratio (population/class)
Derbyshire	4	14,759	3,690
Leicestershire	3	13,723	4,574
Lincolnshire	5	17,596	3,519
Northamptonshire	0	8,883	-
Nottinghamshire	1	13,245	13,245

5.3.2 Spatial analysis

5.3.2.1 Derbyshire

Figures 9, 10 and 11 show the GIS maps that illustrate the location of exercise classes in Derbyshire set against the percentage of the population over 65 (Figure 9), the levels of deprivation (Figure 10) and the level of urbanisation (Figure 11).

Figure 9 Location of exercise classes in Derbyshire overlaid with the percentage of the population over 65.



There were 201 exercise classes for older people in Derbyshire, spread relatively evenly across the county. There were four dementia-specific exercise classes, one in the city of Derby, one in the south of the county and two in mid-Derbyshire. Over 75% (n = 156) of the classes were in areas where under 20% of the population was over 65, with just over 20% (n = 45) of these classes in areas where over 20% of the

population was over 65. These classes were specifically for older people, yet the majority were in areas with a low proportion of the representative population.

Figure 10 Location of exercise classes in Derbyshire overlaid with the index of multiple deprivation.

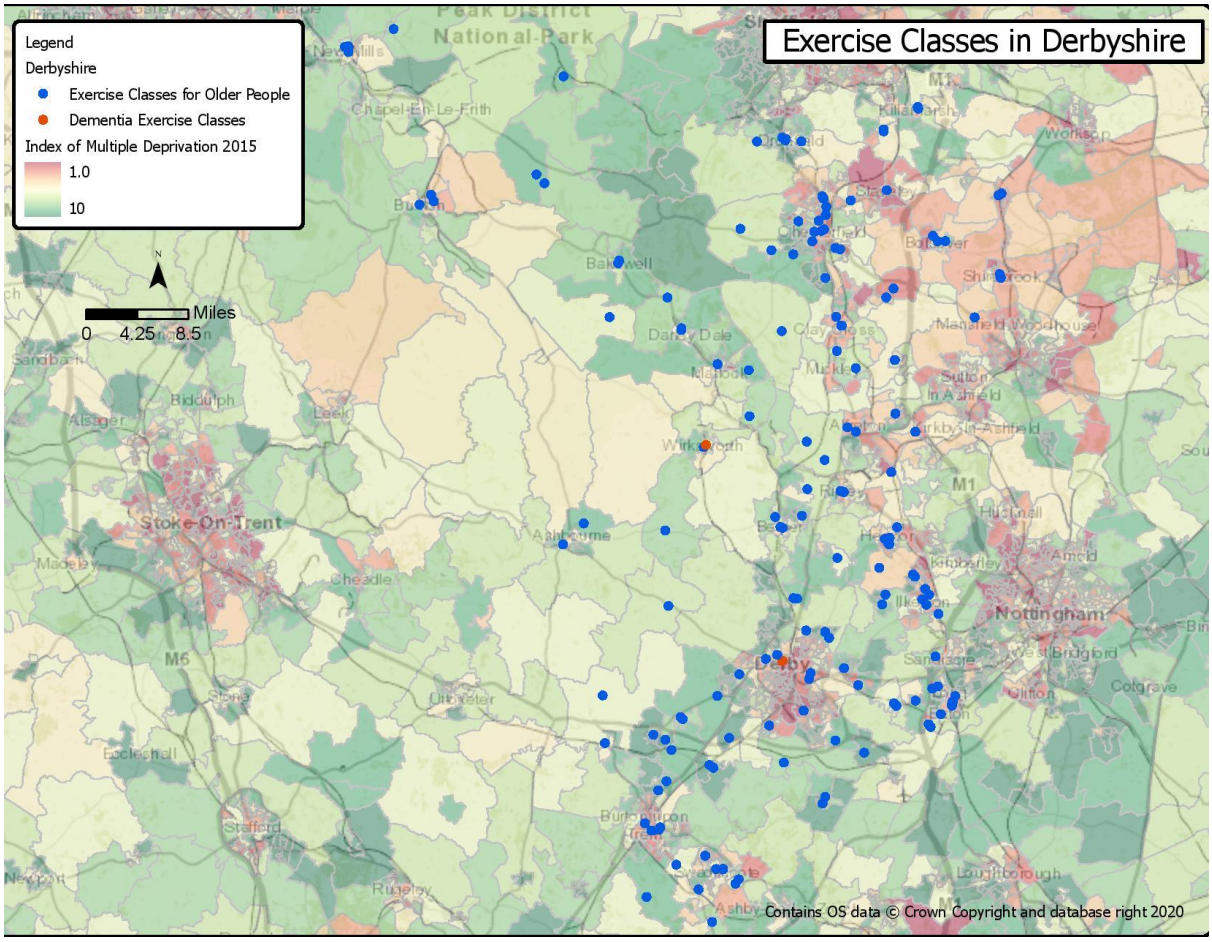
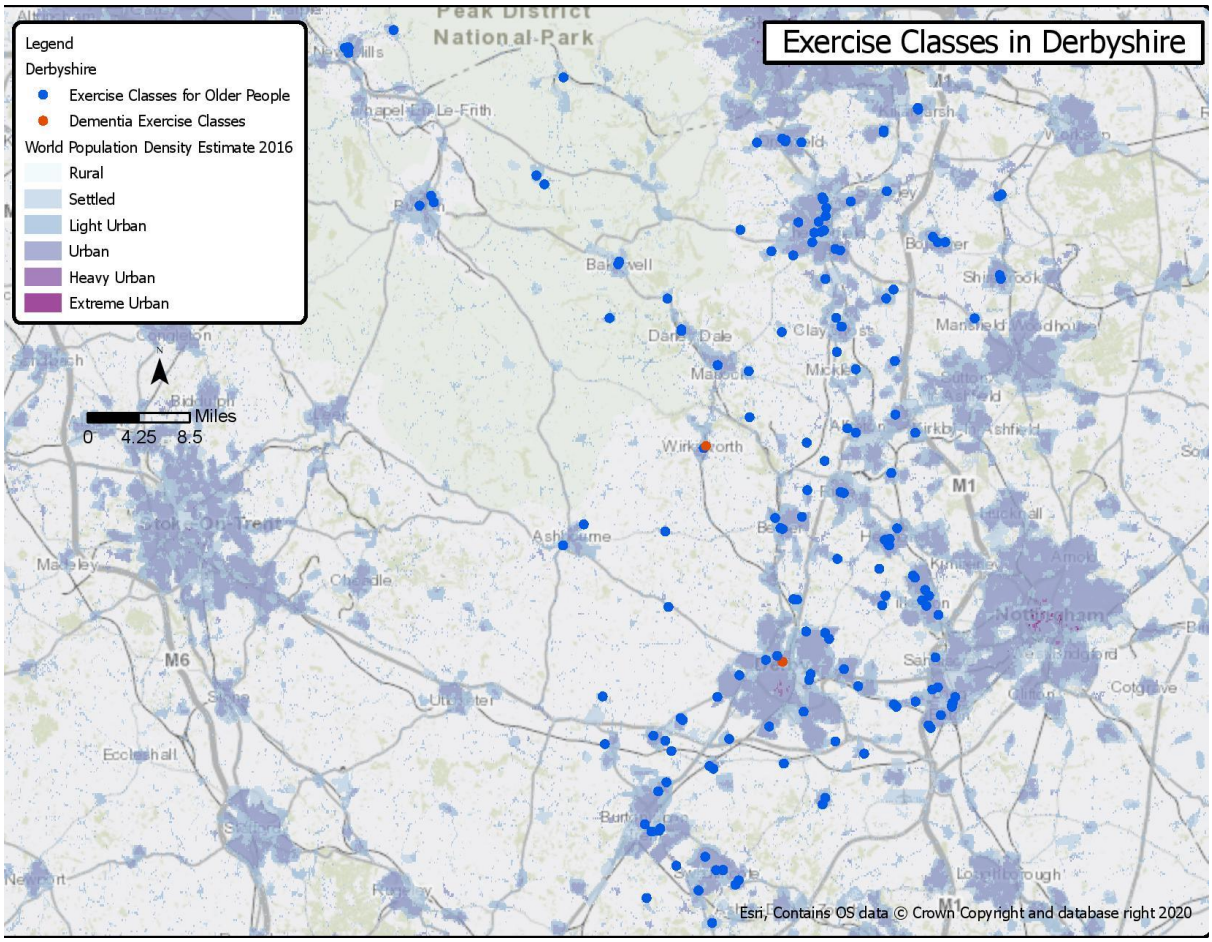


Figure 10 shows the location of exercise classes in Derbyshire compared to the Index of Multiple Deprivation. This index ranks small areas in the UK from the most deprived (1) to least deprived (32,844). The map above shows the deprivation deciles describing the area's percentile, e.g., 1 being the most deprived 10% and 10 being the least deprived 10%.

Derbyshire had a mixture of areas of both high deprivation (1.0) and low deprivation (10). Classes were well distributed in all areas, ranging from nine classes in the

highest areas of deprivation to fifteen classes in the lowest areas. Overall, 45% (n = 94) of classes were in areas rated from 1 - 5 on the index of multiple deprivation, with 55% (n =115) of classes in areas rated from 6 – 10.

Figure 11 Location of exercise classes in Derbyshire overlaid with population density estimates.

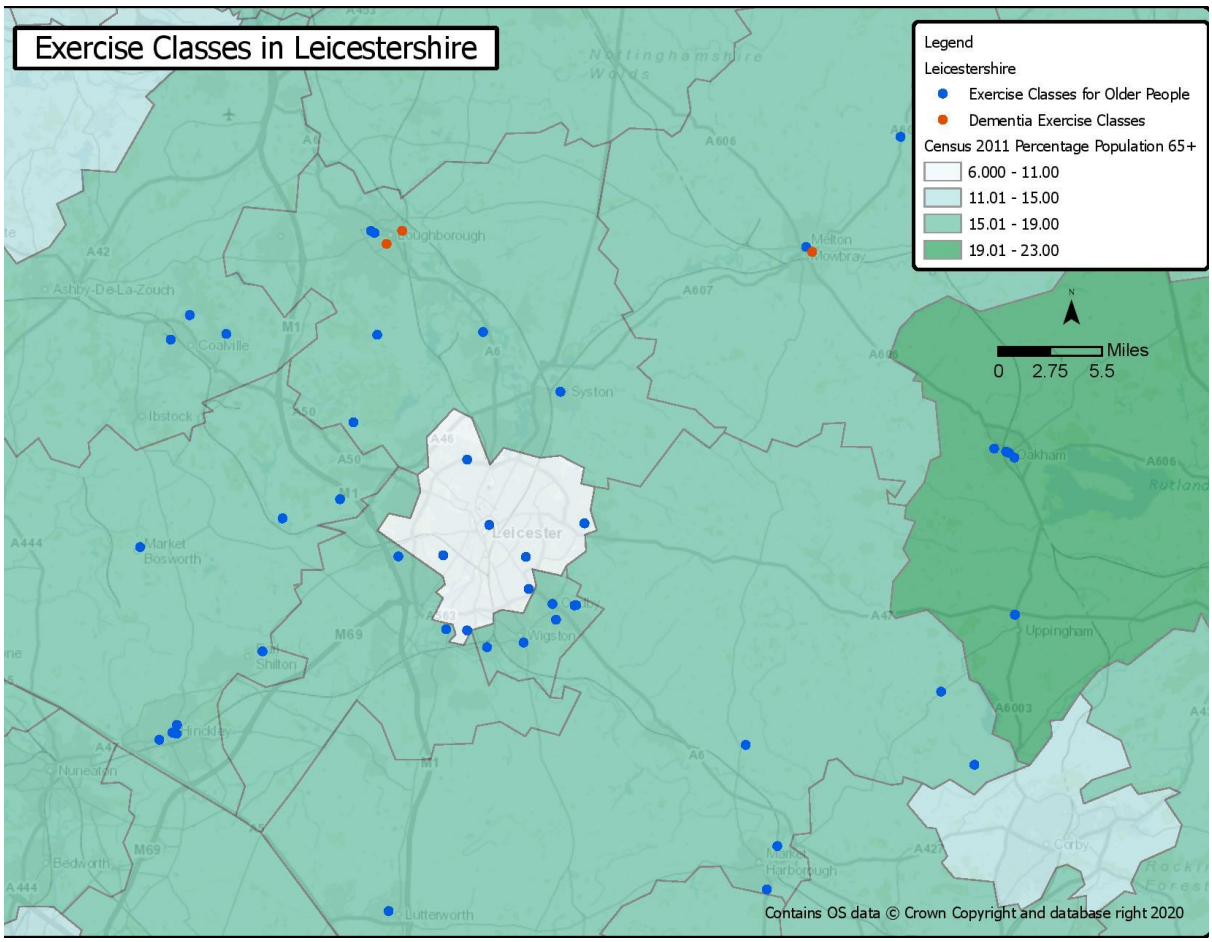


Most exercise classes in Derbyshire were in urban environments, with 32% (n = 64) of classes found in light urban and 62% (n = 125) urban areas. Six % (n = 12) were located in settled areas, some of which were found within the Peak District National Park, although others within the park were situated in small towns classed as urban or light urban areas. There was a tendency for classes to be located along major roads in the county.

5.3.2.2 Leicestershire

Figures 12, 13 and 14 show the GIS maps that illustrate the location of exercise classes in Leicestershire set against the percentage of the population over 65 (Figure 12), the levels of deprivation (Figure 13) and the level of urbanisation (Figure 14).

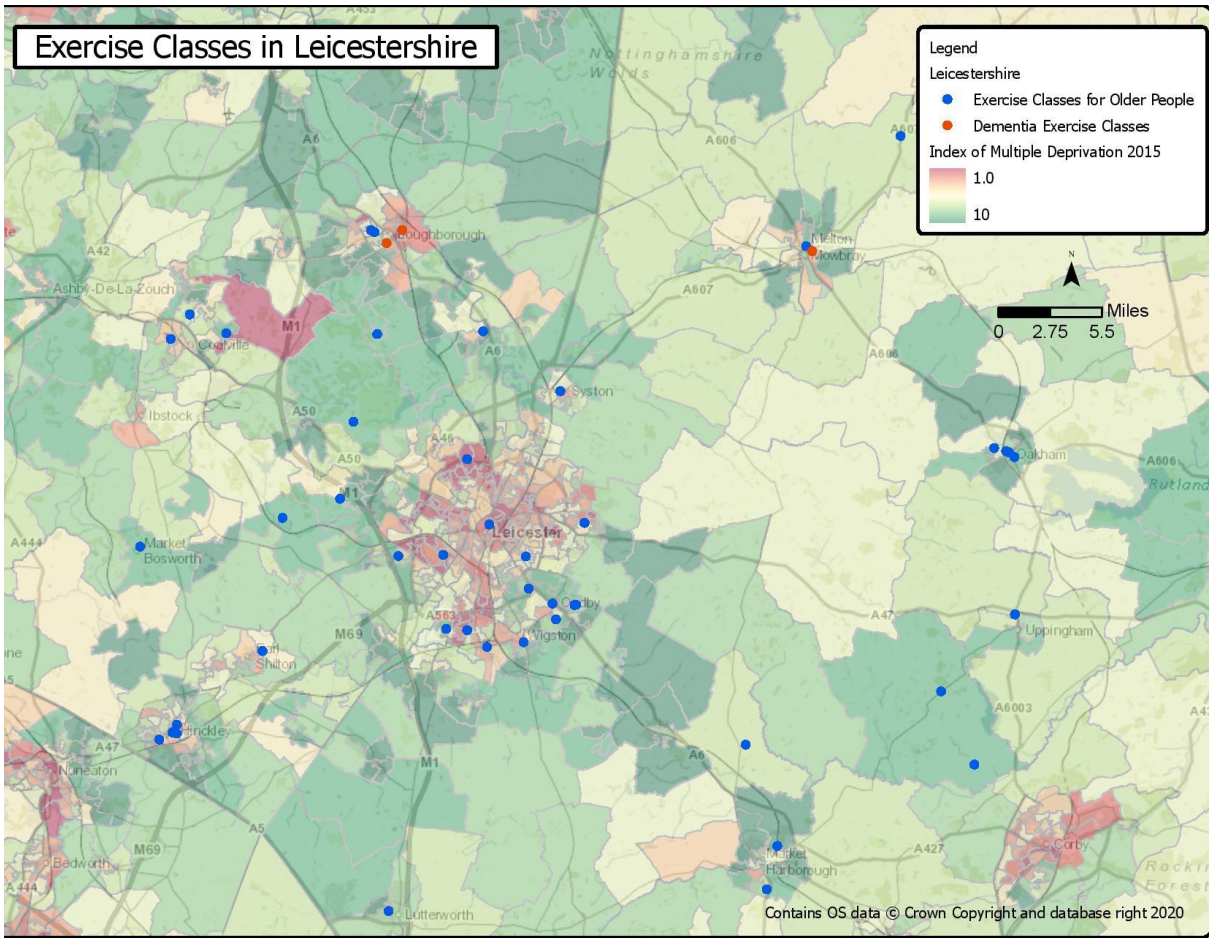
Figure 12 Location of exercise classes in Leicestershire overlaid with the percentage of the population over 65.



There were 82 exercise classes for older people in Leicestershire, spread across the county, with a cluster of 14 classes in Leicester and its surrounding areas. There were three dementia-specific classes, two in the north of the county in Loughborough and one in the east in Melton Mowbray.

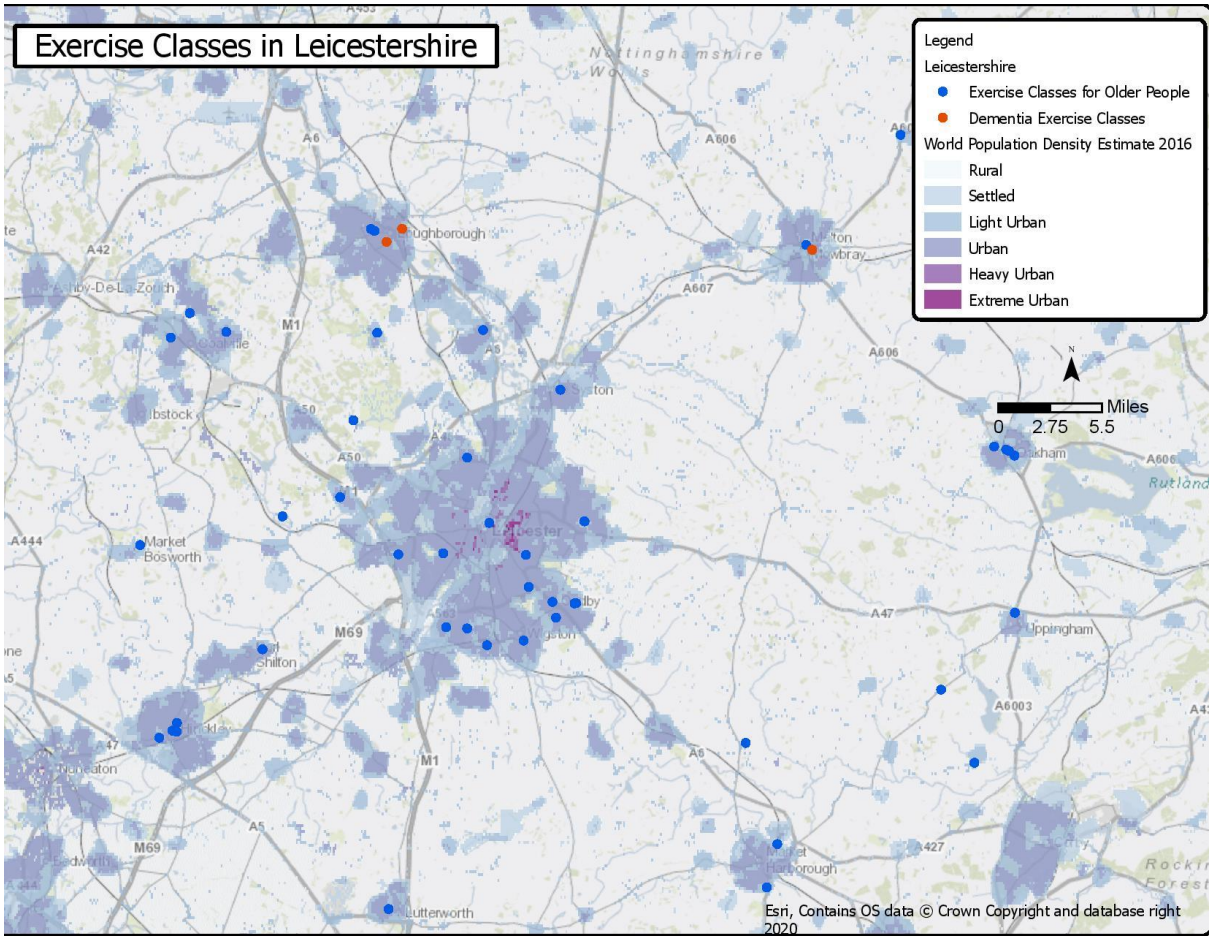
Over 20% (n = 19) of the classes were in areas where less than 15% of the population was over 65, with a further 70% (n = 58) in areas where 15.1% and 19.9% of the population was over 65. Just 6% (n = 5) of these classes were in areas where more than 20% of the population was over 65. Therefore, over 90% of the classes were in areas where there was under 20% of the representative population.

Figure 13 Location of exercise classes in Leicestershire overlaid with the index of multiple deprivation.



Leicestershire also had a mixture of areas of both high deprivation (1.0) and low deprivation (10). Classes were well distributed in all areas, with 63% (n = 52) of classes in areas rated from 1 - 5 on the index of multiple deprivation and 37% (n = 30) of classes located in areas rated from 6 – 10.

Figure 14 Location of exercise classes in Leicestershire overlaid with population density estimates.

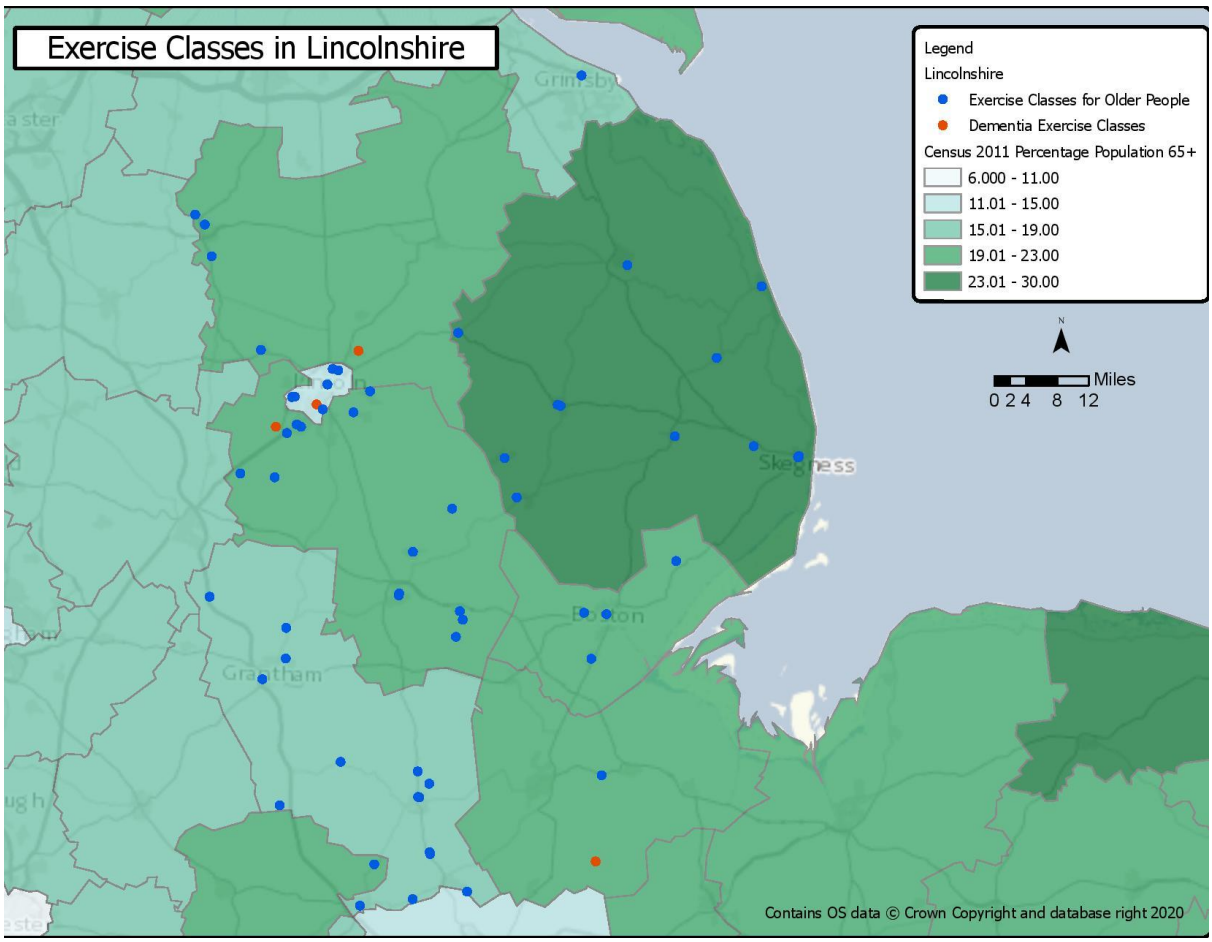


Exercise classes in Leicestershire were predominately found in an urban environment, with 85% (n = 70) in urban areas and the remaining 15% (n = 12) in light urban areas. There were no classes found in rural or settled areas.

5.3.2.3 Lincolnshire

Figures 15, 16 and 17 show the GIS maps that illustrate the location of exercise classes in Lincolnshire set against the percentage of the population over 65 (Figure 15), the levels of deprivation (Figure 16) and the level of urbanisation (Figure 17).

Figure 15 Location of exercise classes in Lincolnshire overlaid with the percentage of the population over 65.

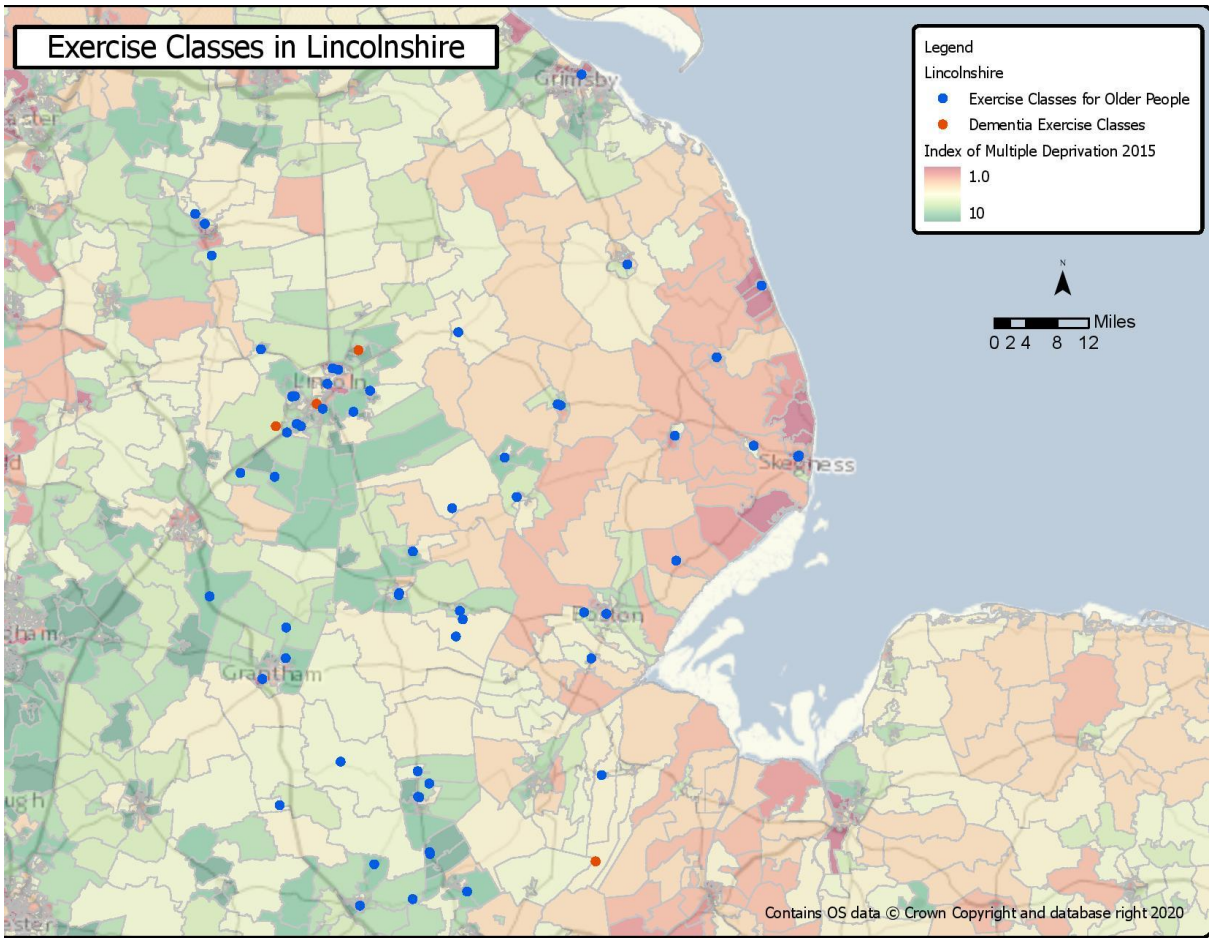


There were 91 exercise classes for older people in Lincolnshire. These were spread widely across the county, with classes from Grimsby in the northeast of the county to Stamford in the southwest. There was a cluster of classes in Lincoln and its surrounding area. There were five dementia-specific classes in Lincolnshire, one in Lincoln and two in surrounding villages. However, there was also one in the south of the county in Spalding and one in the east in Louth. Lincolnshire had the highest

number of dementia-specific classes in the East Midlands, which were spread across the county.

Most classes in Lincolnshire were in areas with a high proportion of the representative population. 23% (n = 21) of classes were in areas where under 15% of the population were over 65, all within Lincoln and its surrounding area. 58% (n = 53) of the classes were in areas where over 20% of the population was over 65 with 16% (n = 15) found in areas where nearly 30% of the population was over 65.

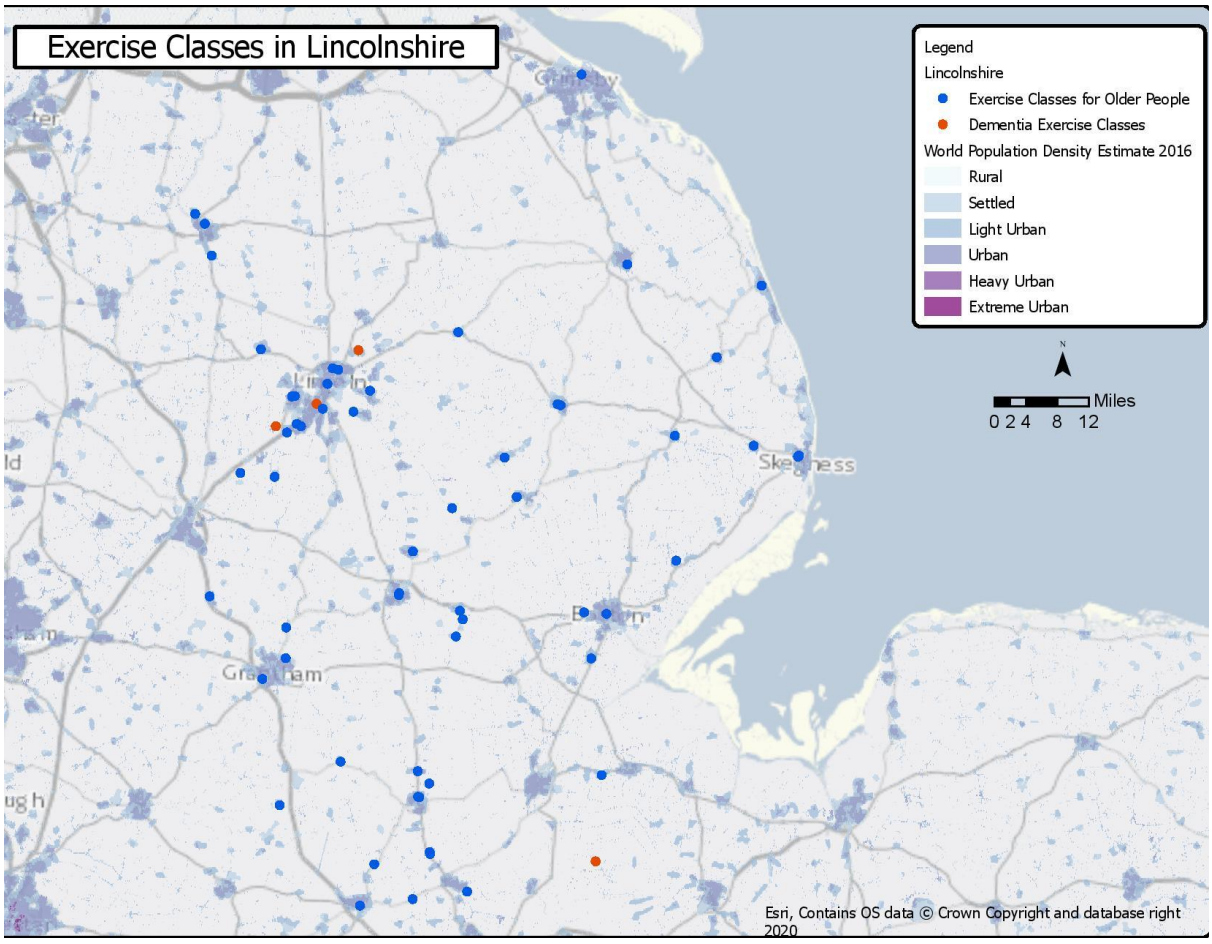
Figure 16 Location of exercise classes in Lincolnshire overlaid with the index of multiple deprivation.



Lincolnshire had an even distribution of classes across high (1.0) and low deprivation (10) areas, ranging from eight classes in the highest areas of deprivation to five

classes in the lowest areas. Overall, 54% (n = 49) of classes were in areas rated from 1 - 5 on the index of multiple deprivation with 46% (n = 42) of classes in areas rated from 6 – 10.

Figure 17 Location of exercise classes in Lincolnshire overlaid with population density estimates.

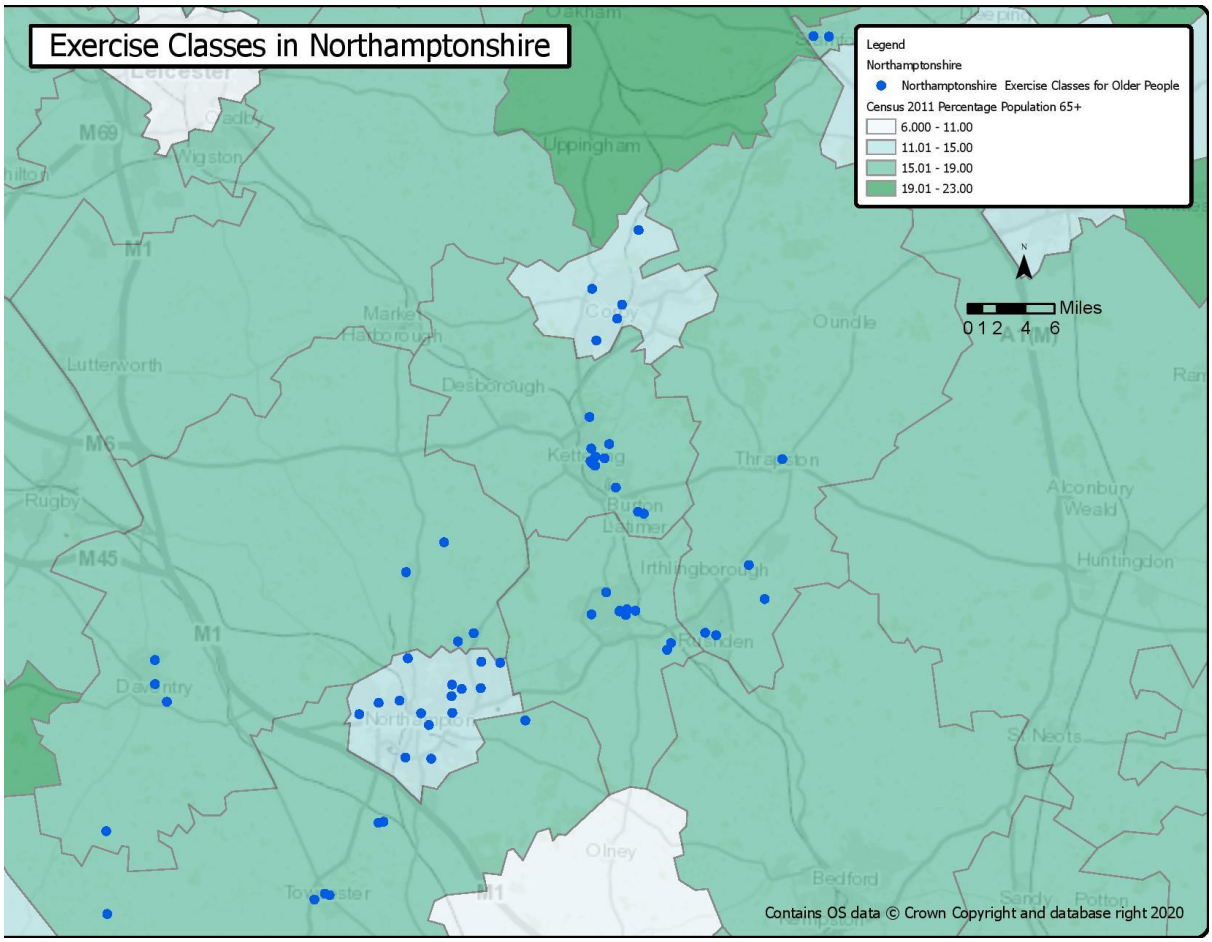


Fifty-nine (65%) of classes in Lincolnshire were located in urban areas, 31% (n = 28) in light urban areas, 4% (n = 4) of classes in settled areas and none in rural areas.

5.3.2.4 Northamptonshire

Figures 18, 19 and 20 show the GIS maps that illustrate the location of exercise classes in Northamptonshire set against the percentage of the population over 65 (Figure 18), the levels of deprivation (Figure 19) and the level of urbanisation (Figure 20).

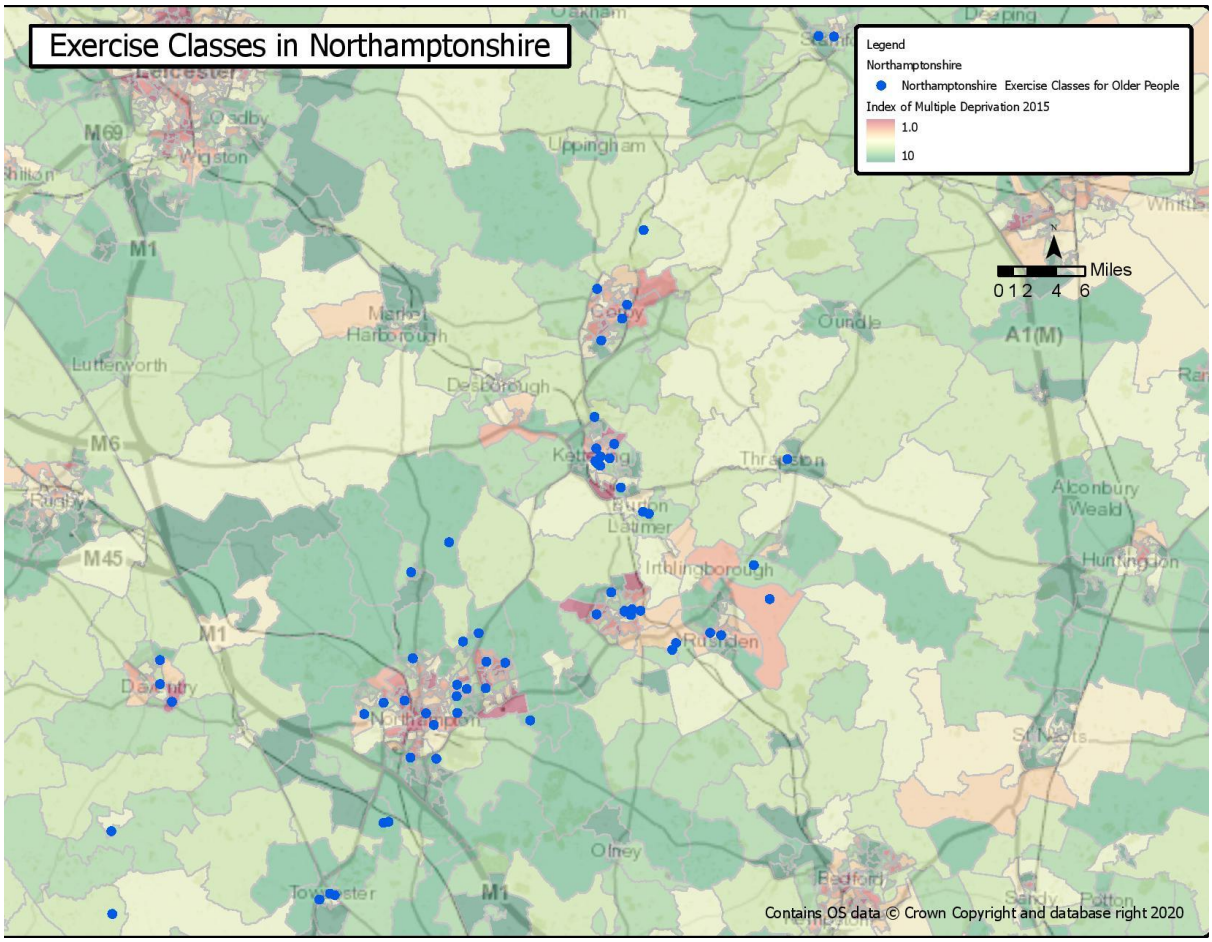
Figure 18 Location of exercise classes in Northamptonshire overlaid with the percentage of the population over 65.



There were 79 exercise classes for older people in Northamptonshire. These were clustered around the towns of Northampton, Kettering, Wellingborough, and Corby. There were no dementia-specific exercise classes in the county.

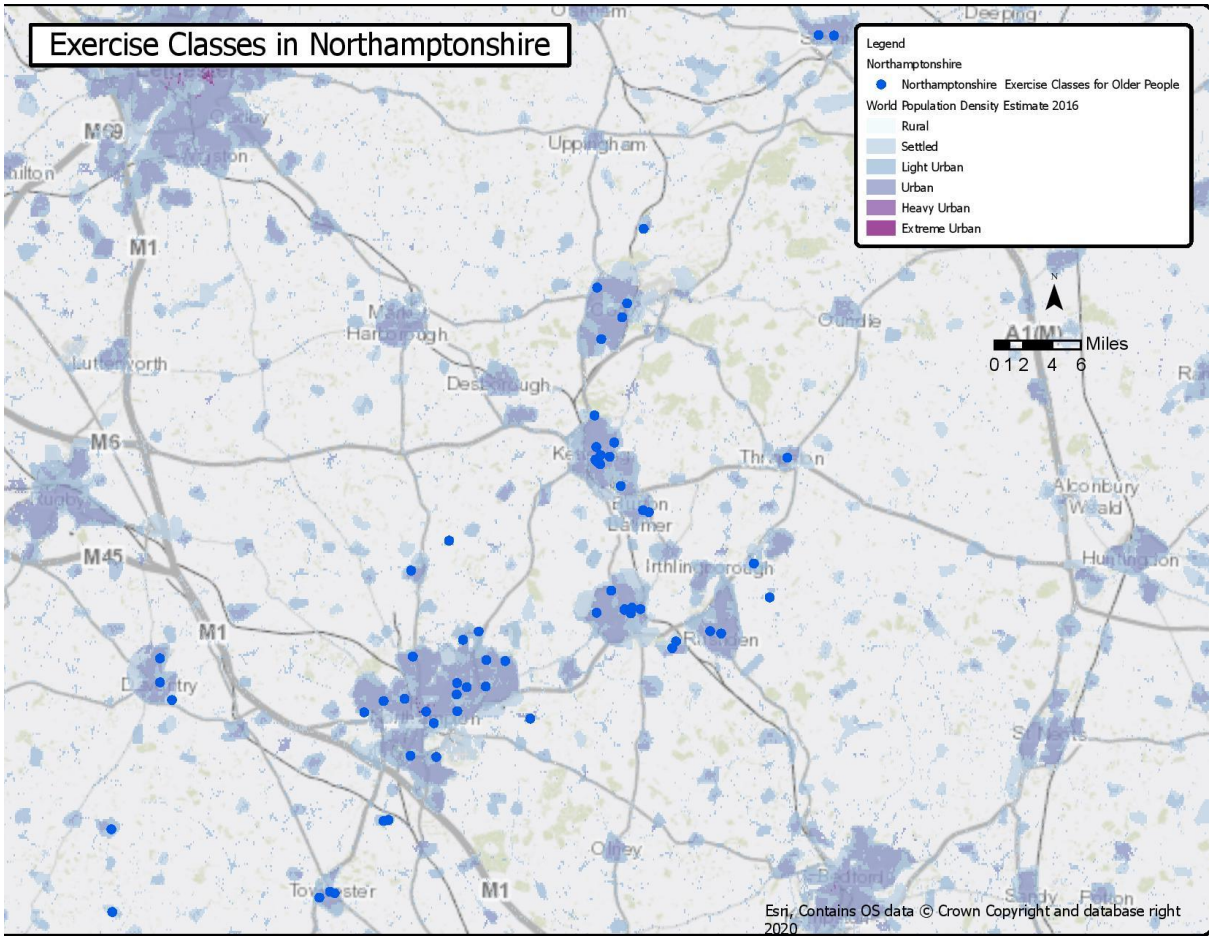
There were no classes in Northamptonshire located in areas with a high proportion of the representative population. All classes were found in areas where under 20% of the population was over 65. Forty-four % (n = 35) of classes were situated in areas where under 15% of the population was over 65, with 56% (n = 44) of classes found in areas with between 15.1 and 19.9% of the population over 65.

Figure 19 Location of exercise classes in Northamptonshire overlaid with the index of multiple deprivation.



Northamptonshire had an even distribution of classes across high (1.0) and low deprivation (10). There were fewer classes in areas of high deprivation with 46% (n = 36) of classes located in areas rated from 1 - 5 on the index of multiple deprivation and 54% (n = 43) of classes located in areas rated from 6 – 10.

Figure 20 Location of exercise classes in Northamptonshire overlaid with population density estimates.

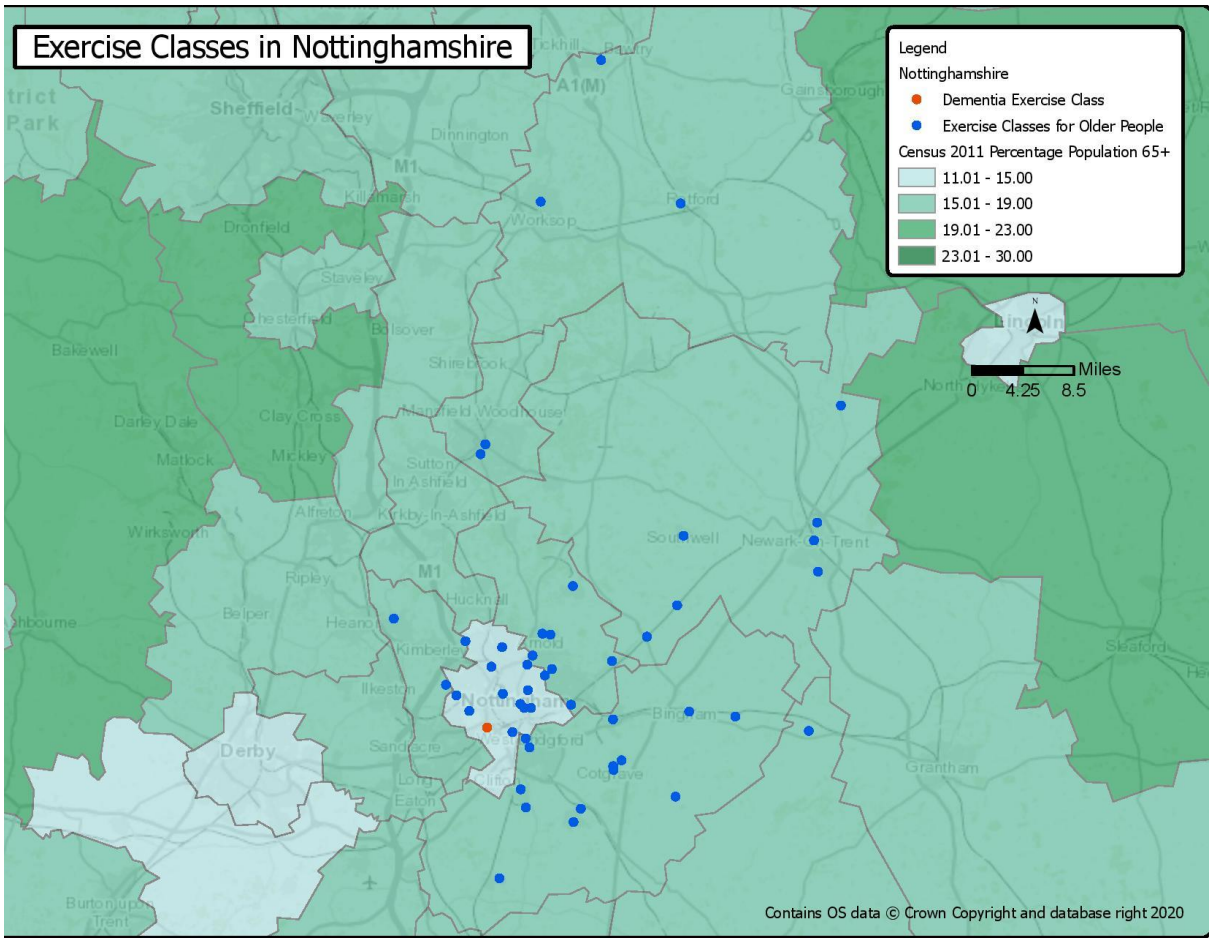


Classes in Northamptonshire were mainly clustered around light urban (27%, n = 21) and urban areas (72%, n = 57), with just 1% (n = 1) of classes found in settled areas and none in rural areas. There was also a tendency for the classes to be located along major roads within the county.

5.3.2.5 Nottinghamshire

Figures 21, 22 and 23 show the GIS maps that illustrate the location of exercise classes in Nottinghamshire set against the percentage of the population over 65 (Figure 21), the levels of deprivation (Figure 22) and the level of urbanisation (Figure 23).

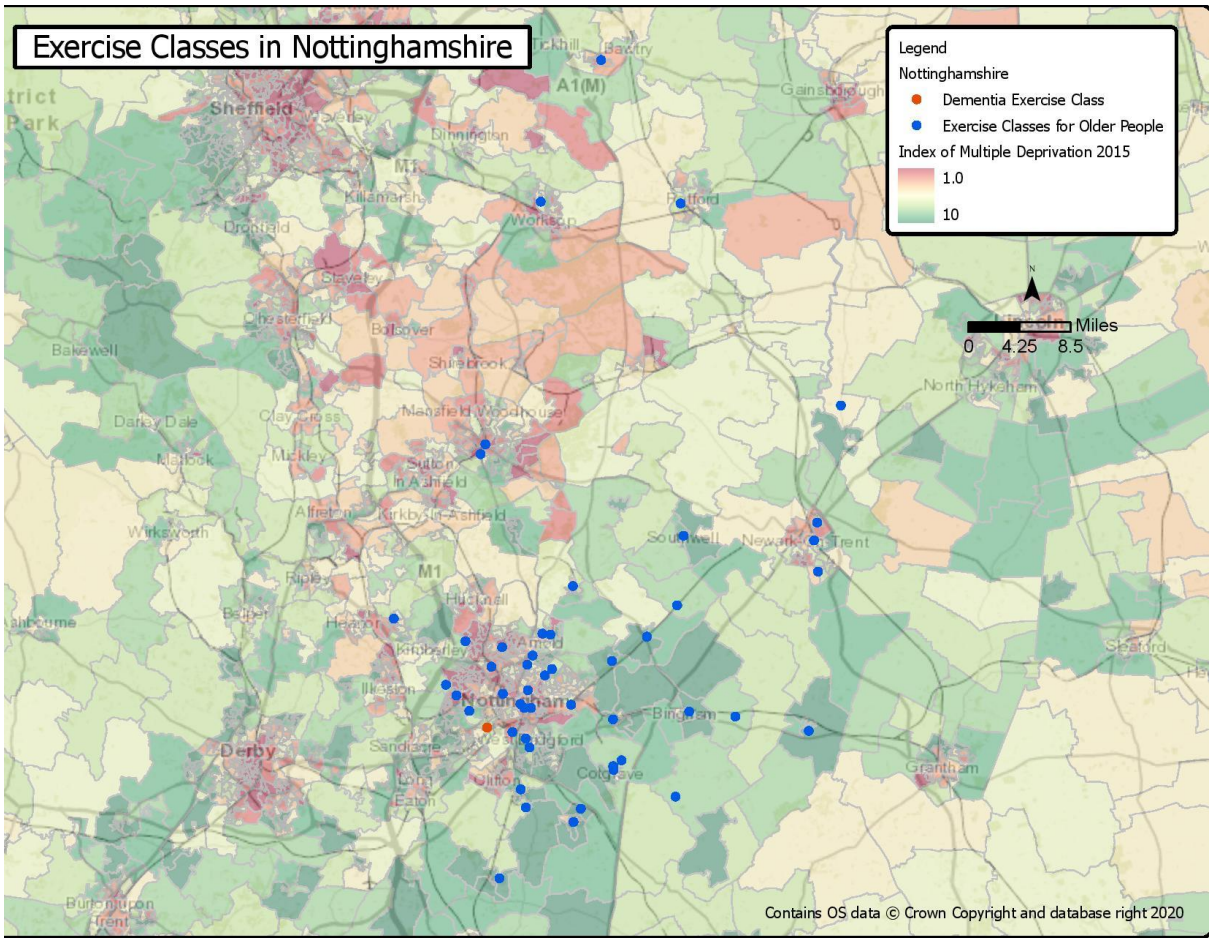
Figure 21 Location of exercise classes in Nottinghamshire overlaid with the percentage of the population over 65.



There were 67 exercise classes for older people in Nottinghamshire, which spread from Bircote in the north to East Leake in the south, with a cluster of classes in Nottingham City and its surrounding area. There was one dementia-specific class in Nottingham.

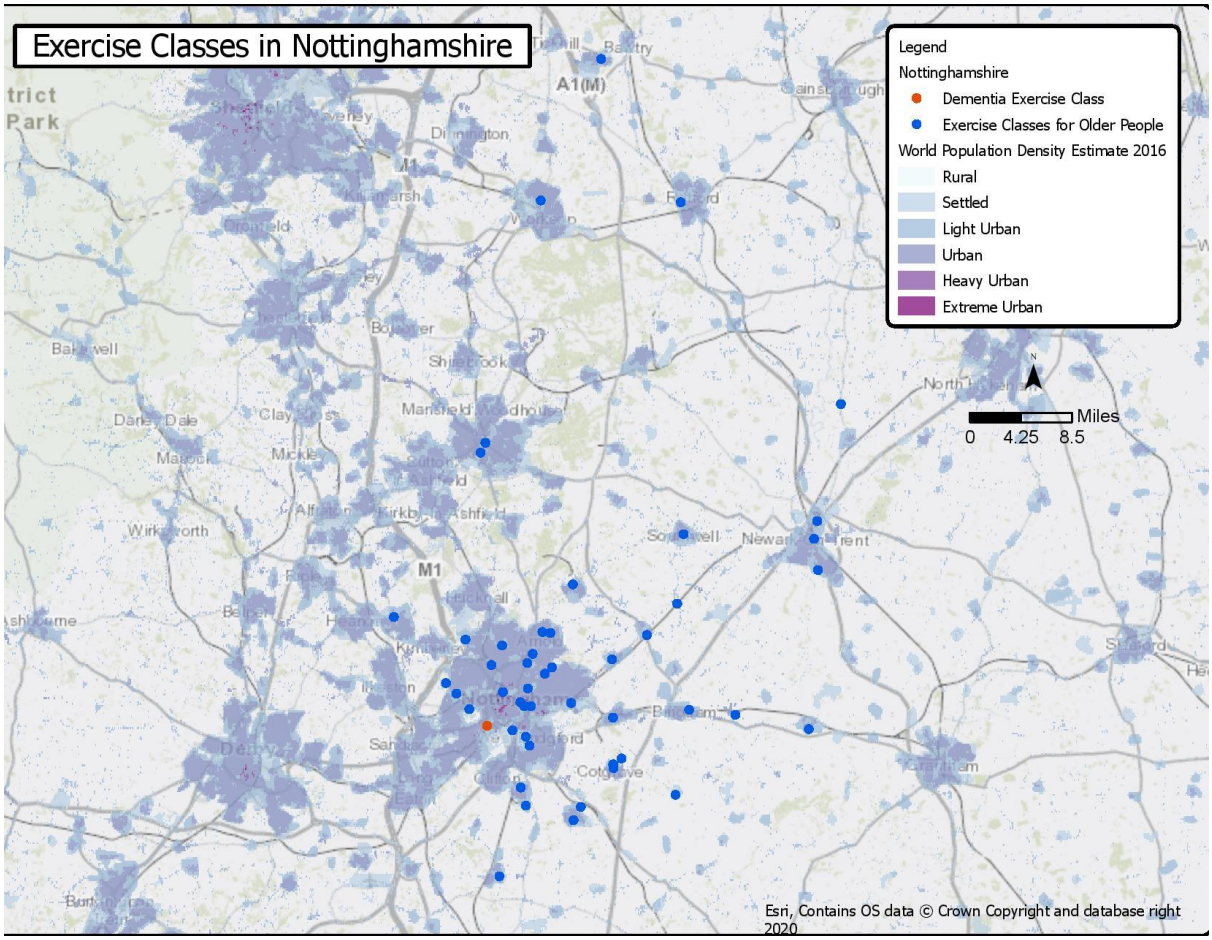
There were no classes in Nottinghamshire in areas with a high proportion of the representative population, with all classes found in areas where under 20% of the population was over 65. However, only 18% (n = 12) of the classes were found in areas where under 15% of the population was over 65 with 82% (n = 55) situated in areas where there was between 17.1 and 19.9% of the population over 65.

Figure 22 Location of exercise classes in Nottinghamshire overlaid with the index of multiple deprivation.



Nottinghamshire had a mixture of areas of both high deprivation (1.0) and low deprivation (10). Classes were well-distributed in all areas with 39% (n = 26) of classes in areas rated from 1 - 5 on the index of multiple deprivation and 61% (n = 41) of classes located in areas rated from 6 – 10.

Figure 23 Location of exercise classes in Nottinghamshire overlaid with population density estimates.



Of all the five counties in the region, Nottinghamshire had the evenest distribution of classes, with 10% (n = 7) found in settled areas, 51% (n = 35) in urban areas and 39% (n = 27) in light urban areas. No classes were located in rural areas.

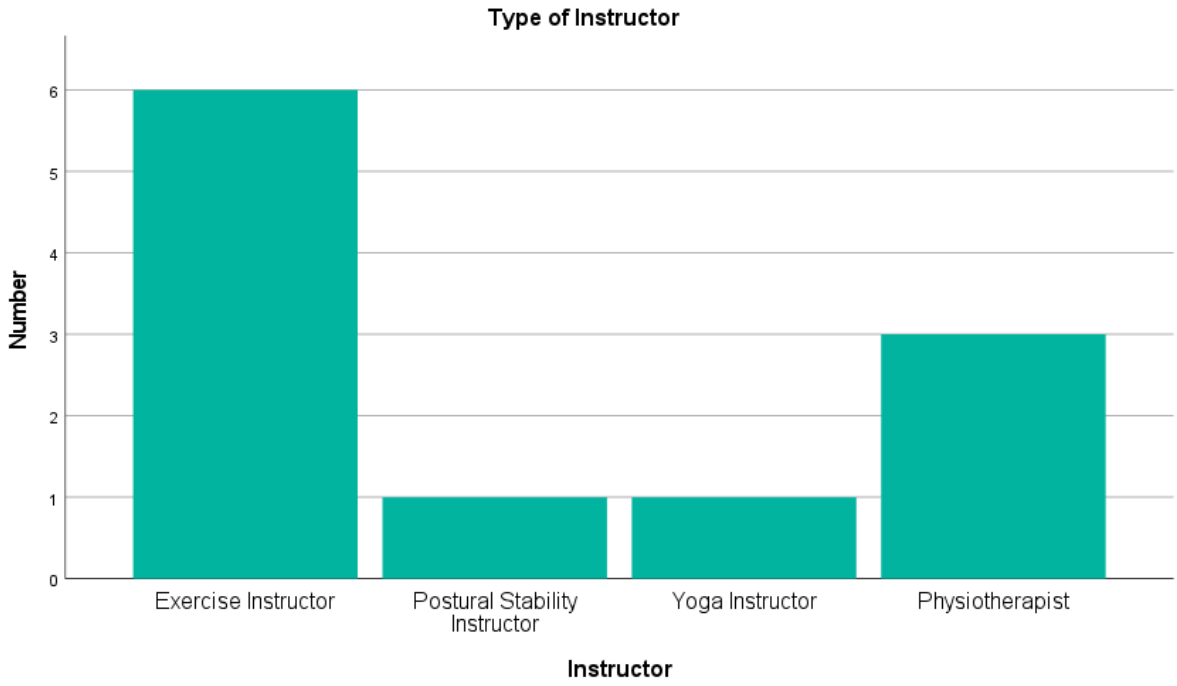
In summary, 520 exercise classes were dedicated to older people across the East Midlands region. Without knowledge of the number of classes available for other regions, we cannot tell whether the number of exercise classes for older people living in the East Midlands is high or low. However, only 13 (2%) of those classes were advertised as appropriate for people with dementia, which suggests that in this area there were limited opportunities for this cohort to participate. Putting this into context, there were over 68,000 people with dementia living in this area in 2019; if

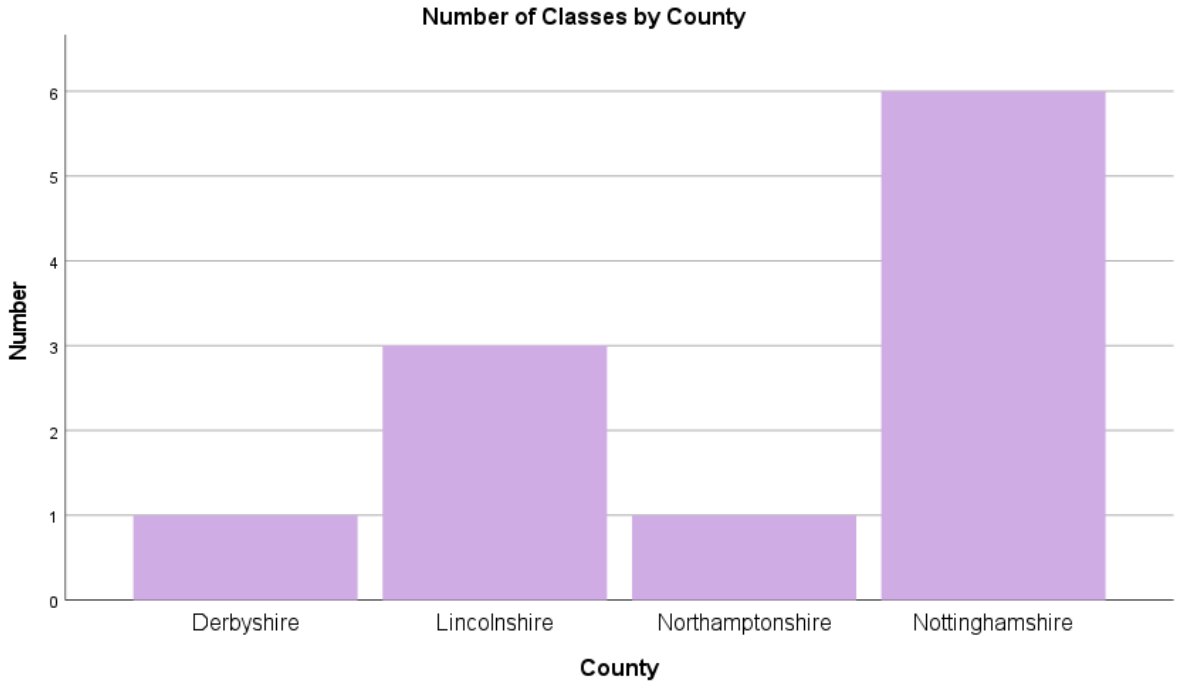
all wanted to attend, each class would have over 5,000 attendees. Many classes were held in locations where a low percentage of the population were over 65 years, limiting their accessibility to many older people. Most classes (67%) were in urban areas, meaning older people in rural areas were disadvantaged. Some classes were located along major roads, which may have increased accessibility for car users but may have deterred public transport users and pedestrians. Classes were located evenly between areas of low (51%) and high (49%) socioeconomic status which will have encouraged use.

5.3.3 Survey

All 520 classes identified in the mapping exercise were invited to participate in the study, and 258 potential participants accessed the survey. Six class leaders completed the survey representing 11 classes (from 8th June 2020 to 10th June 2020); there were no further responses after this date. Six (55%) classes were run by exercise instructors, three (27%) by a physiotherapist, one by a postural stability instructor and one by a yoga instructor.

Within these roles, there was a variety of qualifications. Exercise instructors were qualified at either Level 2, Level 3 or Level 5, the postural stability instructor held a Level 4 qualification, and the physiotherapist was qualified at BSc Level or above.





Six (55%) classes were in Nottinghamshire and three (27%) in Lincolnshire, one in Derbyshire and one in Northamptonshire. Within these locations, four (36%) classes took place in a village hall, three (27%) in a church hall, two (18%) in a gym or leisure centre and two (18%) in community centres.

Ten (91%) classes were aimed at people over 65 with just one (9%) open to anyone over the age of 18; however, most attendees in this class were over 65. Ten (91%) classes had members with dementia. Two (18%) classes were designed specifically for people living with dementia, whilst nine (82%) were designed for older adults. All eleven classes reported that they could be adapted for people living with dementia.

There were a range of attendee numbers both for older adults and people living with dementia. Eight (73%) classes had between 11 and 20 people attend the class, two (18%) had 21 to 30 attendees, and one (9%) had between 1 and 10 attendees. Within the classes, eight (73%) had between 1 and 10 people living with dementia attending, and two (18%) had 11 to 20 such attendees. One (9%) was unaware if any of their attendees had any form of dementia.

5.4 Discussion

5.4.1 Summary of findings

A total of 520 exercise classes were identified across the East Midlands, and eleven participated in the survey. A range of professionals delivered the classes, most designed for older people. Despite the number of classes, only 2% were advertised as appropriate for people with dementia, and these were spread widely across the region. There was huge variation within the five counties with no classes available in Northamptonshire and five in Lincolnshire.

Across the region, there were many similarities in the distribution of exercise classes for older people. In most counties, classes were in areas where a low percentage of the population was over 65. Only 20% of classes were in areas where more than 20%

of the population were over 65, with Lincolnshire (58%) being the outlier. Most (80%) classes were in areas where less than 20% of the population were over 65 with 17% located in areas where less than 15% were over 65. Classes in city centres, predominantly occupied by a younger population, may not be ideally located to serve the population they are designed to help.

Most classes (67%) were in urban areas, with 29% in light urban and just 4 % in settled areas. Despite the rural nature of Lincolnshire and the Peak District in Derbyshire, most classes were in urbanised areas. The East Midlands is a relatively urbanised area with three major cities, one smaller city and several large towns. The four central counties (Derbyshire, Leicestershire, Nottinghamshire, and Northamptonshire) have population densities ranging from 319/km^2 to 538/km^2 (256). However, there are more rural parts, with Lincolnshire having an average population density of 157/km^2 and the High Peak in Derbyshire with 170/km^2 (256). Despite these pockets of rurality, there were no classes in rural areas and just 4% of classes in settled areas.

In both Derbyshire and Northamptonshire, there was a tendency for classes to be located along major roads such as the A38 which traverses the whole of Derbyshire from Burton on Trent to Mansfield and the A43, which runs south to north in Northamptonshire through Northampton and Corby; this pattern may support increased accessibility. In the other counties, the distribution of classes was more scattered.

Across the region, the distribution of classes was similar in areas of high (49%) and low (51%) socioeconomic status. However, this was not uniform: Leicestershire had 63% of classes located in areas of high deprivation and 37% located in areas of low deprivation; by contrast, Nottinghamshire had only 39% of classes located in areas of high deprivation with 61% located in areas of low deprivation.

That classes were widely distributed across the region can be viewed positively. They were located evenly between areas of low and high socioeconomic status across the whole region, although there were some differences within counties. Some counties had a pattern of classes located along major roads which may increase accessibility; this advantage may be limited to car drivers unless public transport follows these major routes.

5.4.2 Comparison with other studies

There is very little literature that has studied the distribution of facilities or services in relation to age, socioeconomic status, or urbanisation, with most focusing on socioeconomic status. Christie et al. (257) analysed the spatial accessibility of renal replacement therapy units in South and Mid Wales and found these were less available in more deprived areas. This finding paralleled the data for Nottinghamshire in this study. Higgs et al. (258) also studied accessibility to a wide range of sporting facilities in Wales and found access was higher in more socially deprived areas and lower in the more affluent areas. Again, this was comparable to the data in this study from Leicestershire.

There have been very few studies which have explored accessibility in relation to urbanisation, and many of these have concentrated on distance, travel times and use of public transport. Yin (259) studied differences in accessibility to pre-natal care in Georgia (USA) and found that access decreases as rurality increases. Chandak et al. (260) explored rural-urban differences in accessibility to breast cancer screening in Nebraska (USA) and found that people who lived in rural areas had higher rates of late-stage diagnosis and had to travel further for screening. These results are similar to those found in this study, with the majority (96%) of classes in the East Midlands region located in light urban or urban areas.

A further study by Pedersen et al. (235) found that reliance on public transport led to longer travel times to attend cardiac rehabilitation classes in Denmark, with both public transport and an extended travel time acting as a barrier to attendance. Classes in Derbyshire and Northamptonshire were often located on major roads through the county, which may have increased accessibility for a car owner but may have had no discernible benefit for a public transport user. As household access to private transport decreases in older populations (261), reliance on public transport increases and can be a significant barrier to attendance at exercise classes (235,262).

Accessibility has rarely been explored in relation to age generally and even less so regarding accessibility to healthcare facilities or physical and recreational activities. Love and Lindquist (263) used GIS to measure accessibility to hospitals for people over 65 living in Illinois (USA). They found that most people over 65 lived within 4.8 miles of a hospital, but there was a difference in distance between those who lived in urban areas to those living in more rural areas. However, there was no evidence

that people over 65 had worse hospital access than the rest of the population. A more recent study by Horner et al. (264) in Florida (USA) found that for most activities, including recreational and physical activity, people over 65 had similar access to other age groups.

These international studies have explored access for older people to facilities open to all ages. However, this study has explored access to activities that were specifically designed for older people in relation to their areal distribution; this may explain the disparity between the results. Older people living with dementia experience additional barriers, including reliance on others for access, reduced social confidence and difficulties with motivation (87), which may not be considered when planning the location of new facilities, further widening inequalities.

5.4.3 Strengths and limitations

This study was the first to systematically seek to identify all exercise classes across the East Midlands and explore who operates and takes part in them, whilst also examining their distribution in terms of population age, socioeconomic status, and population density. The internet search to identify classes was completed systematically, ensuring that all classes with an online presence were identified for further contact. The snowballing technique, used to identify further classes that did not have an online presence, was adopted to secure the inclusion of all community exercise classes. The questionnaire was piloted with an experienced physiotherapist before going live to ensure that the questionnaire worked as expected and could be completed within an appropriate time frame.

Geolocation from postcode data through ArcGIS for the UK is of very high quality, and the results are accurate in providing an x.y coordinate for specific buildings. It also allows prevalence estimates to be made for any geographically defined population, such as age range, rural areas, and socioeconomically deprived areas. Alongside the use of mapping software and universally available datasets for population, levels of deprivation and population density, comparisons can potentially be drawn between the distribution of exercise classes related to these datasets in the East Midlands with classes located over the UK and worldwide.

This study demonstrated the effectiveness of GIS as a tool to inform public health decisions, including the location of new facilities. The additional data that can be extrapolated from the distribution patterns can be used by researchers, local authority planners and policymakers to explore the equity of services for not only older people or those living with dementia but other hard-to-reach communities. The data provided in this study can inform decisions on where to best locate new exercise classes to ensure they are located where they would best serve the population they are designed to support. The internet search for classes was completed systematically, although some may have been missed if they had no online presence.

The survey response was limited, with only six respondents accounting for 11 of the 520 exercise classes identified in the geographical mapping exercise. Therefore, it was only able to offer a limited view of available classes in the region. The small sample size precluded an exploration of the attendance at these classes by people living with dementia. The survey was distributed during the first national lockdown

when all exercise classes had ceased, and instructors were either furloughed or, if self-employed, not working. Hence, it was unlikely that they would have read emails from their umbrella company. Many of the potential participants who responded via Twitter could have been located outside of the East Midlands and having read the initial page, realised that they were not eligible for the study. There was also a time limitation to this study. The original internet search was completed in 2020, just before the COVID-19 pandemic and the subsequent lockdown, with some exercise classes not returning. Hence, this can only provide a snapshot of what was available at the time of the search.

Limitations also arose from the form of data analysis. Density estimates were not available in polygon data and needed to be converted from their original format in raster data. There was not a 100% match between the original data when it was converted, which may mean classes on the external boundaries of the region could have been missed.

Although it was noted that classes in Derbyshire and Northamptonshire were located on major roads, accessibility in terms of distance or travel times to a class was not included as part of this study. A spatial analysis, which included distances and travel times to exercise classes based on both access to a car and use of public transport, could provide additional data for planners or policymakers when making decisions on the location of new services.

5.4.4. Recommendations

Exercise has been recommended in several guidelines (265–267) to prevent falls, reduce immobility and help people with dementia remain independent. However, this research has shown a lack of dementia-specific exercise classes available for this population. It has also shown that older people living with dementia in rural locations and those that do not have access to private transport may have even more difficulties finding and accessing an appropriate class. If new classes are to be set up it is vital to consider their location in terms of accessibility for both public and private transport users to ensure equitable access for both.

It is also crucial that any new services that may be commissioned are studied to ensure that they are meeting the needs of the people living with dementia. The use of GIS in this study has highlighted its potential as a tool for planning future public health decisions, as it can highlight inequalities across seldom-heard communities, including those living with dementia. Considering additional barriers that may exist for these communities may allow facilities to become more inclusive for the communities they serve.

5.5 Conclusion

This study successfully located and mapped 520 exercise classes for older people in the East Midlands, enabling a survey to be distributed to exercise instructors. Although classes were widely distributed across the region as a whole, they were not uniformly distributed regarding the specific population, with many held in locations where a low percentage of the population were over 65. Significantly few exercise classes state they are appropriate for people with dementia, meaning there were

limited opportunities for this cohort to participate. There are a variety of professional roles and a range of qualifications among those who instruct and run exercise classes for older people in the region. Many of these classes had both older people and those living with dementia attending, and instructors who were surveyed thought that their classes could be adapted for the latter group.

Most classes were in urban areas, and where <20% of the population is over 65 years of age. However, classes are spread evenly across the region between areas of differing socioeconomic status. Understanding where exercise classes are currently located with reference to these variables can be useful for policymakers, enabling them to effectively plan where to locate any new classes to increase accessibility for the population for whom they are designed.

Evidence presented in Chapter Four confirmed that people living with dementia in the East Midlands want to participate in exercise classes. This chapter has established where such classes (as well as those in the 65+ age range) are located in the region. The results in this chapter have informed the purposive sampling of groups for the next chapter.

Chapter Six

6 Ethnographic Study

6.1 Introduction

The classes studied so far in this thesis were delivered face-to-face before the COVID-19 pandemic. However, as outlined in the introduction (Chapter One), there were significant changes to the delivery of classes for older people, including those with dementia, in 2020. Some classes transitioned to online delivery during this time, which led to a unique opportunity to assess the impact of exercise classes for older people with and without dementia, both during restrictions when classes were offered online and as restrictions were eased when classes returned to be delivered face-to-face.

This study aimed to explore the context-specific characteristics of, and barriers and facilitators to existing classes and to what extent these differed during the pandemic and after the COVID-19 restrictions were lifted. Two objectives were identified:

- to investigate the core components that encourage older people with and without dementia to attend and continue to take part in an exercise class
- to examine if these core components can be consistently provided through different modes of delivery and maintain the benefits that participants reported before the pandemic

6.2 Methods

The geographical mapping exercise and online survey described in Chapter Five provided the relevant information which underpinned the purposive sampling of classes for this ethnographic study.

6.2.1 Design

The study consisted of three mini-ethnographies in which the researcher participated in exercise classes over six weeks and in additional activities (e.g., refreshments), adopting the role of participant-as-observer (129). At the end of each observation period, focus groups or interviews were held with participants, carers, and exercise instructors to develop an understanding of the barriers and facilitators to attendance (138,142).

Ethical approval was obtained from the Faculty of Medicine and Health Science Research Ethics Committee of the University of Nottingham (Ref No. 114-1120) (Appendix Z).

6.2.2 Recruitment

An online survey was issued in June 2020 to initiate purposive sampling. This had a limited response but was sufficient to allow access to three exercise classes. The instructors who responded were contacted to seek permission for the researcher to join their class in a participant-observer role (Appendix AA and BB). The classes included: an online exercise class for older people, a face-to-face class for older people, and a dementia-specific gym-based class.

At the end of the observation period, attendees at all classes were asked if they wished to participate in a focus group, to support the development of an understanding of barriers and facilitators to attendance and the benefits they thought they derived from participation. In addition, exercise instructors were invited to be interviewed about their experiences running their classes. Carers were invited to attend a focus group to capture their views on the barriers and facilitators to attendance, alongside the benefits they perceived for themselves and the attendee.

6.2.3 Procedures

The instructors at all sites had informed the class that a researcher would be attending the next session and, having been introduced to the members, the principal researcher (AL) outlined the purpose of the study and explained the protocols that would be followed, primarily that anyone who did not want to be included in the observations should inform either the researcher or the instructor. The researcher confirmed that, as part of the research, they would be a participant and that they would be writing notes at the end of each session. However, consent would be requested to write up any informal conversations that took place within the sessions.

6.2.3.1 Observations

6.2.3.1.1 Online exercise class (older adults)

Due to the nature of ethnographic research, as previously stated, all observations have been written in the first person. The online class was observed for a four-week

period (April 2021), after which classes ceased as the gym was preparing to re-open. Following this, I was able to observe one face-to-face class.

The class took place via the Zoom online communications platform, and the session began about five minutes before the official start time. Observations lasted approximately an hour and included a brief period after the class, where participants chatted with each other and the instructor. I participated in each exercise session and observed other participants who were visible.

6.2.3.1.2 Face-to-face exercise class (older adults)

The face-to-face class for older adults was observed for six weeks (May – July 2021), at which point there was nothing new to observe. The class took place in a village hall, and the room was set up with chairs spaced out for social distancing in an arc shape with the instructor at the front. Participants entered the hall via one entrance and were encouraged to use the hand sanitiser on entry and keep their masks on until the class started.

The class was organised so that participants could undertake exercises seated, standing or a combination of the two. Observations initially lasted about 75 minutes and included setting-up time, the class itself and clearing up. Two weeks into the observation period, social distancing rules changed, and the group could gather outside for a coffee and a chat after the session. This increased observation time to approximately 90 minutes as I spent time talking with participants. I took part in all the classes, usually sitting at the back so I could observe without distracting participants.

6.2.3.1.3 Face-to-face gym-based class (dementia-friendly)

The face-to-face, dementia-friendly gym-based class was observed for five weeks (Jan – Feb 2022), after which there was nothing new to observe. This was a separate cohort from those that had taken part in the study before the pandemic (Chapter Four). The class was initially established as part of the Dementia and Physical Activity trial (DAPA) (184) for people living with dementia. It had not been running during pandemic restrictions but restarted in December 2021. Many previous attendees had passed away or deteriorated over this time. The instructor also ran classes for people with Parkinson's and suggested combining the classes whilst numbers were initially low. Four of the attendees were living with dementia.

The class took place in a gym situated in a leisure centre where the participants used cardiovascular and weight machines. Approximately two hours were spent observing the class and with participants and carers in the café following the sessions. Due to the nature of this class, it was not possible to take part in the activity and observe, so I assumed an observer-only role and helped the instructors with COVID-19-related cleaning tasks as a way of participating.

Brief notes were written up before all the sessions and included the number of participants, their gender and whether they had been observed before. More detailed field notes were written up directly after each class whilst they were still fresh in my memory. Observations helped to identify areas that would be worthy of further exploration during the focus group sessions. This was especially useful as the parameters of the study frequently changed over the pandemic. A topic guide was

produced to support discussions based on concepts that emerged from the literature review and the insights gained from observations and informal conversations.

6.2.3.2 Focus groups

All participants over 65 were invited to participate in either a focus group or a one-to-one interview, depending on personal preference and social distancing restrictions in place at the time. Carers of participants were also invited to engage with a separate focus group which was conducted face-to-face. Participant information sheets were provided to those who registered their interest (Appendix CC). Focus groups or interviews took place a week after the observation period; this allowed participants a minimum of 24 hours to consider their involvement, and informed consent was collected before the start of each session (Appendix DD). The topic guide was used as a template to stimulate discussion (Appendix EE). However, a flexible approach was adopted to allow for any relevant new topic that emerged during the sessions to be considered.

All focus groups and interviews were conducted by the principal researcher (AL) and recorded on a digital audio recorder. Notes were taken during the sessions to highlight any salient points.

6.2.3.2.1 Online exercise class (older adults)

Participants were offered an online focus group session instead of the cancelled online class. Only one participant who met the inclusion criteria could participate in an online interview via Zoom.

6.2.3.2.2 Face-to-face exercise class (older adults)

Two focus group sessions were offered to participants of this class (before and after the session) to ensure compliance with COVID-19 regulations in place at the time (six people allowed to mix). These sessions took place in a separate room in the village hall where the class was run. Refreshments were provided.

6.2.3.2.3 Face-to-face gym-based class (dementia-friendly)

Two focus group sessions were offered to participants and carers. One session was provided for participants before the class, and a separate session was organised for carers whilst the exercise class was taking place. Two participants who met the inclusion criteria were able to take part, but due to differing arrival times, interviews were held with each participant separately. These sessions were held in the leisure centre café.

6.2.3.3 Interviews

All exercise instructors were invited to take part in an interview. An interview guide (see Appendix FF) was used as a template to shape the discussion of their experiences of running the class, alongside their experiences of people living with dementia taking part in the session. However, a flexible approach was adopted to allow for any new or relevant topics that emerged. These sessions took place at a time and location convenient to each instructor.

6.3 Data analysis

6.3.1 Observations

Field notes were typed up into Microsoft Word and then uploaded onto NVivo 12 (214). The data was extracted and coded using the code book developed during the focus group and interview coding process (see below) and analysed alongside the focus group transcripts by the principal researcher (AL).

6.3.2 Focus groups/interviews

Focus group and interview data were transcribed verbatim, checked, and fully anonymised by one researcher (AL) using the audio field notes to confirm for accuracy. Audio files and transcription files were uploaded onto NVivo 12 (214). Each transcript was coded by one researcher (AL) using a thematic, flexible mixed approach (216). If during the coding process, novel themes were identified from the transcripts, new codes were generated. All codes were mapped and subject to expansion, restriction or modification using concept maps within NVivo 12 (214). The codes were presented and discussed with the supervisory team (PL, ST, VB, CDL) until a final list of codes was agreed upon. A codebook was then developed (Appendix GG), and the data extracted and coded by one researcher (AL).

Initial data from the online and face-to-face classes for older adults were transcribed, extracted, and coded. Analysis was paused whilst data collection was carried out for the dementia-friendly class. These data were then transcribed, extracted, and coded using the initial code book by one researcher (AL). New and adapted codes developed from this data and the initial data set were re-examined by the same researcher to ensure that all data had been coded within the adaptations.

6.3.3 Synthesis

Using the matrix developed in the systematic review (Chapter Three), the qualitative data were mapped against the benefits, barriers and facilitators suggested in the literature as important to people living with dementia. This approach complemented that used in the exploratory study (Chapter Four) and enabled findings from all the data sets to be synthesised.

6.4 Results

6.4.1 Observations

6.4.1.1 Online exercise class (older adults)

The class was held weekly during the period of pandemic restrictions using Zoom and was run by an instructor from the Corby Leisure Centre.

Participants logged into the class about five minutes before the start, often before the instructor logged in. The instructor typically started each class at 9.30 am with a five-minute social conversation. Usually, four or five people were in each class, although participants varied from week to week. Only two participants attended all the observed sessions.

Each class followed a similar structure, starting with a five-minute aerobic warm-up followed by five minutes stretching of the major muscle groups. The main part of the session was split into ten minutes aerobic work, ten minutes strength work with weights and five minutes balance work. It finished with ten minutes aerobic work at a lower level to cool down and five minutes of stretching. The class usually finished allowing five minutes for social conversation.

All participants who attended over the four weeks were regularly active older people; the class was quite energetic and required reasonable levels of coordination. The music was mainly from the 1960s and 1970s and was very cheerful. Many of the participants were singing along with the tunes, and it looked like they were having fun whilst taking part.

The instructor offered various levels for specific exercises, such as single or double hamstring curls or adding in a hop during certain aerobic moves. Most participants who attended online tended to choose the higher levels. The instructor commented on several occasions that she was impressed that class members were accepting the challenge of more demanding levels. During one session, all participants got on the floor for abdominal work, and the instructor said:

> *"I am really pleased you have all managed to get on the floor, but when the class is live, we do have ladies who can't get on the floor, so I can adapt these exercises for people sitting in a chair." (IN0102)*

When the class returned to face-to-face in July 2021, I attended one session to check if there were differences between participants who attended online and those who attended face-to-face. A wider range of participants attended the class face-to-face, and they were an older population than those who attended online. Despite this, the class was very energetic, although some of the older ladies chose to work at the lower levels of exercise. Some of the older ladies stayed behind after this session, and over coffee, I invited them to take part in an interview or focus group to clarify

why they had not attended the online sessions. Although none took up the opportunity, two commented:

> *"We enjoy the socialising as much as the exercise, and you didn't get that online." (OB0106)*

> *"I don't really like computers; I'd rather see people face-to-face." (OB0107)*

Following one session, we talked about the myths that circulate about classes for older people, particularly the perception that a class for this age group merely involves sitting in chairs doing very gentle exercises. By contrast, this class is called 'Active Agers' and does not look like a stereotypical older person's exercise class. It is energetic and challenging for a fit and active person. Not all older people would find the class beneficial, but many would. Labelling classes as 'exercise for older people' may act as a barrier to participation for those who may not view themselves as 'older'.

As the participants in the online class were reasonably fit, the instructor gradually increased the activity levels over the four weeks. Some challenging strength exercises were added in one of the later sessions, including an overhead press with weights and holding a squat or lunge position for ten seconds.

In a face-to-face class, an instructor would often check on participants to ensure that exercises were completed correctly, although this was not possible in the online format. To ensure participants were carrying out activities safely, I observed that the instructor took occasional breaks during the strength exercises to check how

participants were performing. She often turned sideways to model the movement and told class members that they needed to use their cameras like a mirror so they could check their own position.

Despite the small numbers (the average attendance was four), all the participants were disappointed to learn that the online classes were stopping and that there would be a two-week break before they returned face-to-face in the gym, which, in July, was fully booked with 12 people (the maximum allowed due to COVID-19 restrictions). Although online classes were helpful for many people during the early part of the pandemic, the instructor reported that attendance had gradually dropped following the second national lockdown. Perhaps the novelty of being able to exercise at home had worn off.

6.4.1.2 Face-to-face exercise class (older adults)

The class took place in the village hall in Essendine, a small village five miles from Stamford, Lincolnshire. The facility had toilets, free parking and a kitchen which had been used to organise refreshments before the COVID-19 pandemic.

Led by an instructor who was a qualified personal trainer, the class was operated through the 'Move it or Lose it' organisation. The organisation has developed exercise classes specifically for older people, which can be completed sitting or standing.

The instructor usually arrived 15 minutes before the class started to complete preparatory tasks. The room was laid out with socially distanced chairs to comply with COVID-19 regulations, and masks were encouraged until the class started.

Attendees were encouraged to sanitise their hands on entry while the instructor took attendance. The class had recently started again following a relaxation in restrictions, and I attended the second class since the return. Attendees tended to sit in similar areas of the room each week, conversing with the same people, and many group members appeared to know each other. Some participants were attending after being invited by the instructor because their local class had not yet restarted.

The class was set up to enable people to take part sitting, standing or a combination of the two. Around three-quarters of the class did the exercises standing, with the remainder sitting.

A consistent structure was followed. The instructor explained the moves for each song before beginning the routine. The first song was a gentle warm-up followed by about 30 minutes of aerobic work. After this, participants sat and completed strength exercises using a theraband.

All the music was relatively modern, and the instructor commented:

> *"…the company likes us to use music that 'takes them back', but I have found my groups prefer more modern stuff, so that's what I use." (IN0210)*

All members appeared to enjoy the class, and there was a great deal of camaraderie between the instructor and the attendees, creating a positive atmosphere. At one point, the instructor performed a movement incorrectly, and all the class laughed, one member commenting:

> *"It's not just us then." (FG0207)*

One session was held on a particularly warm day, and the instructor reminded everyone to take a drink at the end of each song. This led to a discussion about how much liquid you should be drinking per day, to which the instructor replied:

"…four or five pints, which doesn't include tea or coffee...or gin!" (IN0210)

The attendees were very welcoming and encouraging to new members. On one occasion, a participant brought her grandson, and he joined in the class and appeared to enjoy himself.

On another occasion, a lady attended the class with a social prescriber. Due to the COVID-19 pandemic, the lady had not been out of her house for six months and was highly anxious. She attended on several occasions and, initially, could only sit in the corridor and take part. However, as time went on, she was able to enter the hall and participate more actively. There were occasions when to accommodate her, the start of the class was delayed, but the group were very understanding and keen for her to be able to participate.

Before the COVID-19 pandemic, attendees had often stayed after the class for coffee and a chat. Under the restrictions that were in place at the time of the observations, this was not permitted, but meeting outside was possible. As the weather was quite warm, the following week, at the instructor's suggestion, the class and post-session socialising took place outside. Members appreciated the opportunity to socialise, many reporting that they had missed this aspect of the class as much as the exercises.

The routines that were used have been developed to be completed in sitting or standing positions. Many members of the class stood throughout; others sat. On one occasion, following a recommendation, I completed the session in a sitting position and discovered that some of my muscle groups worked harder when sitting rather than standing; this approach produced a worthwhile workout. Over the six weeks, most participants did not change positions from sitting to standing. However, one lady, who had sat for the earlier sessions, could stand and hold on to a chair to complete the exercises during the final session, demonstrating significant progression.

During this final session, one participant mentioned recently attending a family event. Usually, she would sit, but this time, she danced. She reported that her family were amazed and asked how it happened. She replied:

> *"It's coming to these classes each week." (OB0211)*

The instructor would regularly explain the purpose of an exercise. When she introduced some upper body exercises, she explained that these were to counteract the constant forward posture adopted during daily activities such as driving, writing, or reading. This was raised in one of the focus groups as something participants particularly appreciated.

6.4.1.3 Face-to-face gym-based class (dementia-friendly)

This class was held weekly in the gym area of Loughborough Leisure Centre, which had on-site parking. Being located on the ground floor, the area was easily accessible and was close to the disabled toilets.

The class was led by a qualified exercise instructor with experience in running sessions for people with dementia. It had initially been part of the DAPA trial (184), had continued after the study ended, stopped during the pandemic but restarted in December 2021.

Participants gathered to chat outside the gym area until the instructor arrived. They were then invited into the gym individually so the instructor could set them up on an appropriate cardio machine (e.g., static bike, rower, treadmill). Carers then headed upstairs to the café where, before the pandemic, they had used the facilities. These had not re-opened, but carers still used the area, bringing their own refreshments.

Each participant used the cardio machines for approximately 20 minutes. The instructor moved members around to try to ensure that everyone had some time on the static cycle. Following this, participants used the weight training machines. The gym had a selection of Life Fitness Circuit Series machines. These enabled participants to perform various strength exercises for the major muscle groups (e.g., biceps, triceps, quadriceps) without worrying about adjusting weight racks. Each machine had a set of buttons (1-12) which could be used to regulate the resistance.

Participants worked through a variety of machines which provided for exercises in leg extension, leg curl, shoulder press, chest press etc. and completed three sets of ten repetitions before moving on. The instructor set up each participant on a piece of equipment, and if they had not used it before, she demonstrated its use before setting an appropriate resistance. She then checked that the participants were doing the exercise correctly before moving on.

The class finished with five minutes seated stretching outside the main gym area. Following this, some participants joined the carers' group using the lift where necessary.

Unlike the other observed classes, which were attended mainly by women, the attendees at this class were all men. There was very little interaction between the participants during the session, and it was not possible to determine whether this was due to the type of session (gym based as opposed to the more aerobic sessions observed previously) or if it was due to the gender of the class members. The instructor chatted with all of them individually, and they were happy to talk to me after I had explained the purpose of my research.

However, the atmosphere was very different at one session, which followed an FA Cup tie between two local teams, then second-tier Nottingham Forest and premiership Leicester City. In the wake of the former's victory, there was much more interaction (standard football banter) between participants as well as participants and the instructors. This occasion produced the most interaction I observed between the participants over the five weeks.

Following the sessions, I joined the carers upstairs. The group was kept going following the end of the DAPA trial by a lady whose father continued to attend and whose late mother was part of the trial. Two other carers still attend for coffee, although their husbands have passed away. On a couple of occasions, two of the participants living with dementia joined the carers following the session, and I was able to talk with them about the project and what I hoped to achieve.

Most of the interactions were between carers who often swapped tips and information. They seemed to have developed the same kind of informal peer support network as I had observed in the class at the David Ross Sports Village before the pandemic (Chapter Four). There were more wide-ranging conversations about current affairs and on topics from rule-breaking in parliament to misogyny. Strong opinions were expressed, and although this was mainly directed by the carers, the people living with dementia were not afraid to chip in their views.

6.4.2 Focus groups and interviews

Twelve participants were included in either the focus groups or interviews (n = 2 people living with dementia, n = 10 older people). Seven carers participated in a focus group, and two exercise instructors were interviewed.

Table 19 Participants' demographics

Pseudonym	Gender	Role	Mode of Delivery	Living with Dementia Y/N
FG0101	Female	Participant	Online	N
FG0201	Female	Participant	Face to Face	N
FG0202	Female	Participant	Face to Face	N
FG0203	Female	Participant	Face to Face	N
FG0204	Female	Participant	Face to Face	N
FG0205	Female	Participant	Face to Face	N
FG0206	Male	Participant	Face to Face	N
FG0207	Female	Participant	Face to Face	N
FG0208	Female	Participant	Face to Face	N
FG0209	Female	Participant	Face to Face	N
FG0301	Male	Participant	Face to Face	Y
FG0302	Female	Participant	Face to Face	Y
FG0303	Female	Carer	N/A	Carer
FG0304	Female	Carer	N/A	Carer
FG0305	Female	Carer	N/A	Carer
FG0306	Female	Carer	N/A	Carer
FG0307	Female	Carer	N/A	Carer
FG0308	Male	Carer	N/A	Carer
FG0309	Female	Carer	N/A	Carer
IN0102	Female	Instructor	Online	N/A
IN0210	Female	Instructor	Face to Face	N/A

6.4.2.1 Themes

Data analysis identified four key themes: facilitators to attendance at classes, barriers to attendance at classes, exercise class delivery and sustainability.

6.4.2.1.1 Facilitators to attendance at classes

Health was a strong initial motivator to attend an exercise class, and both physical and mental health benefits were identified as motivators to continue attending.

> *"I believe that exercise is a very useful way to keep fit, it improves cardiovascular function, which is one of the important things." (FG0301)*

"I came before my husband died, and that was good to come anyway, but now, I need to come." (FG0203)

Many participants identified that, although they had originally attended for physical health benefits, they continued to attend for the social benefits as much as the exercise. Several also stated that these social motivations had increased since the pandemic, during which many had felt isolated.

"I come for social." (FG0201) "Yeah, I think I do now since I've been bereaved, I think I do." (FG0203)

"Oh, definitely. I mean, I could go if I didn't see my family at the weekend apart from saying 'morning' 'evening' I probably didn't speak to anybody." (FG0207)

Carers commented on the peer support they received from the group whilst their spouse or parent was attending the class. They found the support and sharing of useful information valuable, and some carers continued to attend after their spouses had passed away.

"I think it's that you don't feel that you are alone with it because these days there's no direction, someone gets dementia, there's no one to tell you what to do, where to go or anything." (FG0303)

"Well, it's somewhere, I would never go out if I didn't come here. I'm still getting the support from these ladies." (FG0309)

The ability to access a class was a common facilitator, with many participants commenting that they attended their class because it was local to them.

> *"It was on the doorstep." (FG0202)*

However, as all classes were cancelled during periods of national lockdown, some members commented on how technology had been helpful in these circumstances. This was not a common theme amongst these groups, as many had found access to online classes too challenging.

> *"I did watch it on YouTube with my daughter cos she was on furlough, so we used to watch it and do it a couple of times a week." (FG0202)*

> *"I use it I mean Zoom I think it's marvellous, I've got a son living in Torquay we have a get-together on a Sunday night, all of us." (FG0207)*

Having trained and knowledgeable staff was seen as key to encouraging people with dementia to attend classes. Carers commented that it made a real difference when they felt that the staff understood the person with dementia.

> *"It's the reception staff are fantastic, and I mean they must have had some training, but they really recognise the people, and they know how to direct you and all this." (FG0307)*

> *"…that's right, and they seemed to understand ever such a lot, and I mean, I don't know if they've had extra training or if it's because they've had people in this situation, but I've found the cafe staff really really good." (FG0307)*

6.4.2.1.2 Barriers to attendance at classes

Accessibility was considered a key barrier to attendance. Participants commented that many people 'out there' would benefit from attending these classes but lack knowledge of what is available.

> *"There's got to be lots more of us out there in our local area…well, how do we know where they are then?" (FG0201)*

Others commented that they struggled to find classes to attend.

> *"I think the main problem really trying to get exercises for someone whose got dementia or is disabled is just finding enough places to go." (FG0307)*

These contrasting comments highlighted the different experiences of participants and carers in trying to access classes, especially for those living with dementia.

> *"I think part of the problem is that sometimes GPs and others think that there isn't that much of a call for it because GPs aren't using their own facilities to tell people, so they're not having people wanting it and asking for it because people don't know it exists…" (FG0306)*

Other issues, such as transport limitations and financial considerations, were also mentioned as barriers.

> *"Maybe just that they can't get to them, you know, I would say...I don't drive, but I am lucky cos I live across the road, so that's handy anything in the hall is handy for me." (FG0205)*

"Do you think finance comes into it sometimes as well? for some people too. I mean, with this one, it's £5 you can get at it all right and cope with the price, and I don't know how to word it, but I think that might in some cases." (FG0208)

Participants hypothesised that the pandemic had put off many people from attending, and instructors did comment that not everyone had returned once the classes were again face-to-face.

"Well, perhaps the situation in the country at the moment might stop might have put a lot of people off as I mean, it's been 18 months now, hasn't it (yep yeah) that might have put...they don't want to mix with people oh no I don't want to do that, but you know." (FG0206)

"It has changed because a lot of people decided that they weren't gonna come back yet, and I don't feel like everyone has still come back, so that's still happening." (IN0102)

Many participants acknowledged that they had not attended online classes during the pandemic and commented that difficulties and problems with technology had put them off.

"Definitely more difficult a lot of them bless them their husbands did it or when you could start having people coming round and socially distanced, they'd have like their granddaughters or grandsons setting it up for them." (IN0102)

The instructors in the study were all keen to have people with dementia attend their classes, and all believed that the classes were appropriate. However, their insurance policies would not always allow them to accept people living with dementia due to their lack of specific training. This gap in the provision of training was felt to be an important barrier to having inclusive classes.

> *"…she was saying could she come up and do PT with you now although I want to say yes my insurers won't cover me because I don't have a specific qualification." (IN0210)*

> *the real answer to your question is a skilled and trained workforce we've had people, if I remember...whose primary disability was a heart, but as soon as somebody mentioned dementia to the heart-smart person, then the dementia had to be the greater disability that she ran a million miles away from…she didn't like dementia at all." (FG0304)*

Both participants and instructors highlighted the need for more specific training not only for dementia but other conditions that are likely to affect older people.

6.4.2.1.3 Exercise class delivery

The delivery of classes was discussed from a wide range of viewpoints. Many people who had not been diagnosed with dementia said they would be keen to continue attending their current classes if they were diagnosed in the future. They felt that mixed classes were both appropriate and needed.

> *"Yes, I'd like to come to this class if I had a dementia of any sort." (FG0201)*

"…be of benefit to them, wouldn't it, definitely…even more than as time goes on, but I would like to think that they could go on for quite some time because I mean at whatever stage they come at, but it does depend on the individual." (FG0204)

The views of participants on the adaptability of the classes reinforced this. All instructors offered various levels of exercise and could adapt classes for diverse needs.

"In the case of an injury, you think I hadn't better do that, or she will tell you, you know, don't do that one. I think it's needed that personally, especially for oldies!" (FG0203)

"…if you have a class like the one I did with the dementia lady in, I did the routine differently, I did a lot of repetitive movements, I did a lot of cross-body movements, and I played different music." (IN0210)

Many participants commented on the importance of treating people as individuals and accepting each other's differences.

"…yeah, but I mean, it's like that other lady, I don't think she came last week, she only come a couple of weeks, but it took her ages to get in." (FG0201)

The anxious lady had not been able to come last week. Found it more difficult again to enter the building after having a week gap…the class was very patient and happy to wait as they all seemed keen for her to succeed. (Obs.)

However, this was not always the case. Some carers felt that specific classes for people with dementia were more appropriate, as not everyone showed an understanding of the issues people living with dementia may face.

> *"I've found that before my husband was diagnosed, we used to go to one that was just for older people, and you didn't have anybody organising it, you know you just paid and went in...he was not himself even then before we were diagnosed and he was very upset one time because some people were mocking him and he wouldn't go again..." (FG0307)*

Many participants commented that there were a lot of assumptions about people with dementia and that the general perception of dementia was someone in the later stages of the condition.

> *"Isn't the...people, the assumption of the public is that dementia is for the elderly." (FG0202)*

> *"Well, I mean you talking about dementia as though it's one thing and everybody with dementia is the same." (FG0307)*

Many also felt that there was a general assumption of what an older person's exercise class was like and that this could put off many people who did not view themselves as 'older'.

> *"Isn't that perhaps why people from Essendine don't come to this class because they see elderly keep fit? I'm not elderly." (FG0202)*

"This lady had emailed that her mum is in the early throes of dementia, active, wants to keep active, so I went, oh yes, you want to come to Move it or Lose it, and she's just replied back to say oh yes mum has been to your class and didn't think it was active enough." (IN0210)

Participants at all sites agreed that classes had a variety of exercises which they found beneficial, and many commented that being told the purpose of an exercise or how it was helping them was particularly useful; this was not something many had experienced when taking part in 'keep fit' classes in the past.

"I like the wide variety myself you know as well, I think it's all your body as well, isn't it, you know, doing the phys…good for it all of you, you hope." (FG0209)

"In fact, I'm quite amazed, and she tells us what it's for, nothing big and laboured…I mean, I'm going back a few years when I've been to keep fit, I mean, nobody told me what I was doing it for...you know what bit, or you know, whereas you know she does, and we do." (FG0201)

Instructor explained the purpose of these exercises, which was to counteract our constant forward position whilst writing, driving, reading etc. (Obs.)

All participants commented that they had struggled with the online delivery of classes, some due to the lack of technology, although many found that they had much less motivation to take part in an online class.

"At the end of it all, I just couldn't be bothered to do...if there is someone with

you, you do it together, and it encourages you, but when you're standing there by yourself...I know it's weak, it really is weak, but I can't be bothered." (FG0208)

"There were days when even with my kind of gym ethic, I thought I just can't be bothered today, but some of it is a mental state of mind." (FG0101)

6.4.2.1.4 Sustainability

Sustainability was discussed in relation to individuals' continued attendance and the sustainability of the class itself.

Individual sustainability was often a product of social interaction. Many members commented that they had missed the camaraderie during the pandemic, and some found that social interaction had become increasingly important since then. All instructors had a great rapport with their classes, and participants appreciated the rapport with both instructors and their fellow attendees.

"I think the thing that I missed during lockdown was the fact that I'd only got a few people of the classes numbers so we could talk, and I'm there thinking, well, I wonder how people are." (FG0302)

"I think you've said the big one there was the laughter, the banter and laughter we have, I feel it's wonderful." (FG0206)

"The cohesive downstairs, the bit of camaraderie is as much to do with the instructors." (FG0304)

However, socialisation was not seen as essential to all participants. One instructor reported that, in some of her groups, members were too busy to want to stay behind for a chat.

> *"It depends on the class, I tried on my Monday morning class, I tried to get them to stay behind and have a cup of coffee, no, there'd got so much stuff going on in their lives they couldn't." (IN0210)*

During the pandemic, some participants thought it was important to attend classes to show support for the instructors.

> *"It's so difficult for the instructors, especially through this pandemic, that I think the least I can do is to try and turn up for a class just...they might not realise it, but just to give them a little bit of moral support." (FG0101)*

Concerning organisational sustainability, some participants, especially those attending the dementia-friendly class, commented on the lack of overall responsibility to provide classes and whether this should be within the remit of local authorities or central government. This class had started as part of the DAPA trial and had only continued due to the knowledge and persistence of a family member of one of the trial participants.

> *"It was all to do with if the local CSP - county sports partnership hadn't got it in their agenda, there's no doubt we wouldn't have continued because it did require a degree of perseverance as well as reminding people of their responsibility, yes so you have to be able to tell people why it is they need to*

do what they should be doing automatically." (FG0304)

"You could argue this group should exist in every local authority, that's probably the answer, if there was one at every borough level, that would probably be geographically reasonable for people to get to." (FG0304)

6.4.3 Synthesis

In Table 20 (below), the qualitative data has been mapped onto the matrix developed in the earlier systematic review chapter.

Many attendees were looking to maintain their physical fitness or improve their health; this was consistent with the literature findings. However, this study suggests that this finding also applies to older people without dementia.

Social interaction was assessed as important both in the literature review (Chapter Three) and the exploratory chapter (Chapter Four). Participants in this study reported that they attended the class as much for the social interaction as the exercises, many suggesting that the social interaction element had become more important following the pandemic.

Members of face-to-face classes commented on the rapport and camaraderie that developed within the group and that even when reluctant to attend, they did so because they felt confident that it would improve their mood. This confirms the exploratory study results, where attendees also reported wanting to gain psychological benefits from a class. However, participants in the online class did not mention psychological benefits.

Two classes in this study did not include carers. However, those who attended the dementia-friendly class reported similar findings to those found in the literature review and exploratory study in that they appreciated the supportive community and knowledge sharing. Three carers continued to attend this class for support once their spouses had passed on, and other group members appreciated the depth of knowledge they could contribute.

The barriers reported in the literature review did not appear to be an issue in these classes; all had accessible parking, were adaptable, flexible and (before the pandemic) had offered the opportunity for social interaction, a feature that was slowly returning. Some classes had produced innovative ways to continue with the social and support elements despite on-site cafés remaining closed.

Instructors noted that there appeared to be very little training available for exercise professionals on dementia. This may have impacted individual instructors' willingness to allow people living with dementia to join their classes. Others also commented that, without specific training, many insurance companies would not allow instructors to accept people living with dementia.

Many of the barriers noted in this study related to difficulties accessing classes online due to a lack of suitable equipment or technological expertise. These issues did not emerge in the literature review or the exploratory chapter as, before the COVID-19 pandemic, there were very few, if any, online exercise classes. However, following the pandemic, the difficulties that many older people experienced using

technology or having suitable equipment became a common theme within all three groups.

Table 20 Matrix synthesis

Interventions	Mode of Delivery	Psychological Benefits	Social Benefits	Physical Benefits	Carer Benefits	Positive Attitudes	Environmental Attributes	Physical Barriers	Carer/Staff Barriers	Environmental Barriers
Standing Multicomponent incl; aerobic and strength	Online	None were specifically mentioned.	Missed social interaction during the pandemic. Minimal social interaction online.	Needed something physical to do. Maintained fitness and tone. Fitness levels dropped during the pandemic.	None mentioned – class for older people.	Instructor has a really good rapport with class. Think that PlwD should be able to attend any class they can. People need to feel comfortable in class.	Instructor offers different levels of activity. During the pandemic, people could try different classes and, if didn't like it, could turn off the computer – less guilt than leaving a class.	Trying to take part at home was difficult as you had to deal with furniture and screen glare. Older people had difficulties setting up online classes and often needed a family member to do it for them.	Instructors were not keen on doing online classes. Some instructors are fearful of teaching people with dementia. There is a lack of training around dementia for exercise professionals.	Difficult to motivate yourself for an online class. A lot of older people didn't take part in online classes. Many people have not yet returned to live classes after the pandemic. Not having the right technology.
Sitting/Standing Multicomponent incl; aerobic and strength	Face to Face	Don't always feel up to it but helps you when you get there. Getting out, so you are not alone or feeling lonely. Stops you from getting stuck and feeling unable to get out. Improves mood.	Come for social interaction since bereavement. Finding socialisation more important following lockdown. Come for social aspects as well as exercises.	Improved mobility. Wide variety of exercise. Covers the whole body. Improve health. Weight loss. Prevent stiffness. Improved coordination.	None mentioned - class for older people.	Able to adapt classes for the different sorts of people who come. Accepting of different people in the class. Good atmosphere. It does everyone good to mix with others.	Local. Can stay sat down if needed. Music can encourage you to exercise. More social when it is face-to-face. Music can help trigger memories.	COVID-19. Lack of available technology or expertise to use it during COVID-19. People who were struggling before are struggling even more now. Lack of support. Poor internet connection. Finance. Transport difficulties.	Unable to do online classes due to lack of functioning equipment. Lack of specific dementia training. Unable to get insurance.	Online classes are not social. Don't know where people are in order to attract them. People don't view themselves as elderly. Difficulties with labelling/marketing to attract people. Difficult to motivate yourself for an online class/on your own.
Gym-based multicomponent incl; cardio and strength	Face to Face	Not looking forward to the class, but the buzz afterwards you get. Puts you in a good	Looks forward to afterwards, the people. Having coffee and chat after the session and	Exercise useful way to keep fit. Improves cardiovascular function. Makes me feel healthy.	Feeling less alone with it. Groups help navigate the systems. Continued	Supportive instructors. Knowledgeable and trained instructors. Instructors'	Staff available who understood what was needed. Availability of someone with local knowledge	Difficulties with online classes as not able to see what you are doing wrong. Transport	Difficulties facilitating online no interest and difficulties in concentrating.	No one in the social care system to direct you. Need local knowledge to find services. GPs are not aware of

		mood when you have finished.	a chat in a separate room was brilliant. People with dementia often gather together after the session and have their own chats.	Needed more exercise. Looked for 3 years for something like this. People getting less and less physically fit.	support from group members. The group is supportive. It's a community. Resource for other members. Finding other groups to attend.	attitudes create a cohesive group and camaraderie among participants. People with dementia want to feel like I'm just like you.	and knowledge of how the system worked enabled the group to sustain itself. Trained and understanding reception staff and café staff. Provision of free drinks for class members post-session.	difficulties as couldn't attend independently. GPs not organised and not aware of what people with dementia want.	Needed someone to facilitate a one-to-one online. Not aware of what is out there, so don't know where to look. Nobody to direct you, need to search for yourself and know what you are looking for.	what is out there and don't think there is a call for these groups. GPs not utilising their own resources and inconsistent support, e.g., practice carers meetings only happening once.

6.5 Discussion

6.5.1 Summary of findings

The mini-ethnographies were conducted during different periods and levels of pandemic restrictions. This led to a wider variety of exercise classes being observed, including classes held online and classes with no members living with dementia. Despite these differences, there were commonalities in the findings.

Motivation towards taking part in online classes was low. They were not well attended, and many regular attendees at face-to-face classes had not participated in online classes during the pandemic. A lack of equipment and technological expertise prevented many older people from participating in online classes.

The combination of classes chosen for the study enabled people not living with dementia to share their views on attending classes if they were to be diagnosed and having mixed classes of people with and without dementia. This prompted exercise class delivery to emerge as an unexpected theme. Many attendees in this study supported an inclusive approach acknowledging that classes could easily be adapted. However, this was not always the case, with some participants having a less positive experience in mixed classes.

The expectation of health benefits appeared key to initial attendance, although social interaction became more important for sustained attendance. Inevitably, the latter feature was greatly missed during the pandemic and had become an increasingly important aspect of the class after the return to face-to-face delivery.

All groups, especially those with members living with dementia, appreciated knowledgeable, trained, and motivated staff. However, exercise instructors found that the lack of specific training required by insurance companies limited their ability to offer inclusive classes.

6.5.2 Comparison with other studies

This study confirmed some findings that have been reported in the existing literature. In their qualitative study in Canada, Hobson et al. (268) found that people with mild cognitive impairment and early dementia attended exercise classes to improve their physical and mental function, whilst Karssemeijer et al. (269) found that both people with dementia and their carers reported beneficial health effects as the most important motivator to attending classes; this is similar to the findings reported in this study not only for people living with dementia but for older adults in general.

Hobson et al. (268) also found that having someone to exercise with was a strong motivator; this was also identified by some participants in this study. Hobson et al. (268) also reported that people with dementia viewed exercise as a social activity; this was confirmed by the participants in this study and suggested that social interaction provided them with ongoing motivation to attend classes. Olsen et al. (270) also found that the social relationships that developed within an exercise group between people living with dementia and instructors facilitated exercise participation and positively affected exercise adherence.

Malthouse and Fox (271) found that social attitudes towards dementia can play a key role in facilitating or obstructing exercise and physical activity participation. Their findings suggested that activities need to be led by instructors who understand dementia. Olsen et al. (270) also recognised that knowledgeable staff members were crucial in gaining trust and facilitating participation. This study further concluded that both people living with dementia and older people, in general, appreciated trained, knowledgeable, and motivated staff, acknowledging that their expertise was an important facilitator to attendance. As in Malthouse and Fox (271), this study also found that when someone with appropriate knowledge and skill did not facilitate classes, their absence could act as a barrier.

Malthouse and Fox (271) also proposed that the encouragement and maintenance of active lifestyles should provide the focus rather than the provision of specific structured exercise classes for people living with dementia. However, in this study, the evidence points to the value of a structured exercise class as participants could engage in a more active lifestyle once it became part of their routine. This was highlighted by members of the dementia class, who reported that Friday became exercise day. Other participants also stated that including exercise as part of their routine encouraged them to attend, even on occasions when they were reluctant to do so.

The themes outlined in this chapter were similar to those found in the exploratory study (Chapter Four). That study also highlighted that people living with dementia attended an exercise class to maintain their current physical abilities and prevent deterioration. They also valued the social interaction of the class, whilst carers

benefitted from the sharing of knowledge. The engagement of knowledgeable and motivated members of staff and volunteers was also proposed as a key characteristic for continued participation in the class.

This study has provided further evidence of the multi-level influences which promote the participation in exercise of older people. As this study involved both people living with and without dementia alongside carers, it allowed comparisons to be made both with the findings in Chapter Four and Boulton's social ecological model for promoting participation in older people (89).

Individual factors that were motivators for continued attendance were similar to the findings in Chapter Four and the model proposed by Boulton (89). Health benefits, including increased mobility, better health and fitness, and improved mood were the main drivers for initial attendance; this was the case for all groups in this study. Interpersonal factors again included social interaction, as was seen in Chapter Four and the study by Boulton (89). In addition, the carers and people living with dementia in this study highlighted the positive attitudes of the members of staff towards people living with dementia, which encouraged participation and increased the level of camaraderie within the group.

Instructors in this study commented on a lack of dementia-specific training, which limited their ability to offer inclusive classes. This would act as an organisational factor and overlap with policy factors. The responsibility for providing dementia-specific training courses for exercise instructors lies with organisations. However, with no national policies or guidelines in place specifically for training those working

with people living with dementia, there is no impetus to provide such courses. Marketing and labelling of classes were seen as essential organisational factors in Chapter Four and the UK study by Boulton (89). Participants in the latter study were frustrated by the labelling of classes for 'over 50's' and could not identify with such a wide age range (89); similar findings emerged from this study where participants commented that the label 'elderly' or 'older people' could preclude engagement.

6.5.3 Strengths and limitations

The timing of this study provided a unique opportunity to review the provision of exercise classes through the lens of the pandemic when a range of restrictions gave rise to a variety of novel delivery methods. This enabled an exploration of whether different delivery methods could offer the core components needed to support people living with dementia to sustain their engagement in exercise.

Several themes emerging from the study were similar to those discussed in the exploratory study (Chapter Four), which occurred before the pandemic. This level of commonality has helped to consolidate the core components of the successful delivery of classes for both people living with dementia and older people without dementia. Differences in views pre- and post-pandemic are mostly related to the use of technology.

The study was limited by its small sample size: only three exercise classes were recruited due to a lack of response to the survey. Moreover, the COVID-19 pandemic led to the closure of all exercise classes and gym facilities. There was limited availability of online classes for older people, and the changing restrictions meant

that most classes did not return to face-to-face delivery until May 2021, which limited data collection. In addition, classes designed specifically for people living with dementia did not return until much later in 2021; this further restricted access.

All class members had regularly attended before the pandemic, and their motivation was evident from their return to classes as soon as restrictions were lifted. It was not possible to obtain the views of less regular members due to the limited periods with each group. It was also not possible to gather the views of those who did not attend or had only attended once or twice; this limitation affects other studies but was accentuated by the pandemic restrictions.

6.6 Conclusions

Physical and psychological benefits are key to initial attendance at exercise classes for older people, both those with and without dementia. However, social interaction is pivotal for sustained attendance, as is evidenced by participants' views on the absence of this feature during the pandemic and its welcome return after restrictions were lifted.

Participants, especially those living with dementia, who undertake exercise classes appreciate knowledgeable, trained, and motivated staff. However, a lack of specific training available to exercise instructors often limits their ability to offer inclusive classes.

Online classes were not well attended. They could be difficult to access and may not provide all the components necessary to support people living with dementia and

many older people without a dementia diagnosis to sustain their long-term engagement in exercise.

The main findings from the literature review (Chapter Three), the exploratory study (Chapter Four) and the ethnographic study (Chapter Six) have explored both the characteristics of an effective exercise intervention and other constituent components that facilitate attendance at classes for older people both with and without dementia. To enable recommendations to be produced which would support appropriate exercise classes to be implemented for this group in the community, the next chapter will synthesise these findings to seek to understand the key characteristics and core components of an exercise class for older people living with dementia.

Chapter Seven

7 Discussion and Conclusions

7.1 Introduction

In this chapter, the main findings from the literature review (Chapter Three), exploratory study (Chapter Four) and ethnographic study (Chapter Six) have been synthesised to establish the key characteristics and core components of an exercise class for older people living with dementia. Findings are then discussed in the context of the theoretical concepts explored in the introduction and synthesised in the development of a social ecological model designed to promote exercise participation amongst people living with dementia. These combined findings have informed recommendations for individuals and organisations looking to set up or adapt an exercise class for people living with dementia in the community, alongside the broader implications of the findings for future research. Finally, an overview of the researcher's reflections on the thesis and the research process is presented.

7.2 Summary of findings

The evidence presented in this thesis strongly suggests that exercise classes should focus on improving the general health and physical activity levels of older people with and without dementia. Multi-component classes, which incorporate an aerobic element alongside strength and balance exercises that exercise and health professionals value for these groups, should provide the framework for a successful class.

Although not evident from traditional outcome measures, older people, both with and without dementia, reported that the social interaction element of classes increased their motivation to attend and boosted their mood. Participants and their carers also stated that classes that offered opportunities for social interaction before, during and after the class were an important part of their experience. Therefore, this feature should be confirmed as a core component of a successful class.

7.3 Key characteristics and core components

7.3.1 Physical benefits

The three studies suggest that older people, including those living with dementia, may place a lower priority on specific physical outcomes, such as improving balance and increasing muscle strength, than improved mobility, health, and general fitness. Moreover, they appreciated familiar and enjoyable exercises that were easy to understand. Within the literature review (Chapter Three), nine of the twelve studies measured the physical benefit of the exercise intervention. Five had an aerobic element; two showed a statistically significant improvement, with a further two demonstrating a positive but non-significant improvement. Interventions that did not include an aerobic element had more mixed outcomes, suggesting that including an aerobic element may increase the likelihood of a positive outcome.

Participants in a study designed to reduce falls in people with early dementia and mild cognitive impairment reported that specific exercises which focused on strength and balance were ‘not for them’ despite many of them having experienced falls. They expressed a preference for hobbies and leisure activities such as golf, walking

and dancing. They were more interested in maintaining their ability to carry out daily activities independently rather than concentrating on specific exercises to prevent falls (272). These attitudes are similar to those shown in the qualitative studies in this thesis; participants were more interested in the general benefits of exercise, such as improved mobility and increased physical fitness, rather than working on their lower limb muscle strength to improve their mobility.

Other studies (33,89) also reported that a reason for continuing with an exercise programme was to maintain or improve health. Cedervall et al. (273) reported that motivations to improve specific physical functions were rarely mentioned by participants and that they prioritised physical activity and exercise to prevent ill health and improve general well-being. A study by Suttanon et al. (274) examined reasons why people with Alzheimer's disease started and continued with a home-based balance programme to reduce falls. Despite the specific nature of the programme, participants still placed greater emphasis on improving their physical condition and improving their walking ability.

The WHO Guidelines (265) for older people recommend at least 150 minutes of moderate activity weekly, alongside varied multi-component physical activities that emphasise strength and balance. However, the guidelines highlight that older adults should be as physically active as their ability and fitness allows and that doing any amount of physical activity is better than nothing; even those not meeting these recommendations will gain health benefit from doing some activity. Indeed, the tagline for the release of their 2020 guidelines was 'Every Move Counts'.

Multi-component exercise classes could offer the benefits of strength and balance, which are priorities for exercise and health professionals. Moreover, including an aerobic element would offer the more general benefits sought by participants in the qualitative studies.

7.3.2 Psychological benefits

Although there is no clear evidence of the benefit of exercise for mood in the literature review (Chapter Three), the studies undertaken to contribute to this thesis indicate that older people living with or without dementia reported improved mood and increased confidence after participating in a group exercise class. Positive attitudes towards both dementia and exercise, alongside the camaraderie and rapport that developed within a group, were reported to increase motivation to attend classes even when members were reluctant to do so. Participants in the exploratory study (Chapter Four) reported that alongside their improved mood, attending the class had given them increased confidence to participate in other activities. Some carers reported that they had tried to build up a bank of different activities, and although not all of these were specifically for people with dementia, attendance at mixed classes along with others had built confidence to take part.

A systematic review of older people's perceptions of participation in physical activity completed in 2014 (275) identified increased confidence as an outcome which encouraged participation in other activities, with one participant commenting, *"your self-confidence is reinforced when you come here. The sense of well-being and ability and you can do things"* (276); this aligns with many comments of participants in the exploratory study (Chapter Four). The same study also highlighted the vital role of

the instructor. Participants commented on the instructor's enthusiasm and motivational expertise, with many reporting that the instructors were a key reason for continuing to participate. One participant stated, *"she motivates us, she makes it fun, I hope she never resigns"*, whilst the review (275) suggested that good rapport with instructors motivated participants to continue attending. Many older people taking part in the ethnographic study (Chapter Six) expressed similar sentiments about their instructors, whilst carers of people living with dementia commented that the group's success was partly due to the instructors' attitudes.

This strongly suggests that an instructor's positive attitude towards both older people and those living with dementia promotes camaraderie within the class. Moreover, instructors trained to understand the condition will be more aware that people with dementia are willing and able to access exercise classes.

7.3.3 Social benefits

This thesis has provided clear evidence that social interaction and peer support are important to both people living with dementia and older people in general. Carers also appreciated the social interaction and informal support networks that developed through the group exercise classes, offering carers an opportunity to share knowledge.

The systematic review of Franco et al. (275) also touched upon the importance that older adults placed on social interaction and the benefits of familiarity through weekly group-based exercise sessions. A qualitative study completed in 2008 (276) on the experiences of older adults from ethnic minorities taking part in a group-

based exercise class (EnhanceFitness [EF] program) in Seattle (USA) highlighted the importance of the social element and the support network, especially for those who lived alone, the latter group reporting that the class gave them a reason to get up and get dressed. A 'network of peers' was created, providing mutual support by sharing journeys and keeping in touch outside the class by telephone. The value of the network was exemplified by one participant's comment, "*it's our exercise family"*. Paralleling this comment during a focus group discussion arising from the exploratory study (Chapter Four), one participant stated that she had lost a lot of friends after her husband was diagnosed with dementia but that the class had given her a new group of friends who she *"wouldn't want to be without"*.

A more recent article (277) investigated the same programme (along with three others) with older people living in Los Angeles (USA) and found that, after six months, participants showed a statistically significant improvement in both loneliness (measured by the UCLA Loneliness Scale) (211) and social connectedness (measured by the Duke Social Support Index) (278). A recent study undertaken in 2019 in Washington DC (USA) (279) with older adults from ethnic minorities reported that the social dimension was an important driver for participation in exercise. A further study completed in Scotland in 2020 (280) examined the benefits of walking groups to promote social health in people living with dementia. The main benefit identified by participants was the increase in their social interaction, with many reporting that they had joined the group more for social contact than the physical benefit of walking (280). They also highlighted how the groups offered social support, providing the opportunity to discuss difficult choices and share knowledge.

These insights paralleled findings in the exploratory (Chapter Four) and ethnographic study (Chapter Six).

There is evidence, from reports of older people with and without dementia, that lockdowns during the COVID-19 pandemic increased awareness of the importance of social interaction. Online classes developed during the pandemic provided exercise opportunities but lacked social interaction, reducing motivation to participate in classes. In the ethnographic study (Chapter Six), there was a 200% increase in attendance between the class which took place online (n = 4) to when it returned as face-to-face (n = 12).

Only two of the twelve quantitative studies in the literature review (Chapter Three) examined the benefit of exercise for quality of life and used three different outcome measures. Lamb et al (184) used the EQ5D3L (281), which does not include a social dimension and the Quality of Life in Alzheimer's Disease (QoL-AD) (282). This does include questions about relationships with family and friends but no other social element. Telenius et al. (183) used the Quality of Life in Late-Stage Dementia scale (QUALID) (283), which is administered with care providers but not the person living with dementia. These traditional outcome measures do not effectively measure social benefits to either participants or carers.

The exploratory study (Chapter Four) used the UCLA loneliness scale (211) as a proxy measure for social interaction. It showed a reduction in loneliness for both people living with dementia and their carers. The UCLA scale (211) was used by Choi et al. (284) to measure the effect of a remotely delivered behavioural activation

intervention on social connectedness; the study found a subsequent decrease in loneliness scores. In this trial, Choi et al. (284) also used the Duke Social Support Index (278) to measure the level of social interaction for older people. This is a 14-item self-administered questionnaire designed to measure the level of social support and has been validated for use in several populations, including community-dwelling older people (285) and health promotion strategies. It may provide a valuable outcome measure when exploring the social benefits of exercise or other physical activity interventions.

7.3.4 Online environment

The ethnographic study (Chapter Six) provided evidence that an online exercise class was not always the best mode of delivery for older people with or without dementia.

Although telemedicine was used before the COVID-19 pandemic, it emerged rapidly during this period to enable care for patients, including those living with dementia, to continue (286). Delivery in the home required patients to have access to a smartphone, tablet or a computer with audio and a camera along with a stable internet connection (287). However, it also required people to be confident in the use of technology, have the ability to troubleshoot problems and be able to see, hear and understand the clinician (286). People living with dementia and indeed, many older people find these requirements challenging due to both sensory and cognitive changes and a lack of experience with the technology.

A systematic review completed in 2020 confirmed that there were significant barriers to people living with dementia engaging successfully with telemedicine,

including both the lack of equipment and the ability to use the technology independently (286). In most studies, participants relied on family members to set up equipment and troubleshoot problems. Many older people in the ethnographic study (Chapter Six) also had difficulties with technology during the pandemic, with participants reporting that they needed support from family members to access online classes. *"My husband set it up for me, and if he hadn't been around, I wouldn't have bothered to take part"* (FG0208). Alternatively, they needed instruction in the use of the technology. *"I've done more since I found her (Instructor on YouTube), but I couldn't do it before, but my partner he wrote me instructions which I can follow"* (FG0201). Alongside this, a scoping review completed in 2021 (288) reported that although telerehabilitation had been implemented with older adults with mild cognitive impairment, social support is often required to improve its adherence and effectiveness.

It was difficult for instructors to monitor whether exercises were being completed correctly, and participants commented that they were also unsure of this. During the online class, the instructor took short breaks to check the participants' form and reminded them to use their screen as a mirror to check their position. A small feasibility study that was undertaken in Canada before the COVID-19 pandemic (289) using a cycle ergometer experienced no problems during a four-week intervention but reported that to ensure safe delivery, further investigation would be needed before more telehealth exercise programmes were trialled.

A mixed methods systematic review by Jagoda et al. (290) found that people living with dementia who successfully participated in telerehabilitation owed much to the

presence of a carer. Alongside this, the study by Dal Bello-Haas et al. (289), undertaken before the pandemic, found that the presence of carers at sessions facilitated the engagement of the person living with dementia. A memory clinic in Spain, which transitioned to online visits during the pandemic, received positive feedback from most patients and their families but did report that some were reluctant to engage in telemedicine even under these unusual circumstances (291).

In the studies within this thesis, older people, both with and without dementia, reported reduced motivation to attend classes online due to the absence of camaraderie and social interaction. There is very little literature which examines whether online groups can provide the level of social interaction sought by older adults. However, one study in Brazil carried out an intergenerational remote intervention programme explicitly designed to promote the well-being and social connection of older adults, mainly those with dementia, during the COVID-19 pandemic: this included clowning, dancing, storytelling, and cooking. Participants reported that they found the programme supportive and that it had reduced feelings of social isolation. One participant commented, *"older adults are usually slower; people don't have much patience……here we have someone to talk to and listen to"* (292).

Although the studies in this thesis have provided evidence that online classes do not promote the level of social interaction that participants gain from attending face-to-face classes, Brandao's study above (292) questions whether a generalisation can be established. Moreover, the lack of relevant literature indicates that this issue warrants further investigation.

7.3.5 Environmental attributes

The literature review (Chapter Three) suggested that providing an appropriate space and reducing physical barriers for people living with dementia can encourage attendance at exercise classes. Complementing these findings, the exploratory study (Chapter Four) advocated that open, accessible environments with suitable parking, accessible toilets, and the ability to provide refreshments were ideal for encouraging people living with dementia to attend a class. A study which investigated the motivators and barriers to physical activity and exercise in Washington DC (USA) also found that low-cost physical activities located at local community centres and designed for older people encouraged participation (279). Although the environments in the centres were not described, the fact that they could accommodate older people suggests they may have had appropriate facilities. Russell et al. also reported that people living with dementia achieve feelings of well-being from participation in physical activities in familiar and comforting environments (293). Linking environmental attributes with creating social networks, they reported that valuable social interactions could flourish within safe, supportive, and engaging environments, enhancing the lives of people living with dementia (293). These social networks were highlighted in both the exploratory study (Chapter Four) and the ethnography (Chapter Six) as important not only to people living with dementia and their carers but to older people generally.

As identified in Chapter Five, lack of transport can be an issue for this group, particularly those living in rural or isolated areas. Harrison et al. noted that an increased number of community centres offering a variety of classes would probably

lead to higher numbers of older adults engaging in physical activity and exercise (279). A further study in Scotland also noted that older people with no daily access to a car were more likely to be sedentary and that providing activities at convenient times supported by a good public transport system may increase the number of older people engaging in physical activity (294).

A study by Bechard et al. in Canada investigated dementia-inclusive exercise specifically with community exercise professionals; few studies had explored this group, most focusing on health professionals (295). As in the exploratory study (Chapter Four), they found that exercise classes needed to be flexible to meet the needs of individuals on any particular day. Instructors interviewed for the studies used ad hoc strategies to overcome barriers, including selecting exercises that would provide functional benefit, adapting them to meet the needs of each participant and progressing or regressing programmes to circumstances. One instructor commented on the benefit of a carer being able to attend and, if preferred, participate, this being a short-term or long-term practice depending on the individual (295).

The exploratory study (Chapter Four) provided strong evidence of the value of an appropriate ratio of staff/volunteers in classes for people living with dementia. Additionally, training for the staff/volunteers to meet the client group's needs enhanced their confidence and that of staff members. Bechard et al. found that exercise professionals who had experience in supporting people with mild cognitive impairment and dementia were more likely to recognise diverse levels of ability and respond accordingly (295). This paralleled evidence from the exploratory study (Chapter Four), where a knowledgeable volunteer (a retired physiotherapist) could

adapt exercises for a group of active men in the early stages of their dementia journey.

As in the ethnographic study (Chapter Six), Bechard et al. found that exercise instructors were inclusive in their attitude to people living with dementia participating in their programmes but were conscious of a lack of training in cognitive impairment and dementia. They highlighted the limited training opportunities available for dementia compared to other health conditions, such as heart failure and osteoporosis (295). This complemented the findings of the ethnographic study (Chapter Six) in which instructors commented on the plethora of training opportunities for conditions such as chronic obstructive pulmonary disease (COPD) or cardiac issues and even menopause but nothing for dementia. The training offered by Dementia Friends (which is accessible online) may not be at an appropriate level for this group. Compounding the difficulty, many insurance companies do not permit exercise instructors to include people living with dementia in all their classes without specific training.

Dementia-specific exercise classes often focus on people at a more advanced stage in their journey, leaving those who are younger or more physically able without access to classes that meet their needs. Therefore, they may turn to generic older adult classes in which, evidence from this thesis has indicated, providers may not have a thorough understanding of dementia (295). The findings of the ethnographic study (Chapter Six) and Bechard et al. highlight the need for training and education for instructors to promote a consistent understanding of dementia and those living

with it. This could facilitate more inclusive general exercise classes in which the need for adaptations on an individual basis is acknowledged (295).

Article 30 of the United Nations Convention on the Rights of Persons with Disability concerns participation in cultural life, recreation, leisure, and sport. It confirms the right of every person with dementia to access an exercise class appropriate to their needs and interests (296) and highlights the need to design and deliver dementia-inclusive classes to widen participation. To meet this objective, specific dementia training packages designed for exercise instructors of different levels are needed to enable them to provide inclusive classes and to satisfy insurance companies that they have the relevant training to lead them.

7.3.6 Environmental barriers

People with dementia and their families who participated in the ethnographic study (Chapter Six) reported difficulties navigating the 'system' to find classes to attend. Many reported that they had found a class by word of mouth, and that primary medical services such as GPs and social workers were unaware of appropriate available classes. A study undertaken in Australia explored the perspectives of frail and pre-frail older people on being advised about exercise. They reported that although participants wanted advice from their GP about exercise, it was not provided consistently. In the study, 11 of the 12 participants reported having no or limited conversation about participating in exercise. One only received information after taking the initiative and requesting it from his GP (297). Another study in the UK which examined social prescribing also reported that GPs did not play a central

role in referring people to the social prescriber, with 50% of the referrals being made by the managers of sheltered accommodation facilities (298).

Jadczak et al. reported that information provided for older people living in the community was insufficient, with participants asserting that local authorities should be more engaged in physical activity promotion. Conversely, they found that people living in retirement villages had much greater access to information about exercise and physical activities available to them (297). The ethnographic study (Chapter Six) established a variation in how individual counties and individual GP surgeries provide information about facilities available for people with dementia and their carers. The absence of an overarching system to secure consistent advice indicates that GPs need education and greater awareness of what is available for their patients. Baker and Irving concluded that lack of knowledge was often the reason for non-referrals to social prescribers (298).

The ethnographic study (Chapter Six) also explored difficulties from the providers' perspective. One instructor, who ran a class for older people, considered that it would be suitable for people living with dementia and was happy for them to take part. However, she lacked the knowledge to market the class to encourage people with and without dementia to attend. A key characteristic of the walking groups in Robertson et al. was that they were not exclusive to people living with dementia and their carers. Following an inclusive strategy, people living with dementia were supported to participate and engage with a broader spectrum of the population, and this acted as a pivotal component to the improved social health of the attendees (280).

A study by Phinney et al. in Vancouver (Canada) explored a walking activity that was part of a wider programme specifically designed for people living with young onset dementia. Although the group was exclusive to people living with dementia, the diagnosis was 'left at the door'. The walks took place in the local neighbourhood and provided an opportunity for class members to be a part of and contribute to their local community. Although the focus of the study was not specifically on social interaction or social connectedness, members continued to attend for several years, suggesting that they found value in the activities (299). A further study by Russell et al. in England also found that community leisure centres could provide a safe environment for people living with dementia who could acquire social connections and a sense of community engagement through their participation in the activities provided (293).

These different ways of providing exercise opportunities, both inclusive to all and exclusive to those with dementia, highlight the difficulties of marketing groups and activities to relevant audiences. All approaches have provided physical and social benefits and have given those living with dementia a place in their communities, perhaps suggesting that the inclusive/exclusive nature of the provision is of secondary importance. Robertson's work highlights that an integrated, inclusive offering is both possible and well received by those living with and without dementia and the need for more 'dementia-specific classes' is less important than the need to make all classes more inclusive.

7.4 Ecological perspectives and the social ecological model

In the introduction to this thesis, an ecological perspective was outlined. It posited that health behaviour is influenced at many levels and that these influences interact across those different levels. It provided examples of social ecological models for physical activity in general and more specifically, for promoting physical activity amongst older adults.

The studies presented in this thesis have provided clear evidence that organisational, institutional, environmental, and economic factors all play a role in influencing the behaviour choices of people living with dementia. A limitation of many studies, including this one, is not being able to speak to people who do not attend exercise classes. However, a hypothetical question was posed to participants about why they thought others might not attend classes. Suggestions included lack of transport (environmental), finances (economic), and lack of awareness of classes (institutional) alongside the individual choice not to attend.

The social ecological model has not previously been applied to the promotion of physical activity or exercise for older people living with dementia. Instead, there has been a focus on individual behaviour change and the interpersonal level, which includes friends and family (90). The social ecological model takes account of the multi-directional influences linking individuals and their environment and is important for policymakers and public health implementation strategies. Using the model suggested by Boulton (89) as a starting point, a potential social ecological model for promoting participation in exercise among older people living with dementia is presented below.

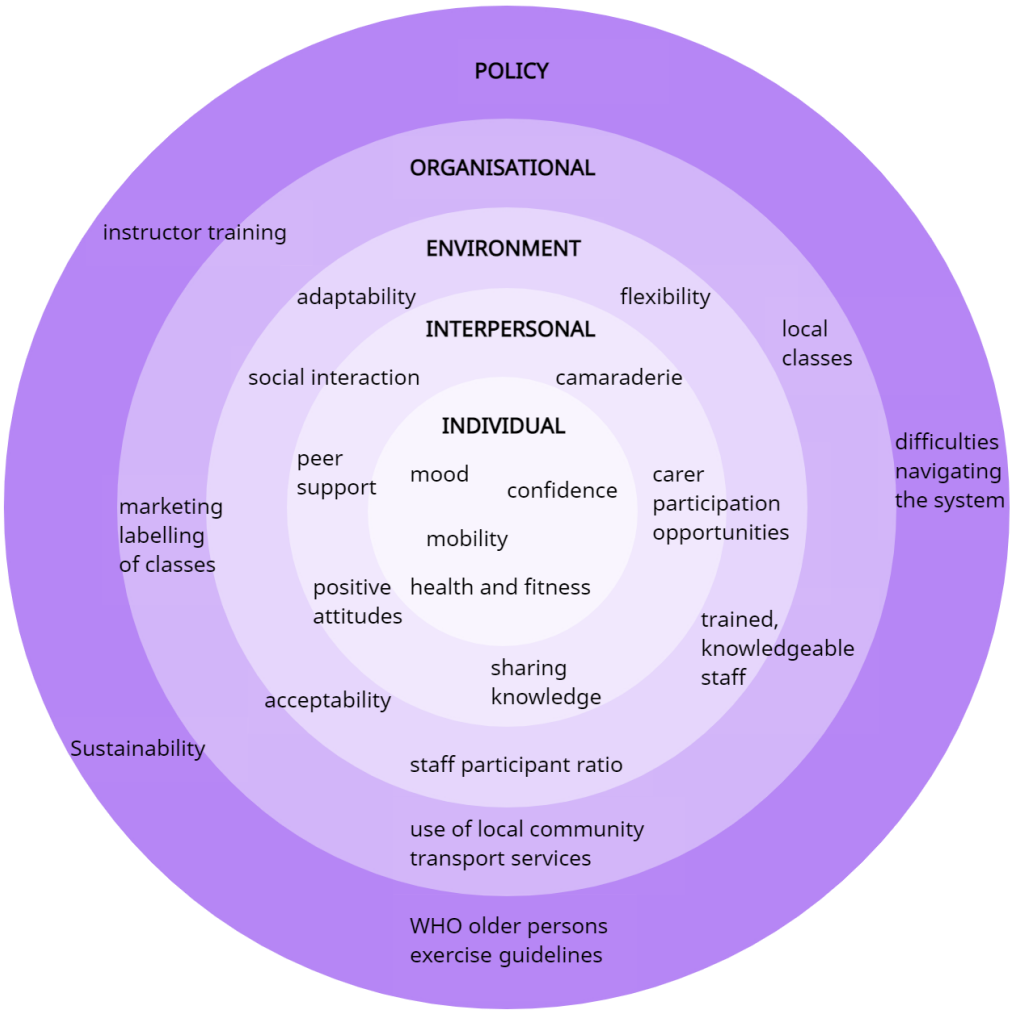


Figure 24 A proposed social ecological model for promoting participation in exercise amongst older people living with dementia

There is an overlap between this proposed model for older people living with dementia and the model for older people proposed by Boulton (89). On an individual level, both models identify physical and psychological drivers as motivation for continued attendance along with social interaction on an interpersonal level. However, the proposed dementia model also includes the peer support offered, sharing of knowledge, positive attitudes of members of staff and camaraderie within the group.

Environmental factors in the Boulton model had several common features with the proposed dementia model, including flexibility, adaptability, sociability, and accessibility (89). However, in the dementia model, environmental factors also included an appropriate staff/participant ratio and having trained and knowledgeable staff. The latter overlaps with organisational factors, as without specific training courses being available, instructors cannot offer inclusive classes.

Marketing and labelling of classes were important organisational factors within the Boulton model (89). Evidence in both Chapter Four and Chapter Six suggested that marketing and labelling were similarly crucial for people living with dementia, as participants struggled to find dementia-specific groups to attend. Instructors also reported difficulties marketing classes to their target group, who may not regard themselves as 'older' or 'elderly'.

On the outer ring of the proposed model, policy factors included difficulties navigating the 'system', sustainability, guidelines on exercise for older people and instructor training. Sustainability and national policy frameworks were also indicated in the model presented by Boulton (89). At the policy level, the lack of a coordinated system for the provision and promotion of activities for people living with dementia, and inconsistencies in who holds information on relevant classes act as further barriers to the needs of potential clients being met; evidence from participants indicated that much of this information is received via word of mouth.

The WHO guidelines on physical activity and sedentary behaviour for older people recommend that all older adults should undertake regular physical activity, at least

150 – 300 minutes of moderate-intensity aerobic exercise weekly or 75 – 150 minutes of vigorous aerobic physical activity; this is the same recommendation for adults aged 18 – 64. They also recommend identical advice for all adults living with disability, including diseases and disorders that impair cognitive function (265). For older adults and adults living with disability, the advice also confirmed that minimal physical activity is better than none, and that there are no significant risks to adults living with disability engaging in physical activity, when it is appropriate to the individual's current activity level, health status and physical function (265).

Hence, the international guidance clarifies that older people, both with and without dementia, should participate in exercise, however minimal, as sedentary behaviour is associated with poor health outcomes (265). Despite this, there is a dearth of dementia-specific training available for exercise instructors, and without specific dementia training, insurance companies limit the classes that instructors can offer.

These limitations further impact the sustainability of classes, a shared feature with the Boulton model (89). Many classes for older people, including those for people living with dementia, are local initiatives. Two classes studied as part of this thesis were formed following large randomised controlled trials and continued beyond the trials due to the commitment of organisers and participants. There has been no significant growth from these locally organised classes.

Within the Boulton study, participants raised concerns regarding sustainability and expressed the view that local authorities should provide financial and practical support for physical activity sessions (89). Similarly, in Chapter Six of this thesis,

carers of those living with dementia had concerns about the funding and sustainability of classes. They also argued the case for dementia-specific classes to be offered in every local authority, although they were not confident there was the political will for this to happen.

The social ecological model used in this thesis offers the opportunity to explore the exercise provision for people with dementia from a societal and multi-dimensional perspective. Carer participation and social interaction are integral to both the interpersonal and environmental levels, whilst staff training spans environmental, organisational and policy levels. This highlights the importance of the relationships and interactions between the different system levels and how promoting sustained engagement in physical activity and exercise needs to be planned with a clear recognition of these interrelationships.

7.5 Recommendations

The studies undertaken within this thesis and the subsequent synthesis have highlighted the key characteristics and core components which could enable exercise classes for people living with dementia in the community to be set up or adapted. These characteristics and components have informed the development of a set of recommendations that are tabulated below.

Table 21 Summary table of implications that informed guidelines.

Summary of implications for guidelines from individual chapters			
Implications Literature Review	Implications Exploratory Study	Implications Ethnographic Study	Summary for guidelines
Aerobic exercise seems to be an essential element, so would need to be included. Multicomponent classes would offer the benefits of strength and balance but would need to have an aerobic element. PlwD want to focus on general fitness rather than specific outcomes and benefit from familiar and enjoyable exercises that are easy to understand.	PlwD want to maintain current physical abilities and increase their overall activity levels and are less interested in improving specific physical outcomes such as strength and balance.	PlwD and OP are looking to improve their mobility, general physical fitness and overall health and are less interested in improving specific physical outcomes such as strength and balance.	• Exercise classes should have an aerobic element to help with overall health and physical fitness. • Multicomponent sessions would also provide strength and balance exercises which work on more specific physical outcomes that exercise professional's value for this group of people. • Effective exercise classes would include an aerobic element alongside strength and balance exercises.
There is no clear evidence of the benefit of exercise for psychological outcomes. Positive attitudes towards the provision of exercise for people with dementia does increase motivation to take part.	There were non-significant improvements in psychological outcomes. PlwD reported more confidence from taking part in classes. Classes where there was camaraderie between the attendees and the instructors, had a positive benefit on PlwD.	PlwD and OP were more likely to keep attending and attend on days when they were not feeling motivated if there was camaraderie between the group and the instructors.	• Instructors benefit from having a positive attitude towards people with dementia taking part in classes as this positive attitude encourages camaraderie both between the instructors and the attendees and also between the attendees. • Dementia training can help awareness that PlwD can and want to access exercise classes which may encourage positive attitudes and reduce stigma.
Social interaction appears to be an important part of a group exercise session. The outcome measures that are being used are not necessarily measuring this.	Social interaction is important to PlwD, and having increased opportunities for this during and after the class is beneficial for both PlwD and carers.	Social interaction appears to have become as important as the exercises for PWD and OP following the pandemic.	• Offer opportunities for social interaction during and around the class, as the social element often increases people's motivation to keep attending. • PlwD, Carers and OP appreciate the opportunity to chat with others and share knowledge. This can act to create an informal support network.
Reducing physical barriers can encourage attendance as can having appropriate spaces for the exercise class.	Having access to accessible parking and toilet facilities makes things easier for PlwD to attend.	Local classes and accessible transport can act as facilitators to attendance, whilst finance and transport difficulties may act as barriers.	• Ideal venues have open and accessible environments with plenty of suitable parking and accessible toilets. • It can be useful to provide transport, but this may not always be appropriate.

			• Having classes in local facilities rather than clustered in city centres may reduce the need for transport. • Local community transport services may be an option to allow people to attend classes who are more reliant on public transport/others.
Tailoring exercises to each participant's needs and abilities can encourage continued attendance.	Classes which are flexible and adaptable and allow carers to take part if wanted are beneficial.	Adaptable and flexible classes encourage attendance.	• Ensure classes are flexible and adaptable, as attendees' needs and abilities could change from week to week. • Opportunities for carers to attend and take part can be beneficial to both the carer and the PlwD.
Appropriate staff-to-patient ratios can encourage attendance. Reported ratios were variable, ranging from 1:2 – 1:8.	A good ratio of staff/volunteers to PlwD helped the class run smoothly. The ratio was usually 1:4. Staff need to be knowledgeable and trained.	There is little dementia training available to exercise instructors. Insurance companies require specific training to allow instructors to accommodate PlwD.	• An appropriate ratio of staff/volunteers to PlwD is important for classes involving this group. There is no agreed ratio in the literature. • It is important that staff are knowledgeable and trained on dementia. Dementia Friends training can offer some general training about dementia. • There appears to be a need for specific dementia training for exercise instructors to give them the confidence to accommodate PlwD in their classes and satisfy the training requirements of insurance companies.
		Online exercise classes are unlikely to be a suitable long-term replacement for face-to-face classes.	• Online classes can offer exercises but are often difficult to manage. • They do not offer the other elements that PlwD and OP gain from exercise classes, such as social interaction. • They should not be the first choice of delivery unless it is essential.
		Classes are difficult to find, and we are not getting the right people to the right classes.	• Classes need to be marketed to encourage both PlwD and OP to attend.

			• If more exercise instructors had specific dementia training, there could be a wider range of classes available that were accessible for both PlwD and OP

7.5.1 Recommendation one

To be effective, exercise classes need to be multi-component and include aerobic alongside strength and balance elements. This combination would meet the needs of attendees who are aiming to improve their overall health and fitness whilst working on strength and balance, which exercise professionals identify as a key outcome for this group. Classes should aim to offer familiar and enjoyable exercises as this will encourage continuing attendance.

7.5.2 Recommendation two

People living with dementia are willing and able, in an appropriate setting, to participate in exercise classes. However, from over 500 exercise classes for older people available in the East Midlands, few are dementia specific. This is despite evidence from the ethnographic study that instructors are willing to accommodate people living with dementia in these classes. Positive attitudes towards this group participating in exercise classes can enhance motivation, and increased awareness about dementia may help engender positive attitudes amongst instructors and reduce the stigma that continues to exist around dementia.

7.5.3 Recommendation three

Social interaction is an important dimension of group exercise classes for both people living with dementia and older people in general, and its importance has increased since the pandemic and ensuing lockdowns. Where possible, classes should include opportunities for social interaction during and after classes. The evidence gathered in preparation for this thesis confirms that time set aside after the class for refreshments and conversation can be motivational and provide an

opportunity for both social conversations and sharing knowledge and experience. This facilitates the creation of informal support networks valued by people living with dementia, their carers, and older people in general.

7.5.4 Recommendation four

Venues with open and accessible environments, including plenty of suitable parking and accessible toilets, are ideal for this client group. Where possible, transport could be provided to classes, especially for people living with dementia. Chapter Five outlined the high percentage of classes in city centres with a younger population demographic. Establishing classes in smaller towns and villages, rather than in city centres, would not only reduce dependence on expensive transport but integrate them into clients' local communities. Local community transport services to classes could be expected to positively impact attendance.

7.5.5 Recommendation five

Exercise instructors need more access to training and awareness of dementia-related issues. Training available through *Dementia Friends* can enhance awareness but is unlikely to be sufficient to satisfy the requirements of insurance companies. Classes which accommodate people living with dementia need to be flexible and adaptable, as attendees' needs vary from week to week. Increased knowledge about the capabilities of people with dementia would enable instructors to design appropriate sessions, enabling participants to access classes based on their present individual needs. The absence of appropriate training for instructors necessitates the creation of a more comprehensive training package to encourage them to have the

confidence and skills to support people living with dementia to attend and participate inclusively in classes available for all older people.

7.5.6 Recommendation six

There are no guidelines recommending an appropriate ratio of staff/volunteers: participants. In the literature review (Chapter Three) undertaken for this thesis, ratios varied from 1:2 (which was considered high) to 1:15 (which is more usual in an exercise class). A set of professionally-endorsed ratios for people living with dementia needs to be determined to enable classes to be run safely and effectively for all participants. They would need to be graduated and relate to where people were on their dementia journey and their previous exercise experience. Classes that provide the opportunity for carers to attend and participate could offer a solution of a 1:1 ratio, although this may not always be possible or preferred. Another option in a class that included people living with and without dementia could be a 'buddy system', pairing an attendee living with dementia with another member of the class. Harrison et al. (279) reported that having a 'work buddy' who encouraged them during the session acted as a motivator for attendance for older people who took part in exercise classes.

7.5.7 Recommendation seven

Online exercise classes allowed people to continue with exercise during the pandemic. Many older people, both with and without dementia, found access to these classes difficult from a technological or motivational standpoint. Evidence in the literature found that online classes can be effective and create opportunities for

social interaction, but this warrants further investigation. At present, this mode of delivery should not be regarded as ideal for older people with or without dementia.

7.5.8 Recommendation eight

People with dementia find it difficult to access appropriate exercise classes, whilst organisers also experience problems in trying to attract the appropriate client group to their classes. Knowledge of where classes are located is uncoordinated, as is information on target groups leading to potential attendees often relying on word of mouth. To address these issues, classes need to be marketed more effectively and led by a coordinating body responsible for disseminating basic information through primary healthcare providers, local authorities, and other health providers.

The recommendations suggested within this thesis have used the proposed social ecological model for promoting participation in exercise amongst older people living with dementia to ensure that classes would be adapted or set up with a recognition of these relationships. On an individual level, ensuring that classes contain an aerobic element and consist of familiar and enjoyable activities will work to sustain participation by using the physical and psychological drivers that motivate both older people and those living with dementia. Positive attitudes towards the capabilities of people living with dementia and maximising opportunities for social interaction use the interpersonal level to maintain continued attendance.

On an environmental level, offering open and accessible venues with suitable facilities, e.g., parking and toilets and located in areas of potential demand will ensure that classes are appropriate for the target group. Classes that are adaptable

and flexible and have an appropriate staff-to-participant ratio could also be expected to positively impact attendance. Having trained, knowledgeable staff was key for older people with and without dementia, but the lack of specific training prevents instructors from offering inclusive classes. Acting on both the organisational and policy levels, there is a need for specific dementia training packages to enhance awareness of dementia to not only engender positive attitudes about the capabilities of people living with dementia but also to offer them the choice, as is their right under the United Nations Convention, to have access to an exercise class appropriate to their needs and interests (296).

The marked similarities between the proposed dementia model and that of Boulton (89) for older adults confirm the key factors needed to promote engagement for both groups. These similarities suggest that, if planned appropriately, mixed classes for both older people with and without dementia could provide a way forward for increasing access for the former group.

7.6 Future research

The recommendations that have emerged from this thesis have also highlighted gaps in the knowledge base and offered directions for further research.

A key finding was the lack of specific training for instructors to enable them to provide inclusive classes for people living with and without dementia that meet the demands of their insurance companies. *Dementia Friends* training (300) is available online and face-to-face. However, exercise instructors need a programme tailored to their specific needs, and a discrete training package would be a significant step

forward to promoting greater inclusivity. This could include resources such as exemplar classes and techniques for adjusting the difficulty levels of exercises to meet the needs of the participants.

To ensure a training package is appropriate and successfully implemented, it needs to be explored through the same social ecological perspective as this thesis. As shown in Figure 24 (pg. 238) instructor training crosses the environmental, organisational and policy levels. Having a trained and knowledgeable workforce sits at the environmental level but you cannot have a trained and knowledgeable workforce without the availability of specific training. The ability to provide training packages falls within the organisational level. Exercise instructors receive training through specific registered exercise training providers who offer both initial training to allow the instructors to become registered exercise professionals and training for continued professional development.

Exercise instructors also reported that the ability to offer inclusive classes was limited by their insurance companies which would not allow them to include people living with dementia in all their classes unless they had undertaken specific training. This is a further organisational and policy barrier which would need to be considered. Therefore, to successfully implement an appropriate training package all the levels within the social ecological model need to be considered and to ensure this all stakeholders need to be involved in the project from the beginning. Figure 25 below illustrates how this would fit within the social ecological model.

Figure 25 A social ecological view of the implementation of a training package

The benefit of social interaction was not measured in the studies within the literature review. Some other studies, including those in Chapter Four of this thesis, have used recognised measures as a proxy for social interaction, such as the UCLA loneliness scale (211) or the Duke Social Support Index (278) and shown a positive improvement. As the importance of social interaction was highlighted during the pandemic for many groups, not just those who are older or living with dementia, it may be pertinent to develop and trial an outcome measure that can effectively assess the benefit of social interaction.

Evidence emerging from several sources indicated that a critical barrier to class attendance was systemic, arising from a lack of coordination of information about what classes are available and their location. Many participants in the studies within this thesis discovered the classes they attended by word of mouth, reporting that their GPs had no knowledge of available classes and that other healthcare professionals, such as social workers, who had previously provided that information, were now less actively involved in dementia casework.

Lack of knowledge of the location of potential clients also acts as a barrier to those organising and running exercise classes. The data provided in Chapter Five indicates that classes are not necessarily conveniently located. Given the paucity of information about the availability of classes, this underlines the difficulty of targeted marketing. Further research needs to focus on the means of creating a more effective flow of relevant information between providers, health professionals and potential clients. Targeted marketing via flyers, posters or online advertisements is needed to attract and encourage older people with and without dementia, whilst the availability of appropriate classes needs to be more effectively marketed to primary health care providers, local authorities and other health providers.

These systemic issues which revolve around the flow of information would also need to be examined through a social ecological lens. Much of this information is held at the individual or interpersonal level, people who know about the class tell others, and the information flows through word of mouth. However, this information flow does not seem to go beyond the interpersonal. To effectively disseminate the knowledge of where classes are located and whom they are suitable for, the

information needs to flow upwards to the environmental level, where health and exercise professionals sit, and the organisational level, where the providers such as the NHS and the exercise training providers sit. Ensuring that the information flows both upstream to the environmental and organisational levels, as well as downstream from the interpersonal and individual levels, can best be achieved by taking an ecological approach to the problem.

It was proposed earlier in this thesis that exercise classes located within the communities of the target population are ideal to encourage older people to attend; however, many classes are located in city centres with a predominantly younger population. Compounding this mismatch, household access to private transport decreases in older populations (261), and a reliance on public transport can be a significant barrier to class attendance (235,262). To address this issue, many local authorities (either directly or through supported charities) provide community transport services for older people to promote access to a variety of facilities. A local example of this is Nottingham Community Transport's partnership with Age UK Nottingham and Nottinghamshire to provide transport to a specialist dementia day centre (301). Further research is needed to explore how closer links between community transport organisations and exercise providers can be developed to increase access to classes.

A majority of the studies in the literature review highlighted the need for a 'high' staff/volunteer to participant ratio when providing exercise classes for people living with dementia. Ratios varied from 1:2 to 1:15, indicating that a professionally-endorsed standard has not been established, leaving experienced staff to make *ad*

hoc judgements, which is unhelpful to those less experienced in leading classes, including members with dementia. Further research is needed to determine an agreed safe ratio which can offer a guide and considers the point in the dementia journey of each individual in a class. A study by Harrison et al. (279) which explored the motivators to attendance at an exercise class for older people, reported that having a 'buddy' could be successful. During focus group discussions detailed in Chapter Six, participants reported that a motivating factor for attendance was not wanting to let down fellow class members or instructors. For participants at an early stage in their dementia journey, a 'buddy' could reduce the need for high staff numbers. Moreover, the complementary pairing could not only provide encouragement to attend classes but also a level of social interaction. The viability of a 'buddy' system in classes for people living with dementia is an approach that could valuably be further explored.

7.7 Reflections

7.7.1 Thesis strengths

The strengths and limitations of each study have been discussed in the relevant chapters; the following sections will discuss the strengths and limitations of the thesis as a whole.

The main strength of the thesis is the combination of several distinct elements which have offered a broad perspective of exercise provision for people living with dementia. As far as the author is aware, the mixed methods systematic literature review is the only synthesis of this kind that has been undertaken. Previous systematic reviews have been completed on the effectiveness of exercise for people

living with dementia, but these have mainly focused on studies of people exercising individually. Very few qualitative reviews have examined barriers and facilitators to exercise for those living with dementia. The matrix synthesis enabled an exploration of why some interventions appeared more effective than others and whether considering what people living with dementia wanted from an exercise group made a difference in the effectiveness of the intervention; this approach provided a novel, in-depth examination of provision.

As the research questions were complex, a mixed methods approach was a strength of the thesis. The explanatory sequential design meant that initial quantitative data was gathered on the number and location of exercise classes. This provided a focus for qualitative data collection. Although there were a limited number of dementia-specific classes (13), 520 in the East Midlands region were suitable for older adults. This opened the possibility of changing the focus from setting up dementia-specific classes to adapting classes for older people to make them dementia-appropriate.

The COVID-19 pandemic was instrumental in providing a unique insight into the provision of exercise classes; this served as a strength to the thesis. Under 'normal' conditions, exercise classes had not been run online. However, in these circumstances, the use of technology was extended beyond those with limited access to facilities due to their rural location or lack of transport. This enabled the use of online exercise classes to be investigated and an assessment made of whether they could offer the same benefits derived from face-to-face classes. As originally envisaged, the research did not include this element and the additional data collected was used to analyse the benefits of online classes.

Using a geographical information system to map the distribution of exercise classes regarding population age, socioeconomic status and population density was a novel addition to the thesis. Maps have been used in other studies, mainly to look at the distribution of services in relation to socioeconomic status. Data from this thesis showed a relatively even distribution of classes across the region in relation to this factor. However, tracking distribution for other population characteristics identified a disparity in the location of classes for the other two factors. Local authority planners and policymakers could use this additional data to explore the equity of services for this age group and inform decisions on where to locate new classes.

The data informed the proposed social ecological model for promoting participation in exercise in the target group. The model is based on data from a small sample and, as such, may not comprehensively capture the components needed to promote participation, whilst the changing nature of exercise provision during the COVID-19 pandemic also imposed limitations. Hence, the model is proposed as a preliminary framework to guide future studies. Further iterations and formal validation would be needed before it can be generalised.

7.7.2 Thesis limitations

As well as providing a strength to the thesis, the research was limited by the COVID-19 pandemic in several ways.

The survey was distributed during the first national lockdown when many exercise instructors were either furloughed or, if self-employed, not working. Under these

circumstances, it was unlikely that they would have read work-related emails; this almost certainly severely limited the response to the survey.

The limited response also meant that the observed exercise classes could not be purposively sampled as initially anticipated. Sampling was to be used to provide a broad range of settings such as local authority, private and charity-run classes, rural and urban areas, and areas of diverse socioeconomic status. However, of the six respondents to the survey, one took part in the exploratory study (Chapter Four), so it could not be used again for further observations; only one respondent offered online exercise classes to older people, and the first respondent that restarted classes following the second national lockdown was chosen for expedience. The final class was chosen as it was the first dementia-specific class to return during the restriction period. Therefore, classes were chosen due to availability and may not comprise a representative sample.

A further limitation was imposed by the need to use a variety of data collection methods due to different levels of restrictions being in place. The initial plan was to complete focus groups with all classes and another with instructors. However, due to the changing restrictions and the differing needs of participants, both online and face-to-face interviews were completed alongside face-to-face focus groups. Hence, there was no standard method of data collection. Jordan et al. (302) used interviews and focus groups with nurses discussing the challenges of their work during 'The Troubles' in Northern Ireland and found consistency in the accounts irrespective of the interview format; this challenges some assumptions about mixing data collection

methods. Using the focus group topic guides for both formats with standardised questions and areas to cover offers repeatability despite the differing formats.

A further limitation arises from data being collected from group members of the classes that were observed. Hence, they could only offer views on why they attended classes and not why others might not. As in other exercise and physical activity studies, obtaining views of non-attenders or those who only attend once is a widespread problem. During a period of restrictions, recruitment within classes was difficult, and at the time of data collection, instructors reported that not all attendees had returned following the pandemic. Attempting to locate people who had attended once was not feasible during this period. However, it must be recognised as a limitation of this, and many other studies conducted in more favourable circumstances.

A further consequence of the pandemic was that sample sizes were small. The online class had an average of four attendees, and when it returned to face-to-face, numbers immediately rose to twelve, although, due to social distancing guidance, this was fewer than before the pandemic. The dementia-friendly class also reported that numbers had dropped since the pandemic, with several participants having either passed away or deteriorated during the 21 months the classes did not take place. Moreover, some former class members were initially wary of returning as restrictions gradually eased. The first class I attended in early January 2022 had four attendees, whilst the last one in March had six, possibly pointing to increased confidence.

7.7.3 Researcher background

The background of the researcher must be acknowledged. I am a physiotherapist by training with several years of experience in a research environment. I did not disclose to participants that I was a physiotherapist unless specifically asked and introduced myself as a PhD student. This was done to reduce the possibility of participants answering questions in what they deemed an appropriately courteous way to 'please' the interviewer and provide answers that they thought I would want to hear as a physiotherapist looking at exercise. However, my experience is likely to have influenced the way that questions were posed and may have resulted in participants making some assumptions about my knowledge and opinions.

The research process was also designed to reduce the likelihood of those interviewed trying to make that 'good impression'. Each class was observed for several weeks before the focus groups were held, and I assumed the role of a participant-as-observer. This approach was intended to establish myself as a member of the group, building up trust to enable me to be given answers and opinions that were untainted by expectations during the focus groups and interviews.

Unless specifically asked, my role as a physiotherapist was also withheld as I did not want to blur the boundaries between being a researcher and a clinician. Once my clinician role was known, participants did tend to ask questions about their physical health and recent injuries. I aimed to create boundaries between roles, advising class members to talk to their own health professionals about their medical conditions. On reflection, this may have been due to having spent several years out of frontline

delivery of services while working in research; it may have been more challenging to create these boundaries had I still been working as a frontline clinician. However, I still experienced an element of guilt about not being able to help participants, as many of the questions required simple answers, which I could have provided.

7.7.4 Position of the researcher

I began this research journey believing that more dementia-specific classes were needed, similar to those I had observed in Chapter Four. Undertaking this work has changed my thinking substantially, although I remain positive about the potential value of dementia-specific classes. However, I now consider that, for a more inclusive approach to exercise classes, people living with dementia should be able to access classes that they feel are appropriate for their needs; these classes may not necessarily be dementia-specific.

As Article 30 of the United Nations Convention implies, it is the right of every person to have access to an exercise class appropriate to their needs and interests (296). Many of the older people who were not living with dementia that were interviewed for this thesis, stated that they would have wanted to continue with their current classes if they were to be diagnosed with dementia. The men observed in Chapter Four, who were at an early stage in their journey, may not have wanted to attend a less physically demanding class. Dementia-specific classes can be viewed as being for those with more extensive cognitive or physical needs, leaving those who are more cognitively able and/or physically fit believing they have no access to alternative provision (295). A wider variety of classes appropriate for people living with dementia would offer a more inclusive and socially acceptable approach.

I started this journey with a limited understanding of a theoretical framework in which my work could be set. In general terms, I knew what I wanted to achieve but struggled to identify a concept that could underpin my underdeveloped thoughts. I was encouraged by members of my supervisory team to consider behaviour change theory as an underpinning concept, as this had been used in previous research into exercise interventions. However, I found it difficult to conceive how behaviour change theory would support the whole story I was trying to tell.

Further reading led me to explore an ecological perspective on the factors influencing an individual's behaviour and the relationships between personal, environmental, organisational and institutional factors. Behaviour change theory is limited by not considering the social and environmental contexts of an individual's life, which are of central importance in promoting the long-term maintenance of behaviour (71). However, the social ecological model incorporates influences which impact on engagement in physical activity not only on the individual and interpersonal levels but environmental, organisational and policy levels (89). Ecological and systems thinking offer theoretical concepts that align with the research story of this thesis: sustained change in an individual's behaviour is a product of their relationship with the entire social, political and institutional context, which provides the framework to their lives.

7.7.5 Methodology/ontology

As the research has utilised a mixed-method approach, it draws on pragmatism as its underlying philosophy (100). This impacts the conclusions; had a critical realism

approach (107) that can also be employed to underpin mixed method research been adopted, this would have influenced both the research process and conclusions.

Responses and opinions in interviews and focus groups were regarded as 'truth.' However, it must be acknowledged that participants may be presenting a view of themselves in response to their assumptions about the background of the interviewer. Hence, data was analysed, recognising that an interview is a constructed environment.

This approach draws on the stance of Dewey, who views knowledge as being both constructed and based on the reality of the world we experience and proposes that different 'knowledge' results from engaging with the world in different ways. Asserting that knowledge is concerned with relationships between actions and consequences and not about 'truth' as no form of knowledge is more valid than any other, justifies the assumption that the views offered by participants were a 'true' representation of their thoughts provided in the socially constructed environment of an interview (112).

A mixed methods approach allowed the research questions to be explored from different angles and changes made as the research progressed. The initial quantitative exercise was a survey of exercise instructors. However, due to the severely reduced response, the quantitative data collected was of limited value and was only used in a geographical information system. This allowed further quantitative analysis of the distribution of exercise classes which offered additional

information on the distribution patterns with regard to age, population density and socioeconomic status.

7.7.6 COVID-19

The first COVID-19 national lockdown began six months after the start of my PhD programme. The original aim was to produce a toolkit to support setting up an exercise class for people living with dementia in the community; this remained the aim at twelve months following the confirmation review. However, as restrictions continued and a further national lockdown followed, a decision was made to narrow the scope of the thesis. After 18 months, there had been no opportunity for data collection, and the response to the survey had been limited. Data collection began in April 2021, and it soon became clear that the data that could be collected would not be complete or rich enough to provide evidence for a robust toolkit. By December 2021, there had been no opportunity to collect data from people living with dementia. Even after recruiting a specific dementia exercise class, only two participants' views were captured.

However, the pandemic did bring about different opportunities. During the national lockdowns, the information collected for the survey distribution was analysed within ArcGIS to provide maps and additional analysis of the distribution of classes. It also provided the opportunity to track the online provision of exercise classes and collect the views of older people with and without dementia on the usefulness of these classes.

As specific classes for people living with dementia were the last to return following the easing of restrictions, it also provided the opportunity to discuss the option of mixed classes comprising people with and without dementia with both cohorts. The data from the mapping exercise showed that there were 520 classes appropriate for older adults, 13 of which were specifically targeted at people living with dementia. This led to the conclusion that fully inclusive classes could be a cost-effective way to increase provision for those living with dementia.

7.8 Conclusions

The central conclusions of this thesis can be summarised as follows:

- exercise classes can provide physical, psychological, and social benefits to older people and people living with dementia
- the benefit of social interaction is not being accurately reflected in standard outcome measures, and a specific outcome that can determine this benefit needs to be developed
- classes are best offered in a face-to-face format
- a social ecological model for promoting participation in exercise amongst older people living with dementia has been proposed
- the proposed model has many commonalities with that presented by Boulton for promoting physical activity in older adults (89), suggesting that classes, where older people with and without dementia participate together, should be feasible to deliver effectively to both cohorts
- recommendations have been provided that are designed to support a provider in setting up or adapting an exercise class to encourage people living with dementia to participate
- further research is needed into the dementia training needs of exercise instructors and the production of a training package to enable them to offer a wider variety of inclusive classes
- classes that are currently available are not being effectively targeted, and further research is needed into their marketing

However, the debate on whether people with dementia should be included in all exercise classes or whether provision should be made exclusively for those with the condition is a false dichotomy. Only by providing the choice of participating in either format can the expectations and needs of people living with dementia be fully addressed.

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Appendices

Appendix A: Search Strategy

Medline (Ovid)

1 exp Dementia/ or exp Dementia, Multi-Infarct/ or exp Frontotemporal Dementia/ or exp Dementia, Vascular/

2 dementia*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

3 "vascular dementia*".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating subheading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

4 ("frontotemporal dementia*" or "frontal lobe dementia*").mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

5 ("multi-infarct dementia" or "multi infarct dementia" or "multiinfarct dementia").mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating subheading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

6 exp Alzheimer's Disease/

7 Alzheimer*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

8 exp Cognition Disorders/ or exp Cognitive Dysfunction/ or exp Dementia/

9 ("cognitive dysfunction" or "cognitive disorders").mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

10 Lewy Body Disease/ or Lewy Bodies/ or Dementia/ or Alzheimer's Disease/

11 "lewy bod*".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

12 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11

13 exp Exercise Therapy/ or exp Circuit-Based Exercise/ or exp Exercise/

14 "physical activit*".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

15 "aerobic exercise*".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

16 exp Physical Fitness/

17 ("chair based exercise*" or "chair-based exercise*").mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

18 ("group exercise*" or "group based exercise*" or "group-based exercise*").mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

19 exp Tai Ji/

20 "tai chi".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

21 exp Walking/

22 ("walking" or "bicycling" or "cycling" or "swimming" or "danc*" or "yoga" or "pilates").mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating subheading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

23 exp Bicycling/

24 exp Swimming/

25 exp Dancing/

26 exp Yoga/

27 exp Exercise Movement Techniques/

28 "mind body exercis*".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating subheading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

29 exercis*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

30 activit*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

31 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30

32 exp Homes for the Aged/ or exp Group Homes/ or exp Nursing Homes/

33 ("care home*" or "old people's home*" or "nursing home*" or "residential home*" or "sheltered hous*").mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

34 exp Home Care Services/

35 Day Care, Medical/

36 "day centres".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

37 exp Residential Treatment/

38 exp Residential Facilities/

39 exp Community Health Services/

40 exp Assisted Living Facilities/ or exp Long-Term Care/

41 exp Home Care Agencies/

42 domesti*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

43 resident*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

44 home*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

45 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44

46 12 and 31 and 45

47 barrier*.mp.

48 facilitator*.mp.

49 47 or 48

50 46 and 49

Including limits - human, English, over 65 and over 80

Search was conducted on 26th March 2020.

Appendix B: Critical Appraisal Instruments

1. Randomised Control Trials

JBI Critical Appraisal Checklist for Randomized Controlled Trials

Reviewer_____Date_____

Author _____Year_____Record Number_____

		Yes	No	Unclear	NA
1.	Was true randomization used for assignment of participants to treatment groups?	☐	☐	☐	☐
2.	Was allocation to treatment groups concealed?	☐	☐	☐	☐
3.	Were treatment groups similar at the baseline?	☐	☐	☐	☐
4.	Were participants blind to treatment assignment?	☐	☐	☐	☐
5.	Were those delivering treatment blind to treatment assignment?	☐	☐	☐	☐
6.	Were outcomes assessors blind to treatment assignment?	☐	☐	☐	☐
7.	Were treatment groups treated identically other than the intervention of interest?	☐	☐	☐	☐
8.	Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	☐	☐	☐	☐
9.	Were participants analyzed in the groups to which they were randomized?	☐	☐	☐	☐
10.	Were outcomes measured in the same way for treatment groups?	☐	☐	☐	☐
11.	Were outcomes measured in a reliable way?	☐	☐	☐	☐
12.	Was appropriate statistical analysis used?	☐	☐	☐	☐
13.	Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

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2. Quasi-Experimental Studies

JBI Critical Appraisal Checklist for Quasi-Experimental Studies (non-randomized experimental studies)

Reviewer_____Date_____.

Author _____Year_____Record Number_____.

		Yes	No	Unclear	Not applicable
1.	Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	☐	☐	☐	☐
2.	Were the participants included in any comparisons similar?	☐	☐	☐	☐
3.	Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	☐	☐	☐	☐
4.	Was there a control group?	☐	☐	☐	☐
5.	Were there multiple measurements of the outcome both pre and post the intervention/exposure?	☐	☐	☐	☐
6.	Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	☐	☐	☐	☐
7.	Were the outcomes of participants included in any comparisons measured in the same way?	☐	☐	☐	☐
8.	Were outcomes measured in a reliable way?	☐	☐	☐	☐
9.	Was appropriate statistical analysis used?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

_____

_____

_____

3. Qualitative Studies

JBI Critical Appraisal Checklist for Qualitative Research

Reviewer_____Date_____

Author _____Year_____Record Number_____.

		Yes	No	Unclear	Not applicable
1.	Is there congruity between the stated philosophical perspective and the research methodology?	☐	☐	☐	☐
2.	Is there congruity between the research methodology and the research question or objectives?	☐	☐	☐	☐
3.	Is there congruity between the research methodology and the methods used to collect data?	☐	☐	☐	☐
4.	Is there congruity between the research methodology and the representation and analysis of data?	☐	☐	☐	☐
5.	Is there congruity between the research methodology and the interpretation of results?	☐	☐	☐	☐
6.	Is there a statement locating the researcher culturally or theoretically?	☐	☐	☐	☐
7.	Is the influence of the researcher on the research, and vice- versa, addressed?	☐	☐	☐	☐
8.	Are participants, and their voices, adequately represented?	☐	☐	☐	☐
9.	Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	☐	☐	☐	☐
10.	Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

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_____

Appendix C: Characteristics of Included Studies

1. Randomised Controlled Trials

Study	Setting	Participants	Inclusion Criteria	Intervention	Control	Outcomes	Results
Miu 2008	Hong Kong: Memory clinic of a regional hospital	Exercise group: n = 36 mean age 75 Control group: n = 49 mean age 78	Over 65 Community-dwelling, ambulatory, MMSE 10 – 26, carer willing to participate.	Aerobic training using treadmill, bicycle, and arm ergometry (12 wks., 1 hr x 2pw)	Usual care	Functional reach (cm) Berg Balance Scale (BBS) 6-min walk (m) Cornell Scale for Depression in Dementia	Functional Reach – significant difference post-intervention. 6-min walk – significant difference post-intervention. BBS – significant difference post-intervention Cornell Scale – exercise group worse post-intervention
Lamb 2018	UK: NHS care settings – delivered in community gym facilities	Exercise group: n = 329 mean age 76.9 Control group: n = 165 mean age 78.4	Mild to moderate dementia, community-dwelling. Independent stand from chair, walk 10m without human assistance.	Multicomponent cycling 25 mins Resistance work with weights (4 mnths, 1 hr x 2pw)	Usual Care	EQ5D QoL-AD	No difference between groups for either measure
Telenius 2015	Norway: Nursing Homes	Exercise group: n = 87 mean age 86.9 Control group: n= 83 mean age 86.9	Over 55, Mild to moderate dementia (CDR 1 or 2) Stand with 1, Walk 6m with or without aid	Multicomponent High-Intensity Functional Exercise programme, including strength and balance exercises. (12 wks., 1 hr x 2pw)	Usual Care	Berg Balance Scale (BBS) 30-sec chair stand test 6 m walk (m/s) Cornell Scale for Depression in Dementia QUALID	BBS – significant difference post-intervention 30 sec CST – no significant difference post-intervention 6 m walk – no significant difference post-intervention Cornell Scale – no significant difference post-intervention QUALID – no significant difference post-intervention
UMDEX 2015	Sweden: Residential Care Facilities	Exercise Group: n = 93 (18 clusters); mean age = 84.4 Control group: n = 93 918 clusters); mean age = 85.9	Over 65 MMSE 10 or greater Stand with 1, Assistance of 1 for ADLs Understand Swedish	Multicomponent High-Intensity Functional Exercise programme, including strength and balance exercises. (4 months 45 mins x 5 per fortnight)	Usual Care	Berg Balance Scale (BBS) Gait Speed GDS-15 MADRS	BBS – significant difference post-intervention Gait Speed – no significant difference post-intervention GDS-15 – no significant difference post-intervention MADRS – no significant

							difference post-intervention
Venturelli 2010	Italy: Assisted living centre	Exercise group: n = 15 mean age 83.3 Control group: n = 15 mean age 84.1	Over 65 MMSE 15 – 25, Assistance of 1 for ADLs, serious mobility limitations, Max POMA score = 5	Upper limb resistance work using weights and theraband (12 wks. 45 mins x 3pw	Usual Care	1RM arm curl	Statistically significant difference post-intervention
Nyman 2019	UK: community settings	Exercise group: n = 42 mean age 77.9 Control group: n = 43 mean age 78.2	Over 18 Diagnosis of dementia M-ACE score of 10, Living at home, physically able to do standing Tai Chi	Tai Chi classes and home-based practice (20 wks. 45 mins x 1pw)	Usual Care	Timed up and go (TUG) Berg Balance Scale (BBS)	No significant difference between the groups for either measure.
Huang 2019	China: community long-term care facilities	Exercise group: n = 40 Mean age 81.9 Control group: n = 40 mean age 81.9	Over 60 Diagnosis of dementia with CDR score less than 2	Tai Chi (10 mnths 20 mins x 3pw)	Usual Care	GDS-15	Significant difference post-intervention
Kemoun 2010	France: Nursing homes	Exercise group: n = 20 mean age 82 Control group: n = 18 mean age 81.7	Diagnosis of Alzheimer's Disease with MMSE less than 23. Ability to walk 10 m without aid	Aerobic exercises including walking, ergocycle and dancing (15 wks. 1 hr x 3pw)	Usual Care	Gait Speed	Significant difference post-intervention

2. Quasi-Experimental Studies

Study	Setting	Participants	Inclusion Criteria	Intervention	Control	Outcomes	Results
Henwood 2017	Australia: residential care facilities	Exercise group: n = 29 mean age 80.5 Control group: n = 27 mean age 84.3	Diagnosed with dementia, able to walk 10 m with or without aid, past history of swimming	Aerobic exercises in water (12 wks. 45 mins x 2pw)	Usual Care	Grip Strength Standing Balance Chair Stands 2.4m walk test Timed up and go (TUG) Functional Reach	Grip Strength - significant difference post-intervention Standing Balance – no significant difference between the groups Chair Stands – significant difference post-intervention 2.4m walk – no significant difference between the groups TUG – no significant difference between the groups Functional Reach – significant difference post-intervention
Tsugawa 2020	Japan: Nursing Homes	Exercise group: n = 19 mean age 83.2 Control group: n = 18 mean age 85.9	Cognitive impairment Requiring long-term care	Aerobic exercises in sitting (12 mnths 40 mins x 2pw)	Usual Care	Grip Strength GDS-15	Grip Strength – significant difference post-intervention GDS-15 – no significant difference between the groups
Sampaio 2019	Portugal: Nursing Homes	Exercise group: n = 19 mean age 84.8 Control group: n = 18 mean age 83.3	Over 65 Diagnosis of Alzheimer's Disease at mild to moderate stage according to CDR, no regular exercise training in last year, resident for more than 6 months	Multicomponent including aerobic, strength flexibility, balance, and posture exercises (6 mnths 45 – 55 mins x 2pw)	Usual Care	30-sec Chair Stand Test (CST) Arm Curl 2 min step test Timed up and go (TUG)	30 sec CST – significant difference between time points for exercise group but no significant difference between groups Arm Curl – significant difference post-intervention 2 min step test – significant difference post-intervention TUG – significant difference between time points for exercise group but no significant difference between groups
Thurm 2011	Germany: Nursing Homes	Exercise Group: n = 8 mean age 84.2 Control Group: n = 11 mean age 86.4	Older adults, record of dementia and MMSE less than 24, physically frail	Multicomponent including aerobic, strength, balance, and flexibility exercises (10 wks. 45 mins x 2pw)	Usual Care	GDS-15	No significant difference between the groups post-intervention

3. Qualitative Studies

Study	Methods for Data Collection	Country and Setting	Phenomenon of Interest	Participants	Results
Barrado – Martin 2019	Semi-structured observations, field notes and focus groups – thematic analysis	UK: community settings	Acceptability and feasibility of Tai Chi intervention in community setting for PWD and carers	Dyads taking part in Tai Chi intervention. Observations: n = 9 Focus Groups: n = 7	Instructional methods – clear, calm speech, developed rapport, regular positive feedback, adapted intervention to participants' needs. Participants' reactions to intervention – participants verbalised enjoyment of intervention and social component, carers did not report joint participation as a burden. Facilitators to engagement – benefits perceived for both members of dyad, physical benefits, social interaction with others
Brett 2018	Semi-structured interviews – thematic analysis	Australia: Nursing Homes	Views about PWD participating in exercise, feasibility of sustaining exercise in the long term	Nursing home care staff: n = 10 Family members of people who had participated in intervention: n = 9	Participants generally reported benefits including – social engagement, psychological and unmet needs, reduced agitation, improvements in mood, physical improvements to mobility, pain, energy levels and independence and a reduction in falls. Barriers included ill health, increased aggression, staffing, time, resources, and environment. Positive attitudes of participants, staff and family members a facilitator, whereas negative attitudes of staff and family members was a barrier
Wright 2018	Ethnographic approach with observation and interviews – thematic analysis	UK: community settings including day centres and wellbeing cafes	Factors that influence how PWD in community participate in physical activity and how this impacted their wellbeing	PWD who attended the centres regularly: observations n = 19 Interviews n = 11 Staff/Carers: observations n = 7	Most people had positive attitudes and beliefs towards physical activity, the degree of social support available and a secure, spacious social environment influenced participation. Music, rhythm, and playful activities facilitated engagement, whilst activities that were too cognitively demanding could present a barrier. People enjoyed being with people who also had dementia and that shared experience. People enjoyed the exercises and found it improved their mood. Carers appreciated the opportunity to define their relationship as equal

					partners rather than care provider and recipient. Poor cramped, and chaotic environments with rule-bound activities and a lack of social support created barriers to engagement, but sometimes, even with an incongruous environment, participation happened anyway.
Guzman – Garcia 2013	Grounded theory approach to develop theoretical models using interview – analysed using grounded theory guidelines	UK: care homes	Positive and negative impressions of a dance intervention	PWD who had participated in intervention n = 7 Care staff n = 9	Residents who took part looked forward to the intervention and showed positive psychological benefits and expressed joy at taking part. Staff noticed an increase in social interaction. People watching the intervention were interested and reminisced with staff, and other residents whilst the intervention was taking place. Care staff expressed a sense of professional satisfaction but also noted that environment and staffing as potential barriers.
Post 2018	Interviews – thematic analysis	Australia: residential care facilities	Perceptions of benefit and acceptability of an exercise programme	Care staff n = 15 Family members of people who had participated in the intervention n = 9	Staff and family members were generally in favour of the intervention but sceptical as to its benefit or longevity. Residents were perceived to have benefited physically as well as social and behavioural benefits – staff reported residents to be calmer and more social. Also noted that the intervention provided some purposeful occupation for the residents which was a significant impact. Family members indicated that the intervention provided a sense of achievement for participants. Care staff reported time and staffing could be potential barriers.
Lamb 2018	Observations and interviews – thematic analysis	UK: community settings	Participants and carers' attitudes and experiences to taking part in an intervention	Observations: 5 sites observed 4 times for 1.5 hrs Interviews: participants n = 8 Carers n =6 Physiotherapists delivering intervention n = 5	Participants enjoyed taking part and enjoyed the social interaction with others. Carers appreciated the opportunity to be with other carers in a similar position and the break from the burden of caring. There was not always good communication between the physios and the participants, which led to over or underestimating what they could do. Participants and carers both felt that the

					intervention improved their physical health and functioning but not their cognition. Physiotherapists found it challenging to deliver the intervention to PWD and how to navigate the stigma of the diagnosis.

Appendix D: Barriers and Facilitators

Synthesised Findings	Categories	Findings	Illustrations
1. Barriers to physical activity encountered by both people living with dementia and their carers can be overcome with positive attitudes and beliefs and the right environmental attributes.	1. Physical barriers to participation.	1. Barriers to physical activities for people with dementia. (U) (239)	"It would be great if we had someone just dedicated to that. If we just had that extra set of hands that was just dedicated to that, I think they would all benefit from it" (lifestyle and recreational officer, 13). pg. 16 (239)
	2. Barriers for care staff.	2. Barriers to implementation. (C) (240)	You need someone else there to do that. Like I said there was a particular resident in the walking frame that would always be asking um, '... .if you've got 5 minutes or 10 minutes, can you take me for a walk?', but you know you can't, well not all the time, well not regularly anyway.... (care staff 11) pg. 8 (240)
		3. Barriers/difficulties for care staff. (C) (238)	P9: 'In some homes, some carers need a prompt, they need a little push to say ''come on you are not here to sit around and take them to the toilet and bath and feed them''. You know who they are, but really they're here to make their [residents'] lives as happy as possible.' pg. 529 (238)
		4. The therapeutic alliance between participant and physiotherapist. (C) (229)	They are frightened to death that you're going to do something and injure yourself . . . if I pick up a dumbbell and start doing oh my . . . [they say], 'just a minute, just a minute' . . . and I think well I've just had a bit of a [telling off] for doing something on my own and there's these other people they're doing the same. Patient 8 (male) (229)
		5. Dementia symptoms and delivering the intervention. (U) (229)	I've had to physically guide them through the movement. It's taken them longer to actually get the feel of what we're asking them to do, but not to the extent that they haven't fitted in with the class. Getting on and off a bike is something that is not as straightforward as you might think, I mean you can demonstrate it, you can talk them through it and you could actually physically get them to do it, but then they get off. When they get back on again 2 seconds later they really haven't got it, they don't know physically what they're doing. Physiotherapist 1 (229)

		6. Navigating the stigma of dementia. (C) (229)	That was a concern for me because I couldn't really tell where each individual was as far as, you know, their diagnosis was concerned. So if this is someone who hasn't accepted it, I don't want to be trying to shove it down their throat, and if this is someone who has, how do I know? So I sort of let them initiate the conversations [until] I had a definite idea of where the individual stood with, you know, dementia in general. Physiotherapist 21 (229)
	3. Environmental barriers to participation	7. Wanting to but not quite getting there. (C) (237)	Similarly, at Chellowfont Day Centre, rule-bound and inflexible activities could render engagement difficult. Sometimes the lack of social support prevented physical activity completely. pg. 534 (237)
		8. It's just not happening. (C) (237)	Sometimes physical frailty, inhibition and chaotic environments combined to form a powerful barrier which prevented physical activity from taking place. pg. 534 (237)
		9. The intervention as a burden for participant and carer. (C) (229)	I find I'm getting very tired in an afternoon, I don't like the bikes. They are very, very uncomfortable. Patient 4 (female) (229)
	4. Environmental attributes	10. Social and Physical environment – degree of support available enhanced participation. (C) (237)	Certain characteristics of the physical space were found to be influential. Spacious environments in which activities were undisturbed facilitated participation. Conversely, this was much less likely in cluttered, noisy environments. pg. 530 (237)
		11. Engaging in activity. (U) (237)	Individuals identified benefits arising from the performance of physical activity. For example, Jacinta (60 years) reported that walking provided diversion for her and kept her mind off her difficulties. Jack (80 years) commented that dancing at the wellbeing café enabled him to burn off energy that had accumulated over previous days pg. 531 (237)
		12. Expressing identities. (U) (237)	Dancing at the wellbeing cafés provided an opportunity for couples to define their relationship as equal partners rather than care provider and recipient. pg. 533 (237)
		13. Doing it anyway. (C) (237)	At times people were defiant and refused to conform. They could engage in activities and express well-being despite in-congruous music, minimal social support and chaotic environments. pg. 534 (237)
		14. Participants getting to the classes. (C) (229)	When I pulled into her drive I could see her figure behind the door waiting, so she was just ready for me. Carer 1 (son) (229)
	5. Positive Attitudes and Beliefs	15. Attitudes and beliefs – motivated to take part in physical activity. (U) (237)	'My first passion is to get out there and walk! And I mean a real walk. Not from here to town. You know, from here to Bridgeworth and back [a hilly ten-mile round trip]. A really good walk' (Jacinta, 60 years) pg. 528 (237)

		16. It's all coming together. (C) (237)	The combination of a supportive and accepting social and physical environment, recognisable music, familiar activities and a celebratory ambience was particularly successful. pg. 533 (237)
		17. Perceptions. (C) (240)	I was really excited about the program. Always thought it would be of benefit and was really pleased that someone was going to do something for the residents. (care staff 2) (240)
		18. Acceptability. (C) (240)	.. . [care staff] now certainly see...the fact that these people [residents] are occupied for a significant amount of time, so I think there's been that switch, if that makes sense, of 'oh my goodness this is just something else we need to do, to wow doesn't this actually assist us in our day with our residents'. (care staff 6) pg. 8 (240)
		19. Instructional methods – facilitators. (U) (131)	Adaptation of the classes to participants' needs or requests (instructor and researcher). "Tai Chi is about you, this is your Tai Chi (...)everybody has different flexibility, different hips. Please don't worry about looking as anybody else" (Instructor-O). pg. 173 (131)
		20. Positive activity (family members). (C) (238)	P5: 'When they come to visit them, they [residents] don't actually say that they've done the activities. So, it was nice when they [families] came in and got involved in the dancing. They enjoyed and talked about it with their families. pg. 528 (238)
		21. Carer's perspective on the experiences of participants of the intervention. (C) (229)	[He] really, really does enjoy it, yes. I think it's the men all getting together and they just all of them get on with the exercises. It is really good. Carer 11 (wife) (229)
2. People with dementia and their carers experience a wide range of benefits from taking part in physical activity.	6. Psychological benefits.	21. Feeling good. (U) (237)	Many individuals reported experiencing pleasure from engaging in physical activity. pg. 532 (237)
		22. Psychological improvements and benefits. (U) (239)	Other elements of psychological health showed improvements, such as mood, alertness and cognition: "Yeah, I noticed a huge difference in a lot of, a lot of the residents……. Yeah. Their willingness to participate, especially [resident]. [Resident] improved in her behaviour and, and her mood. I mean [she's] a lot happier

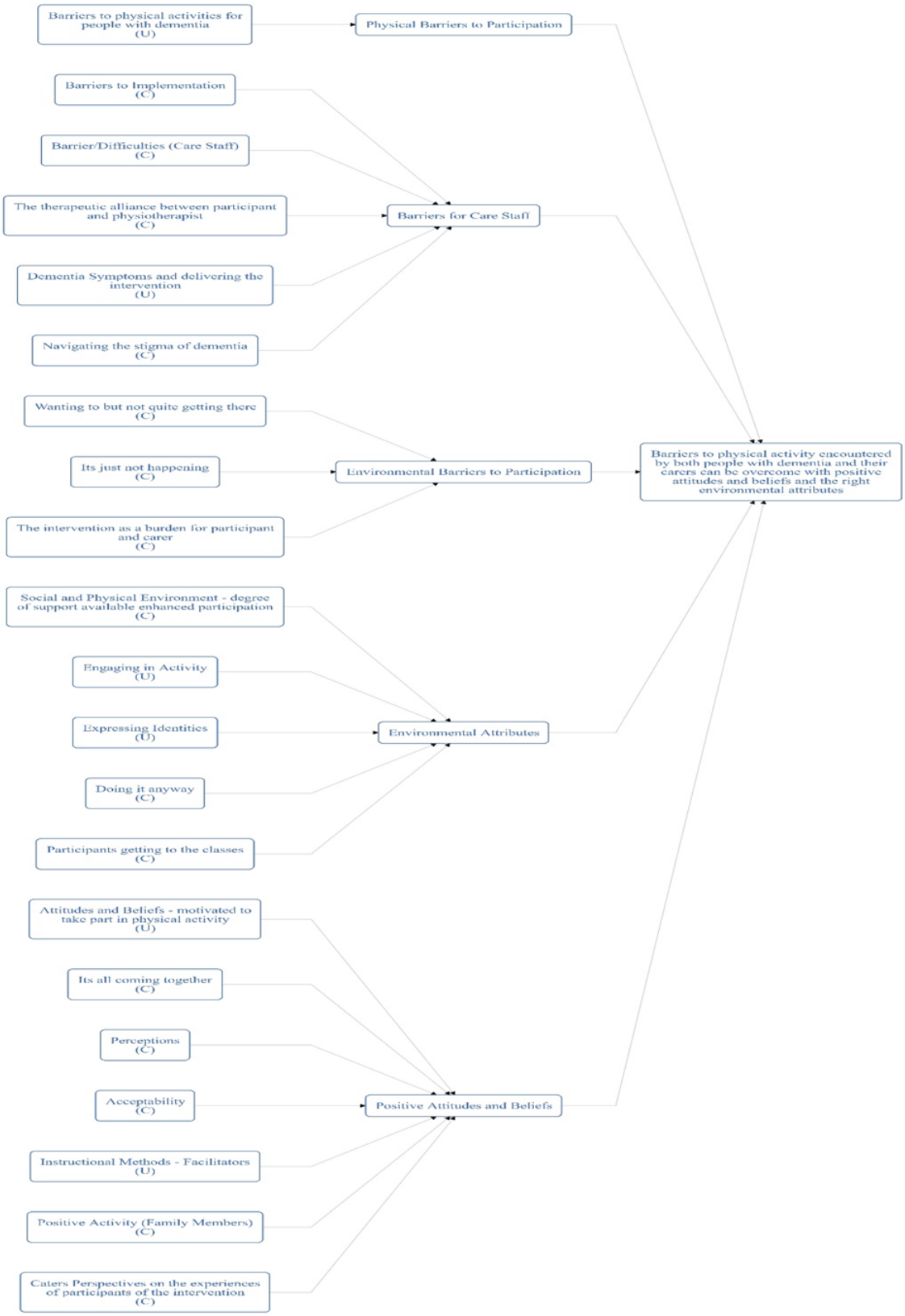
			and, and different. So she's, she's smiling, laughing, willing to hop up. Not so tired or lethargic" (lifestyle and recreational officer, interviewee 9). pg. 14 (239)
		23. Benefits to mood. (PWD) (C) (238)	P7: 'Well, I just can say that if you are feeling miserable and you dance, it cheers you up and that's what I can say about it.' pg. 530 (238)
		24. Benefits to behaviour. (PWD) (C) (238)	P2: 'Mrs A can get agitated; she wants to go into town and stuff. After the dancing, she didn't seem to think about that, she focused more on the dancing' pg. 527 (238)
		25. Reminiscence. (PWD, spectators) (C) (238)	P5: 'I was in the ladies' army, so I did a lot of dancing, fashion dancing, you know, anything, just enjoying ourselves, I enjoyed my life.' pg. 530 (238)
		26. Mental stimulation. (PWD) (C) (238)	P8: 'It definitely tells you that they are learning whatever degree that might be. Maybe a little bit, they might just remember one step, some might remember five you know but that doesn't really matter you can just see that they are trying to take it in.' pg. 527 (238)
		27. Affective states. (PWD, spectators) (C) (238)	P1: 'It was an activity that even though they were not doing it, they still wanted to watch it.' pg. 528 (238)
		28. Participants gain pleasure from exercising. (C) (229)	I'm enjoying it. I'm very tired when I come out because I do 25 minutes on the bike, about 2 miles on the bike. Patient 10 (male) (229)
		29. Little or no change in cognitive function. (C) (229)	I don't know whether it's done my dementia any good but I know now that yes I can lift those heavy weights. Patient 4 (female) (229)
	7. Social benefits.	30. Social improvements and benefits. (U) (239)	Staff participants also reported improvements in social interaction between the individuals that were involved in the physical exercise intervention. "It's actually given them something to look forward to…… Working with a smaller group ……. having that one-on-one I mean even though it's not a one- on-one group but having that more intimate sort of connection" (lifestyle and recreational officer, interviewee 13). pg. 13 (239)
		31. Interactions with others. (C) (131)	Allowing time at the end of the sessions for participants' socialization was perceived as something positive particularly for carers (participants). (131)
		32. Socialising. (C) (238)	P7: 'Having three floors everybody could meet different people. Residents of this floor would not necessarily see the ones upstairs, but in the dancing sessions they were seeing each other and dancing with each other, socialising. pg. 527 (238)
		33. Participants enjoy being with other people. (U) (229)	I think the company of everybody you know. I mean we all had a sit down afterwards and we had a good laugh while we're doing it.

			Patient 12 (male) (229)
	8. Physical benefits.	34. The lived body. (C) (237)	Bodies could act as repositories of embodied skills and abilities that could be employed in the context of physical activity. These included the ability to dance, to maintain a rhythm during activities such as clapping, and to throw and catch objects effectively pg. 530 (237)
		35. Types of physical activities. (U) (237)	The use of music and rhythm could be very effective in facilitating physical activity. This was evidenced by people tapping their feet, twirling their wrists and rocking from side to side. Spontaneous, playful and collaborative activities which included the use of balloons, balls and parachutes also facilitated engagement. At Chellowfont Day Centre where people rarely inter- acted spontaneously with each other, two people with dementia were able to engage with each other using a balloon independent of staff. "Joe (76 years) bounces the balloon on his head before using his knee and then his foot to keep it in the air. Ronald (78 years) takes Joe's lead and bounces it on his knee before kicking it. The balloon passes between them and they both stand up and reach for it at the same time. There is a buzz of excitement in the room." (Fieldnote: Chellowfont Day Centre) pg. 531 (237)
		36. Physical improvements and benefits. (U) (239)	"I've noticed his mobility has increased 'cause it was getting at a point there where he was getting pretty bad where we were having, we were afraid that we weren't gonna be able to get him into the car anymore. And, funnily enough, that's when you started doing the exercises and yeah, sometimes like he gets out of the car before I even get the wheelchair around to him……So his mobility has increased quite substantially like, which is good" (family carer, interviewee 5) pg. 14 (239)
		37. Benefits (physical). (U) (240)	There was one resident that was doing it [the exercise] with her legs and her arms, and we can stand transfer [where the resident is assisted by two care staff to stand and walk] her, and she's meant be a stand transfer. I mean after this program, I've seen this woman get up out of her chair and walk, and I'm like what is she doing? (laughs) (care staff 3) (240)
		38. Mobility. (PWD) (C) (238)	P7: 'You feel good, because you can manage to stretch on as best as you can. I mean some people have to struggle on but they can still manage quite easily, that's it.' pg. 530 (238)
		39.Physical health. (PWD) (C) (238)	P9: 'Because a lot of people are just sitting around they find it harder to empty their bowels. So by doing exercises, it helps them to go to their toilet more and we found that by doing more activities, a lot less people were constipated. Previously a lot of them were on Senna. pg. 527 (238)
		40. Improving physical health and functioning. (C) (229)	I think these classes were very, very good, before I went to them I struggled with my walking . . . I had to have walking sticks and everything. Now I'm walking normally. I don't like to feel that I'm helpless, I don't like

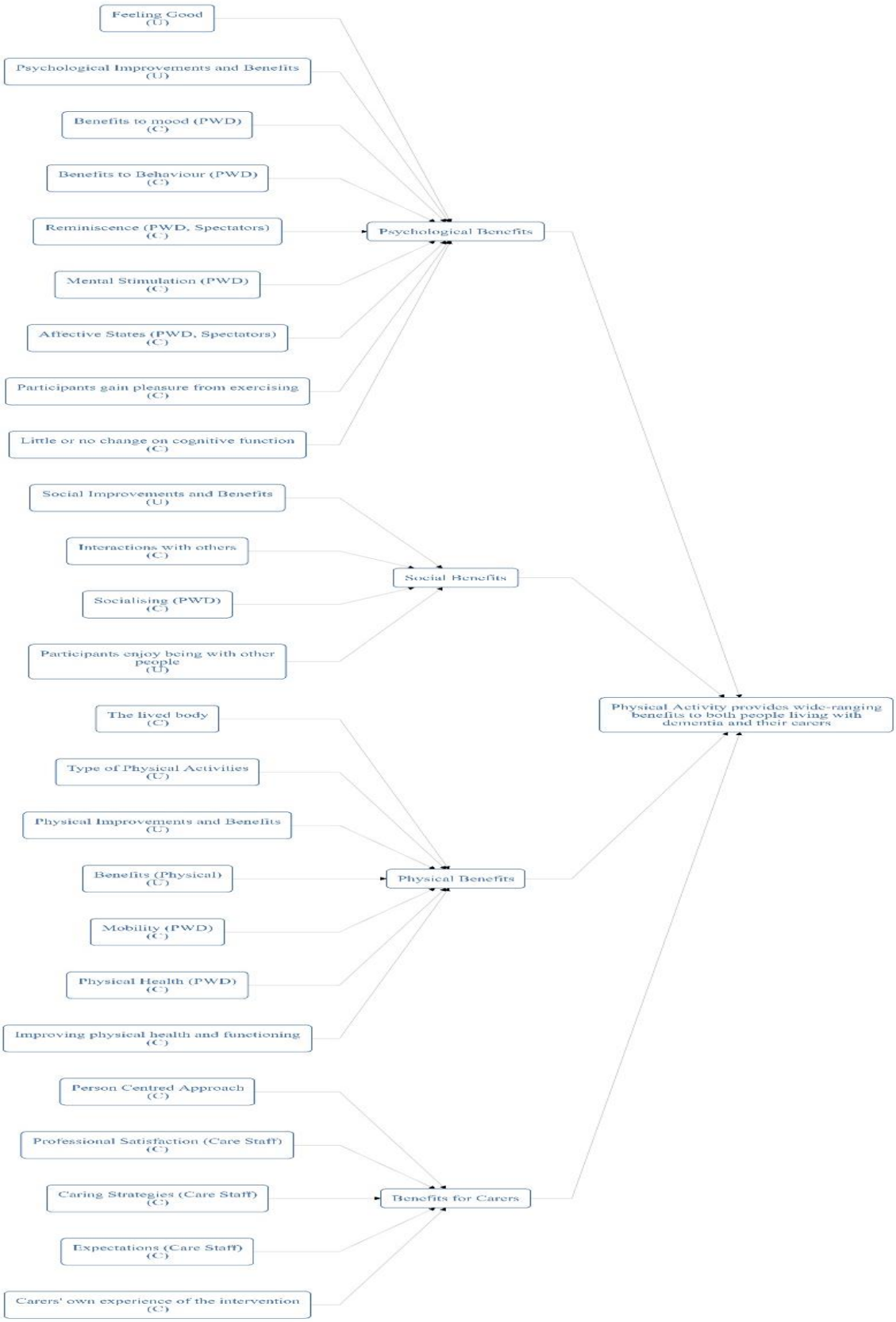
			to feel like . . . a disabled person. People look at you and say 'oh look at that poor old gentleman' . . . I don't want to be old. Patient 12 (male) (229)
	9. Benefits for carers.	41. Person-centred approach. (C) (240)	I mean [resident], she used to ride her bike to work, so she likes that bike thing, they would move their feet and that. She done that once when I was there...and I thought they could give her [resident] a bit more of that bike riding exercise maybe. (family member 5) pg. 9 (240)
		42. Professional satisfaction. (care staff) (C) (238)	P7: 'I think it helped us to build up trust, communication, stuff like.' pg. 528 (238)
		43. Caring strategies. (C) (238)	P8: 'I think that the carers did get a benefit because it gave us a little bit of a break. It gave us time to enjoy the residents, and just have fun and interact with them instead of just doing personal care tasks.' pg. 528 (238)
		44. Expectations. (C) (238)	P8: 'Their balance may have improved, because of the way they are learning the steps. But whatever their activity level in general is better.' pg. 528 (238)
		45. Carer's own experience of the intervention. (C) (229)	I've actually appreciated the opportunity to talk about it [being a carer/dementia] with you know, outside of just friends, that's been quite good for me to be able to talk about it and . . . it has been nice to talk to other carers. Carer 3 (wife) (229)
		46. Expressing identities. (U) (237)	Dancing at the wellbeing cafés provided an opportunity for couples to define their relationship as equal partners rather than care provider and recipient. pg. 533 (237)

Appendix E: Meta-Aggregative Flowcharts

1. *Meta-Aggregative Overview Flowchart Synthesized Finding One*



2. Meta-Aggregative Overview Flowchart Synthesized Finding Two



Appendix F: Ethical Approval

University of Nottingham
UK | CHINA | MALAYSIA

Email: FMHS-ResearchEthics@nottingham.ac.uk

Faculty of Medicine & Health Sciences
Research Ethics Committee
c/o Faculty PVC Office
School of Medicine Education Centre
B Floor, Medical School
Queen's Medical Centre Campus
Nottingham University Hospitals
Nottingham, NG7 2UH

15 February 2019

Mrs Anabelle Long
Research Assistant-PrAISED Study
Division of Rehabilitation, Aging and Wellbeing
B109, Medical School
QMC Campus
Nottingham University Hospitals
Nottingham, NG7 2UH

Dear Anabelle

Ethics Reference No: 203-1902 – **please always quote**	
Study Title: An Impact Evaluation of a Dementia-Friendly Exercise Class	
Chief Investigator/Supervisor: Dr Veronika van der Wardt, Assistant Professor, Division of Rehabilitation, Ageing and Wellbeing, School of Medicine.	
Lead Investigators/student: Anabelle Long, Research Assistant	
Other Key Investigators: Dr Victoria Booth, Research Associate, Mrs Louise Howe, Research Assistant, Division of Rehabilitation, Ageing and Wellbeing, School of Medicine	
Proposed Start Date: 01/02/2019	**Proposed End Date:** 31/08/2019

The Committee considered this application by electronic meeting on 22 January 2019 and the following documents were received:

- FMHS REC Application form and supporting documents version 1.0: 07/01/2019

These have been reviewed and are satisfactory and the study has been given a favourable opinion.

A favourable opinion has been given on the understanding that:

1. The protocol agreed is followed and the Committee is informed of any changes using a notice of amendment form (please request a form).
2. The Chair is informed of any serious or unexpected event.
3. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely

Professor Ravi Mahajan
Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

Appendix G: Participant Information Sheet

Participant Information Sheet
Final version 1.0: 07/01/19

Title of Study: An Impact Evaluation of a Dementia-Friendly Exercise Class

Name of Chief Investigator: Dr Veronika van der Wardt
Local Researcher: Mrs Annabelle Long, Dr Vicky Booth, Mrs Louise Howe

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

Exercise has multiple benefits but in people with mild cognitive impairment (MCI) or dementia, physical activity has also been shown to improve activities of daily living, behavioural problems, mood and the risk of falls. Group exercise can support people taking part and continuing with exercise, as being involved with a group can reduce social isolation and loneliness.

This study is looking to evaluate the impact of the group exercise programme for people with dementia and their family carers established by the University of Nottingham in 2017. We propose to explore what benefits people feel they have gained from attending the exercise group as well as the impact of the exercise on mobility, physical activity levels, independence, loneliness, mood, well-being and quality of life.

Why have I been invited?

You are being invited to take part because you currently attend these exercise sessions. We are inviting up to 40 participants like you to take part in this study. This will involve you completing some assessments and questionnaires to help us understand what benefits people may gain from attending these exercise sessions. You may also be asked to take part in a focus group to help us further understand how you feel you have benefited from taking part in the exercise sessions.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?

If you take part in the study a researcher will complete some physical assessments with you during your normal exercise class. They will then ask you to complete some questionnaires either at the end of the class or at a later prearranged appointment at a location convenient to you. After 3 months the researcher will complete the assessments and questionnaires with you again during and after the exercise session.

Following these assessments you may be asked to take part in a focus group. If you take part in the focus group this will last between 45 and 60 minutes, involve up to 10 people altogether and will take place at the University of Nottingham. You will be invited to discuss your experience of the exercise class and your perceptions of the impact that the exercise class has had on your life as a whole.

It will be audio-recorded using a digital recorder, and then later written up. Any details that would enable you to be identified will be removed.

Expenses and payments

You will not be paid to participate in the study. Light refreshments will be offered after the exercise session to provide participants with the opportunity to complete the questionnaires following the session if they wish. A voucher to purchase light refreshments from the local coffee shop will also be given to all participants who return their questionnaires. Travel expenses will be offered to those people who take part in the focus groups to enable them to travel to the University to attend.

What are the possible disadvantages and risks of taking part?

Taking part in this study will mean that you will have to put aside time from other commitments.

There is also a chance you may feel uncomfortable about answering specific questions. You do not have to answer questions that make you feel uncomfortable.

What are the possible benefits of taking part?

We cannot promise the study will help you, but the information we get will help us evaluate the benefits that are being provided by this class. This may well help inform further research into the benefits of exercise and what needs to be in place for people like you to enjoy and benefit from exercise classes like this in the future.

We also hope that you will enjoy meeting and talking to our researchers and contributing to this valuable work.

What happens when the research study stops?

We will let you know when the study stops and we no longer need any more of your time.

Once the study has been completed and the data analysed we would like to share our findings with you. If you would like us to continue to contact you after your participation has ended you can let us know and we will continue to keep your contact details for this purpose.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting the FMHS Research Ethics Committee Administrator, c/o The University of Nottingham, Faculty PVC Office, B Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: FMHS-ResearchEthics@nottingham.ac.uk
Please quote ref no: FMHS REC ref no:xxxxxxxx
In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham but you may have to pay your legal costs.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty. Quotations from the focus group may be used when we write academic reports about the study and when we present findings at conferences. We will be careful to change your name so that your quotes will not be identified.

All information collected from you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

Any information about you which leaves the university will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Your contact information will be kept by the University of Nottingham for 12 months after the end of the study so that we are able to contact you about the findings of the study and possible follow up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible.

What will happen to the results of the research study?

All data including anonymised transcripts will be stored at the University of Nottingham either in a secure office, and locked in a filing cabinet or held on a secure computer drive in keeping with University's information governance protocols. When the study has ended this data will then be analysed by the study team electronically. Quotations may be shared when we write reports on our findings and when we present these at conferences. However, all identifiable information will be removed.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by the University of Nottingham.

Who has reviewed the study?

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Faculty of Medicine & Health Sciences (FMHS) Research Ethics Committee.

Further information and contact details

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Appendix H: Consent Form

University of Nottingham
UK | CHINA | MALAYSIA

CONSENT FORM
Final version 1.0: 07/01/19

Title of Study: An Impact Evaluation of a Dementia-Friendly Exercise Class

Name of Researcher:……

Name of Participant:…… **Please initial box**

1. I confirm that I have read and understand the information sheet version number 1.0 dated 7th January 2019 for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐
3. I understand that relevant sections of my medical notes and data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that the focus group will be recorded and that anonymous direct quotes from the focus group may be used in the study reports. ☐
5. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐
6. I confirm that I would like to be kept informed about the progress of the study and understand that my contact details will be kept by the researchers for this purpose. ☐
7. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

2 copies: 1 for participant and 1 for the project notes

Appendix I: Berg Balance Scale

Participant ID: _ _ _ _

Berg Balance

A chair of reasonable height and depth (e.g. dining room chair) with arms and a back rest should be used, unless otherwise specified.

Regardless of feeling like supervision is needed or not, you should try to keep close to the participant at all times, in case assistance is required.

All tasks should be done in front of a chair, but not leaning on it, so that if the participant needs to, they are able to step back and drop into the chair.

During timed tasks, encourage the participant by telling them how long there is left (e.g. half way. 10 second count down etc.)

Scoring guidance:

Tick one box per task

If you are unsure where the participant should score between two options, *select the lower option.*

If your assistance is required to prevent the participant from falling, this would mean they are *unable to complete the task.*

If you feel as though you need to be close to the participant to prevent them from falling, but your assistance has not been required, this is considered *supervision.*

Sitting to Standing

Please stand up. Try not to use your hand for support.

- 4 Able to stand without using hands and stabilize independently.
- 3 Able to stand independently using hands.
- 2 Able to stand using hands after several tries.
- 1 Needs minimal aid to stand or stabilize.
- 0 Needs moderate or maximal assistance to stand

Standing unsupported.

Now I would like you to stand for two minutes without holding on to anything.

4 Able to stand safely for 2 minutes. → *(Score full points for sitting unsupported on 0. and proceed to item **Error! Reference source not found.**.)*

3 Able to stand 2 minutes with supervision.

2 Able to stand 30 seconds unsupported.

1 Needs several tries to stand 30 seconds unsupported.

0 Unable to stand 30 seconds unsupported.

Sitting with back unsupported, but feet supported on floor or on a stool.

Please sit with your arms folded for 2 minutes. *If the participant leans backwards, ask them to sit forward without leaning back.*

4 Able to sit safely and securely for 2 minutes.

3 Able to sit 2 minutes under supervision.

2 Able to sit 30 seconds.

1 Able to sit 10 seconds.

0 Unable to sit without support 10 seconds.

Standing to sitting

If task 0. was completed: **Please stand up. Now please sit down.**
If task 0. was skipped: **Please sit down.**

4 Sits safely with minimal use of hands.

3 Controls descent by using hands.

2 Uses back of legs against chair to control descent.

1 Sits independently but has uncontrolled descent.

0 Needs assistance to sit.

Participant ID: _ _ _ _

Transfer

Arrange 2 chairs at right angles to one another for pivot transfer. Ask participant to transfer one way toward a seat with armrests and one way towards a seat without armrests. **Could you please come and sit here** *pat chair you are referring to. You may use two chairs (one with and one without armrests) or a bed and a chair if needed.*

- 4 Able to transfer safely with minor use of hands.
- 3 Able to transfer safely definite need of hands.
- 2 Able to transfer with verbal cuing and /or supervision.
- 1 Needs one person to assist.
- 0 Needs two people to assist or supervise to be safe.

Standing unsupported with eyes closed

Please close your eyes and stand still for 10 seconds.

- 4 Able to stand 10 seconds safely.
- 3 Able to stand 10 seconds with supervision.
- 2 Able to stand 3 seconds.
- 1 Unable to keep eyes closed 3 seconds but stays safely.
- 0 Needs help to keep from falling.

Participant ID: _ _ _ _

Standing unsupported with feet together

Place your feet together and stand without holding on to anything.

4 Able to place feet together independently and stand 1 minute safely.

3 Able to place feet together independently and stand 1 minute with supervision.

2 Able to place feet together independently but unable to hold for 30 seconds

1 Needs help to attain position but able to stand 15 seconds feet together.

0 Needs help to attain position and unable to hold for 15 seconds.

Reaching forward with out-stretched arm while standing.

Please lift your arms to 90 degrees. *Place the laminated measure at the end of fingertips when arm is at 90 degrees.* **Stretch out your fingers and reach forward as far as you can.**

Fingers should not touch the measure while reaching forward. The recorded measure is the distance forward that the fingers reach while the subject is in the most forward lean position. When possible, ask subject to use both arms when reaching to avoid rotation of the trunk.

4 Can reach forward confidently 25 cm (10 inches).

3 Can reach forward 12 cm (5 inches).

2 Can reach forward 5 cm (2 inches).

1 Reaches forward but needs supervision.

0 Loses balance while trying/requires external support.

Participant ID: _ _ _ _

Pick up object from the floor from a standing position

Please pick up the stopwatch, which is in front of your feet.

4 Able to pick up stopwatch safely and easily.

3 Able to pick up stopwatch but needs supervision.

2 Unable to pick up stopwatch, but reaches 2-5 cm (1-2 inches) from stopwatch and keeps balance independently.

1 Unable to pick up stopwatch and needs supervision while trying.

0 Unable to try/needs assistance to keep from losing balance or falling.

Turning to look behind over left and right shoulders while standing.

Turn to look directly behind you over your left shoulder. Now do the same over your right shoulder. *Researcher may pick an object to look at directly behind the subject to encourage a better twist turn.*

4 Looks behind from both sides and weight shifts well.

3 Looks behind one side only other side shows less weight shift.

2 Turns sideways only but maintains balance.

1 Needs supervision when turning.

0 Needs assistance to keep from losing balance or falling.

Turn 360 degrees

Participant ID: _ _ _ _

Turn completely around in a full circle. Pause. Then turn a full circle in the other direction.

4 Able to turn 360 degrees safely, in both directions. Each turn is complete in 4 seconds or less.

3 Able to turn 360 degrees safely. Only one turn is complete in 4 seconds or less.

2 Able to turn 360 degrees safely but slowly. (each turn takes more than 4 seconds)

1 Needs close supervision or verbal cueing.

0 Needs assistance while turning.

Place alternate foot on step or stool while standing unsupported

Place each foot alternately on the step/stool. Continue until each foot has touched the step/stool four times. Do this with the participant to demonstrate

4 Able to stand independently and safely and complete 8 steps in 20 seconds

3 Able to stand independently and complete 8 steps in > 20 seconds.

2 Able to complete 4 steps without aid with supervision.

1 Able to complete >2 steps needs minimal assistance.

0 Needs assistance to keep from falling/unable to try.

Participant ID: _ _ _ _

Standing unsupported one foot in front

Demonstrate to participant. **Place one foot directly in front of the other. If you feel that you cannot place your foot directly in front, try to step far enough ahead that the heel of your forward foot is ahead of the toes of the other foot.**

4 Able to place foot tandem independently and hold 30 seconds.

3 Able to place foot ahead independently and hold 30 seconds.

2 Able to take small step independently and hold 30 seconds. (The length of the step exceeds the length of the other foot and width of stance is approximately participant's normal stride width)

1 Needs help to step but can hold 15 seconds.

0 Loses balance without stepping or standing.

Standing on one leg

Stand on one leg as long as you can without holding on. Count down ten seconds

4 Able to lift leg independently and hold >10 seconds.

3 Able to lift leg independently and hold 5-10 seconds.

2 Able to lift leg independently and hold ≥3 seconds.

1 Tries to lift leg unable to hold 3 seconds but remains standing independently.

0 Unable to try or needs assistance to prevent fall.

Appendix J: Timed up and Go

Participant ID: _ _ _ _

Timed Up and Go (TUG)

Measure 3 metre walkway, and mark the end of the 3m walkway with masking tape.
Place a standard height chair (ideally a chair with arms that is not very low or deep, such as a dining room chair) at the beginning of the walk way.
When doing the task, walk alongside the participant if you feel you need to.
If the participant would normally use an aid to walk, they should use this.

Time from when you say go to when the participant's bottom touches the seat.

Standard TUG

"When I ask, please stand up, walk around the marker, and return to sitting. I would like you to walk at a comfortable speed using any equipment you would normally use. I will be timing you and will start when I say 'go' and stop when your bottom is back on the chair. Ready? Off you GO."

TUG practice: ☐ (sec)

TUG Trial: ☐ (sec)

Record how the TUG was completed:

1 Unaided
2 Researcher supervision (i.e. felt necessary to walk alongside them to ensure safety.)
3 With mobility aid (*describe which aid*: ……)
4 Tried but unable to complete
5 Refused

Appendix K: Hopkins Verbal Learning Test (HVLT)

Participant ID: _ _ _ _

Hopkins Verbal Learning Test

Form 1: four-legged animals, precious stones, human dwellings

Part A: Free Recall

Now I am going to read a list of 12 words to you and I would like you to try to remember them. Listen carefully and when I have finished tell me as many words as you can remember. It doesn't matter what order you say them in.

Read the list of words below at a rate of one word every 2 seconds
Record word recalled in Trial 2

	Trial 1	Trial 2	Trial 3
Emerald			
Horse			
Tent			
Sapphire			
Hotel			
Cave			
Opal			
Tiger			
Pearl			
Cow			
Hut			
Lion			
No. Correct			

Now I am going to read the same list for a second time and I would like you to remember and tell me as many words as you can, including the words you said first time.

Read the list of words again at a rate of one word every 2 seconds
Record words recalled in Trial 2

Now I am going to read the same list for a third time and I would like you to remember and tell me as many words as you can, including any words you have said before.

Read the list of words again at a rate of one word every 2 seconds
Record words recalled in Trial 3

Participant ID: _ _ _ _

Part B: Recognition

Now I am going to read you a list of 24 words and I would like you to say "Yes" if you hear any words that you heard on the previous test and "No" if you did not hear them previously.

Read the list of words below at a rate of one word every 2 seconds

HORSE	**ruby***	**CAVE**	**balloon**	**coffee**	**LION**
house*	**OPAL**	**TIGER**	**boat**	**scarf**	**PEARL**
HUT	**EMERALD**	**SAPPHIRE**	**dog***	**apartment***	**penny**
TENT	**mountain**	**cat***	**HOTEL**	**COW**	**diamond***

12 of these words were on the list and 12 were not (distractors). Half of the distractors are from the same semantic categories as the targets (related distractors) and half are drawn from other categories (unrelated distractors)

No. True Positives:_____/12

No False-Positive Errors: Related:_____/6

Unrelated:_____/6

Discrimination Index: (no. true-positives) – (no. false-positives) = _____

Appendix L: LASA Physical Activities Questionnaire (LAPAQ)

Participant ID: _ _ _ _

LAPAQ

Do you walk outside (excluding walking for leisure/ exercise)**?**
By walking outside we mean walking to go shopping or doing other daily activities, like visiting someone. We do not mean: walking for leisure or exercise

☐ Yes ☐ No (go to question 0)

Did you walk during the past two weeks?

☐ Yes ☐ No (go to question 0)

How many times did you walk during the past two weeks?

☐ times

How long did you usually walk each time?

☐ hours ☐ minutes

Do you cycle (excluding cycling for leisure/ exercise)**?**
By cycling we mean cycling to go shopping or doing other daily activities, like visiting someone. We do not mean: cycling for leisure or exercise.

☐ Yes ☐ No (go to question 0)

Did you cycle during the past two weeks?

☐ Yes ☐ No (go to question 0)

How many times did you cycle the past two weeks?

☐ times

How long did you usually cycle each time?

☐ hours ☐ minutes

Participant ID: _ _ _ _

Do you have a garden (or allotment)?

☐ Yes ☐ No (go to question 0)

During how many months per year do you work regularly in the garden (or allotment)?
By regularly we mean at least once a week.

☐ months

Did you work in the garden during the past two weeks?

☐ Yes ☐ No (go to question 0)

How many times did you work in the garden during the past two weeks?

☐ times

How long did you usually work in the garden each time?

☐ hours ☐ minutes

Did you dig in the earth in the garden during the past two weeks?

☐ Yes ☐ No

Participant ID: _ _ _ _

Did you do any sports in the past two weeks?
By sports we mean activities such as those on the list below (see question 0).

☐ Yes ☐ No (go to question 0)

Which sport did you do for the <u>most time</u> during the past two weeks?
Sometimes it happens that a respondent does a sport, which is not on the list. This should be recorded in 'other'.

☐ Distance walking	☐ Rowing
☐ Distance cycling	☐ Sailing
☐ Going to the gym	☐ Playing billiards (pool / snooker)
☐ Swimming	☐ Fishing
☐ Cycling on an exercise bike	☐ Playing soccer (football)/ basketball/ hockey
☐ Dancing	☐ Exercise Class
☐ Bowling	☐ Other, please describe:
☐ Tennis / badminton	……
☐ Running / fast walking	……

How many times did you do this sport during the past two weeks?

☐ times

How long did you usually do this sport each time?

☐ hours ☐ minutes

Participant ID: _ _ _ _

Did you do another sport in the past two weeks?

☐ Yes ☐ No (go to question 0)

Which other sport did you do during the past two weeks? *(choose the activity that the you did for the most time, except the activity already recorded above)*

☐ Distance walking	☐ Rowing
☐ Distance cycling	☐ Sailing
☐ Going to the gym	☐ Playing billiards (pool / snooker)
☐ Swimming	☐ Fishing
☐ Cycling on an exercise bike	☐ Playing soccer (football)/ basketball/ hockey
☐ Dancing	☐ Exercise Class
☐ Bowling	☐ Other, please describe:
☐ Tennis / badminton	……
☐ Running / fast walking	……

How many times did you do this sport during the past two weeks?

☐ times

How long did you usually do this sport each time?

☐ hours ☐ minutes

How many times did you perspire while sporting during the past two weeks?

☐ times

Participant ID: _ _ _ _

Do you do light household tasks?

By light household tasks we mean washing the dishes, dusting, making the bed, doing the laundry, hanging out the laundry, ironing, tidying up, and cooking meals.

☐ Yes ☐ No (go to question 0)

How many days did you do light household tasks during the past two weeks?

☐ days

How long per day did you usually do light household tasks?

☐ hours ☐ minutes

Do you do heavy household tasks?

By heavy household tasks we mean window cleaning, changing the bed, beating the mat, vacuuming, washing or scrubbing the floor, and chores with sawing, carpeting, repairing or painting.

☐ Yes ☐ No (go to question 0)

How many days did you do heavy household tasks during the past two weeks?

☐ days

How long per day did you they usually do heavy household tasks?

☐ hours ☐ minutes

Participant ID: _ _ _ _

You just told me about [the participant's] usual activities of the past two weeks. Were the past two weeks normal as compared to the rest of the past year?

☐ Yes (end of questionnaire) ☐ No (go to question 0)

Why were the past two weeks not normal?

i. Disease	☐ Yes	☐ No
ii. Depression	☐ Yes	☐ No
iii. Bad weather	☐ Yes	☐ No
iv. Family Occasion	☐ Yes	☐ No
v. Holiday	☐ Yes	☐ No
vi. Other, *please specify:*	☐ Yes	☐ No

……

Appendix M: Nottingham Extended ADL Scale (NEADL)

Participant ID: _ _ _ _

Nottingham extended ADL scale

The following questions are about everyday activities. Please answer by selecting one option for each question. Please tell us about what you have actually done in the last few weeks (e.g. last three to four weeks).

(circle one answer for each question)

Did you...	Not at all (0)	With help (1)	On your own with difficulty (2)	On your own (3)
Walk around outside?	0	1	2	3
Climb stairs?	0	1	2	3
Get in and out of a car?	0	1	2	3
Walk over uneven ground?	0	1	2	3
Cross roads?	0	1	2	3
Travel on public transport?	0	1	2	3
Feed yourself?	0	1	2	3
Did you...	**Not at all (0)**	**With help (1)**	**On your own with difficulty (2)**	**On your own (3)**
Make yourself a hot drink?	0	1	2	3
Take hot drinks from one room to another?	0	1	2	3
Do the washing up?	0	1	2	3
Make yourself a hot snack?	0	1	2	3
Manage your own money when out?	0	1	2	3

Participant ID: _ _ _ _

Did you...	Not at all (0)	With help (1)	On your own with difficulty (2)	On your own (3)
Wash small items of clothing?	0	1	2	3
Do your own housework?	0	1	2	3
Do your own shopping?	0	1	2	3
Do a full clothes wash?	0	1	2	3
Did you...	**Not at all (0)**	**With help (1)**	**On your own with difficulty (2)**	**On your own (3)**
Read newspapers or books?	0	1	2	3
Use the telephone?	0	1	2	3
Write letters or emails?	0	1	2	3
Go out socially?	0	1	2	3
Manage your own garden?	0	1	2	3
Drive a car?	0	1	2	3

Appendix N: UCLA Loneliness Scale

Participant ID: _ _ _ _

UCLA Loneliness Scale

The following statements describe how people sometimes feel. For each statement, please indicate how often you feel the way described by circling one of the responses below. Here is an example:

How often do you feel happy?

If you never felt happy, you would respond "never"; if you always feel happy, you would respond "always."

1. How often do you feel that you are "in tune" with the people around you?

Never Rarely Sometimes Always

2. How often do you feel that you lack companionship?

Never Rarely Sometimes Always

3. How often do you feel that there is no one you can turn to?

Never Rarely Sometimes Always

4. How often do you feel alone?

Never Rarely Sometimes Always

5. How often do you feel part of a group of friends?

Never Rarely Sometimes Always

6. How often do you feel that you have a lot in common with the people around you?

Never Rarely Sometimes Always

7. How often do you feel that you are no longer close to anyone?

Never Rarely Sometimes Always

8. How often do you feel that your interests and ideas are not shared by those around you?

Never Rarely Sometimes Always

9. How often do you feel outgoing and friendly?

Never Rarely Sometimes Always

10. How often do you feel close to people?

Never Rarely Sometimes Always

11. How often do you feel left out?

Never Rarely Sometimes Always

12. How often do you feel that your relationships with others are not meaningful?

Never Rarely Sometimes Always

13. How often do you feel that no one really knows you well?

Never Rarely Sometimes Always

14. How often do you feel isolated from others?

Never Rarely Sometimes Always

15. How often do you feel that you can find companionship when you want it?

Never Rarely Sometimes Always

16. How often do you feel that there are people who really understand you?

Never Rarely Sometimes Always

17. How often do you feel shy?

Never Rarely Sometimes Always

18. How often do you feel that people are around you but not with you?

Never Rarely Sometimes Always

19. How often do you feel that there are people you can talk to?

Never Rarely Sometimes Always

20. How often do you feel that there are people you can turn to?

Never Rarely Sometimes Always

End of questionnaire

Thank you

Appendix O: Hospital Anxiety and Depression Scale (HADS)

Participant ID: _ _ _ _

HADS

To be completed by participant, or with the researcher if the participant prefers.

Please read each statement and tick the reply that comes closest to how you have been feeling the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

I feel tense or 'wound up':

- ☐ Most of the time
- ☐ A lot of the time
- ☐ Time to time, occasionally
- ☐ Not at all

I feel as if I am slowed down:

- ☐ Nearly all the time
- ☐ Very often
- ☐ Sometimes
- ☐ Not at all

I still enjoy the things I used to enjoy:

- ☐ Definitely as much
- ☐ Not quite so much
- ☐ Only a little
- ☐ Not at all

I get a sort of frightened feeling like 'butterflies in my stomach':

- ☐ Not at all
- ☐ Occasionally
- ☐ Quite often
- ☐ Very often

Participant ID: _ _ _ _

I get a sort of frightened feeling like something awful is about to happen:

- ☐ Very definitely and quite badly
- ☐ Yes, but not too badly
- ☐ A little, but it doesn't worry me
- ☐ Not at all

I have lost interest in my appearance:

- ☐ Definitely
- ☐ I don't take as much care as I should
- ☐ I may not take quite as much care
- ☐ I take just as much care as ever

I can laugh and see the funny side of things:

- ☐ As much as I always could
- ☐ Not quite so much now
- ☐ Definitely not so much now
- ☐ Not at all

I feel restless as if I have to be on the move:

- ☐ Very much indeed
- ☐ Quite a lot
- ☐ Not very much
- ☐ Not at all

Worrying thoughts go through my mind:

- ☐ A great deal of the time
- ☐ A lot of the time
- ☐ From time to time but not too often
- ☐ Only occasionally

Participant ID: _ _ _ _

I look forward with enjoyment to things:
☐ As much as I ever did
☐ Rather less than I used to
☐ Definitely less than I used to
☐ Hardly at all
I feel cheerful:
☐ Not at all
☐ Not often
☐ Sometimes
☐ Most of the time
I get sudden feelings of panic:
☐ Very often indeed
☐ Quite often
☐ Not very often
☐ Not at all
I can sit at ease and feel relaxed:
☐ Definitely
☐ Usually
☐ Not often
☐ Not at all
I can enjoy a good book or radio or TV programme:
☐ Often
☐ Sometimes
☐ Not often
☐ Very seldom

Appendix P: Dementia Quality of Life Scale (DemQoL)

Participant ID: _ _ _ _

DEMQOL

Now I would like to ask about how you find life at present. *(Give prompt card).*
Look at the card to choose which answer best describes how you feel (even if it is not exact).

First, I'm going to ask you about your feelings.

In the last seven days, have you felt ...

	A lot	Quite a bit	A little	Not at all
...Cheerful?**	*4*	*3*	*2*	*1*
...Worried or anxious?	1	2	3	4
...That you are enjoying life? **	*4*	*3*	*2*	*1*
...Frustrated?	1	2	3	4
...Confident?**	*4*	*3*	*2*	*1*
...Full of energy?**	*4*	*3*	*2*	*1*
	A lot	**Quite a bit**	**A little**	**Not at all**
...Sad?	1	2	3	4
...Lonely?	1	2	3	4
...Distressed?	1	2	3	4
...Lively? **	*4*	*3*	*2*	*1*
...Irritable?	1	2	3	4
...Fed-up?	1	2	3	4
...That there are things that you wanted to do but couldn't?	1	2	3	4

Participant ID: _ _ _ _

Now, I'm going to ask you about your memory. In the last seven days, how *worried* have you been about...	A lot	Quite a bit	A little	Not at all
...Forgetting things that happened recently?	1	2	3	4
...Forgetting who people are?	1	2	3	4
...Forgetting what day it is?	1	2	3	4
...Your thoughts being muddled?	1	2	3	4
...Difficulty making decisions?	1	2	3	4
...Poor concentration?	1	2	3	4

Now, I'm going to ask you about your everyday life. In the last seven days, how *worried* have you been about...	A lot	Quite a bit	A little	Not at all
...Not having enough company?	1	2	3	4
...How you get on with people close to you?	1	2	3	4
...Getting the affection you want?	1	2	3	4
...People not listening to you?	1	2	3	4
...Making yourself understood?	1	2	3	4
...Getting help when you need it?	1	2	3	4
...Getting to the toilet in time?	1	2	3	4
...How you feel in yourself?	1	2	3	4
...Your health overall?	1	2	3	4

Participant ID: _ _ _ _

We've already talked about lots of things: your feelings, memory and everyday life. Thinking about all of these things <u>in the last seven days</u>, how would you rate ... *(use prompt card)*				
	Very good	Good	Fair	Poor
Your quality of life overall? **	*4*	*3*	*2*	*1*

Appendix Q: Focus Group Topic Guide

Focus Group Topic Guide

Prior to the focus group starting

- Check participants have all read the information sheet, signed the consent form and are still happy to take part. Answer any questions and reiterate that involvement is optional and they can change their mind at any point.
- Ensure that all participants are still aware that the focus group will be audio recorded and that they are still happy with that.

Explain to the group:

- That everyone's view is valid and that there is no right or wrong answer.
- Discussion needs to be grounded in mutual respect and people should be given the chance to express their views without interruptions and the importance of listening.
- That everything said in the focus group should remain confidential and if they talk to other people about the discussion people should not be identifiable.
- The audio recording of the discussion will be securely stored at University of Nottingham and all participants will be anonymised in any reports or publications that arise from the research.
- Participants are free to withdraw at any time and can leave the discussion at any point
- The discussion will last between 45 and 60 minutes
- It is fine to ask questions or take a break if needed.

Topic 1

What motivated you to attend this class?

(physical health, mental health, something to do, social aspect?)

- What makes is suitable for you
- Does is help that it is something that you could do together as opposed to something specifically for the person with dementia

Topic 2

Why do you continue to attend?

- Do you think that attending the class may help you progress back to things that you have had to stop doing?
- What particularly are you enjoying about the exercise class
- Would it be helpful if the exercises changed every so often?
- Specifically ask people with dementia what it is they enjoy (if they haven't answered)
- Do you tend to talk to the same people during the class
- Do you tend to go for coffee afterwards? If yes do you tend to talk to the same people then?
- Do you find chatting to people afterwards useful/helpful?

Topic 3

How has attending these classes influenced or affected your life?

(prompts – has is led to any changes e.g. physical health, mental health, independence, confidence, social??)

- Any further activities attended? Did they stem from attending this class?
- Did attending this class give you more confidence to attend other activities/events? Why?

Topic 4

Do you think that classes like this would be beneficial other people living with dementia and/or the people who support them?

- Do you think it would be useful for other people with dementia to have access to classes like this
- Would you attend a class for older people if it wasn't marketed as dementia-friendly? If not why not? Why is that important?
- What makes it more comfortable for you to attend a class that is marketed/labelled as dementia friendly?
- Do you think it is important that you could attend together?
- Would you now feel more comfortable attending a class that wasn't labelled as dementia friendly?

What exercises have you found to be most useful/enjoyable?

- Has anything been useful with your day to day activities
- Do you think that there is a reason why those exercises haven't transferred to everyday tasks?

Topic 5

What do you think needs to be in place to allow other people with memory problems and/or the people who support them to attend a class such as this?

(prompts - facilities, environment, instructors??)

- If you could design at ideal class what would you put in place to enable people to attend
- Is it helpful to have the extra staff/students to help with the class flow

- Why did having the University of Nottingham banding encourage you to attend the class

Does anyone have anything else to add on what we have discussed today?

At the end of the focus group

- Thank all the participants for their contribution
- Explain what will happen now – transcribing, analysis, writing up the study.
- Ask if they would like to know the findings of the study and that you would be happy to come back and tell them what happened and what may happen next
- Check if anyone has any particular questions or concerns
- Stop the recording

Appendix R: Code Book

Code	Definition	Example
Able to attend together	Carer and PWD able to attend together	*It would be something we could both enjoy.*
Activity Transfer	Whether exercises were being transferred to everyday activities or not	*I think the step, the one where you step up and down, I think that's helpful to keep my mum going up and down the stairs, so that's good.*
Benefit of volunteers	Benefit of having extra volunteers for class	*And the volunteers are wonderful. Of course.*
Benefit of exercise	Benefits of exercise in general	*Any amount of extra exercise is good for everybody.*
Benefits of experience	Benefit of the overall experience of the class	*It's just the whole package really.*
Changes in support network	Changes in support network since diagnosis	*I'm amazed at some people we were very friendly with, we never see them, gone.*
Class adaptable	Able to adapt exercises to own physical capability	*You can do as much or as little as you like…it's adaptable.*
Coffee	Availability of coffee afterwards	*We go for coffee afterwards to make the whole thing last a bit longer.*
Continuing/Returning to previous activities	Whether exercise was helping people continue with previous activities or allowed them to return to activities they may have stopped	*We've done this sort of thing, like waking for years and so on. And yeah so it's carrying on.*
Dealing with Diagnosis	Being able to deal with the specific diagnosis of dementia.	*With the diagnosis it can be a relief. It was a relief.*
Dementia Friendly Label	Class is specifically advertised as being for people living with dementia	*I wouldn't think of taking my mum to any class unless it said it was specifically for dementia.*
Difficulties being a carer	Difficulties of caring for someone living with dementia	*It's so important for the carers as well as the people with the problem, and I do enjoy a bit of free time on my own.*
Enjoyment of exercise	Enjoying the exercise itself	*I quite like exercise*
Environmental factors	Factors that were specific to this class environment	*The space…and the light as well.*
Fatigue	Lack of sleep and fatigue as a carer	*And lack of sleep, it distorts everything.*

Finding out useful information	Able to find out information on other classes/benefits/ other groups from other attendees	*It's interesting what you find out as well from other people.*
Frequency	Class happens weekly as opposed to fortnightly or monthly	*To have this nearly every week it's just awesome.*
Getting out of the house	Being able to get out of the house	*It's getting out isn't it?*
Increasing activities	Exercises leading to a general increase in activity level	*I walk more.*
Increasing confidence	Increasing general levels of confidence	*I just went to the lady that runs them and just said look, if it's a problem just say.*
Instructor knowledge and experience	The knowledge and experience of the instructor	*Well the support, the people's experience and their knowledge.*
Interaction with others	Being able to see and chat to other people	*Well it's mixing with other people basically.*
Keeping Moving	Generally keeping you moving	*I think it's kept my mum continue to be mobile.*
Lack of other activities	Difficulties finding other activities to do together	*We didn't have a lot, mum wasn't doing a lot*.
Legitimacy of UoN Banding	Class is marketed as being at the University	*The leaflet we were given originally because it said University of Nottingham that might have had an influence on why we came*.
Level of facilities	The level of facilities available in this class	*The quality of everything you've got.*
Maintaining abilities	Maintenance of current functional abilities	*Perhaps that would have deteriorated if she hadn't been coming to the classes.*
Parking	Availability of suitable parking	*I was a bit worried for a while about the parking...eventually Vicky did say there is parking.*
Participation in other activities	Exercises led to participation in other activities elsewhere	*There's a singing class that we go to as well and another exercise class that Vicky has.*
Preventing deterioration	Preventing a deterioration of current functional abilities	*Whereas if we didn't keep doing it he would probably deteriorate.*
Supportive Community	People attending the group	*We've met these lovely people I never want to be without.*

Appendix S: Internet Search Data

Age UK available from: https://www.ageuk.org.uk/information-advice/health-wellbeing/exercise/

The Crossing available from: https://www.nottshelpyourself.org.uk/kb5/nottinghamshire/directory/service.page?id=E9FGtbyb1wc

Yogafit4life available from: https://www.nottshelpyourself.org.uk/kb5/nottinghamshire/directory/service.page?id=fNh6gIw4nIQ&newdirectorychannel=10-10-29

Swing into Shape available from: https://www.nottshelpyourself.org.uk/kb5/nottinghamshire/directory/service.page?id=K8gYlqoPFRY&newdirectorychannel=0

Move it or Lose it available from: https://www.moveitorloseit.co.uk/find-a-class/

Keep Fit Association available from: https://keepfit.org.uk/-

EMD UK available from: https://www.classfinder.org.uk/

Extend available from: https://extend.org.uk/home#class

Your Space available from: https://www.yourspacetofeelgood.com/mansfield/classes/

https://www.yourspacetofeelgood.com/bircotes/classes/

https://www.yourspacetofeelgood.com/retford/classes/

https://www.yourspacetofeelgood.com/worksop/classes/

Active Notts available from: https://www.activenotts.org.uk/

Nottingham Rehabilitation Gym available from: https://www.nrgcic.co.uk/

InDerby available from: https://www.inderby.org.uk/active/classes/timetable/

Forever Active available from: https://www.derbycountycommunitytrust.com/programmes/health/forever-active

Active Derbyshire available from: https://www.activederbyshire.org.uk/

Active Charnwood available from: https://www.active-charnwood.org/#Active%20Charnwood%20website

Leicestershire and Rutland Sport available from: https://www.active-together.org/getactive

Alzheimer's Society available from: https://www.alzheimers.org.uk/find-support-near-you#!/search%C2%A0

Vitality available from: http://www.vitalitylincs.co.uk/find-a-class/

Connect to Support Lincolnshire available from: https://lincolnshire.connecttosupport.org/directory/#/activities?sortOptions=Rank,Id;asc&pageNumber=1&locations.distance=1609

Active Lincolnshire available from: https://letsmovelincolnshire.com/find-activities/

Magnae Vitae available from: https://magnavitae.org/activity/health-wellbeing/ageless-agile/

Corby Borough Council available from: https://www.corbyleisure.co.uk/fitness

Northants 50+ Network available from: https://northamptonmagazines.com/magazines/50-plus-network-news/

Northamptonshire Sport available from: https://www.northamptonshiresport.org/our-programmes/get-up-go/find-a-get-up-go-session/

Trilogy Leisure available from: https://www.trilogyleisure.co.uk/health-fitness/50-plus/

Appendix T: Survey

A survey to investigate exercise provision for people living with dementia

Introduction

About the Study

A survey to investigate the current provision of exercise classes available for older people living with dementia.

Thank you for your interest in taking part in this online survey. You have been invited to participate as you are an exercise instructor who delivers exercise classes to older people in the East Midlands. Please read through this information carefully before agreeing to participate.

This study is being done by Mrs Annabelle Long PhD researcher from the University Of Nottingham. We are investigating the current provision of exercise classes for older people living with dementia in the East Midlands. The overall aim of the PhD study is to develop an evidence based implementation toolkit which will provide the necessary framework for exercise classes aimed at older people in the community, enabling them to be inclusive for people living with dementia and their carers.

This survey is designed to establish how many and what type of exercise classes are available for older people living with dementia.

We are aware that many instructors deliver more than one class and we are interested in all the classes that you may provide. The survey has been designed to allow you to complete the details about each exercise class that you run.

The survey consists of 12 questions which takes about 10 mins to complete. If you deliver more than one class you will be asked an additional 6 questions for each class you deliver. These questions take approximately 2 minutes per class to complete.

Target Participants:

We are interested in all exercise classes advertised as being available for older people. We would like exercise instructors from all sectors including Local Authority, National

Health Service, Public Health, private and charity run classes to take part in the survey.

Privacy Notice

How will your data be used?

Your answers will be completely anonymous and we will use all reasonable endeavours to keep them confidential. The data generated will be securely stored in a password-protected file and all participants' data will be anonymised using a unique study number. Your IP address will not be stored.

This survey is part of a PhD project. Some exercise classes may be chosen to take part in the next stage of the study which involves observations and focus groups. Taking part in the survey does not obligate you to take any further part in the research. This data will be used for research purposes only.

Your participation in the research is voluntary and you are free to withdraw at any point during the questionnaire before final submission by clicking the Exit button/closing the browser. The data will only be uploaded on completion of the questionnaire by clicking the **FINISH** button.

Who will have access to your data?

The University of Nottingham is the data controller for the purposes of Data Protection. Your data may be shared with study staff and investigators and any relevant regulatory authorities.

We believe there are no known risks associated with this research study; however, as with any online related activity the risk of a breach is always possible. We will do everything possible to ensure your answers in this study will remain anonymous. We will minimize any risks by storing all survey data on a secure dedicated web server. Access will be restricted by user identifiers and passwords (encrypted using a one-way encryption method).

The results of the study will be written up as a thesis and may be published in scientific journals and presented at academic conferences. The data will be reported anonymously, with any identifying information removed.

If you have any questions about this project, please don't hesitate to contact the lead researcher Annabelle Long at annabelle.long1@nottingham.ac.uk or if you have any concerns about any aspect of this study please contact the Research Supervisor Professor Pip Logan at pip.logan@nottingham.ac.uk.

If you remain unhappy and wish to complain formally, you should then contact the FMHS

Research Ethics Committee Administrator, c/o The University of Nottingham, Faculty PVC Office, E41, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH. E-mail: FMHS-ResearchEthics@nottingham.ac.uk.

This survey has been reviewed and given a favourable opinion by the University of Nottingham, Faculty of Medicine & Health Sciences Research Ethics Committee (insert FMHS REC ref no here]. By continuing, you acknowledge that you have read and understood the above information and agree to participate in this survey.

Thank you very much for your participation in this research project. If you are happy to proceed with the survey please press **NEXT**.

Information about you

What do you consider as your main occupation when delivering exercise classes?

More info

- ○ Exercise Instructor
- ○ Fitness Instructor
- ○ Postural Stability Instructor
- ○ Personal Trainer
- ○ Physiotherapist
- ◉ Other

If you selected Other, please specify:

What do you consider is your highest level of qualification for exercise instruction?

- ○ Level 2 Certificate
- ○ Level 3 Certificate
- ○ Level 3 Diploma
- ○ Level 3 NVQ Diploma
- ○ Level 4 Higher National Certificate
- ○ Level 5 Higher National Diploma
- ○ BSc (Physiotherapy or other equivalent course
- ○ Other

If you selected Other, please specify:

Which county are you located?

- Derbyshire
- Leicestershire
- Lincolnshire
- Northamptonshire
- Nottinghamshire

Class information

Where does this exercise class take place?

- Gym or Leisure Centre
- School
- Village Hall
- Church Hall
- Other

If you selected Other, please specify:

Is this class primarily for older adults (over 65)?

- Yes
- No

If No what age range is the class aimed at?

What is the approximate age of the majority of your attendees?

- 18 - 25
- 26 - 40
- 41- 55
- 56 - 65
- 65+

Are any of your attendees living with dementia?

- ○ Yes
- ○ No
- ○ Don't Know

If YES approximately how many attendees are living with dementia?

- ○ 1 - 10
- ○ 11 - 20
- ○ 21 - 30
- ○ 30+

Is the class specifically designed for people living with dementia?

- ○ Yes
- ○ No

If No can the classes be adapted for people with dementia?

- ○ Yes
- ○ No

What exercise does the class offer? Please tick all that are applicable

- ☐ Chair Based Exercise

- [ ] Circuits
- [ ] Dance
- [ ] Keep Fit
- [ ] Movement to Music
- [ ] Pilates
- [ ] Strength and Balance
- [ ] Swimming
- [ ] Tai Chi
- [ ] Walking
- [ ] Walking Sports (such as football, netball)
- [ ] Yoga
- [ ] Zumba
- [ ] Other

If you selected Other, please specify:

Approximately how many people attend the class?

- ○ 1 - 10
- ○ 11 - 20
- ○ 21 - 30
- ○ 30+

Which town or village does the exercise class take place?

Do you run any other classes for older people in the East Midlands?

- Yes
- No

10 / 70

Appendix U: Ethical Approval

University of Nottingham
UK | CHINA | MALAYSIA

Faculty of Medicine & Health Sciences
Research Ethics Committee
Faculty Hub
Room E41, E Floor, Medical School
Queen's Medical Centre Campus
Nottingham University Hospitals
Nottingham, NG7 2UH
Email: FMHS-ResearchEthics@nottingham.ac.uk

4 June 2020

Ms Anabelle Long
PhD Student
c/o Professor Pip Logan
Professor of Rehabilitation Research
B108a, Medical School
Division of Rehabilitation, Ageing and Well-being
School of Medicine
QMC Campus, Nottingham University Hospitals
NG7 2UH

Dear Ms Long

Ethics Reference No: 31-0420 – **please always quote**
Study Title: A survey to investigate the current provision of exercise classes available for older people living with dementia in the East Midlands.
Chief Investigator/Supervisor: Prof. Pip Logan, Professor of Rehabilitation, Division of Rehabilitation, Ageing and Well-being, School of Medicine.
Lead Investigators/student: Anabelle Long, PhD student, Rehabilitation, Ageing and Well-being.
Other Key investigators: Prof. Stephen Timmons, Professor of Health Services Management, Centre for Health Innovation, Leadership and Learning (CHILL), Nottingham University Business School, Dr Vicky Booth, Assistant Professor, Dr Claudio Di Lorito, Research Fellow, Division of Rehabilitation, Ageing and Well-being.
Proposed Start Date: 01.06.2020 — **Proposed End Date:** 30.09.2020

Thank you for submitting the above application which was considered at the Committee meeting on 24 April 2020 and the following documents were received:

- FMHS REC Application form and supporting documents version 1.0: 24.03.2020

These have been reviewed and are satisfactory and the project has been given a favourable opinion.

A favourable opinion has been given on the understanding that:

1. The protocol agreed is followed and the Committee is informed of any changes using a notice of amendment form (please request a form).
2. The Chair is informed of any serious or unexpected event.
3. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely

Dr Bethan E Phillips, Associate Professor
Clinical, Metabolic & Molecular Physiology, Medical Sciences & Graduate Entry Medicine
Acting Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

Appendix V: Map of East Midlands

Appendix W: Email Invitation

Email Invitation
Subject: Exercise Classes for Older People

Body:
Dear Sir/Madam

We would really like your help in understanding how many and what type of exercise classes are taking place in the East Midlands and would like to invite your members to take part in a very short survey.

We are looking for exercise instructors that run exercise classes for older people to take part in the survey and your organisation has been identified from the internet as promoting exercise classes for older people in the East Midlands.

The survey will ask a couple of questions about them as an exercise class instructor and then a few questions about the classes they run. These questions will be a mixture of 'tick box' and 'drop down' style questions. We are aware that many instructors lead more than one class and the survey has been designed to allow them to complete details for all the classes they run.

Their answers will help us to understand the current provision of exercise classes for older people living with dementia in the East Midlands and support us with further research to enable exercise classes that take place in the community to be inclusive for people living with dementia.

We would be very grateful if you could share the link to the survey with your members who carry out exercise classes for older people in the East Midlands.

https://nottingham.omlinesurveys.ac.uk/group-exercise-classes-and-dementia

Many Thanks

Annabelle Long
PhD Student
Division of Rehabilitation, Ageing and Well-being
School of Medicine
University of Nottingham
B115 Medical School, QMC
Nottingham, NG7 2UH

annabelle.long1@nottingham.ac.uk

Appendix X: Twitter Invitation

Twitter Invitation

"Do you run exercise classes for older people in the East Midlands? We are looking for exercise instructors to take part in our short survey on the current provision of exercise classes for older people. Please complete and share this link https://nottingham.omlinesurveys.ac.uk/group-exercise-classes-and-dementia

Appendix Y

1. Population over 65 years

Percentage Population 65+	< 15		15.1- 17		17.1 – 20		>20	
County	Number	%	Number	%	Number	%	Number	%
Derbyshire	0	0	47	24	109	54	45	22
Leicestershire	19	23	12	15	46	56	5	6
Lincolnshire	21	23	0	0	17	19	53	58
Northamptonshire	35	44	20	25	24	31	0	0
Nottinghamshire	12	18	0	0	55	82	0	0

2. Socioeconomic Status

Socioeconomic Status	Low (0-1)		High (6 – 10)	
County	Number	%	Number	%
Derbyshire	91	45	107	55
Leicestershire	50	63	30	33
Lincolnshire	49	54	42	46
Northamptonshire	36	46	43	54
Nottinghamshire	26	39	41	61

3. Population Density

Level of Urbanisation	Settled		Light Urban		Urban	
County	Number	%	Number	%	Number	%
Derbyshire	11	6	59	32	115	62
Leicestershire	0	0	12	15	66	85
Lincolnshire	3	4	20	31	54	65
Northamptonshire	1	1	23	27	60	72
Nottinghamshire	7	10	27	39	35	51

Appendix Z: Ethical Approval

University of Nottingham
UK | CHINA | MALAYSIA

Faculty of Medicine & Health Sciences
Research Ethics Committee
Faculty Hub
Room E41, E Floor, Medical School
Queen's Medical Centre Campus
Nottingham University Hospitals
Nottingham, NG7 2UH
Email: FMHS-ResearchEthics@nottingham.ac.uk

20 January 2021

Ms Annabelle Long
PhD Student
Division of Rehabilitation, Ageing and Wellbeing
B115, B Floor, School of Medicine
QMC Campus
Nottingham University Hospitals
NG7 2UH

Dear Ms Long

Ethics Reference No: FMHS 114-1120 – **please always quote**	
Study Title: An Ethnographic Study to Explore the Context Specific Characteristics of, and Barriers and Facilitators to Exercise Classes for Older People in the East Midlands	
Chief Investigator/Supervisor: Pip Logan, Professor of Rehabilitation Research, Rehabilitation, Ageing and Well-being	
Lead Investigators/student: Annabelle Long, PhD Student, Rehabilitation, Ageing and Wellbeing, School of Medicine	
Other Key investigators: Stephen Timmons, Professor of Health Services Management, Dr Vicky Booth, Assistant Professor, Dr Claudio Di Lorito, Research Fellow, Rehabilitation, Ageing and Wellbeing	
Proposed Start Date: 01/01/2021	**Proposed End Date:** 31/05/2021

Thank you for responding to the comments made by the Committee at the meeting on 20 November 2020 and the following revised documents were received:

- FMHS REC Application form and supporting documents version 1.0: 18.01.2021

These have been reviewed and are satisfactory and the project is approved.

Approval is given on the understanding that:

1. The protocol agreed is followed and the Committee is informed of any changes using a notice of amendment form (please request a form).
2. The Chair is informed of any serious or unexpected event.
3. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely

Dr John Williams, Associate Professor in Anaesthesia and Pain Medicine
Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

Appendix AA: Observation Information Sheet

University of Nottingham
UK | CHINA | MALAYSIA

Faculty of Medicine & Health Sciences
School of Medicine
Room B115, Medical School
QMC Campus
Nottingham
NG7 2UH

Supervisor: Professor Pip Logan
Supervisor contact details: pip.logan @nottingham.ac.uk
Lead researcher: Annabelle Long (PhD Student)
Lead Researcher contact details: annabelle.long1@nottingham.ac.uk

Study Title: An Ethnographic Study to Explore the Context Specific Characteristics of and Barriers and Facilitators to Exercise Classes for Older People in the East Midlands

PARTICIPANT INFORMATION SHEET (EXERCISE INSTRUCTORS)

Research Ethics Reference: FMHS 114-1120
Version 1.0 Date: 18/01/21

We would like to invite you to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. One of our team will go through the information sheet with you and answer any questions you have. Please take time to read this carefully and discuss it with others if you wish. Ask us anything that is not clear.

What is the purpose of the research?

Exercise has many benefits but in people living with dementia it has been shown to improve mobility, daily function and mood. It is important to consider how exercise is provided for people with dementia to enable and support long term participation. Taking part in group exercise can support engagement and adherence with exercise as it can reduce social isolation and loneliness.
This study is looking to explore the characteristics of the exercise classes (what takes place during the class) through participant observation. The researcher will take part whilst observing what is taking place during the class.

Why have I been invited to take part?

You have been invited to take part in this research because you run an exercise class for older people living with dementia in the East Midlands.
We will be recruiting up to 3 exercise classes to take part in this study.

Do I have to take part?

No. It is up to you to decide if you want to take part in this research. We will describe the study and go through this information sheet with you to answer any questions you may have. If you agree to participate, we will ask you to sign a consent form and will give you a copy to keep. However, you would still be free to withdraw from the study at any time, without giving a reason by letting the researcher know.

1. What will happen to me if I take part?

If you would like to take part in this study a researcher will contact you to go over the information sheet and explain how the study will work and give you the chance to ask any questions.

The study will involve a researcher attending your exercise class, taking part, and observing the classes for a four-to-six-week period. Observations will be made about the class in general and not about any specific attendees.

The researcher will attend an initial exercise class to talk to the attendees and let them know that the research will be taking place and give them the opportunity to be excluded from the observations. She will also inform them that verbal consent will be sought to write notes or record any informal conversations that take part during the sessions and that this consent is entirely voluntary and that their usual involvement in the class will not be affected by their decisions.

Once observations begin the researcher will inform the class at the beginning of each session that the research is taking place and check if anyone does not want to be included in the observations. A poster confirming that the class is involved in a research project will also be placed at the entrance before each session as a visual reminder for attendees as they enter.

If you are still happy to take part, then you will then be asked to sign a consent form.

At the end of the observation period the researcher will invite the exercise class attendees to take part in a focus group. Separate participant information sheets will be given to those people who are interested in taking part in these focus groups and the researcher will explain this part of the study to any potential participants and given them a chance to ask any questions.

You will also be invited to take part in a subsequent interview/focus group to further explore the characteristics of the classes alongside barriers and facilitators to providing these classes for older people living with dementia. The interview/focus group would be expected to last no longer than an hour and take place at a time and location convenient to you. It will be audio-recorded using a digital recorder and then later written up. Any details that would enable you to be identified will be removed.

2. What is an ethnographic study?

An ethnographic study is a research process based on fieldwork in a particular environment where the researcher will use a variety of techniques to gather information through engaging in the lives of the people they are studying.

This study is looking at how exercise classes are taking place in the community and how easy or difficult it is for people living with dementia to access these classes. The researcher will be observing the exercise classes whilst participating and taking part in any additional activities that may be offered such as refreshments adopting the role of participant-as-observer.

Following the period of observation focus groups will be used to gather additional information from you about the classes themselves and some of the attendees about their involvement in the classes.

3. Are there any risks in taking part?

There are few risks involved in ethnographic studies. Attendees of the class may not be comfortable with being in a class with a researcher who is observing and may choose not to attend whilst the study is taking place. In order to reduce this risk, the researcher will explain to the attendees that the observations will be made about the class in general and not about any specific attendees and that they can request to be excluded from the observations whilst still attending the class. The researcher will also remind the class at the beginning of each observation that the research is taking place and check if anyone wishes to be excluded from the observations.

There are also few risks involved in focus group research. However, one possible risk is of participants disclosing personal information or what has been said in the focus group once the study is over.
In order to reduce this potential risk, the researchers will remind participants to respect each other's privacy and not repeat anything that has been discussed both in the consent form and verbally before the start of each focus group.

4. Are there any benefits in taking part?

There will be no direct benefit to you from taking part in this research, but your contribution may help us explore what exercises can be beneficial and what needs to be in place for people living with dementia to take part and enjoy exercise classes like yours in the future.

We also hope that you enjoy meeting and talking to our researchers and contributing to this valuable work.

5. Will my time/travel costs be reimbursed?

Participants will not be paid to participate in the study.

6. What happens to the data provided?

The **research data** will be stored confidentially on a study database which will be held securely, and password protected. All data will be stored on a secure dedicated web server and will only be accessible by authorised persons from the University of Nottingham who are organising the research.

To help ensure your privacy, you will be assigned a class study identification number (for example EC01 for exercise class 1), and it will be used instead of your name and class details.

If you choose to take part in the interview/focus group, we will assign you an individual study identification number which will be used instead of your name.

The researcher will make a separate confidential record of the exercise class details and class study number and (if needed) your name and individual study number to permit identification of all participants enrolled in the study in case additional follow up is required. This will be kept as personal/sensitive data (see below)

We will save all research data using the exercise class identification number or individual study identification number (as appropriate) so that none of the data will have your real name or other individual identifiers associated with them. Your name and any information about you or the class will not be disclosed outside the study centre.

Personal / sensitive data will be stored confidentially using a locked cabinet.

Only the researcher and their supervisory team will have access to personal / sensitive data / research data.

We would like your permission to use fully anonymised direct quotes in research publications.

All research data and records will be stored for a minimum of 7 years after publication or public release of the work of the research.

We would like your permission to use anonymised data in future studies, and to share our research data (e.g. in online databases) with other researchers in other Universities and organisations both

inside and outside the European Union. This would be used for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. All personal information that could identify you will be removed or changed before information is shared with other researchers or results are made public.

Data sharing in this way is usually anonymised (so that you could not be identified)

7. What will happen if I don't want to carry on with the study?

Even after you have signed the consent form, you are free to withdraw from the study at any time without giving any reason and without your legal rights being affected. Any personal data will be destroyed.

If you withdraw, we will no longer collect any information about you or from you but we will keep the anonymous research data that has already been collected and stored as we are not allowed to tamper with study records. This information may have already been used in some analyses and may still be used in the final study analyses.

8. Who will know that I am taking part in this research?

Data will be used for research purposes only and in accordance with the General Data Protection Regulations. Any electronic data will be anonymised with a code as detailed above. Electronic storage devices will be encrypted while transferring and saving of all sensitive data generated in the course of the research. All such data are kept on password-protected databases sitting on a restricted access computer system and any paper information (such as your consent form, contact details and any research questionnaires) would be stored safely in lockable cabinets in a swipe-card secured building and would only be accessed by the research team.

Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data).

You can find out more about how we use your personal information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx/

Designated individuals of the University of Nottingham may be given access to data for monitoring and/or audit of the study to ensure we are complying with guidelines.

Anything you say during an interview/focus group will be kept confidential, unless you reveal something of concern that may put yourself or anyone else at risk. It will then be necessary to report to the appropriate persons.

Due to the professional responsibilities of some University staff, if you mention something during the focus group which may require reporting the research team will discuss it with you and decide on a course of action. This may involve implementing the University of Nottingham, Safeguarding policy.

9. What will happen to the results of the research?

The research may be published as part of a peer reviewed publication or presented at conferences. Participants will not be identified in any publication.

The research will be written up as a thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives, to facilitate its use in future research.

10. Who has reviewed this study?

All research involving people is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests.

11. Who is organising and funding the research?

The research is being organised by Professor Pip Logan at the University of Nottingham and is being funded by the Applied Research Collaborative East Midlands (ARC-EM) and the University of Nottingham as part of a PhD scholarship.

12. What if there is a problem?

If you have a concern about any aspect of this project, please speak to the researcher [Annabelle Long] or the Principal Investigator [Professor Pip Logan], who will do their best to answer your query. The researcher should acknowledge your concern and give you an indication of how she intends to deal with it. If you remain unhappy and wish to complain formally, you can do this by contacting the FMHS Research Ethics Committee Administrator, Faculty Hub, Medicine and Health Sciences, E41, E Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: FMHS-ResearchEthics@nottingham.ac.uk.
Please quote ref no: FMHS 114-1120

13. Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Mrs Annabelle Long
Division of Rehabilitation, Ageing and Well-being
School of Medicine
Queens Medical Centre
University of Nottingham
NG7 2UH
Email: annabelle.long1@nottingham.ac.uk

Professor Pip Logan
Division of Rehabilitation, Ageing and Well-being
School of Medicine
Queens Medical Centre
University of Nottingham
NG7 2UH
Tel: 0115 8466642
Email: pip.logan@nottingham.ac.uk

Appendix BB: Observation Consent Form

University of Nottingham
UK | CHINA | MALAYSIA

Faculty of Medicine & Health Sciences
School of Medicine
Room B115, Medical School
QMC Campus
Nottingham
NG7 2UH

Participants Consent Form (Exercise Instructors)

Final version 1.0: 18.01.21

Title of Study: An Ethnographic Study to Explore the Context Specific Characteristics of and Barriers and Facilitators to Exercise Classes for Older People in the East Midlands

REC ref: FMHS 114 – 1120

Name of Researchers: Annabelle Long (PhD Student)

Name of Participant: **Please initial box**

1. I confirm that I have read and understand the information sheet version number 1.0 dated 18.01.21 for the above study which is attached and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without disadvantage. ☐
3. I understand that relevant sections of my data collected in the study may be looked at by the research group and by other responsible individuals for monitoring and audit purposes. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that the Interview/Focus Group will be audio recorded using a digital device and that anonymous direct quotes from the interview may be used in the study reports. ☐
5. I understand that information about me recorded during the study will be made anonymous before it is stored. It will be uploaded into a secure database on a computer kept in a secure place. Data will be kept for 7 years after the study has ended and then deleted. ☐
6. **Optional:** I agree that my anonymous research data will be stored and used to support other research in the future and shared with other researchers including those working outside the University. ☐
7. I understand that what I say during the Interview/Focus Group will be kept confidential unless I reveal something of concern that may put myself or someone else at any risk. It will then be necessary to report this to the appropriate persons. ☐
8. I understand that the information discussed in a Focus Group may be sensitive and is confidential. I agree to respect other participant's privacy and will not disclose what others have said in a Focus group. ☐
9. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

2 copies: 1 for participant, 1 for the project notes.

Appendix CC: Participant Information Sheet

University of Nottingham
UK | CHINA | MALAYSIA

Faculty of Medicine & Health Sciences
School of Medicine
Room B115, Medical School
QMC Campus
Nottingham
NG7 2UH

Supervisor: Professor Pip Logan
Supervisor contact details: pip.logan @nottingham.ac.uk
Lead researcher: Annabelle Long (PhD Student)
Lead Researcher contact details: annabelle.long1@nottingham.ac.uk

Study Title: An Ethnographic Study to Explore the Context Specific Characteristics of and Barriers and Facilitators to Exercise Classes for Older People in the East Midlands

PARTICIPANT INFORMATION SHEET (CLASS ATTENDEES)

Research Ethics Reference: FMHS 114 - 1120
Version 1.0 Date: 18/01/21

We would like to invite you to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. One of our team will go through the information sheet with you and answer any questions you have. Please take time to read this carefully and discuss it with others if you wish. Ask us anything that is not clear.

What is the purpose of the research?
Exercise has many benefits but in people living with dementia it has been shown to improve mobility, daily function and mood. It is important to consider how exercise is provided for people with dementia to enable and support long term participation. Taking part in group exercise can support engagement and adherence with exercise as it can reduce social isolation and loneliness.
This study is looking to explore what makes it easy or harder for people living with dementia to take part in exercise classes for older people.

Why have I been invited to take part?

You have been invited to take part in this research because you are over 65 and attend an exercise class for older people in the East Midlands. We are inviting up to 40 people like you to take part in this study. This will involve taking part in a focus group to help us further understand what may make it easier or harder for people living with dementia to attend an exercise class and how we could adapt or set up classes to encourage this group to participate.

Do I have to take part?
No. It is up to you to decide if you want to take part in this research. We will describe the study and go through this information sheet with you to answer any questions you may have. If you agree to participate, we will ask you to sign a consent form and will give you a copy to keep. However, you would still be free to withdraw from the study at any time, without giving a reason by letting the researcher know.

1. What will happen to me if I take part?

If you would like to take part in this study the researcher who has attended your exercise classes will go over the information sheet and explain how the study will work and give you the chance to ask any questions.

If you take part in the focus group this will last between 40 and 60 minutes, involve up to 5 people altogether and will take place following one of your usual exercise classes. You will be invited to discuss your experiences of the exercise class, and, if you are living with dementia, what encouraged you to take part and continue attending. If you are not living with dementia, you will be invited to discuss your experiences of exercising with people living with dementia. All participants will be invited to discuss how they think classes could be adapted to encourage attendance. If you are living with dementia, you are welcome to bring a carer to the focus group. If your carer attends the exercise class with you, they are also welcome to attend and take part in the focus group as a participant.

The focus group will be audio-recorded using a digital recorder, and then later written up. Any details that would enable you to be identified will be removed.

If you are still happy to take part, then you will then be asked to sign a consent form before the focus group starts.

2. What is a Focus Group study?

A focus groups is a small group interview where people are invited to discuss a topic that is of interest to the researchers. It is normally used to gather information from people when it is more helpful to have people discuss the topic in a group rather than one-to-one with the researcher like an interview. People can often feel more comfortable in a group setting and often will talk to each other rather than just the researcher as conversations that occur can spark memories of experiences that you have had that may not have been discussed in a more formal interview setting.

3. Are there any risks in taking part?.

There are few risks involved in focus group research. However, one possible risk is of participants disclosing personal information or what has been said in the focus group once the study is over. In order to reduce this potential risk, the researchers will remind participants to respect each other's privacy and not repeat anything that has been discussed both in the consent form and verbally before the start of each focus group.

There is also a chance you may feel uncomfortable about asking specific questions. You do not have to answer any questions that make you feel uncomfortable and can leave the focus group at any point if you wish. We can provide you with information about support groups if you would like.

4. Are there any benefits in taking part?

There will be no direct benefit to you from taking part in this research, but your contribution may help us explore what exercises can be beneficial and what needs to be in place for people living with dementia to take part and enjoy exercise classes in the future.

We also hope that you enjoy meeting and talking to our researchers and contributing to this valuable work.

5. Will my time/travel costs be reimbursed?

Participants will not receive an inconvenience allowance to participate in the study. Focus groups will be organised to take place in the same venue as the exercise classes following the completion of a session so that participants are not incurring any additional travel expenses.

Light refreshments will be offered to those people who take part in the focus groups, unless these take place online.

6. What happens to the data provided?

The **research data** will be stored confidentially on a study database which will be held securely, and password protected. All data will be stored on a secure dedicated web server and will only be accessible by authorised persons from the University of Nottingham who are organising the research.

To help ensure your privacy we will assign you an individual study identification number (for example FG0101 for focus group 1 participant 1) which will be used instead of your name. We will save all the research data using the individual study identification number so that none of the data will have your real name or other individual identifiers associated with them. Your name and any information about you will not be disclosed outside the study centre.

The researcher will make a separate confidential record of your name and individual study number to permit identification of all participants enrolled in the study in case additional follow up is required. This will be kept as personal/sensitive data (see below)

Personal / sensitive data will be stored confidentially using a locked cabinet.

Only the researcher and their supervisory team will have access to personal / sensitive data / research data.

We would like your permission to use fully anonymised direct quotes in research publications.

All research data and records will be stored for a minimum of 7 years after publication or public release of the work of the research.

We would like your permission to use anonymised data in future studies, and to share our research data (e.g. in online databases) with other researchers in other Universities and organisations both inside and outside the European Union. This would be used for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. All personal information that could identify you will be removed or changed before information is shared with other researchers or results are made public.

Data sharing in this way is usually anonymised (so that you could not be identified)

7. What will happen if I don't want to carry on with the study?

Even after you have signed the consent form, you are free to withdraw from the study at any time without giving any reason and without your legal rights being affected. Any personal data will be destroyed.

If you withdraw, we will no longer collect any information about you or from you, but we will keep the anonymous research data that has already been collected and stored as we are not allowed to tamper with study records. This information may have already been used in some analyses and may still be used in the final study analyses.

8. Who will know that I am taking part in this research?

Data will be used for research purposes only and in accordance with the General Data Protection Regulations. Any electronic data will be anonymised with a code as detailed above. Electronic storage devices will be encrypted while transferring and saving of all sensitive data generated in the course of the research. All such data are kept on password-protected databases sitting on a restricted access computer system and any paper information (such as your consent form, contact details and any research questionnaires) would be stored safely in lockable cabinets in a swipe-card secured building and would only be accessed by the research team.

Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data).

You can find out more about how we use your personal information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx/

Designated individuals of the University of Nottingham may be given access to data for monitoring and/or audit of the study to ensure we are complying with guidelines.

Anything you say during a focus group will be kept confidential, unless you reveal something of concern that may put yourself or anyone else at risk. It will then be necessary to report to the appropriate persons.

Due to the professional responsibilities of some University staff, if you mention something during the focus group which may require reporting the research team will discuss it with you and decide on a course of action. This may involve implementing the University of Nottingham, Safeguarding policy.

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The research may be published as part of a peer reviewed publication or presented at conferences. Participants will not be identified in any publication.

The research will be written up as a thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives, to facilitate its use in future research.

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All research involving people is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests.

11. Who is organising and funding the research?

The research is being organised by Professor Pip Logan at the University of Nottingham and is being funded by the Applied Research Collaborative East Midlands (ARC-EM) and the Alzheimer's Society as part of a PhD fellowship.

12. What if there is a problem?

If you have a concern about any aspect of this project, please speak to the researcher [Annabelle Long] or the Principal Investigator [Professor Pip Logan], who will do their best to answer your query. The researcher should acknowledge your concern and give you an indication of how she intends to deal with it. If you remain unhappy and wish to complain formally, you can do this by contacting the FMHS Research Ethics Committee Administrator, Faculty Hub, Medicine and Health Sciences, E41, E Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: FMHS-ResearchEthics@nottingham.ac.uk.
Please quote ref no: FMHS xx-xxx

13. Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Mrs Annabelle Long
Division of Rehabilitation, Ageing and Well-being
School of Medicine
Queens Medical Centre

University of Nottingham
NG7 2UH
Email: annabelle.long1@nottingham.ac.uk

Professor Pip Logan
Division of Rehabilitation, Ageing and Well-being
School of Medicine
Queens Medical Centre
University of Nottingham
NG7 2UH
Tel: 0115 8466642
Email: pip.logan@nottingham.ac.uk

Appendix DD: Consent Form

University of Nottingham
UK | CHINA | MALAYSIA

Faculty of Medicine & Health Sciences
School of Medicine
Room B115, Medical School
QMC Campus
Nottingham
NG7 2UH

Participants Consent Form (Class Attendees)

Final version 1.0: 18.01.21

Title of Study: An Ethnographic Study to Explore the Context Specific Characteristics of and Barriers and Facilitators to Exercise Classes for Older People in the East Midlands

REC ref: FMHS 114 – 1120

Name of Researchers: Annabelle Long (PhD Student)

Name of Participant: **Please initial box**

1. I confirm that I have read and understand the information sheet version number 1.0 dated 18.01.21 for the above study which is attached and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without disadvantage. ☐
3. I understand that relevant sections of my data collected in the study may be looked at by the research group and by other responsible individuals for monitoring and audit purposes. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that the Focus Group will be audio recorded using a digital device and that anonymous direct quotes from the interview may be used in the study reports. ☐
5. I understand that information about me recorded during the study will be made anonymous before it is stored. It will be uploaded into a secure database on a computer kept in a secure place. Data will be kept for 7 years after the study has ended and then deleted. ☐
6. **Optional:** I agree that my anonymous research data will be stored and used to support other research in the future and shared with other researchers including those working outside the University. ☐
7. I understand that what I say during the Focus Group will be kept confidential unless I reveal something of concern that may put myself or someone else at any risk. It will then be necessary to report this to the appropriate persons. ☐
8. I understand that the information discussed in the Focus Group may be sensitive and is confidential. I agree to respect other participant's privacy and will not disclose what others have said in the Focus group. ☐
9. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

2 copies: 1 for participant, 1 for the project notes.

Appendix EE: Topic Guide (Participants)

Focus Group Topic Guide

Prior to the focus group starting

- Check participants have all read the information sheet and have signed the consent form and are still happy to take part. Answer any questions and re-iterate that involvement is voluntary and that they can change their mind at any point.
- Ensure that all participants are still aware that the focus group will be audio-recorded and that they are still happy with that.

Explain to the group

- That everyone's view is valid and there is no right or wrong answer.
- Discussion needs to be grounded in mutual respect and people should be given the chance to express their views without interruptions and the importance of listening.
- That everything said in the focus group should remain confidential and if they talk to other people about the discussion, people in the group should not be identifiable.
- The audio recording of the discussion will be securely stored at the University of Nottingham and all the participants will be anonymised in any reports or publications that arise from the research.
- Participants are free to withdraw at any time and can leave the discussion at any point.
- The discussion will last between 45 and 60 minutes.
- It is fine to ask questions and take a break if needed.

Topic 1

What motivated you to start attending this class?

Topic 2

What do you find useful or helpful about the exercise class?

Prompts

- does it encourage you to do anything differently outside of the class?
- has it led to any changes that you have noticed in your physical health/mood/confidence/social aspects (if appropriate)
- any particular exercises useful?

Is there anything that you would like to change?

Topic 3

What encourages you to continue to attend the classes?

- (specifically for people living with dementia but other answers useful too)

If you were diagnosed with dementia tomorrow, would you want to carry on attending this class? (would you want to attend a dementia specific class?)

What would make it more difficult for you to attend a class?

- What stops people attending classes?
- Is there a reason why you have chosen this class in particular?

Topic 4

Should all classes be open to all – if a person feels like they could manage a particular class – regardless of any diagnosis?

Is anyone aware if anyone in the class does have a diagnosis of dementia or mild cognitive impairment? (If Yes..)

How have you found exercising in a class with people living with dementia?

- Does it make any difference?
- Were you even aware?

(If No…) would you mind exercising in a mixed class with people living with dementia?

Topic 5

Do you think that the class is suitable for both people living with and without dementia?

- Do you think there is anything that would encourage people living with dementia to attend?
- Are there any adaptions that you could think of that would help?

Do you think that mixed classes are the way forward or would it be better to have specific classes? (e.g. dementia, Parkinson's cardiac etc)

Topic 6

Did anyone attend any online classes during the periods of lockdown?

- If Yes – what sort of classes did you attend?
- Was it relatively straightforward to attend?
- Do you think online classes would have been appropriate for people living with dementia?

- If No – why not? What stopped you?

Thinking generally about online classes

Do you think it would be as motivating to exercise online as face to face with other people?

Would you be as motivated to exercise at home?

When the classes first restarted the coffee and chat was not taking place but has now been re-introduced – do you enjoy that part of the class?

- Do you consider that as part of the class or an additional extra?
- Does it give you extra motivation to come to know you can have a chat after or is the exercise class enough?

- Did you miss people during the lockdowns?
- Are you finding the social element more important to you now?

Does anyone have anything else to add on to what we have discussed today?

At the end of the focus group

- Thank all the participants for their contribution.
- Explain what will happen now – transcribing, analysis, writing up the study.
- Ask if they would like to know the findings of the study and that you would be happy to come back and tell them what we have found and what may happen next.
- Check if anyone has any particular questions or concerns.
- Stop the recording.

Appendix FF: Interview Guide (Instructors)

Interview/Focus Group Schedule

Prior to the focus group starting

- Check participants have read the information sheet and have signed the consent form and are still happy to take part. Answer any questions and re-iterate that involvement is voluntary and that they can change their mind at any point.
- Ensure that participants are still aware that the interview/focus group will be audio-recorded and that they are still happy with that.

Explain to the participant(s)

- That everyone's view is valid and there is no right or wrong answer.
- Discussion needs to be grounded in mutual respect and people should be given the chance to express their views without interruptions and the importance of listening.
- That everything said in the interview/focus group should remain confidential and if they talk to other people about the discussion, people in the group should not be identifiable.
- The audio recording of the discussion will be securely stored at the University of Nottingham and all the participants will be anonymised in any reports or publications that arise from the research.
- Participants are free to withdraw at any time and can leave the discussion at any point.
- The discussion will last between 45 and 60 minutes.
- It is fine to ask questions and take a break if needed.

Topic 1

How long have you been running these classes?

What motivates you to run these classes?

Topic 2

What is your experience of delivering these classes?

Have you noticed any changes in the class over time? (before pandemic!!)

- Mode of delivery
- Types of exercises delivered
- Types of people who come – already fit and healthy or have there been more people come with other problems – frailty, dementia Parkinson's etc

Topic 3

Thinking more specifically about the last 15 months how have you found delivering exercise classes?

- How easy/difficult was it to run online classes – structure, motivating people, safety aspects?
- Was there a lot of changing from online back to 'live' back to online etc?

How did you find delivering the online classes itself?

Did you run online classes in the first lockdown? Has there been a change in participation over the last 15 months?

- Where there more people attending earlier on in the pandemic?
- How have the numbers changed in attendance for online classes?
- Have the numbers got smaller as the pandemic went on/were there less people attending in the second lockdown than the first?

Do you think that there was a novelty factor to attending online classes? Do you think that this has worn off to a certain extent? Why??

How hard was it for you to motivate yourself to run classes online?? Did you find this more difficult/easier than motivating yourself to run a 'live' class?

Do you think that it was easy for older people to access online classes? What do you think would have made it more difficult? Is there a way to make this easier?

Do you think this was harder for people with other underlying conditions e.g dementia, parkinsons, fraility etc.

Have you found that attendance has increased since you returned to face to face? – slowly or rapidly??

Topic 4

How have you found adapting classes over time to make it suitable for a wider range of people? (if appropriate)

OR

How easy /difficult would it be to adapt classes to make them suitable for people living with dementia.

Topic 5

How do you think that we can encourage people living with dementia in the community to take part in exercises?

Topic 6

Do you think that mixed classes are the way forward? (people living with dementia exercising alongside people who do not have dementia)

- Do you think people with dementia would prefer inclusive classes as opposed to having a class specifically for them?
- Do you think mixed classes would encourage people with dementia to attend?
- Do you think labels are helpful or not "active agers" "dementia friendly" or do they prevent inclusivity?

Does anyone have anything else to add on to what we have discussed today?

At the end of the focus group

- Thank all the participants for their contribution.
- Explain what will happen now – transcribing, analysis, writing up the study.
- Ask if they would like to know the findings of the study and that you would be happy to come back and tell them what we have found and what may happen next.
- Check if anyone has any particular questions or concerns.
- Stop the recording.

Appendix GG: Code Book

Code	Definition	Example
Accessibility	Unable to find appropriate classes	*I think the main problem really trying to get exercises for someone whose got dementia or is disabled is just finding enough places to go.*
Changes due to COVID-19	People not confident enough to return to classes	*It has changed because a lot of people decided that they weren't gonna come back yet.*
Financial Considerations	Cost of attending classes	*Do you think finance comes into it sometimes as well for some people too?*
Inconsistencies in the System	Services offered to people different dependant on where you live	*At one point they had these lovely green Nottingham booklets these green ones with telephone numbers, and you could get a carers card and that sort of thing via the booklet.*
Lack of Instructor Training	Little dementia-specific training for instructors	*In that the qualification I've got with the designing exercise programmes for the senior population I feel like there should be a chapter in there about dementia, about Parkinson's, age related stuff.*
Problems with Technology	Difficulties using or accessing technology	*I didn't know how to do zoom.*
Transport Limitations	Difficulties accessing without transport	*But cos I can drive, and we get out and we can come here and that sort of thing.*
Peer Support	Benefits of peer support for carers	*I'm still getting the support from these ladies.*
Sharing Knowledge	Carers sharing knowledge between each other	*It's through this group that I found other groups, I found the Forget Me Notts and that group is terrific.*
Health Motivations	Attend for health benefits	*Well certainly I think it keeps me fitter and more toned.*
Importance of Being Local	Easier access if local	*It was on the doorstep.*
Mental Health Benefits	Benefits to mental health	*I don't actually look forward to the class it's actually the buzz afterwards you get.*
Physical Health Benefits	Benefits to physical health	*I've probably got more*

		muscular strength than I would otherwise have.
Social Motivations	Attend for social reasons	*I just wanted to do something where I met other people.*
Technology can be useful	Benefits of technology	*We even recorded one and everything in the studio when we came back after the first lockdown…that was for people at home who weren't ready to come back*
Trained, Knowledgeable and Motivated Staff	Benefits of having staff that are trained in dementia	*They seemed to understand ever such a lot and I mean I don't know if they've had extra training or if it's because they've had people in this situation.*
Use of Music	Music can help motivation	*Because you do it to music it seems easier to set to.*
Importance of Social Interaction	Social Interaction important for continued attendance	*It's a social thing, isn't it.*
Local Responsibility	Responsibility for classes at a local level	*You could argue this group should exist in every local authority that's probably the answer.*
Missing Social Interaction	Increased importance of social interaction following COVID-19	*Yes, I have missed the interaction.*
National and Corporate Policy	Responsibility for classes at a national level	*Is sports development a statutory responsibility of which that could relatively easily be provided?*
Rapport within Group and with the Instructor	Importance of rapport within group	*You get a nice rapport with everybody now as you have probably noticed.*
Socialisation not Always Appropriate	Socialisation is not always possible	*The one I do on a Monday afternoon I don't have the facility to do coffee and stuff.*
Support for Instructors	Attendees want to support instructors.	*I'd phoned her and said I'll come…I'd made a commitment on the phone but getting here was really hard.*
Accepting of Differences	People supporting others with different needs	*I come here on this (Scooter) and you know if I'm having a bad day occasionally I'll even stay on this.*
Adaptability within Classes	Classes can be adapted to different needs	*If you have a class like the one I did with the dementia*

		lady in, I did the routine differently.
Appropriateness of Mixed Classes	If classes should be separate or mixed.	*Well, I think it's good for you all...don't you think it's good for you all to mix as well?*
Assumptions about Dementia	Public perception of dementia	*The assumption of the public is that dementia is for the elderly…and they always tend to think of the end product*
Assumptions of 'Older People's' Exercise	Public perception of exercise classes for older people	*Isn't that perhaps why people don't come to this class because they see elderly keep fit…I'm not elderly.*
Continue to Attend if Diagnosed with Dementia	Not wanting to stop classes just because of diagnosis	*I'd like to come to this class if I had a dementia of any sort.*
Dementia-specific Classes	Dementia-specific classes are still needed	*Local authorities should also provide what I would call a class for people like us.*
Less Motivation for Online Classes	Difficult to motivate yourself for an online class	*At the end of it all I just couldn't be bothered to do it.*
Treating People as Individuals	Not treating all people with dementia as the same.	*We've got to take each individual as an individual and, we accept and hopefully cater for each individual person.*
Variety and Function of Exercises	Offering a wide variety of different exercises	*I like the wide variety myself you know as well; I think it's all your body as well isn't it.*